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| |  | | --- | | **David <coonbear4@gmail.com>** | | Dec 6  https://mail.google.com/mail/u/0/images/cleardot.gif |  |  |

Here's a letter I wrote my Dr because I was being cut back too far by my pain doctor, he's told me 3 times now he needs to cut me back so he can keep his license. Is that medicine?

-------- Original message --------  
From: David <[coonbear4@gmail.com](mailto:coonbear4@gmail.com)>   
Date: 8/15/17 8:35 AM (GMT-08:00)   
To: David Email <[coonbear@charter.net](mailto:coonbear@charter.net)>   
Subject: Pain kills, Greenberg's an a\*\*\*\*\*\*

Dr.Webb, Brian,

These new CDC guidelines have put me in a very bad place, my pain medication is not adequate. I'm sick of spending everyday stressed out and contemplating suicide. The thoughts going through my head when I get stuck in high levels of pain are not good. I need to make some kind of a change here, before I kill myself or somebody else. I've almost been in a car wreck and burnt down my house because I was thinking about pain.

I don't know what dr. Greenberg thinks he's doing, the CDC guidelines had nothing to do with pain doctors. This guy is yelling at me, throwing a little tizzy fits, stomping out of his room. I don't need this crap. I can guarantee you there's nobody on this planet that would rather not have to take opiate pain medication then me. He tells me he needs to taper me so he can keep his license, that's not what the guidelines say they clearly say don't taper somebody to the point of harm. They clearly talk about how people who have been on long-term opiate therapy, have different and unique needs. My mind is going, it's about ready to snap, I've had just about all I can take.

Now I'm reaching out you guys because I feel safe there, but I don't know what to do I've tried everything I can possibly think of to reduce my pain levels naturally, I spent over $9,000 this last year-and-a-half on pills, potions, light therapies, you name it I've done it.

So I would like you guys to get me a meeting with the top dog of Providence, so I can get you the clearance to give me the pain medication I need until I can find a way to reduce my pain levels. Because what's going on now is not helping me, its is killing me. It's clear, after taking an average at 325 mg of opiates a day for 8 years, I'm at no risk of becoming addicted or overdosing. I can't believe for one minute that the CDC guidelines were intended to kill us. Yet every month I read about another suicide of a chronic pain patient, or they turn to heroin or some other illegal drug, and now I've read about two cases where people have went into pain clinics and shot people. I know how this is happening because I know what goes through my head when I get stuck in these high-levels of pain.

I'd go see a psychiatrist but they've already told me they don't do pain, and if one more person hands me a coloring book, or tells me to go think my pain away, exercise my pain away, or yoga my pain away or anything else. I might just kill them.

Now I'm going insane and I know something bad is going to happen and I need to stop it now.

Please, please, please help me figure out something to do. I do not want to die or hurt anyone else.

Sincerely

David W Cole

From Mary Elizabeth Downs

I started off on Fentanyl patches I don't remember the dose we went down to oxy and now I am down to Vicodin 5mg. My doctor is not going to be prescribing narcotics anybody anymore. So she's tapering all her patients. I'm on to doctor waiting list to try to get an appointment to be seen somewhere else but they are scheduling into April of next year already. I have had genetic testing done on how my body responds to pain medication and Fentanyl is the only medication that my body responds to and even that I metabolize too fast. I literally feel like I am taking Tic Tacs and not actual medication. I've been acting like a 95 year old and staying home by myself most of the time instead of acting like a 22 year old and be able to go out with their friends or do anything active. It's like it in the cycle of either lonely depression or my body giving out bc my pain is unmanaged. I tried years of alternative therapies and every possible treatment that we could come up with before resulting in the use of opioids. Even with using fentanyl I was down to a 2 or 3 on Pain Scale we're right now and staying at 8. I have five to six major dislocations of my major joints a day and 15 to 20 subluxations. I use braces crutches or wheelchair depending on how my body is on any given day. Some days I can't even get out of bed or take a shower. I'm totally fine with you citing me. Im from Eastern NC in case you need to know that. Let me know if I can answer anything else for you!

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my name is eli. i've been struggling with chronic pain since i was 12 years old. i was diagnosed with a rare nerve disorder called complex regional pain syndrome. it is most common to develop the condition around middle age, usually after an injury, but i developed the condition young. it causes your nerves to be caught in a feedback loop of pain, most often in the limbs. for me it started in my feet after i got a stress fracture on the left and sprains in both sides during a school marching band practice camp we did the summer before highschool started my freshman year.

it causes marked changes in circulation in the limbs, changes in hair and nail growth, muscle spasms, and more. but worst of all- severe- unrelenting chronic pain that is made worse by all normal sensations, including clothing, light touch, vibration and at its worst even wind moving over the skin. these things have felt painful to me since the age of 12. starting on my feet, and spreading later to my hands after IV treatments in the hospital.

that is the other part of this condition. even minor injuries can cause this severe pain and dysfunction to spread.

i have experienced other types of pain that i can compare this too. - for example ive suffered kidney stones over 9 times due to a kidney condition i also have. kidney stones are considered a severe pain- compared often to childbirth . i was medicated repeatedly in the hospital to control that pain. my pain from my crps is much more severe than the pain of kidney stones was. i would rather be in the same pain with kidney stones, than experience crps pain every day. it ranges from feeling like my flesh is being burned off my body to feeling as if my limbs are being slowly crushed & impaled with spikes. the pain and spasms mean i use a wheelchair and walker most often.

i have tried all variety of treatments. multiple nerve pain medications, spinal nerve blocks, an implant in my spine at the age of 13. intensive physical therapy, many different drugs to manage symptoms. psycotherapy, meditation. and narcotics- which i was constantly discouraged from turning to despite being the only thing before receiving my medical marijuana card at the age of 18 that even touched the pain for me.

today the only pain management tool at my disposal is marijuana because no pain management doctors will treat me with narcotics while i am using my medical card, despite the fact ive received the most marked improvements in symptoms using these two treatments that halfway work for my body in conjunction. i chose marijuana over narcotics because the amount or marijuana i can get is limited more by finances than regulation.

why should i be condemned to a life of severe disability and suffering without the treatment that i have already experienced WORKING, just because of the risk of my addiction & death. instead i am left to keep trying dozens of other even more risky treatments. including being put in a chemically induced coma, which i feel is much more likely to kill me than taking narcotics as perscribed while also using medical marijuana.

the dea regulations arent supposed to effect people who genuinely need narcotics to live their life due to the severe pain they experience daily. from what i understand they shouldnt even be targeting pain management clinics but when pain management clinics are striving to reduce their narcotic scripts as much as they possibly can even when other options have been tried and have failed for patients there is something very wrong.

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| |  | | --- | | **Mark Shires <fishires1964@aol.com>** | |  |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |

My injury began in 1998 due to a slip and fall down icy stairs. Blew out two discs and spinal fractures. For two years I did every medical step there was to get better. refused surgery thinking I was just hurt and not injured, I was 33 years of age and in my prime. I was a tractor trailer mechanic and CDL driver with a class A license. Referring back to hurt and injured, being hurt will pass with time. When one is injured, it’s a lifetime battle with chronic pain and lots of medical procedures. After two years, in 2000 I was bed ridden and had no other choice than a spinal fusion. During the two years I tried every treatment available at that time. Went through two more years of recovery and maintenance only to find out my fusion had failed. I did not redo fusion, miserable miserable surgery. I was taking narcotics off and on from 1998 to now. I always took as prescribed by my doctors. It was very hard to find work after this, unable to do the work I was at time of accident. Refused filing for disability, although doctors advised me to file. Bounced around job to job doing work overqualified for. In 2010 doctors decided to remove hardware thinking this was causing chronic pain. During surgery they found my spine was still not fused, it was still fractured. Too long of a surgery to replace hardware so they packed bone once again from my hip and casted me up for another 6 months. It was then I filed for disability and received full benefits. At that time primary doctors could treat for pain with medication. Not long after, law required pain clinics and primary doctors could no longer prescribe narcotics. Still taking narcotics I then decided to try the spinal stimulater. Very successful, although still having to take narcotics at times for flare ups. This was 2014. Two years of 80 percent of leg pain decrease and 10-20 for lower and mid back. 2016 I was rear ended by 2 vehicles totaling my car and worse, disabled my stimulater. Never worked after that so it was removed. Back to the bottom I went, pain meds, injections, etc. I can only speak for myself, going to pain management I feel I am treated like an addict. When one needs pain blockers for chronic pain, that is what I used it for. I have never abused. My issue is why insurance will not cover narcotics, if ones doctor prescribes from the clinic. Insurance covers the visit and consult, then what that professional doctor prescribes should be covered also. I have been researching canabis oil for my chronic pain. Lots of successful reviews, this is our future for chronic pain and certain diseases such as cancer. My social life through the years has been way down, as well as an active life. Being an energetic person, this really discourages me as a man. Not being able to live up to my potential at times depresses me. Well that’s my story in a nutshell, please don’t look down on those who need blockers for chronic pain. And do research on canibus oil, it is our future for not only pain relief, but the cure of disease.  
  
Mark Shires

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In 1990 I had a horse crash that resulted in 2 neck surgeries. The surgeries corrected the initial hideous pain, but the daily intractable pain that lasted for a few years post surgery made my life and work as an illustrator very difficult. There were times I thought it wasn't worth the pain to be alive. I couldn't think or even just sit quietly pain would overtake every aspect of my physical experience. I would not have been able to make a living without Vicodin. Even in 2007 I was very strictly regulated in how many pills I was allowed to have and I saved them for the very worst of times. Over the years I've found strategies to address pain including bodywork (massages) and acupuncture and changing my work. 10 years post 2nd surgery, Advil is my go-to pain reliever. My point is for 5-6 years I used Vicodin as a tool, a bridge from catastrophic pain and long term intractable daily pain to the grateful place I am now. When I didn't need the Vicodin anymore, I didn't take it. I now get 20 pills a year for management and I had 8 left in 2016. This is an opioid success story.

But now, in classic totalitarian form, the innocent will pay for the weaknesses and poor judgement of others. My own doctor treats less and less pain patients because he is terrified of the government. When I think of the pain I was once in (and I am talking writhing around unable to be still level pain) and imagine being denied pain relief because some person somewhere might abuse this life saver? I am certain that suicide would have been considered. No one who has never experienced chronic intractable pain should be legislating medical therapies for people who are.

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Hi please use this version my dates are off in the first.

In 1998 I had a horse crash that resulted in 2 neck surgeries, 2 years apart. The surgeries corrected the initial hideous pain, but the daily intractable pain that lasted for a few years post surgery made my life and work as an illustrator very difficult. There were times I thought it wasn't worth the pain to be alive. I couldn't think or even just sit quietly pain would overtake every aspect of my physical experience. I would not have been able to make a living without Vicodin. Even in 2007 I was very strictly regulated in how many pills I was allowed to have and I saved them for the very worst of times. Over the years I've found strategies to address pain including bodywork (massages) and acupuncture and changing my work. 10 years post 2nd surgery, Advil is my go-to pain reliever. My point is for 5-6 years I used Vicodin as a tool, a bridge from catastrophic pain and long term intractable daily pain to the grateful place I am now. When I didn't need the Vicodin anymore, I didn't take it. I now get 20 pills a year for management and I had 8 left in 2016. This is an opioid success story.

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During my first 18 years of getting treatment for my INTRACTABLE MIGRAINES & HEAD PAIN~  
~My PCP sent me to many doctors; procedures, etc. & tried many medications trying to "FIX" them~  
~ALL to no avail.~MIGRAINE can't be fixed or cured.   
~They CAN be managed.  
  
He finally Rx'd Fioricet #3~to see if that would manage them.   
  
~I was also having to get an injection of Demeral & Phenergan at least 2x a week. Somehow I got through the days......BARELY.  
  
~I was on a "ROLLER COASTER" up & down.   
~I now know that Fioricet #3 + injections were the wrong type of MED for INTRACTABLE CP.   
~Both are SHORT-ACTING.  
  
~I didn't realize that until I had found a competent PAIN DOCTOR.   
  
In the mid 90's, his final try was sending me in-patient to STANFORD MEDICAL CENTER in California~  
  
~Their theory was take all CPP off their PAIN MEDS & gave us SMALL differing amounts of METHADONE.   
  
~Once again, we were treated like ADDICTS & felt like LAB RATS & none of the CPP got ANY PAIN relief.  
  
Also under my PCP's care~  
~I ended up with another chronic illness because I now have an extremely INFLAMED stomach lining~  
  
~From having to take TOO many EXCEDRIN during ALL of these days/months/years~which gave me ULCERS.  
  
~Which led to bleeding ULCERS.   
  
~At one point~I ONLY had 1/3 of the BLOOD VOLUME that I should've had & ended up hospitalized~having to be TRANSFUSED with 4 UNITS of blood.   
  
~I also have a NARROWED GASTRIC OUTLET from ULCER SCAR tissue; that will most likely need corrective SURGEY.   
  
And after nearly 20 years, my PCP "let me go" because I WASN'T FIXABLE.   
But I was. Or my symptoms of this "NON-FIXABLE" DISORDER could be.  And I was about to find out how.  
  
~Actually my PCP "letting me go" turned out to be a blessing in disguise, because in 1999.  
  
~I found what TRUE PAIN MANAGEMENT was!!   
~I was put on LONG-ACTING OPIOID THERAPY with a SHORT-ACTING OPIOID for breakthrough PAIN.   
  
FINALLY, I got RELIEF.  
  
~LONG-ACTING OPIOID MEDS + B/T MEDS were the KEY!   
  
~And once my SEVERE IP was controlled.  
~I was able to LOWER my dose.  
~I NEVER went UP a DOSE once we found out the CORRECT dose.  
~I was able to LOWER my doses.  
  
~And since 2000~instead of having to get PAIN injections 2x a week.  
~I've gone 4 or 5 times all total.  
~Obviously when on the correct DOSE for INTRACTABLE CP~WORKS!!!  
  
TAKING CPP OFF THEIR MEDS IS NOT THE SOLUTION!!  
  
~NOT giving CPP anything or VERY small doses of PAIN MEDS & us having to supplement with NSAID's for INTRACTABLE PAIN things like BLEEDING ULCERS will happen~  
  
~Or end up with problems due to out of control HIGH BLOOD PRESSURE~  
  
~IF CPP's EVEN MAKE IT THAT LONG  
   ~~MANY will commit SUICIDE~~  
  
So FAST FORWARD to the PRESENT. ~DUE to circumstances beyond my control~I'm on my 3rd PAIN Doctor since 1999.   
(1st Pain Doctor sold his practice to 2nd Pain Doctor who passed away~which led me to my 3rd & current Doctor.)   
~Under Doctor #3's care, I was KEPT on ~my SAME dose/SAME meds as what ~Doctor #1 & #2 Rx'd.  
  
And then I started hearing about this 90 MG. MORPHINE equivalent cut off.   
  
~I was on 180 mg. LONG-ACTING + B/T meds & THAT had already been lowered & I was NO longer on the right B/T MED.  
  
~So the thought of 90 MG a day seemed like "NO WAY" will LESS work.   
  
~This current dose kept my #10 IP at a ONLY #5. Try living with PAIN every.single.day.   
  
~Let alone #8 to #9 PAIN because a Doctor CAN'T/WON'T Rx PAIN MEDS for CPP.   
  
~It's NOT LIVING ~It's EXISTING in HELL.  
  
And then in Oct. 2016~Doctor #3 started talking to me about SUBOXONE.   
  
~I didn't think an OPIOID + OPIOID ANTAGONIST would work for my INTRACTABLE CP~I didn't know how I'd be MORE stable??  
  
~But I could see how the world of PM was changing & things were turning ANTI-CPP and ANTI-INTRACTABLE PAIN CONTROL.  
  
~I didn't want to be left without a PAIN DOCTOR.  
~So finally after 8 months of going over it with my Doctor.  
~I started on Suboxone in June 2017.  
  
And NOW~6 months into it~I'm still NOT sure it's going to work for my type of INTRACTABLE HEAD PAIN.   
~I have OFF & ON PAIN CONTROL parts of days~NOT a #5.  
~But it swings from a #1 to a #10 and NOTHING for B/T PAIN.   
~OR as low as a #1~but ALOT of those days it takes MORE for IP control than the PROTOCOL amount used for addiction.  
~And I'm NOT getting anything for B/T PAIN right now~ONLY Suboxone.  
  
I am NOT an ADDICT.   
I am an INTRACTABLE MIGRAINE/HEAD PAIN PATIENT & after 35 years of off & on PAIN CONTROL~  
I find myself ONCE again BACK to SQUARE ONE~  
or WORSE.   
  
What happens if I~like MANY others, CAN'T get GOOD PAIN control or ZERO PAIN control??   
  
I ASSURE you WE CANNOT EXIST in a CONSTANT STATE OF SEVERE PAIN.   
  
It's going to WREAK HAVOC on our bodies. To name a few~  
~HIGH BLOOD PRESSURE problems.  
~ GASTRIC BLEEDING/ULCERS.  
~NO QUALITY of LIFE.  
  
~IF we even MAKE it that long. MANY are committing SUICIDE already~because they CANNOT GET AWAY from the PAIN.   
  
PLEASE~LISTEN  
PLEASE~HEAR US.  
  
WE ARE REAL PEOPLE~  
WITH SEVERE CHRONIC PAIN~THAT IF NOT MEDICATED~  
CANNOT FUNCTION~JUST EXIST.  
  
WE SHOULD NOT HAVE to FIGHT for WHAT is a RIGHT~a FREEDOM--  
to LIVE a LIFE~FREE~  
FROM THIS PRISON OF~PAIN.   
  
THANK YOU. 💜🤕❤  
Sheri LaCross

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To whom it may concern,   
  
I'm a chronic pain patient but I'm also a mother of a heroin addict. I know the situation of this opioid crisis intimately from both sides.These are two separate populations with different needs. Somehow the lines of these two populations have become blurred and  
the lives of the larger population of chronic pain patients is being sacrificed for a much smaller population of addicts. My addicted son needs help but limiting prescription opioids is not the answer for either of us. These blurred lines have left us in a situation where there is now a crisis of pain that mainstream media and government is ignoring. Most chronic pain patients now have difficulty getting prescriptions written and filled...pill mills are long gone; pharmacies are denying legitimate prescriptions; some cancer patients are being denied pain relief unless in hospice;   
ERs regulary turn away people suffering in pain; and its becoming common for surgeries and fractures to go home on OTC pain medication. Here is my/our story...  
  
I have lived with fibromyalgia for 26 yrs. For 13 yrs I struggled with raising a family and taking care of a home. I had tried every alternative treatment possible and even participated in a Harvard study without any success of relieving my pain. I gave up on treatment for many years as it was exhausting and discouraging to participate while receiving little to no pain relief. Thirteen years after I first started having symptoms, I decided to seek treatment again hoping something else had become available. It had been a very difficult few months that spurred me to see the doctor again regarding my fibromyalgia. I was spending more and more time in bed and less time being a mother. I was referred to a rheumatologist. Several opioids & dosages were tried before arriving at one and a correct therapeutic dose that worked beautifully. I felt my life had been given back to me. For 7 years I lived again very close to what I would consider a normal life. As long as I paced myself, I could enjoy activities with my family, gardening, volunteer work and going on vacations. Vacations that included hiking, snorkeling, climbing Mayan pyramids, and spending multiple days at amusement parks to name a few. If I over did it, I'd pay for it later but I also had medication for breakthrough pain if this happened. I was never without pain but it was under control enough that I could participate in these activities. I was involved in my loved ones lives as a wife, mom & friend. It was a wonderful 7 yrs but it all came to a screeching halt when my rheumatologist abandoned me. I was transferred to a pain clinic where my medication was switched to one that was less effective and the equivalent dose was reduced. My life went from vibrant to dull. It went from activities outside of the house with family & friends to mostly homebound. I've missed countless school activities and spending time with my kids outside of my home. My overall health is suffering as I am no longer active. I've since been diagnosed with widespread osteoarthritis. I'm being told now if not for the diagnosis of osteoarthritis I wouldn't receive pain medication at all. For some reason there are studies (false studies) that claim fibromyalgia pain is not relieved with opioids. I'm living proof as are 1000s of others that opioids do help fibromyalgia. I believe these so called studies have been skewed to fit the narrative that opioids don't help chronic pain. In addition to no longer participating in the activities I've mentioned, I do very little cooking, no longer shop for groceries or anything else unless it's online. My last vacation was 2 years ago to Disneyland and I was pushed in a wheelchair. I tire easily because of loss of stamina due to incativity. It's even difficult to bathe on many days. It's hard for me to follow up with doctors I should be seeing for other health conditions. My life has been reduced to living vicariously through tv and books. Pain affects everything...physical, emotional, social and financial aspects of one's life. I want and NEED my life back. On this course of pain and inactivity, I KNOW my life expectancy is being shortened. I'm not able to do simple things I was able to do even last year and I know this is due to inactivity. My elderly parents are in their 90s and I'm unable to help take care of their needs. I'm relying on others when I should be able to help and the sadness of not being with them as I should be is sometimes overwhelming. As it stands, my future looks bleak. I want to be here and enjoy time with future grandchildren and I worry this won't happen. Studies show that less than 1% - 5% become addicted when opioids are taken for chronic pain. Most studies state the lower end. This means that more than 95% of us take our opioid medication responsibly and do not abuse it. We are not the cause for alarm. Please take steps to rectify this horrific injustice that millions of chronic pain patients are in by no fault of our own. I've never broken a rule in 12 years of opioid therapy. It's criminal that our lives have been taken away from us.   
  
My son is a heroin addict. Yes he started on pills but not through a prescription of his own, not mine...mine have always been kept in a safe...or from anyone he knew who had a prescription. He bought them off of the street. Once oxycontin became abuse deterrant, he went on to heroin. Heroin was also cheaper. We spent our retirement savings by putting him through extensive rehab, but he has relapsed several times. He's currently sober. He's had 6 friends die within the last 9 months due to overdoses. These were seasoned heroin users and we suspect that illicit fentanyl mixed with the heroin was what was fatal. There are also fake pills on the street made from this illicit fentanyl and pressed to look like real pills. For the addicted, heroin & illicit fentanyl is where you will find the current crisis. It's not prescription opioids. Please step up programs for treatment. We're now broke because our savings was spent on our son's treatment. I'm not able to work because my quality of life is now gone. My family is broken because our government is failing miserably in trying to fix this situation with horrible policy decisions that aren't working for anyone.

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My story started out like all autos immune suffers first you think it's nothing you're just over worked coming down with something just need to workout. As you get worst you go to the doc who tells that you're so young to be feeling like this, and when you tell them that you can't move your neck that your back is throbbing your hands are going numb your eye sight is failing the doc tells you that's it's all in your head, you ask for something for the pain and immediately your are a pill seeker.

I would be at work in so much pain, I had a special chair ordered for my back pain had pillows surrounding my lower back and by 4pm I'd have ice packs on my neck. During lunch time I'd be so tired I would lay down at work to sleep. This went on for 2 years until finally I couldn't take it any more. In 2005 i left my job and went on SSD now my money is cut in half but at least I can get some rest. But rest I didn't get. The government made me jump through hoops to prove I'm sick and the doc keep telling me you're so young go home and walk. I had Medicaid for insurance what that means is you don't have a regular doc you go to a clinic where you see an intern who still learning his own ass. This went on four 3 years fighting with the docs trying to get someone to believe I'm sick.

Finally in 2009 i went on Medicare with this insurance I was able to see a private doc. With on visit and proper test I was diagnosed with hisimoto thyroid, Rumitiod arthritis, and Multiple sclerosis. I felt like yeah I'm really sick! But then it hits you..DAMN I'M REALLY SICK and there's no cure. I was ok though because I found an angel in my pain management doc. Dr. H. Mandelblum and those in his practice made me feel safe, they listened to me, didn't make me feel like a pest, and if I was in pain he helped me. He would listen if I wanted to try different drugs for pain and never said no. He told me once, these meds are made to help relive pain if this helps you then take them. I was always careful with my prescription I didn't Dell my pills or abuse them I was grateful to have a doc who believe in me. Then one day in August I was told that the DEA  is making Docs cut back on the amount of pills they prescribe. He was going to have to begin to cut me back until I would be on nothing. I didn't agree but what was I going to do. Next visit I went in and he couldn't look me in my eye I was told that unless I had cancer I would not get pain pills and was removed from OXYS & 75mg fyental patch. I was told to go home and take adyrall for the anxiety I was going to go through good bye. The next morning is when the withdrawal began by the evening I was ripping at my skin and vomiting and going to the bathroom on myself. I called a rehab place to see if I could get in but was told they didn't take my insurance. GREAT...

The next day my best friend came over and gave me DOPE.

Well now I'm a 52 year old woman with some serious illnesses and my pain management doc has been replaced with a dope dealer. I want to just die. The only thing that's keeping me here is my first grand child is about to be born. I need to get into a rehab to detox I wish my doctor had set that up, but again my insurance doesn't cover it, and now our government is cutting back on that too.

I tried the weed but it doesn't really work on bone pain and that's the worst. So now I'm not in pain, but I'm a 52yr old JUNKIE.

Well, that's my story, it could have been great instead if I don't get help soon I will be dead by the summer of 2018.

THANK YOU,

Broadies Byas

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| |  | | --- | | **Vicki Coast <merwyncoast@gmail.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |
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Dear Stacey,first off I would like to introduce myself.  My name is Vicki Sulfaro I go by vickicoast on twitter.

I would like to thank you for giving us a voice, all of us who are the forgotten

Victims in the war against drugs.

Before my car accident on June 7th 2000, I was a active productive member of society. I had 2 teenagers a husband and I was a care taker for my wonderful mother in law.

That afternoon I picked my daughter up from school, normally she would have caught a ride home With her brother, but he was Graduating in a week and wanted to hang out with his friends for a few hours.

As we were sitting waiting for traffic to clear so I could turn we were hit from behind at approximately 50 mph.

Since we were stopped the police officer said it was a impact speed of approximately 150mph impact. He hit our car so hard my seat broke.my spine was violently twisted causing my L5-S1 disc to collapse  trapping the nerve root. We both had severe whiplash and we both still have problems with our necks and headaches.  After the accident we went to the er where we received horrible care.  No x-rays  the er doc even then said we only needed Tylenol. I received physical therapy that helped for a while but it continued to get worse.  Finally 3 months after the accident the insurance Co agreed to do a CT scan, they found that it had totally rupture the disc causing the vertebra to overlap. This was 9/00 I saw a neuro surgeon  in November 2000, was told I needed a spinal fusion.I was terrified, but trusted my pcp, he said that the neuro was a great doctor he had himself had been operated on by him. I was in horrible pain, they did horrific tests like a discogram.very painful, very invasive yet I received nothing from the neuro. They finally approved surgery,but it wasn't until the end of March 2001 March 20th to be exact.

I had of course gotten a 2nd opinion. And they agreed no other recourse but surgery.   So on 3/20/01 I underwent spinal fusion through my abdomen. A very painful surgery  as they also took bone from my iliatic crest. After that I was sent home after 2 days with enough pain med's for 3 days . Fast forward 3 months was released to do more normal things.  And I was totally off pain [meds.in](http://meds.in/) August of 01 a started having the same symptoms,lots of pain, I called and was scheduled for a mri. It showed everything looked OK I was told take Tylenol. I continued to get worse to where I could hardly walk. In March 02 I was released by the neuro surgeon  saying there was nothing more they could do  for me. I was adviced to see a phycologist because of my obsession with my pain.  I went to so many doctors seeking answers, I thankfully at this time had some relief due to medication from my primary doc. It took me 3 years to find a doctor who would listen, and after a mri and a nuclear test showing intense inflammation  in the area. He told me he had good news and bad news, I asked for the good.

He told me he could help me but needed to redo the fusion I was elated thinking I would be feeling better soon.

Once he opened me he quickly saw that it wasn't going to be that easy as the cage the first doc put in had shifted in those first few months growing crooked into my spinal canal.

While he could keep me out of a wheelchair he was not able to help me with pain relief.  My pcp had no problem giving me med's and I was able to still enjoy life, different of course how I had planned, but I was OK.

Fast forward to 2010(I believe it was this year) when WA state decided that anyone taking opiods over the equivalent  of 120 mg had to be treated by pain management.  Until December 2016 I had no issues getting my medication  when I saw my pain doc in December 2016 I was informed she would be cutting my med's down due to the "new opiods law" the CDC GUIDELINES she was going by. Since December 2016 I have been cut back from 150mg of oxycodone to 60 mg a day. I never had any issues taking my meds,never abused them, never asked early or went to the er. In reality I was the perfect patient . Now I feel like I've been abandoned  that the doctor don't

Care.  I went from a stable dose of being able to live with my pain from 4-5 to a screaming 10.

I have severe neuropathy from the nerve damage caused by the failed surgery. I've tried everything they asked except the cortisone shots in my spine  because the trial one did nothing.  I'm 61 years old, I've lived with this since I was 43 it's getting harder every day.

Thank you for allowing me to tell my story. I know there are many like myself suffering by the CDC,DEA, AND the FDA mass hysteria.

Thank you again and God bless you

Vick Sulfaro

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| |  | | --- | | **Jenny Hart <4harts4him@gmail.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |

To whom it may concern:

My name is Jennifer Hart, I am a 36 year old wife, mom and Registered Nurse from Oklahoma.  I have a genetic condition called Ehlers Danlos Syndrome.  It causes frequent joint dislocations, subluxations, joint pain, and widespread muscle and joint pain.  I have also been injured in 2 separate motor vehicle accidents and some of those injuries never healed.  As a result, I have 12 chronic pain conditions (Spinal CSF leak, Chiari Malformation, Craniocervical Instability, Chronic Migraines, TMJ, bulging cervical disc, Tendinitis, Trochanteric Bursitis, SI Joint Disorder, Carpal Tunnel syndrome, Scoliosis, & Peripheral Neuropathy).  All but 2 of my conditions are inoperable, so I have had to learn to live with the pain. The car accidents triggered my Ehlers Danlos Syndrome symptoms, so I was healthy until I was 28 years old.  My symptoms began 8 years ago, after my first accident when I was hit by a teen who ran a red light.  For the first 3 years after the onset of my symptoms I tried every other alternative to opioids.  Physical Therapy, Acupuncture, Acupressure, Cognitive Behavioral Therapy, Chiropractor, Alternative medicine, massage, essential oils, anti-epileptics, anti-depressants, muscle relaxers, NSAID’s, injections, blocks, and surgeries.  I even have a neurostimulator implant.  My physician’s all agreed that I at least needed to try to add opioids to my treatment plan as a last resort after my 2nd car accident where I was hit by a distracted driver.  After much research, prayers and the need to return to work, I decided to give it a try.  I’m so glad I did because they allowed me to return to work, serve at church, serve as a house nurse for a sex trafficking safe house, and to function in my responsibilities and run a household.  I have now been in pain management for 5 years and abide by all the rules and conditions put in place by my pain management physician.  My pain had been controlled until earlier this year when my Dr announced he would be tapering my dosages down by 75%.  His reasoning was because of the CDC guidelines.  Even though the guidelines are meant for primary care physicians my Dr is fearful because of the high dosages I am on and says he has to get me below 100MME per legislation in Oklahoma.  He admits I am not at risk for addiction or abuse, however has seen too many physicians lose their practices because of the quantity of pain medications they are prescribing.  So, he is currently weaning me down to below 100 MME.  This is against my will, I have expressed on multiple occasions that my pain is out of control and that I am now bedridden 20 of 24 hours a day, and the 4 hours I am out of bed are severely limited as to what I can do.  I am only upright to spend time on the couch with my husband and children in the evenings after dinner. The rest of my upright time is to eat, drive my children to school, bathe and get dressed.  He says his hands are tied and will not put me back on my previous dosage.  I’m fearful I will be completely bedridden by the time he completes tapering my dosages down.  With my medication I am able to run my home, exercise, run errands, light housework, cook, go on date night with my husband, attend church, finish my Master’s degree to become a Nurse Practicioner, and attend my children’s activities.  I am not the only one suffering, my husband and children are also suffering.  Because of how undertreated my pain is, I have had to pull my children out of sports and activities because I cannot get them there, and my husband has had to work very long hours since I have been out of work.  My disability does not cover our bills. Without my medication, I will be bedridden.  Thank you for taking the time to read this letter.  I am fighting very hard to improve my condition, but feel at this time I have been abandoned by the medical community.  Next month I will travel across the country to Los Angeles to prepare for surgical repair of my CSF leak.  I have spent unthinkable amounts of money to try to improve my condition as I have a lot of living left to do.  I just need access to my medications to be able to do the rest.

Sincerely,

Jennifer Hart

Melissa Eisenstein -- Alexandria, Virginia

I am a victim of the unintended consequences of the “opioid crisis.” In 2014 a cervical myelogram that went wrong left me changed forever with severe neuropathic pain. Because of this I lost my ability to work, live on my own, had to give up my car, and did not even feel like a person anymore. In the beginning, I could barely walk, needed help to get to the bathroom, shower, get dressed and worst of all, was in continuous, excruciating agony. I could barely move in bed without screaming. The only thing that would take the edge off so I wasn’t screaming were my pain meds. I have been on Dilaudid and Morphine since 2014. I do not take them for fun or to get high; I do not abuse these medications, nor do I sell them I need these medications every day just to live my life.

I have been hospitalized 28 times since my botched medical procedure for acute flare-ups of my chronic pain and concomitant medical issues. When I get severe pain flare-ups, the only thing that helps is to go to the ER, then be admitted and put on IV pain medication (delaudid) or a pain pump for a few days. I hate the way the doctors and nurses look at me when I have to go to the ER's lately. I even had one doctor look me in the eye when I was in agonizing pain and tell me that because of the opioid crisis and because six people in his high school died of overdoses, he would not give me any opioids. He would only give me Tylenol. He would not consider my diagnosis, talk to my pain doctor or look at me as a patient, much less a suffering human being. That was the scariest visit of all. Often, I feel like I am looked at as a drug addict when all I am looking for is a little pain relief so I’m not in agony. And I never go to the hospital with acute pain unless I’ve tried to beat it at home for at least a week until I just can’t take it anymore.

My pain doctor that I have now is great but I had to go through many horrible ones to find him. I feel terrible for him because he is under so much pressure from variety of government sources. He told me that because one patient did something illegally his clinic was raided by the police. Like most good doctors he is ethical and does everything by the book. They are just trying to shut down pain doctors down. Yes, of course there are unethical pain doctors out there and unscrupulous pain patients, but good people should not suffer as a result. I feel I’m being punished for their actions while neither my pain doctor nor I have done anything wrong. We need these medications to survive. I need this medication just to be able to get up and move around my house or to go to the supermarket, a small thing to most, but a very big deal to me. That’s not asking for much, is it? To be able to do what most people take for granted every day? To feel just a little bit like a normal human being.

Everywhere you look today all you here about is the opioid crisis and how people are dying from overdoses, but that’s the side of the story the media is telling. What about the hundred million in the U.S. suffering with chronic pain? What about me and the millions of innocents being turned away from the only relief they can get while we wait for science to find cures for our underlying organic diseases. What about the families that have to watch us suffer and are care for us every day? Where are their rights? Why aren’t we getting the same attention as those who are falling prey to illicit drug dealers? How can we get can get our story heard when the cultural narrative is so massively tilted towards the “opioid crisis” and not the far larger “pain crisis”? People in the thousands are killing themselves because the pain is so bad and they can’t get the medication they so desperately need. How is that acceptable in our world today? We need to speak up, stand up for ourselves. Most of us will live with this pain for the rest of our lives. Shouldn’t we have the right to have quality of life? Shouldn’t we have the right to be as pain free as the self-righteous pundits who, pain free, deprive of our lives. Let them feel our pain for five minutes, the intense burning inside our limbs, the sharp stabbing pain in every part of our bodies. Let those who ignore us stand in our painful shoes and then tell us we don’t deserve relief.

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I've been an R.N. for 30 years. My career ended due to back/chest pain. Tests performed and medications prescribed. My orthopedic physician told me my career was over. He stated further that I am permanently disabled. I went into a tailspin. I defined myself as a nurse...and that was lost.

I was sent from doctor to doctor and test to test.

My body was changing with whatever was happening to new. The pain became severe. I discovered that I was comfortable only @ home. The medications reeked havoc on my body and mind. I went to see the usual rheumatologist. I said that my hands hurt so bad that I wanted to cut them off! He didn't even look at them...he just wrote for medications.

I went to a new primary care physician. He straightened out all my medications. I went through 4 pain management specialists. One told me to buy his book for $14.95 and I would find the answer. The last pain specialist said she we ouldn't even know where to start. I had followed the instructions of all of these specialists without relief!

I finally found a rheumatologist who listened.  She ran the tests and did x-rays. I have mixed connective tissue disease. I have been failing treatments. Currently I am on MTX & started Humira. I am only on the 3rd shot of Humira and am willing to offer put up with the side effects if it will stop the progression of the disease. So far, I just feel the side effects, no relief.

After trying all therapies the pain management specialists had to offer, I found the only thing that curbs the pain is Norco 10/325mg q6h as needed. The dose nor drug has been  increased nor changed. I do not go early if I need more.

The MCTD has ruined my hands as well as my feet.

My orthopaedic surgeon said I need a total knee replacement.  "You have the knee of an 85 year old woman...a dead 85 year old woman." were his exact words. My neurologist & rheumatologist said I need carpal tunnel surgery in both wrists. Since the MCTD is not under controll, I am unable to have the surgeries. I have arthritis of the spine as well as my joints. My fingers are morphing into deformity before my eyes. Walking can be so painful. It is like walking on broken glass

My sleep is disrupted due to pain. I am up all day but start to fade about 5pm. Then at 7pm I am awake.  I am thinking how to get to the he bathroom without feeling like I'm walking on broken glass. Then I am awake. How I long to sleep. The sleeping pills does not work. I am experiencing  inconsistent sleep patterns.

With all of this occurring, I have another rare medical issues it seems. I was diagnosed with PGAD. Those initials stand for persistent genital arousal disease. My GYN was inexperienced in dealing with it but tried everything that had been tried without effect. I was evaluated by another GYN who was barbaric, rude and never washed his hands! I silently suffer with this condition, which no one seems to discuss. It's like a dirty little secret. That thought plays with one's mind. It is exactly what a male goes through when he experiences a pryapism. No one laughs nor snickers at that.

The pain from PGAD is severe, rearing itself unpredictably. Little is known about it and there is no money to fund studies to get relief from this disorder.

My Raynaud's is so bad that just removing something from the refrigerator is painful. I have to wear gloves and socks 24 hours a day, 7 days a week. That is all a part of the MCTD.

Along with these conditions comes fatigue, exhaustion, isolation, excruciating pain at times and a sense of being lost since there are no answers. After trying so many avenues of pain management,  the only thing that has at curbs (not take away completely) is the Norco. Without that, when the pain is severe, I am looking down a dark tunnel, with no light in sight.

The Norco is a quality of life drug. I have tried medical marijuan, which only made me nauseated. If you eliminate the Norco, the only pain medication that works at curbing my pain, then you lessen me as a human being, you reduce the quality of my worth.

Medically speaking there are distinct lines between pain management drugs and drug addictions. The lines blurred when the government looked at it. It's easier for you to deal eith when you blur those lines.

Yes, there is a drug addiction issue. Taking the drugs away from everyone is not the  answer. That would be like finding the solution to DUIs by reinstating prohibition. You find your solution but you punish the good with the bad. In the case of opioid, you hurt the patients who truly need the medication to keep the pain at bay.

Young people drinking alcohol leads to smoking cigarettes  (another addiction, another killer) to heroine. Heroine is illegal but somehow they still get it.

People are killing others with guns yet there is no gun control. These people on these shooting sprees are all not suffering from mental illness. These people are angry and feel they have the right to kill. They feel entitled to kill others. The government has shied away from gun control.

People suffering from chronic illnesses that have chronic pain involved do not have a big corporation nor empire to stand up for us.

I am asking you to not devalue our worth. Do not treat us in an inhumane way. Pain is personal. Yet pain is very real, too real. If a patient with chronic illness with chronic pain is monitored closely by a physician, that is reasonable. It certainly is a compromise. Then those who suffer from drug addiction can be helped. You are not throwing the baby out with the bathwater. I am asking you to look at this through the eyes of a victim of a disease that link it's ones' abilities and inflicts severe pain. Let us, at the very least, receive the pain medication to decrease the pain. Without pain control via opioids, sadly there will be an increase in suicide. This is because the pain can be maddening. Please give us our quality of life by giving us our pain medication monitored closely by a physician.

Thank you for your time and efforts.

Respectfully,

Rosemary Pedersen

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Dear Sir or Madam,  
 I am a 47 year old female and I suffer from chronic pain. My journey began in 1998 at the young age of 27. My right lung collapsed. I was in the hospital for twenty three days. In that time I had 4 surgeries ( Thorascopic Wedge Resection,a pluradesis,chemical pluradesis, and the removal of a large hemothorax). I had a total of seven chest tubes and now suffer permanent nerve damage. In 2005,I was diagnosed with Histoplasmosis. In 2009,I had a Bi Lateral Tubligation and again in 2016, both tubal clips had come off and were floating dangerously close to my bladder. One clip was successfully removed however the second one is embedded in a small pocket behind an ovary. In the process it was discovered that I have sizable ovarian cysts. When one burst, it can bring me to my knees. In 2010,I had a Laparoscopic Cholecystectomy after years of unresolved abdominal pain. In 2013,I was diagnosed with a Pituitary Micro Adenoma with Hyperprolactinemia which causes headaches daily. In 2014, I was diagnosed with Tendinitis and early onset Bursitis in both of my hips. In 2014, I was diagnosed with and hospitalized for a deadly Intestinal infection ( I can no longer take NSAIDs, they cause bleeding ulcers). In 2012, I was diagnosed with three bulging Lower Lumbar disks with Sciatic nerve pain. In the years since my initial diagnosis things have worsened to four bulging disks with moderate facet degenerative changes,Spinal stenosis,Symmetric bilateral neural stenosis,Mild and moderate end plate building (depending on the area) and a cyst has been discovered. I have had 60 plus epidural injections. The injections helped at first however the last set of forty two ( in a 6 week period) all failed so my only option is pain medication.  
 Having Chronic Pain for the last 20 years has changed my life. I can no longer work, my home life is different ( I hate to be a burden to my husband or adult son). I often need assistance with everyday tasks such as doing the laundry or the dishes, going to the grocery store. My Sex life is non existent with my husband, I realize that you probably think that is to much information however it has taken a toll on my marriage. My social life has changed. I sometimes must cancel pre made plans because I just can't walk or must lay down. I know what you are probably thinking, that I need to get up,stop feeling sorry for myself and be proactive. Trust me, I don't feel sorry for myself. I feel sorry for my former co workers, friends and family who have watched me decline from and energetic full of life young lady to a middle age woman who needs assistance. Chronic pain wreaks havoc on the mind and body. I also want to tell you that I am proactive in my own health. I do yoga daily (if I am able). I go to water aerobics twice a week (if I am able). I attend Physical Therapy once a week (if I am able). I also have a wonderful Physchiatrist I see every other week I have never missed a doctors appointment or test. What I would like you to understand is that without my pain medication I would not be able to do any of the above things at anytime. My pain medication allows me to function as a productive part of society.  
Thank you for your time,  
Catherine Pridemore  
Omaha,Nebraska

---------- Forwarded message ----------  
From: **Vicki Coast** <merwyncoast@gmail.com>  
Date: Wednesday, November 15, 2017  
Subject: Andrew Kolondy  
To: "lm2892@cumc.columbia.edu" <lm2892@cumc.columbia.edu>  
  
  
I'm writing to you to ask that your please reconsider  hiring this man who had caused so many people to suffer.  He stands to benefit  greatly on the backs of millions of suffering people.

Is this really someone you want in your university. When his goal is to remove opioid treatment for everyone,when there is proof  his campaign about drug addicts is not correct in the fact that the market is  flooded with fentynal and heroin that's causing the addiction and deaths.

I humbly ask your remove him from your consideration for your university

And speak out against the injustices he has caused.

Have a good day

Vick Sulfaro

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| |  | | --- | | **Bonnie Bayers <phoenix.rising@mac.com>** | | 15  https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |

I’m sorry it’s taken a few days to write & get this to you, I’ve been wondering if I should give out my email & just how much info you need. I’m not sure why you are collecting stories like mine so that’s why I’ve left out names, locations, etc. however if my story is what you’re looking for we can talk about me providing records, names, etc.  
Anyways...I guess I will just start from the beginning, kinda ‘readers digest’ it for you to get you caught up to what is going on now. I’m sorry if that’s why it’s so long.  
  
In 2001 I had surgery on my right foot which developed into Reflex Sympathetic Dystrophy (RSD) or as it’s now called Complex Regional Pain Syndrome (CRPS). I was not technically diagnosed with RSD until 2003 at which point I was immediately given the usual protocol of nerve block injections, physical therapy, medication and when that didn’t work I had my first spinal cord stim trial & permanent placement all within that year. At the end of 2003, I fractured my stim lead & needed a replacement, so of course I agreed. It had helped with the pain from the RSD so I was looking forward to getting it replaced.  
You know what no tells you about surgery...any type of surgery let alone something that needs to be implanted in your body? That if you are the type of person who scars easily, it’s probably not a good idea to have it because your body will not be a happy camper. In other words, your body will build up adhesions to ward off that ‘foreign’ object that you have put in your body.  
So there I was getting a replacement stim not knowing what kind of damage I was doing to my spine but the Dr saw it as soon as he opened my back up to remove & replace those leads. It’s written in the OR notes that he took out more scar tissue than what should have been there; but he kept going and replaced the leads with new ones & didn’t say anything to me.  
This explains why that stim & the 3rd one I had trialed, old one removed & a new permanent one placed in, in 2005 never worked like that first ever did.  
I was finally told all this by a Dr in 2010 who I spent all of 1 visit with, he had all my post op records from previous surgeries & took one look at my arm & saw a scar from when I was 6 years old & thought it was only 1 year old. It was then he realized I had a very common condition called keloids.  
  
So going back to 2004, while I’m in the midst of having the 2nd stim & it not working, the RSD Dr at the time had me on multiple medications to find the right protocol. Enter first the usual- neurontin. I was on 400mg along with other meds like anti depressants, pain (Percocet at that time), thyroid, etc., & my roommate comes home to find me unconscious to the point that she needs to call 911. I have no memory of any of this other than going to take a nap then waking up in the ER & the Dr asking me if I tried to kill myself (no!). My blood work came back & showed that I had a nasty reaction to the neurontin so my Dr took me off it.  
  
So far & up until 2011, my pain journey had been very mild compared to others and I considered myself lucky.  
  
  
Fast forward to 2011, I’ve moved out of state & I’m seeing a new RSD Dr. All of a sudden this new Dr wants to send me to this ‘special clinic’ at a major university hospital that specializes in chronic pain therapy & treatments. The way this place was described to me was astounding! They made it seem like the place to offer a one stop shop of PT, mental health help, bio feedback teaching for pain control & medication help too but they work ‘with’ your Dr to come up with a treatment plan. It was sold as a one stop shop & they were there to ‘help me on my journey of pain to regain control of my life’. Man, I fell for that shit hook line & sinker! I was not only desperate for something different from the years of what had been the ‘same old’ treatment but they really got in my head which still surprises me to this day. That place, under the guise of a university hospital name, did nothing but tell me that I did NOT have RSD & all my previous records & Drs were wrong, I was an addict for taking prescription pain medication & if I continued to do so I would need to continue therapy with them for addiction treatment, that hypnosis would cure my pain that’s in ‘my head’ and the therapy sessions I had to attend were constantly looking for problems that didn’t really exist. The things they said & did there were so messed up I can’t begin to explain. They would check my shoes at PT every session for ‘wear patterns’ to make sure I was telling the truth about how I was walking, or the lack there of. They wanted to see my other shoes I wore from home. They checked my hand that I used my crutch with & said because I didn’t have a thick enough callus I must be lying. I said because I buy a pumas stone for my hand I guess I must be crazy?! It was things like that & worse, over & over. Every single visit.  
The Dr who sent me there said it was mandatory I go there in order for him to prescribe the pain meds he was giving me. He ‘relied’ on their opinions for my treatment. I was so confused, crying after every visit, in a different state (literally) & did not know what to do but to stay the course because my PCP was not able to offer any help when I asked.  
After 6 months of this shit show, divine intervention happened, I woke up one morning & took a nasty fall & injured not only my foot with the RSD but my back with the non working stim. The ER Dr sent me to a neuro for a consult because (shocker! my pain Dr didn’t give a crap when the ER Dr called him & asked him if he wanted to see me) the CT scan showed a lot more than just a jacked up stim in my back.  
So my next appointment with my pain Dr was interesting. He actually yelled at me for going to the ER, not calling him first & letting them give me toradol for pain. I’ve never had a Dr actually yell at me before. I was so shocked & crying my eyes out I never wanted to go back. I called the neuro I was sent to the next day & he referred me to a PM&R Dr that to this day I wish I could still see. That PM&R Dr also set me up with a new PCP and up until I moved back home this year I was living a functional independent life.  
\*\*ok this is where the shit show starts to really unfold\*\*  
It’s 2017, I’m back home side & figured after all this time I’ll call the Dr who diagnosed me, was treated under since 2003 & up until I left for another state. Who better to see me then the one person or office who knows me, has my history of no abuse of medications, all the surgeries, etc. Turns out that Dr I saw doesn’t practice anymore but someone else in the same office can see me, which is great or so I thought. My first visit, no more pain meds. I was told that they, nor the state I’m living in now, will let any dr prescribe the amount I’m currently taking which is 12mg of diluadid every 4 hours. Oh, she also threw a little speech in there too about how ‘opioids’ have now been discovered to ‘cause’ pain not help it so it’s better to take me off all pain meds anyways. She hands me a list of how I’m to taper off completely within 6 weeks. No help meds, nothing, just come back clean in 6 weeks & then we can discuss further treatment; but if I need psych help here is a number to call & hands me a business card. So, feeling trapped & completely like this must be a joke but hey lets give this a shot, I do it. I’m willing to try this, what do I have to loose I guess? How can a Dr who has seen my history take me down a path that is so wrong I ask myself.  
My follow up visit I’m down to 4mg diluadid because as I told her the pain was too unbearable & thoughts of harming myself were getting bad. She wanted me to start on graylise 600mg (a neurontin type med) & up my current dose of topomax by 400mg. I reminded her what my history was with the neurontin. She said that if I wanted to stay on the diluadid & wouldn’t come off completely then I needed to ‘comply’ with taking these other 2 meds & she would ‘think’ about transferring me to another dr who ‘might’ take me on as a patient who ‘might’ write for the 4mg of diluadid but he will definitely not write for more.  
I had an appointment with my new PCP the following day, told her what happened & she recommended I see someone else & not go back. The person she sent me to told me they couldn’t help me but said I should see dr so & so. He was more than happy to give me a prescription for anti depressants though if I wanted.  
The next month my appointment with my PCP I’m sitting in her office crying my eyes out, telling her how much pain I’m in, stressed out, etc., & don’t know who to see for help. She has no idea who to send me to & the dr who was recommended to me sent a note back after getting my info saying he didn’t want to see me. No why or anything. 2 more Drs I was referred to sent back notes, 1 wouldn’t work with my insurance & wouldn’t take cash when I offered; the 2nd told me to go the university also.  
Next dr visit was from a google search I did to a local spinal stim dr. He took one look at my records & said he couldn’t help me, doesn’t recommend I get another stim, I’m not a candidate for a pain pump either but ketamine might be an option so I should go to the local university in town.  
So while I’m waiting for my appointment to roll around for the university I called my PCP for a refill on my sleep meds (Restoril) & also asked for a refill for Amitiza. I was told that my Restoril was being tapered & I need to come off of it & no I can’t get the Amitiza but I should go buy aloe & drink it. I said I am out of pain meds, now you want to taper & cut off my sleep meds which are the only thing at this point that gives me any relief at night or any chance of getting sleep? (And asked what is aloe?- to which I just rolled my eyes when she responded)  
Her response was to take melatonin. I started to cry on the phone & said how close to the edge I was & wasn’t sure how much more I could take of all this. The next words out of her mouth were, ‘just wait it out’.  
A few weeks later I saw the Dr & a fellow at the university. They both kept pushing a new stim on me. I repeatedly said no. I repeatedly told them that the dr who sent me here said no! I begged (begged!) them for the ketamine treatment & was told because my bph is so high & I have a history of tachycardia I wouldn’t be a candidate and my insurance wouldn’t pay for it either. I asked for pain medication since everything else was not an option at this point & I’m in so much pain. I was told they don’t prescribe narcotic medication - ‘it’s not you, it’s a policy for everyone’. The Drs recommendation was for me to take VitC for pain (yes she said it!), use a tens unit, take 400mg of topomax & go to PT. At least they agreed the neurontin part was crazy. But they wanted me to see a psychologist who recommends people for the ketamine treatment because she also recommends people for the stims. When I said yet again that I will not have another surgery the dr looked me dead in the face & said ‘just talk to her she will change your mind’.  
I called my PCP the next day, the whole VitC thing was just shocking yet too crazy town for me. Evidently still being in crazy town & not knowing it, my PCP’s response was to tell me that I needed to go to a methadone clinic for pain treatment. Much to my surprise, I calmly responded with simply a ‘no’ & said can u just refer me to one more dr please? I gave the name of someone I found online again.  
That Dr, just like the other one, sent my records back with a response of no, he will not see me.  
  
Before moving here I was able to drive a couple times a week, shop on my own, go out & walk w/the assistance of my crutch. Have a sense of independent living & be productive.  
I’m house bound now because of the pain & no treatment. It’s been about 3 months since I’ve been able to leave. I’m at the point where I’ve got tremors daily from pain, I’m so wobbly I can barely take 5 steps without falling. I can barely bathe at this point on my own. I cry at random times during the day every day, uncontrollably. I feel lost, helpless & abandoned. I don’t go to the ER for my pain because of the horror stories I’ve heard & why would I? Just to get relief for one day? The state I live in mmj is not legal so no options there. Everyone says buy kratom! It’s better than nothing! Can kratom supplement 12mg of diluadid or get close?  
I’ve had RSD for over 15 years, tried (or asked for) just about everything I could over those years to help alleviate my pain & symptoms. To be told by Drs to take some meds that will knowingly harm me, or use a tens unit that I tried over 15 years ago & it didn’t work then was like being told they didn’t care about how much pain I was in or what kind of medical advice they gave out. They all just ignored everything about me, my history & my disease. What do they do with the next patient?  
I want some semblance of my life back because this is not a life I want to continue to live if this is the way it’s going to be.

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| |  | | --- | | **Clarence James <clarencejames61@gmail.com>** | |  |  |  |
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Hello, hope you are all having a Pain free day. You see, I don't have that luxury! I am 60 years old and have severe DDJD. Had 2 MRIs done this year to see what the problem was and see if I could get some relief. Neurosurgeon's told me there's nothing they can do for me.

       I have worked and payed taxes all my life till I was declared disabled. Hope your government program helps the Addicts and Abusers. But you are making relief for Certified Chronic Pain patients,Hell! What am I supposed to do? I am bone on bone from the neck down! I will try anything. Have already tried injections and PT, several times. Now I'm on anti-depressants, which I never had to take before, because the Pain made me feel like I was losing my mind! I had a Dr before the Opioid Crisis that kept me feeling life. After the Opioid Crisis, the Drs cut my meds by two thirds.

    Please, I hope I am not wasting my time writing you, I have so much to tell. Even thought about doing a video on YouTube. Please get in touch with me, so I know you are seriously concerned! My story is a long one. About how Medical professionals got me into this, but won't help me get out!

                   Thank you!

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| |  | | --- | | **Cathy Thomas <clthomas33@aol.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |
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This is a story that never in my life I thought I would have to write. A story in attempt to keep pain medication a humane option to me.  Why has it come down to taking pain medicine away from everyone when not everyone abuses it?   Will we next be taking away antibiotics because not everyone takes them properly or because those have sometimes been over prescribed?  
Let me tell you my story.  I am a 49 year old woman. I have a Bachelors in Biology and I work in medicine, I have been working in doctors offices for 20 years.  I have seen the pill seekers and the abusers. In 20 years I have seen less of them than the ones who actually need the pain medicine.  Those of us who do need it are the last to ask for it because of the stigma.  We live in horrible pain day to day and try to grin and bear it.  
I personally live in pain 24/7 due to 4 illnesses.  I have Lupus, Dermatomyositis, Polymyositis,  and Fibromyalgia. If you don’t know about these illnesses then you really don’t want to and I hope you or no one in your family experiences any of them.  Lupus affects the largest organ of my body, my skin. I can not be in the sun as it causes me to feel like I’m burning alive. My skin hurts 24/7 along with itching 24/7.  Have you ever tried to scratch a very bad case of sunburn ? Have you tried to lay down and sleep with a sunburn over every inch of your body?  This is the closest explanation I can give you to my Lupus pain. Then there’s the Dermatomyositis which also affects the skin so it accentuates the Lupus skin pain.  I always look like a lobster I n hot water, and it feels like flames are shooting out of my skin. Then there is the joint pain that I experience in every single joint. It doesn’t matter how I sit , lay, stand I can’t get comfortable as there is no joint that isn’t painful. Have you ever injured a joint?  Try living with that painful deep throbbing joint pain the rest of your life wether your awake or trying to sleep due to the pain. Then let’s move onto Polymyositis which affects the muscles. This lovely disease causes muscle pain in every single muscle.  It also causes cramps ( Charlie horses) SEVERE cramps in any muscle it chooses for no particular reason. They can be so sever it twists a limb, it’s like watching a horror movie. I watch my limbs muscle tightening in almost like the limb is being vacuum packed and twisted around like the exorcist all while the only thing I can do is cry in pain. This is such fun for a few hours. Have you ever had such severe Charlie horses? Probably not.  It also causes muscle ticks, muscle weakness, muscle burning like you just worked out without the added bonuses of working out.  
And then this brings me to Fibromyalgia which also causes joint pain, a different joint pain. And a muscle pain but a different muscle pain.  This one is so painful that if a butterfly were to brush by my arm it’s excruciating pain to my core.  Imagine not being able to be hugged because it hurts you. Especially when your sick and hurting and you can really use a hug.  
These are just small snippets of a look into my daily 24/7 pain that I experience.  Does this sound like a fun existence????  
I wasn’t diagnosed until 2013 because I did not have insurance and could not afford the doctor visits even though I worked in medicine.  I worked for doctors who would not treat their employees and who did not see the benefits it supplying medical insurance to their employees. I’ve been sick many years.  I have been in pain many years. I did not seek pain meds until a year ago because I just could not go on living in such extreme pain without relief. If I did I was going to have to be locked in a psych ward because I couldn’t even get a full hour of sleep due to the pain. Did you know that going days without sleep is not healthy? It can cause anxiety, depression, suicidal thoughts? It will cause high blood pressure and a whole other myriad of diseases. Your body and brain need rest but it’s impossible to sleep when your in pain 24/7.  
So anyway, a year ago I finally went to pain management to get help. I went to a professional who knows how to treat pain appropriately and not to someone on a street corner.  I go every two months , I pee in a cup to prove I’m taking my meds and not selling them to someone On the street corner ( believe me with the pain I have who has the strength to stand on the corner). I don’t ask for more drugs than he gives me , even when they don’t take away 100% of my pain. I’m happy for some relief.  Maybe I can get 2 hours of sleep in, it’s better than zero.  Did you know a body can’t heal without sleep?  
I work in medicine, I have to go to work in pain everyday.  Working causes more pain. My rheumatologist would like me to not work and be home on disability. He keeps telling me I’ll never be better if I don’t. The problem is to be able to apply for disability I have to quit and have no income.  How would I survive??? How is this right??? How do we treat fellow humans like this??  You want to take away or medicine that helps us semi function, and let’s have you not be able to afford treatment or medicine to prove you are in pain and really disabled.  Sorry I know I’m off on a tangent but it’s 4:20am as I write this letter because...you guessed it I’m in pain and can’t sleep. I could take another pain pill but I won’t because I take them exactly like they are prescribed.  I am not an addict. I am not part of the problem. Taking away my medicine will not make a difference in the war on drugs it will just make it harder for me to live my life, for me to get up and struggle to work because I can’t afford to be on disability.  I AM NOT THE PROBLEM!!!! And neither are my fellow chronic pain patients.  We are begging you to rethink wheat you are doing, how many suicides you will cause, how much mental illnesses caused by pain will increase. WE ARE NOT THE PROBLEM!!! Do not punish us!  I will pray that you or no one in your families ever face the diseases or the pain that we experience and hope they never need access to pain medication. Just think about your decisions and how they affect us and what access your preventing yourself and your families from. And forcing us to live a life of pain 24/7.  Also if you don’t know..... with our diseases and the extensive medications and extreme medications we take, over the counter pain relievers like Tylenol and ibuprofen are not ok for us. They either interact with our medications or we can not take them due to how they will affect our liver and kidneys so for many of us opioids are the only option. Besides when morphine has a rough time touching the pain .... Tylenol and ibuprofen would be like putting a bandaid on a huge crack in the Hoover Dam.  
Thank you for taking the time to read my letter. I know I’m only one person but I hope you can understand that I am not the only one in pain.  
  
Thank you from a 24/7 pain patient,  
  
Catherine Thomas

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I have been a patient in a Pain Clinic for about 20 years, though the syndrome I have, Ehlers Danlos, has been lifelong. I am now sixty years old. I began having orthopedic surgeries as a child, all failed eventually, some with failure to heal. Eventually I was left with cervical, thoracic, and lumbar stenosis, many permanently dislocated and subluxed  joints, and nerve damage, including Complex Regional Pain Syndrome in my left arm and hand.  
  
I raised seven wonderful children, one who was severely brain injured at 19 while in college. He requires 24hour total care, which his dad and I provide with the help of nurses.  
  
Because of good, effective pain control, I was able to provide his care, care for grandchildren, attend class programs at both Chapel Hill and NC State, as well as work with advocacy groups for brain injury. I sit on Boards and Commissions, and communicate regularly with leaders at DHHS and in Legislature.  
  
However, the last year has been a nightmare. I am struggling to walk...to even function as my dosage is cut for no clinical reason.  
  
This approach is misguided at best. It does nothing to address the WHY..why are our youth seeking drugs? In any case, my doctor and my prescription play no part in this 'epidemic'.  
  
Please help me get back to my life, to caring for my son, and advocating for those with brain injury in North Carolina.  
  
Thank you.  
Jean  
  
Jean Andersen  
Stanfield, NC  
[704-985-2640](tel:704-985-2640)  
NC Brain Injury Advisory Council  
NC TBI Collaborative  
Cardinal Piedmont CFAC  
Carolinas Healthcare Systems Patient Advisory Council  
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My name is Erica Moote, I'm 36 and I currently reside in Michigan. I have been dealing with severe pain from endometriosis, recurring ovarian cysts, Fibromyalgia, and several bulging discs/nerve issues since I was 23. I lived on Tylenol until I saw my Dr, then I was initially treated with only prescription NSAIDS for the first 2 years until I developed a ulcer. Afterwards my Drs have had me list NSAIDS in my "allergy" section to avoid them at all costs.

Given that anti-inflammatory medications are off the table for me, it's been a really hard road to begin with..but much more so these last 5 years with the hysteria over opioids getting worse. I am a single Mother of two amazing little girls, a survivor of domestic abuse, and yes..a chronic pain patient. Of those last 2 descriptions...trying to live with pain in this day and age is the most difficult.

Think about that last sentence.  In this day and age with medical advances I am saying in all honesty it was easier to literally survive and endure abuse than try to live with pain in this era.

How is this acceptable? I have been denied medications, medications cut off, I've been dismissed as a patient, I've had to fight for referrals to pain management and after finally getting there I am treated more like a suspected criminal than a innocent patient. I have to sign a contract, I'm subject to random pill counts, and insanely expensive urine screens. I go to a Dr for help and often each visit I'm a bundle of nerves wondering "is this the day I lose the medication I use to just get through my daily routine?".  I do not ask for much...but I would like to live my life with dignity, to be able to relax..to know my health needs will be met, and that my daughter's can have a Mom that not just survives the days - but can thrive.

Please hear our voices.

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When I was 25 I went to Dr. David B. Cohen, head of Neck and Spine surgery at Johns Hopkins, for a 2-part surgery to correct my scoliosis. The first fusion operation to my cervical spine went fine and 6 weeks later I went in to have an anterior/posterior entry fusion and stabilization to my T-10 thru Sacrum, replaced 5 Lumbar vertebrae with slices of a cadaver’s femur, and a metal rod extending through my hip bones for stability.  
I did not wake up from that surgery, instead I was woken up by a stranger- young, white, skinny, tall, and male. I was alone in a dark room with no windows, and the person said “Piper, Piper wake up. You are in the ICU. Your left leg is paralyzed and you need to understand that you may never regain use of your leg or ever walk again. Do you understand what I just said?” Groggy and thinking I was still asleep and dreaming, I nodded my head, and fell right back under the anesthesia. The next thing I knew, there was another stranger at my bedside, waking me up- also young, darker skin, petite with dark, long curly hair, and female. She was holding papers. She asked me “Piper, do you understand what the gentleman said earlier?” I tried wiggling my toes, then nodded my head again. “Okay, great, then I’m going to need you to sign this. It states that you are aware of your surgical outcome…” I couldn’t read anything, or even see where to sign. The woman said, “It’s okay, it doesn’t need to be perfect, here, let me hold your hand where you need to sign” I was still fully under the affects of anesthesia, and couldn’t comprehend what was going on at all, let alone sign my name. I made some kind of mark on the paper and again fell immediately ‘asleep’.  
  
The next few days in the ICU were a blur…I was moved up to a recovery room to do my PT/OT and get discharged. it seemed like Hopkins were in a hurry to get me out of there…often a nurse or physical/occupational therapist would say “it’s okay if you can’t do \_\_\_\_ , just do this little part and I’ll check it as accomplished. I especially remember the Physical therapist saying such things. So, soon I was discharged. Hopkins sent me home with 99 staples and a 5 day supply of medication. When I called the Hospital to ask ‘What the heck?!’, when they couldn’t locate Dr. Cohen, they threatened to call the DEA on me.  
  
Over the next 3 months, I did PT/OT every day and slowly started to get some movement back, but no feeling. Every time I went back to Johns Hopkins for routine, post-op check-ups, Dr. Cohen and his crony, I mean PA, Tanya, they went through the same rehearsed charades: acted VERRRy surprised about my numbness, lack of feeling, weakness etc., as if it happened after I left the hospital, somewhere else. Asked question after question, leaving no time for me to fully answer, and touching the pen to a sheet of paper on a clipboard, but never actually writing anything down. one day when Tanya called me to move an appointment time, I called her out on the ‘charades’. Her reaction was atomic! She fumed and screamed “how dare you accuse me of ‘FALSIFYING’ your records??” I said “Tanya, I didn’t accuse you. I only asked a question” She hung up on me. The next appointment, Dr. Cohen had a student with him instead of Tanya. The poor kid looked terrified, no eye contact, just stood against a wall, stiff, silent, and staring straight ahead, like a soldier.  
  
Within 2 years, I had done multiple types of PT, beginning in a pool. I had regained the ability to use my leg like a cane and walk, but something felt deeply sad inside my hip, and it would make some very loud cracking/popping sounds. One day, I was lying on the floor, gently stretching. My company, Gap, Inc., whom I contracted my designs for, and worked full-time just long enough to get insurance, was transferring a design team out to San Francisco, and I was in a lovely apartment on Panhandle Park. I got up from stretching- mind you, these were all stretches that were assigned to me by the PT ‘team’ at Hopkins. I went to take a step and fell like a tree, “tiiimmmmberrr!”. I gently tried to get up and my left leg was completely unattached from my body. I was alone, terrified, and so dragged myself to my phone to call 911. The woman had the fire company at my door in minutes. I had pulled myself to the corner of my bed, and was balanced near it with my crutches to hold me up. The woman on 911 said that the fire department was at my front door with a battering-ram, about to break down my door. I asked them to wait one second while I tried to unlock my own apartment’s interior door, and as I pulled myself up with all of my weight on my crutches, my hip slipped back into my body. That day was one of over 100 dislocations of my hip, which persisted for the next 13 years.  
  
In San Francisco, I went to the best orthopedic surgeon, Dr. Thomas Sampson. He found that my femoral head was collapsed into itself, called Avascular Necrosis -death from the inside out- which explained the sad feeling inside of me. Dr. Sampson was patient, compassionate, a good man, and a good doctor. He performed my first Total Left Hip Replacement, later performed a surgery to remove some Heterotypic Ossification that had formed on my pelvis and Gluteus Medias,  and was in charge of (and extremely dedicated to) my pain relief. We tried a few medications, and the ones that didn’t work, I gave back to Dr. Sampson, for his work overseas in Doctors Without Borders. Unfortunately, my hip dislocations did not stop, my mother was sleeping on an air mattress on my floor to be with me and help me. My dislocations started happening every day, up to 4 times a day. My Gluteus Medias was torn up, about 20 percent remained in tact. I needed a revision surgery. Between Dr. Sampson, myself, and my mother, we decided that it be best to return to our family home on the east coast, where I went to NYC, a place I’d grown up, to see Dr. Douglas E. Padget for the revision. I was one of the first patients to have received the recalled metal-on-metal Total Hip Replacements for my first replacement in San Francisco, and we needed an expert to revise another surgeon’s work.  
  
By this time, I needed pain management. Long-term pain management. It was 2008, and laws pertaining to pain management were changing quickly. As my G.P. couldn’t prescribe pain medication for me anymore, a law that had changed while I was in CA for 2 years, I found an “interventional” (also new) pain doctor, Dr. Robert Ding, who also did acupuncture, and trigger-point injections, in my small town. I thought when I was leaving CA, that the worst was behind me. I was so wrong.  
  
Dr. Ding prescribed methadone for pain. Methadone, for pain, is about 10% relief and 90% side effects, one of them being resperitory problems. I had 2 accidental overdoses on methadone. I was already having acupuncture, with electro-conduction, to ‘rev up’ my nerves. Dr. Ding was so conservative, he set the electro-conduction on low.It affected my pain and discomfort the same way a soft caress affects a mosquito bite; the treatment ‘reved-up’ my pain and discomfort. Still uncaring that these treatments and medications were not working for me, the Doctor decided to try trigger-point injections, and epidural injections. We started with the latter, to no avail. Dr.Ding decided that I had ‘piriformis syndrome’, and told me that the only way he would be able to reach the right spot of my Piriformis muscle was to go in through my vaginal canal. I said ‘no way’ and went home. Within a week, I was in so much pain that I was throwing up, couldn’t see clearly, everything was blurry, and my hearing would kind of short-out. It felt like a migraine in my whole being. So, I weighed my options, and had my mother call Ding to make my appointment. I had to climb up on some strange table-machine, in a closet-sized room. I asked that a female nurse be present for the whole procedure. As all I could feel in the lower left quarter of my body was pain somewhere deep in my center, I did not feel the doctor start to insert his hand to locate, from inside me, the correct spot on my Piriformis muscle. There was no nurse present, yet. Since the doctor now needed help to fill the syringe, he opened the door and called the nurse in. When the door opened, I made eye-contact with a group of waiting patients. I got up, paid, left, and never returned.  
  
Thus began an eight year struggle to obtain relief, craving compassion in the smallest degree, and struggle I did. I tried everything. I spent 6 weeks at a time, 4 times over the years, at a chronic-pain management and coping strategies workshop, in Tuscon, AZ. I would go out there when I had reached the point of begging my Mother to understand that I. Could. Not. Continue; when I would wake up and just wish I were dead, like a reflex, without even thinking the words. So I would go to Arizona. I would receive coaching and healing modalities- acupuncture, bio-feedback, neuro-feedback, somatic-release-massage, somatic talk therapy, aqua-therapy, brain scans…. pretty much everything one can imagine. I witnessed some traumatizing things happen during my days spent trying to release some of my personal traumas. I witnessed another CP patient have her medication reduced to the point that she couldn’t function, she spent most of what was supposed to be therapy, curled in the fetal position in the medical ward. I knew another pain patient, a man, older, fed-up with the mistreatments he’d experienced in his life, and not entirely cared-for here at this place that was supposed to be helping him. The man hung himself in his shower, pronounced DOA once at the hospital. My fist time there, I noticed that I would trip on a couple areas of the sidewalks, as well, most of the lighting that was supposed to come on at dark was broken. I had taken 3 face dives , all witnessed by patients, nurses etc. . One night I was walking on a path -the grounds needed landscaping- and I tripped-over, de-rooted a barrel cactus. Painful as that was, it was even worse that not a single nurse or doctor on site had the correct education on how to remove cactus thorns. Nothing was fixed until after 3 tries to make an appointment with the director failed, I waited outside of her office for 3 hours until I made a meeting appointment with her, face-to-face. The meeting went like this:  
Me: such-and such happened and the grounds are unsafe for any kind of physical handicaps.  
Director: prove it  
Me: I can show you.  
Director: the grounds are clearly explained on the map that you got in orientation.  
Me: stands up and shows her my bloody, scraped-up hands and legs, and of course the thorns still puncturing my skin. I then said one word that changed everything. I said, “I feel like the only option I have here to protect myself, in a facility that is not only supposed to be safe, but theraputic, is to get my Attorney involved.”  
That changed everything. Within the afternoon, there were crews landscaping, and all off the lights were fixed by that nightfall.  
  
Along this 8-year struggle, I would find myself telling myself two things, when times got near-unbearable. I would hear myself say ‘savor this, Piper. This is as good as it’s going to be, for a long, long time’. And when things were nearly unbearable, I would tell myself ‘It can be worse’.  
  
I was molested by an extremely talented, helpful, partially-blind Massage Therapist that I’ll call “Steven Smith, of Easton, MD”. It turned out that he was not blind but used the notion, and the dark sunglasses, to his advantage, during my trial, his wife used the opportunity to say that he had been caught, by the wife, in their 10-year-old daughter’s bedroom on multiple occasions, and was afraid for her own life and for her daughter after Steven had verbally threatened them. After reports and allegations appeared in the local paper, over 13 women came forward, with matching stories to mine.  
  
I tried doctors, of course. I was told by the many doctors from whom I sought help, these varying responses- always before they ever saw an x-ray, or my foot-tall stack of medical records, or the 2 hours, each, of paperwork I had to have filled out before I could so much as sign-in to the office- these were my responses, each by a ‘new’ doctor or ER surgeon:  
-I won’t treat you.  
-You’re too complicated for my practice.  
-I can’t treat you.  
-I don’t care.  
-I can do everything other than prescribe opiates. (After trying ‘everything’, my pain was getting worse. The doctor actually yelled at me for needing opiates as well)  
-If you don’t get, and keep your pain under control, you won’t live to see age 40 (I was 34). This was told to me by the only doctor who took the time to sit down and look over my history. He confirmed that I had Intractable Pain, Ehlers-Danlos Syndrome, and Adhesive Arachniditis below my L4 Spinal nerve. He also treated me with the appropriate amount of pain medication.His name is Forest Tennant, and he knows what he is doing. He released me to find doctors in Maryland, where I was living, as he was 88, and in California. I soon learned what he meant by ’not live to see age 40’, after:  
-Local ER surgeon: “Your pain is subjective. If it were objective, than I could treat you, so how do I know that you’re not an addict.” (it was not a question. It was his closing statement. I had a severe pain in my pelvis bone, and the X-ray room was 20 yards away. My bed had wheels too! A few days later I was back in that same ER. My false hip-implant had cracked my acetabulum and punctured through my pelvis. I was sent to Shock Trauma, which was indeed a shocking and traumatizing experience: after a 2-hour ambulance ride with no pain drip in my IV, I was told that there was nothing they could do, that I’d have to contact my own surgeon to have it fixed, and I’d have to wait until the end of the shift to leave, as only one ambulance would cross the Chesapeake Bay Bridge, so I waited. A nurse who took pity on me kept coming over to put a needle in my arm. The man in the bay next to me was chatting with me. All of a sudden he stopped and turned purple. The curtain was drawn, Code Blue was announced. Five minutes later he was wheeled out in a body bag. I remember turning to my Mother, who had followed the ambulance there, and I said “I don’t know where I’m going to find the internal recourses inside myself, to carry on through this and whatever lies ahead.”)  
  
By the time I had gotten to HSS in NYC for surgery, it was 5 days later. I had to go into emergency surgery as soon as my surgeon arrived at the hospital.  
  
By now I was living a nightmare, not one single doctor was able to offer me long-term treatment. I was, what felt like, being passed-around, from Pain Specialist to Pain Specialist, each only willing or able to treat me, Prescribing continued Physical therapy, and a myriad of pain medications, antidepressants etc., for 3-4 months at the longest. I knew what worked for me, what I needed to do, but never having a doctor long enough to get an understanding of my “case” as they were now calling it, prevented me from being able to settle into a regimine of exercise and pain control.  
  
Nobody wanted to take on my case. In the Autumn of 2015, my hip dislocated out of a new path, and I required sedation to have it re-placed into my body. 2 months later, I experienced a 4th degree burn from a heating pad, which was given to me at the Therapeutic hospital in AZ, but had no automatic shut-off. Needless to say, I was laid-out, quite literally, for the entire winter. I had no pain medicine, and was unable to get in a vehicle and continue to go Pain-Specialist-shopping around the Baltimore/D.C. metro areas, for help. So, I sucked it up, and began the most awful trip of my life. I lost my appetite, I lost all circadian rhythm, lost weight to the point of wasting, when the body begins to eat itself, within a month I had slipped in to a sort of waking coma- anything I had to do- get a glass of water, choke down an Ensure Protein drink, use the restroom- it would exhaust me to the point of needing to lie down. I would drift in and out of an extremely tired state, but I wasn’t sleeping.  
I was petrified. I thought, and still believe to this day, that I was dying. Because I was, as blood tests would soon show.  
  
By spring of 2016, A local friend/ GP doctor took me in to her practice as an emergency “case”, again for a short period of time. She then found, amongst her colleagues, a Pain Doctor who would begin to treat me and find a more long-term clinic. His name is Dr.Rajesh Jari. He slowly, week-to-week, titrated my opioid pain medication little-by-little, until I was able to get back to PT in a pool. Dr. Jari referred me on to the Rosen-Hoffberg Pain Specialists and Physical Therapy Clinic in Baltimore, MD. I have remained on the same low dose of morphine for the entire time, along with a high dose of Lyrica, for nerve pain, and I have been in Physical Therapy, on my own accord, as I have the body of a dancer, and so I elected to do controlled strengthening 1-on-1 with a Pilates instructor, on a Pilates machine.  
  
These days, I am feeling stronger, and am able to nourish myself because my pain is under control. All it took was a doctor who looked me in the eyes, and learned through exposure to my “case” that I am my own best advocate. I know what and how much my body can physically do, while under the relief of the medications, and along with Dr. Hoffberg and his team, and the support and council of the United Pain Coalition, my struggles will hopefully continue to decrease, and people like Andrew Kolondy, who is not in-touch with the reality of Chronic Pain and what it can do (ultimately, it will kill a person), will not be put in a position to make decisions on the behalf of his own personal monetary gain, at the expense of Human Suffering, difinitively.  
  
by Piper McKee-Wright

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| |  | | --- | | **Patricia <pdcustomk9@aol.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |

To whom it may concern,  
  
My name is Patty Davidson I am a medically retired Professional dog trainer. And a former Emergency Medical Technician.  
I suffer with Multiple Sclerosis, severe Crohn's disease, Lymphedema, I had an infection in my spine which has caused me severe back pain. In addition I have very severe spinal stenosis, severely compressed nerves,a herniated disc and a missing disc. Im having a major multi-level spinal fusion In December 2017. I also have something referred to as (CRPS) Chronic Regional Pain Syndrome in my right arm. This condition is horrifying and very painful. The pain is searing and it is the worse!  
I have under gone Multiple surgeries for my severe Crohn's disease (8 to be exact) and often get bowel obstructions due to strictures in my intestines. As a result of all these operations I have adhesive disease. This causes painful scar tissue to build up in my abdomen.  
Because of all of these diseases I require Opioid medications. I recently was forced to move from Washington state to Texas because Washington state has cracked down and doesn't allow doctors to appropriately treat patients with chronic pain. My pain medication was lowered so low I was bedridden. I was suffering so much I thought about suicide daily.  
People who suffer with chronic pain are treated horribly. We have been lumped together with addicts. People suffering with pain are not trying to or wanting to get high. We just want to function.  
When I was on the right dose of pain medicine I could pursue my occupation as a dog trainer. Because of the 2016 CDC guidelines and other pressures the government agencies are putting on my doctors they can no longer give me the therapeutic dose of medication I need to work and function.  
Since moving to Texas I have found a good pain clinic. I do get enough medicine so that I am no longer bed ridden but I'm still suffering.  
I am scared to death of losing what little pain medicine I get. I live with horrible anxiety and I'm one of the lucky ones. At least I get some medicine.  
There are lies being spread around about Opioid pain medication. The CDC and other government agencies are blaming doctors and treating them like they are drug dealers! Even to the point of prosecution. So now doctors do not want to risk their license or even more important their freedom. Everyday more doctors are getting out of the practice of treating pain patients.  
We have a huge problem!!! There is no Opioid epidemic caused by Doctors and pain medicine. The opioid epidemic should be called what it is! which is "The Heroin/illicit fentanyl Epidemic"  
There is a war against pain patients and many of us who suffer everyday are committing suicide. If we do not get help there will be an even worse epidemic and that will be the “suicide epidemic!”  
WE NEED HELP!!! Our voices need to be heard. We need the government to get out of the doctors offices and let them do what they are trained to do.  
Thank you again for listening to my story.  
  
Sincerely,  
Patty Davidson

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| |  | | --- | | **Sharon McCracken <happygirl414@gmail.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |
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My name is Sharon McCracken and I live in Wilmington NC. I am giving the city name because we are the #1 city for opiod abuse in the country. The new legislation has negatively impacted my ability to obtain a reasonable amount of opiod medications to manage my pain.

I was diagnosed with Anaplasmosis and Lyme disease, along with chronic Epstein Barr virus and other co infections back in 2014. I have been chronically ill and suffering with joint pain for almost 7 years now. My pain, fatigue, depression and anxiety all keep me from caring for myself, my husband and our two children 4&6. I also had a stroke in 2015 and have struggled with seizures, tremors and other neurological and central nervous system symptoms. I have been told, since the stroke, that I MUST keep my pain managed and my stress low or I risk another stroke.

I recently had my disability hearing and am waiting for the judge to decide on my case. Because I am unable to work and most days I have difficulty functioning, my husband has had to take time off work to help me, losing income we desperately need. We recently lost our home to foreclosure and we will have nowhere to go if it is sold on 11/28.

My prescription pain medications (oxycodone 7.5 mg @ 90 per month and Lyrica) have recently been required prior authorization from medicaid. I was the first patient at my primary doctor's practice to require the prior authorization. I was never informed, in writing or otherwise, that my pain medications would need prior authorization. My doctor (a PA) wasn't informed either and when she went to complete the prior authorization form, she was told that it was the wrong one. Meanwhile, I was held up at the pharmacy because of all of this and forced into withdrawal waiting for someone to make a decision on a Friday. I was told my only option was to take a 2 week supply and then my doctor would need to write out a new prescription for the second half of my 30 day supply. I went through all that and finally got everything back on track for a 30 day supply 2 months ago. I was referred to a pain management clinic here and was denied help without explanation. There are no alternative treatments for chronic pain like mine that are even remotely affordable.

Now I am being told that my PA has to meet with the doctor who oversees the opiod practice every 3 months to review my file and discuss my pain management. I am also being told that the prior authorization is good for 6 months. I am extremely concerned that NC medicaid will suddenly stop covering my medications, without warning, at every doctor appointment I go to for refills. If I am cut off without warning and forced into withdrawal, I am at an extremely high risk for another stroke. I have been on the same dose and same amount of opiods for 2 years. I have kept the same prescribing doctor and have used the same pharmacy. I have followed all the "rules" and now I am at risk of losing my only relief from the horrible joint and body pain.

You have my permission to share my story. Thank you

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I am a 63 year old physical therapist assistant that injured my back at work in 1998 while lifting a stroke patient that had fallen out of his wheelchair. Since then, I have had 3 failed spine surgeries, one 7 level fusion and two arthroscopic surgeries on my knee and shoulder. I have quite few tools to deal with my persistent pain, like PT, massage, aqua therapy, yoga and medications. Since the changes in the CDC guidelines, doctors are reluctant to write RXs for the medications that I have used responsibly and I have experienced a decline in my health. It is very difficult to get out of the house some days to do things like go to the grocery store. Many days, I am bed bound laying on ice and heat. This is no way to live and many CPPs are giving up and committing suicide. I see it almost everyday in closed FB groups I help admin in. We are human beings that deserve to be treated with dignity and compassion for the situation we have found ourselves in. We have done nothing wrong but followed the directions of our doctors that had our best interest in mind, however we are being punished by withholding medications from us.  
I am an educated health care professional and this approach doesn't make any sense to me. Death by overdose continues to rise even though RXs are being tightly restricted. It appears we have a heroin epidemic and CPPs are being wrongly impacted. Less than 2% of CPP become addicted to their meds, so the problem is with illicit drugs, not CPP meds.  
  
Sent from my iPad

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| |  | | --- | | **Tawni Hundley <tec051290@gmail.com>** | | Nov 8  https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |

Please read my story.

I have been struggling with pain since I was 13 years old.  42 years ago, it was considered growing pains and not recognized that something was wrong to cause a child to hurt so bad.  I dealt with it until I was 21 and it became bad, so my mother took me to Duke University where they said it wasn't Lupus but was Undifferientated Connective Tissue Disease.  There were meds given, aspirin 4 times a day.  That didn't last long as it totally messed up my stomach.  I used OTC meds for pain at that time and lead a pretty normal life.  It really became a struggle in 2002 and I was diagnosed with Fibromyalgia.  Last year, 2016, after suffering with severe lower back pain and only allowed 2 Loritab 5mg per day, I gave in and had back surgery for a herniated disc at L5 S1.  I have a cage and screws in my back and the pain is even worse than before.  Post surgery, I've been bounced from one doctor to the next with the same end result which is "There's nothing else I can do for you".  I just saw a top Neurologist that could do nothing for my back pain, could do surgery on my neck (which I refused) and referred me back to my pain management Doctor.  He, the PM Dr. is the only person who has helped with the chronic back and neck pain. I do take Loritab 10/325 mg 4 times per day.  It is the only thing that helps the chronic pain in my back, neck and joints.  I stretch the pills out when I'm up for hours that I cannot sleep, and I don't ask for any more.  At least that pain isn't as bad as it was thanks to my pain Mgmt. Dr.  I struggle still with Fibromyalgia and cannot take medicines on the market for it.  They make me want to kill myself, so that isn't an option.  I'll suffer with the total body pain that the disease causes

.

I cannot imagine living without pain medications because it gives me what little quality of life I have.  Please don't let the bad people of the United States of America take away the medication that so many really need and take responsibly.  It's just like this, bad people will still get illegal drugs on the street and overdose while the medication that gives us some of our life back will be gone and we'll have no quality of life.  People who suffer with chronic pain are not those bad people.  I'm not one of those people.

I urge you to come up with a plan that will not ban what gives me some of my life back.  I am 55 years old and I don't want to give that up. I have 4 children and 3 grandchildren that I need to be up and about for, not bed ridden.

Thank you for your time.

Sincerely,

Tawni Hundley

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To whom it may concern, I am writing you in reference to the pain epidemic. I am a 28 year old female with hydrocephalus which has cause 106 brain surgeries. I also have arachnooditis which is a very painful condition. I have been on oxycodone most of my life. But recently the new rules have affected me terribly. First my meds were cut way back now Medicaid is saying they aren't paying for them at all. I can't get out of bed or function without them. The 28 years I've been on meds not once have I touched anything illegal. I am scared for my life that this is going to be horrible. We are not addicts we are chronically ill patients. Please consider this when you are making decisions. If it were your child or yourself fighting this you would better understand. Please take that in consideration.

Sincerely,

Shellie Nelson

Sharpsburg, NC

27878

**From:**[elliott.thomas@sbcglobal.net](mailto:elliott.thomas@sbcglobal.net)

**Date:**Tue, Nov 7, 2017 10:17 AM

**To:**[cronicpainstories@gmail.com](mailto:cronicpainstories@gmail.com);

**Cc:**

**Subject:**My story

As a young man I was told by my father to work hard and do what ever the employer told me to do. As a young father of two I worked all the hours I could, I did every nasty , or hard job that needed to be done. I would do any work like a animal 24/7 . if nobody wanted to do it I did it. All the dirty jobs. If I had know better I would never had done this. My body at 65 is giving out . My knees are weak and painful , along with the injuries to my back, hips, feet and a very painful neck injury. So many areas of body pain. Its a painful adventure everyday. Will it be my hips or back that hurt the most today. Although this is very devastating and real. I did it to myself.

In 2003 I approached my PvP with the problems I was having. It was at that time my doctor descovered I had become type 2 diabetic and several degenerative issues. At that time I was maxed out on all or any otc pain meds a body could take and my kidneys were weakening . at that time my doctor and I put in place a game plan to help me finish my working career . I was 54 at that time. So with that plan I lost 50 pounds exercise every day. Bought. A inversion table for my back and neck and I continued to work. To save my kidneys we decided a mild pain med would be better so at that time I started Tramadol 50mg tablets at max 2 per day and a .5mg lorazepam for rest..

It was a life changer. And a blessing.

I survived and continued to work. I now had a furture to look forward to. Thank God for these life saving meds. Because without these I would never had made it. I would have died!

Today when or if I ask for lorazepam with my new doctor ( my first pcp retired ) he tells me he has too many concerns about addiction. Why I say, I'm 65 I'm looking at the last few years of my life for whatever reason these meds help me cope daily. He has said he will ease my pain with the 2 tramadol per day and dosent want to give me any other or more pain meds..

Then I should attend pain management courses.

I fear that  over obstructionist that believe they know my needs better than I do, will keep instilling fear in our doctors. There is so much hype !

I want to continue taking my pain management meds without the FDA or the DEA deciding.

I do understand that over prescribing pain meds can cause abuse or turning to street drugs. My 34 year old daughter had a heroin addiction for 3 years brought on by over prescribing Vicodin after several surgeries.  She survived and is drug free over 2 years. Although her beautiful 28 year old cousin did not.

 But taking away needed meds from people that have shown real need is unacceptable! I could say so much more and I know this problem needs oversight. But you must understand attacking the ones that need, verses the abuser must be considered and a priority! If not people will die needlessly.

Yours sincerely.

Thomas James Elliott

Battle Creek Mi

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To whom this concerns ,

I am writing you to tell someone ( anyone who will listen ) that the crackdown on opiates is messing with peoples lives who need those medicines.  I am one of those people.  I have suffered from pancreatitis flare ups since 2004.  If you need information on pancreatitis please search it out.  It does effect all who suffer from it in many ways.   I am one of the few who does not need pain medicine EVERY DAY yet but I am someone who needs them OFTEN .  I get admitted to the hospital roughly each 5 weeks for over the last 3 years that I have suffered with this.  I now have doctors who are not willing to give me the pain medicine I need even in the er and I have labs showing I am very sick and in so much obvious pain and vomiting while all that is going on.  I will also share the fact that even after spending a week to 10 days in the hospital I am sent home without any meds even just for a few days.  I am not totally better after being admitted or totally pain free each time.  I am not someone who abuses pain medications either as I have had a bottle of them that I had prescribed for dental work for 2 years that I just finished and it had 30 pills due to the fact that I had a  lot done and it was very painful but I tried to just get through with few of the pain medicine and just taking Motrin or Tylenol. My life is much different since suffering with this disease that has no cure and is causing me more pain each month and nearly most days.  I have to cancel and miss lots of events at this point due to days where I have so much pain I can not move hardly .   I also sit at home , with no real pain medicine to relive it , as my docs do not like to prescribe it now for the worry they face now.  We ( people who have chronic illness ) are the ones suffering for those who choose to abuse things.  Why do we have to suffer because lots of people are dying from heroin or fentanyl overdoses ?  Why is there mass punishment for those who do suffer in pain and try to take as little as possible or what helps them make it through the day at the doctors prescribed dosage?  Please consider what you all are trying to do because you all are not the ones who are and will suffer .  Thanks Jennifer McFarland

From: JoAnn Marucci <[myhousespnj@comcast.net](mailto:myhousespnj@comcast.net)>  
To: [chronicpainstores@gmail.com](mailto:chronicpainstores@gmail.com)  
Date: November 8, 2017 at 4:28 AM  
Subject: choronic pain

I have suffered in chronic pain for many years. After a fall on ice, I had surgery on my left shoulder for a labral tear. I ended up worse then before I went in,

The year after my surgery, I went to a local surgeon who told me that I had a torn rotator cuff and if i did not have surgery, I would get worse. He was adamant about it, the surgeon who did operated on me, sent me to another surgeon  and that surgeon scared me out of having more surgery as he said I could come out worse, I regret not having it done and I dont think it is possible to be in worse pain then what I have had to  endure on a daily basis.

I have seen so many orthopedic doctors for my shoulder, They all have differing opinions.

Along with the shoulder pain, i have severe beck pain, mostly on the let side of my neck,I often cant move it and it hurts to hold my head up.

I finally saw a shoulder specialist. I believe on my initial visit, she said I needed shoulder replacement  but she did not know if it would help. On the second visit, she said, that I may need shoulder replacement. On the last visit, she said, no doctor wanted to operate since I had one bad surgery. I believe she said I have a bone spur, also, arthritis has worn away a good part of my shoulder joint.

I am living a nightmare. I have been treated very badly. I did nothing wrong. I wish these doctors could feel my pain . It keeps me awake at night, I can hardly take care of myself now and for the most part, I am housebound.

The pain affects me non stop and I have really bad days where my shoulder tightens up and the pain just does not let up. I cant go on like this anymore.

I also take pain meds which are given to me by pain management . I take them responsibly, i submit to urine tests which i have always passed, I am tired of being treated like a criminal when I am a responsible, law abiding citizen.

At one point, I went to a local orthopedic group. The first doctor i saw there, told me there is nothing wrong with my shoulder, the pain is coming from my neck. I have seen doctors for my neck and they say nothing is wrong.I went to another doctor in this practice for my neck. On the first visit, he was very sympathetic, on the follow up visit, he treated me cruelly, apparently, he looked u my records, I have nothing to hide, I believe there is a conflict of interest, because he knows the surgeon who operated on me.

I believe he tried to set me up. He offered me a script for pain meds when I told him that I was already given meds from another doctor, I handed the scripts back to him although in the letter he sent to my PCP, he did not mention that, Instead, he talks about me getting meds from more then one doctor , which I have never done, . I would like that letter corrected as it is untrue and it is slandering me,

It is bad enough, that I have to suffer in debilatating pain, I do not need to be stripped of my dignity.

I do not know where to turn, I am sorry that I did not contact the medical board but i was afraid, that if I did, nobody would help me after that, No one is helping me so i have nothing to lose now. I am in such severe pain as I write this letter and I have had very little sleep. I do not know where to turn, I am scared, I cant handle this pain much longer and the pain meds do not seem to be helping much.

I need someone to help me.

My insurance is a form of medicaid and I have been told, I was not going to get the help I needed on Medicaid, I believe I have been discriminated againsnt,

I should not be made to pay because I had a surgery that went wrong, It was not my fault.

I need medical help now, i cant hang on any longer, I am tried of doctors acting like nothing is wrong.

      Please help me, I am running out of Hope,

       Very Truly Yours,

        JoAnn Marucci

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| |  | | --- | | **Leah Dixon <pinkfabulosity@icloud.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |

\*To congress and senate members,

My name is Leah Dixon, and I currently reside in the state of Kentucky. I am 34 years old and have suffered from chronic pain from Crohn's disease for seven years.

I would like to request the consideration of those suffering from chronic pain/illness in the implementation of restrictions involving opioid pain medication.

At the age of 27, whilst working full time, raising my daughter, as well as attending Cosmetology School full time, I began to suffer from undiagnosed abdominal pain. As a resident of Kentucky, where the war on opiates had already begun, I suffered from untreated chronic pain amplified by the reluctance of doctors to prescribe pain medication. I saw countless doctors, visited several hospitals and was assaulted with the stigma attached to patients who request pain medication, and was constantly accused of "drug seeking behavior". After a year of this "Catch-22" of a situation I received orders to see a surgeon to have my gallbladder removed. At my pre-surgery consultation, the surgeon told me he did not believe my gallbladder was the source of my pain. Desperate for relief, I told him that if I could live without it, and there was even a one percent chance that my gallbladder was indeed the source of my pain, that I would like to proceed with its' removal. After the surgery my recovery was brutal. My body was affected in an uncommon way, and I suffered from exaggerated pain and vomiting to the point that I tore the lining from my esophagus to my stomach. It took three days of constant assistance from my father to recover from what is almost always performed as an outpatient procedure. As I recovered, I remained hopeful that once I healed my abdominal trouble would be relieved. Unfortunately this was not the case. Things continued to get worse, affecting my ability to parent my child, work, and attend college, as well as straining my marriage. The debilitating (still undiagnosed) pain began to cause me to lose consciousness several times a week. My parents remained on constant stand by to answer my four year old daughter's phone calls when "mommy said ambulance" or "mommy is on the floor and won't wake up". My college instructors became accustomed to me laying on the floor in the back of the room in the fetal position. I became incapable of reliable, consistent performance at work. The fruitless doctor visits continued. The Gastroenterologists continued to order scans, exams and colonoscopies . After being constantly patronized, dismissed and insulted by so many doctors, I had lost faith in their ability to help me and stopped bothering with Emergency Room visits and suffered at home.  Although I was home often, I was practically incapacitated, prompting my biological mother to come from Arizona to stay with me and help me take of my daughter while my husband continued to work third shift to support the family. It was not long after seeing her daughter in such a crippled state that my mother began taking me back to the Emergency Room. After a year and a half of indescribable suffering I finally received a diagnosis of Crohn's Disease, an autoimmune disease that causes the immune system to attack ones own gastrointestinal tract. By the time I was diagnosed and finally taken seriously the disease had done severe damage. One day the pain peaked and became literally unbearable. I could not move a muscle without vomiting, and was paralyzed by pain on the living room floor, unable to even stand. My mother called my father and step-mother to take me to the emergency room, who were unable to get me into a vehicle and had to call an ambulance.  On what had become a regular trip to a local emergency room, it was discovered that the excruciating pain I had suffered was cause by the

 Chron's disease eating a hole through both sides of the small intestine below the ileum (a hook shaped "connector" from the stomach to the small intestine). My stomach was longer connected to my small intestine (which had begun to liquefy) and I had become septic. I was immediately prepped for emergency surgery. The surgeon who had told me that he did not believe my gallbladder was the source of my pain, now told my father that he did not know if he could save me, but that he would try his best. I was lucky, and after removing the liquefied portion of my intestines along with several feet of damaged small intestine he was able to save my life. I then had an ileostomy bag as my intestine needed to heal before judging the possibility of reconnecting them to my ileum. After three months (half of which were spent in the hospital due to complications) the surgeon performed an ileostomy reversal surgery, and I was finally whole again.

Although my life was saved, I was still in rough waters with my Crohn's pain. After my ileostomy reversal I was still a frequent patient in the ER. One night on a regular visit for unbearable pain, I was given a shot of morphine and sent on my way, still unable to stand upright or walk unassisted. I was not sent home with any pain medication. I visited my family doctor three days later to find out that my surgery site was dangerously infected and was prescribed three powerful antibiotics. My doctor told me if I'd waited much longer I likely would of become septic. This blatant case of neglect prompted my family and I to decide that living in Kentucky was not safe for me. I uprooted my daughter and myself and moved back to Massachusetts in the hopes of receiving better medical treatment. After seven months I achieved remission and was able to move back to Kentucky.

Seven years later my Crohn's disease is still not under adequate control. I have had two miscarriages, as pregnancy flared my Crohn's and caused severe fetal stress. I often suffer from breakthrough pain and flare ups. One would imagine that after what I have survived through, a doctor would provide me with pain management during these upsets, but that is not the case. I have missed my daughters last two soccer games, I lost consciousness due to unbearable break through pain as recently as yesterday.

I did not ask for or do anything to incite my Crohn's disease. This disease has caused: me to lose my job, my marriage to deteriorate (and ultimately end), the premature end of my college career and general upset in the lives of my family and I.

Not having adequate pain management is as responsible for my suffering as my Crohn's disease. I have lost many months of my life to pain. I often miss out on my daughter's extracurricular activities and functions with family and friends due to uncontrollable pain. I am also on disability as I cannot maintain an acceptable level of performance at a job. I am forced to be a non contributor to society and live in absolute poverty. No one deserves to be punished for having a chronic illness and denied pain management.

Sent from my iPhone

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    My name is Fiore Vincent D'Angelo sr.I am a chronic pain sufferer and patient.  
My illnesses and conditions are as follows:Fibromyalgia,degenerative spine disease,  
including stenosis,arthritis,sciatica and damaged back muscles due to surgeries  
inter tibia rodding of left leg with permanent loss,atrophy and deformity.Cervical  
partial fusion with permanent damage,loss and disc disease.Failed rotator cuff   
surgery with loss,chondromalacia of the right knee,myofascial pain syndrome,  
temporomandibular joint syndrome,carpal tunnel syndrome,headaches,essential tremors,  
chronic fatigue syndrome,cognitive dysfuntion due to fibromyalgia,nerve pain,arthrit  
is of the lumber,cervical spine,knees,left hip,shoulder and hands.Restless leg syndrome.  
I've been repeatedly tested and diagnosed mostly by specialists since 1994 to present.

   My symptoms consist of widespread pain in limbs,feet,trunk of body,back,neck and face,  
fatigue,tremors,headaches,joint and muscle pain,tingling,burning,numbness,insomnia,fatigue,  
headaches,leg pain and weakness,pain and tingling in hands and short term memory loss.

  Too alleviate my symptoms i use and have tried many self help and alternative methods  
such as massage,meditation,stretching,walking,hydro therapy,tens unit,physical therapy,  
healthy diet,listening to music.I also use medications as alternative methods alone do not  
help.Gabapentin to control headaches,some nerve pain,essential tremors as well as some  
fibromyalgia symtoms.Robaxin to control severe muscle cramps.Tylenol.  
The only pain medication i am prescribed,Tramadol helps very little.Due to the opioid   
restrictions Tramadol is all the doctors will prescribe.

  My symptoms are exacerbated by sitting,standing walking for any length of time.Any  
part of my body i rest on more than ten minutes,inability to sleep due to uncontrolled  
pain,damp,humid and cold weather.bathing,shopping driving are painful.any lifting and sometimes  
stress.

 As i've written i currently take tramadol for pain.It helps very little.  
I currently reside in New York State.Due to the current opioid laws and restrictions i cannot   
get the proper pain medication for relief.I suffer continuously and needlessly,  
making it nearly impossible to function and sleep.I do push myself as i always have however i  
am severely limited to get my necessary tasks done.Standing,walking,sitting,bathing,dressing,  
typing,light shopping are torture now.I have been to numerous pain management doctors and   
specialists for consults and as a patient with the result of little relief due to the   
restrictions.I have endured spinal injections,epidurals and proceedures.The injections and  
epidurals are excrutiating and cause much distress on my body from the chemicals in them also  
giving none to little relief.It seems all pain management is giving patients these injections  
stating they will help and is proceedure in order to give a pain medication prescription.  
  Before the restrictions i was prescribed adequate pain medication of which i was never became  
to nor abused in any way.I've always been responsible with all my medications and tried to rely   
on all alternative methods in unison with my medication.My doctors always made sure i was educa  
ted on proper use,other methods and proceedures and mentally fit,also that i took a part in   
dealing with my health conditons outside of medications.The proper pain medication gave me a  
quality of life i would not otherwise have.My pain was controllable enabling me to perform   
necessary tasks and get restorative sleep.Now,sadly not so.

  My wish is that chronic pain patients stop being labeled as addicts.That the public is  
educated to realize opioid pain medication is necessary to many sufferers for quality of life.  
That we are prescribed the proper pain medication as many chronic pain patients are being denied  
pain medication or are being severely cut down or abruptly cut off who have never abused their  
medications.That doctors can responsibly prescribe proper pain medication without fear of losing  
their licenses or being told not to.I understand their is a opioid crisis,i acknowledge and  
agree that illegal drugs and bad doctors must be stopped.I acknowledge prevention and treatment   
of addiction,and feel badly for addicts and their loved ones.Chronic pain patients are suffering  
needlessly as a result of restrictions.Myself included.

  The only advice i can give to sufferers of chronic pain and illness are:research,pray,learn,  
educate,continue to try to get the proper help but for the most part be prepared for more suffering  
and disappointment.Hopefully someday quality of life and dignity will be restored.

                                     Thank You,  
                                 Fiore V. D'Angelo Sr.

                                    New York State

To;Thee United States Council of Dr.Government

From; MARY WILLE

Subject matter;personal story of physical pain due to medical conditions

I write this in the hopes that Dr.Government  will end thier willful;,''witch hunt,'' on all CPP's,,,all  P.M.,,and all our MEDICINES,, that help us survive a life in physical pain from a medical condition.

   At the ripe age of 27,,I experienced severe physical pain in my chest..Mostly  left side,,but some on my right side,close to the sternum..I went to  several hospitals,,ie..Burlington Wi,..St Catherines

,Milwaukee,,St.Joes,,,St.Lukes,,Mt.Sinai,,,Adams county Memorial,,,Finally last but not least Mayo Clinic Rochester Mi.,,all   thee Doctors there,ie cardiologist,,names,;;Dr.Walcott,,Dr.Diane Zwicke,,Dr.Brown,Dr.Chapmen,,Dr.Steven Taylor,[mayo],,,..I went to over 25 e.r visits,,,only to be sent home,,with NOTHING,,,,everyone of them doing a ekg,,which was FULLL  OF ARTIFACT,, which they blamed me  or the leads ,,or thee machine itself,,,and a chest x-ray,,,,NO-ONE,,,NO-ONE,,,,INCLUDING MAYO,,, every,  checked my pancreas,gallbladder or ,''special blood work,'  for lipase levels,,,ever in literal 20 years,,,'Dr.Diane Zwicke,,my last appt..with her,,she finally referred to a Pain Management Doc,,out of St.Lukes,,,,however,,,just before thee end of our appointment,at Dr.Zwicke's,,I lifted up my shirt,,to show her this swelling under my sternum,and a couple of busted blood vessels,,,her reply,,''that's normal,everyone has that,,stop imagening things!!!!,'' and I quote,,,,4  hours later,,I was at my appt,,,my 1st appt,,,w/my Pain management Doc,,,It  hurt to breath,,,soo he gave me a nerve injection,,,still hurt,,soo he reluctantly did a chest x-ray,,my lower left lung  was collaspe!!!!They go to insert my chest tube in I start screaming in physical pain more,,telling them to please pull it,,it is making my physical pain worse!!!!!Unbeknown to all,,,my pancreas was in pancreatitis,,which they essentially pushed that tube into swollen lung tissue compression from thee pancreatits!!!!If anyone of you sob care to know what that felt like,,i will be glad to demonstrate!!!!..However,,,once the lung came up,,,,they blamed the Doc,,,,I disagree'd,,stating it had something to do w/what-ever was wrong,they had not found yet!!!

Finally  this Pain Doc,,,did a mri  of my thoracic spine,,they see a tumor,,t-1  thru t-9,, 3 times..they pull me out of that mri machine,,1st telling me to switch hospital gowns,,2nd time,,gives me another gown,,3rd time,,,gives me a blanket only??These men/doctors could not believe their own eyes,,that there was a actual physical reason for my physical pain,,and it wasn't their idealogy that it was in my head because i was a women!!!!,,they tell me,,that the tumor cause  of my physical pain,,,,Still not believing them,,,I purposely scheduled my surgery around my period,,,,for it seemed when I gained/swelled  from water weight around my period,the physical pain got worse.Directly after surgery,,I was meant for a 3 day stay,,,it turned into 2 weeks,,,I kept leaking fluid,,spinal fluid,,Ever experience a dermal leak headache from a surgical cut/breaking my backbone 8 times to get the tumor out of my spine,scar the size of 5 inches !!!!Again,,they blame me,,but after 2 weeks,,insurance  said i had to be released,,,Continued w/spinal headaches for 3 years!!!!!!!It was not healing,,nor did the chest pain EVER STOP!!!!!BECAUSE  UN-BE-KNOWN TO ALL,,,,MY PANCREAS/MY BLADDER WAS SO SWOLLEN IT  was pushing on the spine!!!

Finally,,,,this ,''artifact,'' they kept getting,,turned into inverted t-waves,,QRS morphology changes,,,st segment changes,,my Pain Management Doc,,,calls in Dr.Chapmen,,,he does 17  cardiac ablations,,,now,,,knowing what we know now,,,,,that the pancreas/bladder is /was soo swollen at the time,,and ,''they'' never even checked that,,,,,was it really the heart muscle????They'll never admit  it wasn't,,,,,,but my heart is permanently burned,,17 times,,,,,because of their arrogance/prejudice/thee unwritten code of doctors,,never implicate your own kind,stick together and a  unwillingness to actual listen to a women patient!!!

Frustrated,,,still in physical pain,,I went to mayo clinic,,,but all they did,,was go off the records from thee other hospitals,,,,,I was a women,,thus it was my fault,,,,never ever testing again,,my pancreas or my bladder,,,,,,EVER!!!!,,I get referred back to my Pain Management Doc  out of St.Lukes,,,,,and I am not greeted w/open arms,,THEY TRIED Dr.Kay,Dr.Bruske,other p.m. doctors,,,AND THEN BACK TO MY ORIGINAL PAIN DOC,For every-time he tried to find the true cause of my physical pain,,thee other doctors shot him down,literally ruining he good name at that hospital as a GREAT ANESTHESIOLOGIST,,,,,He quits St.Lukes  and goes  to  another hospital in thee area,,and because I have another actual referral,,,number 5,,btw,,,agrees to treat  me,,,.that was 14 years ago,,and I am still in his care,,,barely,,,after your ,''witch hunt,'' u have put on all P.M.  Doctors,,,,,,

Over 14 years,,I gave up ,,going to e.r.,well over 50 times I was sent home still in physical pain,,Again,,they never ever tested my pancreas/bladder or lipase levels,,,ever!! or tried to find the true cause of my physical pain..After literally 8 hospitals,,well over 20,doctors all just agreeing w/the last,,for that unwritten code,,never go against your own kind,,Going to the so-called ,''finest'' hospital in the land,,and they too adhering to that unwritten code,,i gave up  trying to find the cause,,,Now a days I would of been accused of Doctor Shopping,,even if I never asked for any medicine from anyone,,but my Pain Doc only,,,the same 1 for literally 17 years!!!,,by now i had gain a lot of weight,,bout 100 pounds,,and  my food was not being digested anymore,,,,Soo  I finally got soo sick,,i had to call a ambulance  for the 1st time in my life,i actually passed out....For those 14 years,,I saw my P.M  doc,,,once a year,,,cost me 250 bucks only,,a year,,but now,,i was soo bloated,,,i was haven a hard time simply breathing,literally,,it always hurt to breath,,but now my lungs just didn't seen to be getting air,,,and again,,my food was not being digested anymore,,,,i could never sit down,,that was normal,,,but  this light headeness,,,was not,,,i dialed 911,,,but chicken'd out,,,hung up,,,,i awoke on the floor to a cop pounding on my front door....The ambulance team was rude,,it was 9 degrees out,,no blankets were given to me,,and when I got to the e.r..AGAIN,,,TOOK A CHEST X=RAY,,,,SAW MY BLOATED BELLY AND LITERALLY SAID I WAS FULL OF SHIT!!!!!!  EVEN THOUGH I HAD TOLD THEM I WAS UNABLE TO EAT FOR 5 DAYS!!!!!,,SENT ME HOME!!!!  2 AM,,,SAME THING HAPPEN,,THIS TIME MY HUBBY  PICKS ME OFF THE FLOOR AND TAKES ME IN,,,DIFFERENT E.R. DOCTOR,,,,,,,,,TAKES MY LIPASE LEVEL,,,1000,,,,FIRST TIME IN 17 YEARS ANYONE TOOK MY LIPASE LEVELS,,!!!!!!!!!!SENDS   ME HOME AGAIN,,TELL ME TO GET INTO MY PRIMARY IN 3 DAYS!!!!!!!

I GET INTO MY PRIMARY,, monday  morning,,,she take lipase level,1800,,and does a echo  of my pancrease and bladder,,,,it shows pancreatitis,,and a few stones,,but both a swollen 3 times it normal size,,,I get admitted FINALLY,, tuesday morning,,,,surgery,,wensday,,the surgeon and I quote hime,,,,,'''Your  internal organs are badly beaten up,,your gallbladder was completely calcified,and it looked like a gravel pit,literally,''''''''THIS   DOES NOT HAPPEN OVERNITE!!!!!Echo never showed calcification,,ct,,never showed even gallstones,,ever  nor calsification

Now,,I am going thru all kinds of testing,,to see how much of this ,''badly beaten up,'' is permanent..They are checking my pancreas,,my heart,,my lungs,my diaphragm,and my spinal cord,,I literaly lost 60 pounds of edema in 8 weeks,,water   was literally comming out  of every orifice of my body!!!!!!!

THIS TOOK 20 YEARS   OF MY LIFE!!!!!NO CHILDREN BECAUSE OF IT,,NO STEADY JOBS  BECAUSE OF IT,,,

HAD I NOT  HAD MY PAINMANAGEMENT DOCTOR OF 17 YEARS,,AND MY little bit of  MEDICINE  FOR 15 YEARS,,,I WOULD OF USE SELF TERMINATION TO END MY PHYSICAL PAIN,LITERALLY!!!!

ALL  THRU THIS JOURNEY,,,,DOCTORS WERE  RUDE,,NURSES OUTRIGHT LIED,ON MEDICAL RECORD,,BECAUSE THEY ALL THOUGHT  AS A WOMEN,,I WAS FAKING THE SEVERITY OF MY PHYSICAL PAIN,,,,,,WHEN THEE REALITY WAS I WAS/AM   IN SEVERE PHYSICAL PAIN FROM A MEDICAL CONDITION LITERALLY MISSED  FOR 20 YEARS!!!!!!!!!! EVEN AT 1 POINT  AT ST.LUKES  FORCED  TO SEE A SHRINK,,W/THE THREAT OF NO MEDICINES IF I DID NOT SEE A SHRINK,,,,THAT SHRINK,,,NAMED DR.MICHAEL JORN,,,TRIED TO STATE I WAS OVER EXAGGERATING MY PHYSICAL PAIN,,I WAS IMAGINING MY PHYSICAL PAIN,,I WAS LIEING,,,WHEN REALITY WAS   HE WAS LIEING ON MY MEDICAL RECORDS,,AS I AM SURE A LOT OF PSYCHOLOGIST /PSYCHIATRIST DO, TO GET THE MONIES FROM INSURANCE COMPANIES,,MINE DID,,,,,HOWEVER WHAT THEY PUT ON MY MEDICAL RECORDS CAUSED ME TO SUFFER GREAT PHYSICAL PAIN, FOR 17 YEARS,,,,,,,SHRINKS HAVE NO BUSYNESS IN PAIN MANAGEMENT  EVER,,FOR IF THEIR WRONG,,,PEOPLE DIE OR  ARE FORCED TO ENDURE PHYSICAL PAIN,LIKE ME...WE ARGUED,,EVERY FORCED VISIT I ARGUED W/THIS SHRINKS IMAGERY THEORIES,,,,ONCE THE 10 SESSION INSURANCE PAID FOR WAS OVER,,,NEVER SAW AGAIN,,,,BUT HIS LIEING LITERALLY COST ME MY LIFE!!!!20 YEARS OF IT!!!!!!!!!

This  is the part u politicians,,your cdc guidelines are completely ignorant about,,,,,,,and u willfully excluded stories like mine .Psychiatrist were  never welcome in Painmanagement,,,for their theories can cause soo much physical harm,,if their wrong,,as they were w/me!U politician know nothing about the politics of medicine.For examples,,A surgeon will never  admit he did wrong,,A doctor  will never admit he/she screw'd up,,,,,,Anesthesiologist   are in those surgeries,,they see the screw-ups allllllll  the time,,,This is why many surgeon/some doctors/shrinks  are against Pain management,,,for Pain management docs  literally know,,,doctors  screw up  a lot,,the see it,,and if a person is referred  to P.M,,, for a doctors error,,,it acknowledges that screw up..There are 350,000  medical errors a year,,your ignorant guideline are now FORCING  those injured or misdiagnosed,or diagnosed w/a desease that is not curable to suffer in physical pain,,,,Why  do u think u have that rite??I have always state truth/fact  that it is literally impossible for anyone to physically feel the physical pain of another,,,,,thus,,as a humane civilized society ,,no-one has the rite to decide who is to suffer in physical pain and who is not,,,for the flip side of your actions,,is u are now forcing physical pain onto another humanbeing.,,,,That is not your rite!!!!!!Your  are literally committing torture,,,,onto another human,,,,,Our  physical pain is from a medical condition,,,We  see our medicines  as exactly that  MEDICINE,,,,,

WHEN YOU PEOPLE   started combining us w/addicts,,that was thee biggest mistake you could of ever made,,,for it allowed non-medical people to decide who suffers in physical pain and who does not,,which is literally impossible to do!!

We  see our medicines as medicine,,just like a diabetic see insulin,,,because our MEDICINE   allows a little bit of lessen'd physical pain to function,,No  normal human being would want to live a life in FORCED PHYSICAL PAIN   thee rest of their life,,,and since our physical pain is due to medical conditions,,it is with-in our bodies,,When u take away thee only medicine to lessen that physical pain,thee only choice we have then to stop that physical pain is thru  self termination of that body,,dahh,,,

Can't write no-more,,my physical pain is just too much now,,,from leaning over a computer and using my arm/hands to type,ie,,thoracic,,,,,,,maryw

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| |  | | --- | | **Jaime Sanchez James <onlygodcansave777@gmail.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |
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I am a 38 year old mother of two, and I was a PTA for 7 years, and an RN student, an artist, a writer, an author, a traveler, a child care provider, a server, a manager, a human resources administrative assistant, a home business owner, a swimmer, a hiker, a journalist, an editor, a painter, a sculptor, a blogger, a volunteer for mobile spay/neuter clinics, a home health aide, a youth group leader, a church bus driver, a MOTHER, an online tutor in English, a patient advocate, a bus monitor, a cashier, a hostess, a dancer, a singer, a poet, and I wore many, many other hats, before being hit by a drunk driver and enduring brain surgery and a 7 hour back surgery.  I am now unable to do 98% of the things I used to do, love, and enjoy.  The CDC/lawmakers took my quality of life.  Now remove the word "quality".  The CDC/lawmakers took my life.

   I stayed at UK hospital in Lexington KY for 115 (one hundred fifteen) days.  I was prescribed pain control medication to care for my pain.  I now have failed back surgery syndrome, fibromyalgia, compression fractures in the spine, narrowing spinal cord, metallic fragments in the neck and brain from neurosurgery, and a host of other painful conditions.  I was cut completely from my medicine, without warning, and suffered for 28 days straight, with seizures (which I never had before this crime) and withdrawal from stopping medications abruptly, which by the grace of God, did not kill me.  Lyrica 450mg/day to zero.  Oxycodone 80mg/day to zero.  Cymbalta 30mg/day to zero.  All thanks to my Dr telling me to go to the emergency room because she stated that I had visual deformities in my spine and needed to go to the ER immediately.  I was admitted to Cabell Huntington Hospital, and after 17 hours of admission and finding out that I had a torn disc (annular tear) I never received any pain control.  I asked for tylenol.  I also asked for my home medication which I was supposed to take every 6 hours, as prescribed.  I was then told I was "seeking narcotics" and discharged without treatment.  I then received a certified letter from the same Dr who told me to go to the hospital, that she would no longer see me nor provide services for me, and that I had 30 days to find a new doctor.  I have  complex and very serious health conditions.

   I am now being treated by an excellent Dr who specializes in complex and severe cases only, but I still have to go out of state and he can't prescribed anything yet.  This is an atrocity to say the least.  So many people are suffering in undue pain, and now adding the pain of withdrawal by force, is enough to drive them over the edge.  Which leads me to the next point.

   People are dying in epic proportions due to suicide, and a huge percentage of these people had no mental health issues...they just could not stand the pain and the forced withdrawal or taper, thanks to these guidelines being used as concrete laws.  People are going to use drugs, whether they're legal or not.  The problem still exists.  And now that these prescribing guidelines are being played with, people are not getting pain care, so many have turned to the street, and have been introduced to the world of illicit fentanyl mixed with so called heroin, and they're also dropping like flies.  Kinda retroactive.  The purpose of the CDC guidelines was to decline addiction rates.  The purpose has failed and has caused the rates to NOT decline, NOT stay the same, but INCREASED in dramatically epidemically numbered proportions.  Harm has been caused, and crime has been placed at the doorstep of already suffering patients.  There is blood on someone's hands.  I would think this would bother you, as it does me.  I stay awake at night and cry over the people who are contemplating ending their lives due to this atrocious situation.  Do not punish people who are already suffering!  What about mandatory rehab, rather than jail?  Why make someone who is already suffering, suffer even more...to the point of death?  Pain care gives back the quality of life that many millions of people would not have if their care was abruptly stopped like mine was.  It's time to put a stop to this.  I can put thousands of faces with thousands of names, if you wish.  Let's just hope they're not obituary pictures by the time you make a change.

Sincerely Yours,

Jaime I. Sanchez James

[onlyGodcansave777@gmail.com](mailto:onlyGodcansave777@gmail.com)

[6062259248](tel:(606)%20225-9248)

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Hi I don't know if this will help. I am still with my doctor so can't be identified. I have had my

medication cut in half and he is going to continue to reduce me off of my pain meds, then place me on Suboxone.

Suboxone will not take care of my pain. I will have to have both knees replaced and a fusion of my spine.

I'm not a good candidate for surgery.

I think this is what many pain patients are facing.

Before the CDC guidelines I was on pain medication for the following problems.  Ankylosing Spondylosis of Spine. Osterarthritis of the knee and spine Significant effacement  of the CSF. Bilateral Foraminal Stenosis, Foraminal nerve root impingement, Lumboscoliosis and Torn meniscus, bone spurs on each vertabrae, Degenerative Disk Disease.  I had been with a pain management specialist for 12 years.

I was a 100% compliant patient. After the CDC guidelines came out I was concerned. I was told, don't worry the guideline is just for general practitioners. You see a Pain Management Specialist. You are protected. That was until December of 2016. I was told because of the CDC guideline, and the Surgeon General Letter; Medicare was reducing the amount of medication my doctor could prescribe. There began a rapid withdraw of medication.  I am on half of what I was before 1 Jan 2016.

Please stop blaming long term pain patients for the opioid crises. We know it is the manufactured fentanyl and heroin coming from China. Anyone may google it.

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Jersey, you may edit my story.   I was diagnosed with DDD and my first herniated disc 02-15-2002. When I was a teenager I was told I had an undiagnosed autoimmune disease. I was on bed rest from 04-01-1955 until January 2006 after being hospitalized in mid-January until I was discharged the end of March. I returned to high school in January 2006. After I was diagnosed with DDD I at some point in time took Meloxicam, Diclofenac Sodium, underwent 8 invasive cortisone injections which helped for a few days, Cyclobenzaprine which has helped more than anything else short of opioids. On November 01, 2012 I was diagnosed with uveitis secondary to ankylosing spondylitis. At the end of my evaluation at the University of Illinois-Chicago the, clinic director told my wife and I that I would never get out of my wheelchair and in all likelihood be blind in 3 to 6 months. They referred me to a rheumatologist at Memorial Hospital in South Bend. The following Monday friends of ours drove us to South Bend. The rheumatologist had my file ahead of my visit. When we were called in she told my wife and I that she wouldn't take my case because I was to high risk. In December I learned about a rheumatologist at Elkhart Clinic who treated patients with AS. I met him in December and after talking, he said he would take my case and he recommended a Remicade infusion every four weeks but he would need to see if Medicare and my BC/BS supplement would pay for it because it costs $25,000 per month. Between Medicare and my supplement, they have paid for my infusions since January 2013. Fortunately, I purchased the BC/BS "F" supplement in 2009 which was the best supplement. I was in remission for uveitis and ankylosing spondylitis until January of this year when my AS flared up big time. Since 2013 my AS has attacked my lungs which probably caused pneumonia, attacked my heart and I'm now on a statin, attacked my musculoskeletal system causing my pain to go to 7 to 9 every time we experienced a low-pressure system or a season change from summer to fall or fall to winter. Winter is the worst because my lungs are weak and I'm a sitting duck for flu, virus, colds, and allergies. On August 1, 2016, I was driving our van east on the Indiana toll road (I-80/90) to visit the Pokagon State Park to see if it would be an appropriate place to hold a seminar. I was 4 miles west of Angola, IN about 30 minutes east of Elkhart. I passed out, the van ran off of the right side of the road into a ditch. I managed to get out of the van. I saw a state highway police person walking towards me when I passed out. He called EMS, they transported to a hospital in Angola. They learned that I was in cardiac arrest with a collapsed lung so they made the decision to life flight me to Ft. Wayne about 45 minutes north of Angola. Parkview Hospital kept me in a medical coma for 24 hours and started treating me through IV's. When I woke up about noon on 08-02 my wife was standing beside my bed. They discharged me on 08-03. Friends drove us to Elkhart. That was a Wednesday afternoon. On Saturday morning I work up in tremendous pain. And I had a bruise on my abdomen about the size of a small squash. My wife drove me to the ER. The ER physician did CT scans and blood work and found out that the NORCO that my PMP prescribed had damaged my liver almost beyond repair. He told my wife and I that I might die but he started IV's to cleanse my liver. It took about three days to cleanse it. He asked me if Parkview had run drug tests for opioid overdose and I said I didn't think so. He called Angola and Ft. Wayne and learned that neither had run a urine or blood test for opioid overdose. They had not. He told my wife and me that if we had waited one more day to come to the ER that I would have died. I wear a bracelet so no one gives me Tylenol. It was the Tylenol in Norco that damaged my liver. MY PMP should never have prescribed refills for NORCO without lab tests to learn whether it was damaging my organs. In 2017 AS attacked my voice box and I couldn't talk. After about three months of CT scans and x-rays, an ENT specialist found that my voice box was infected. He prescribed an antibiotic and my voice box healed over several months. I now have my voice back.   
From 02-2002 I took 325 mg of liquid morphine. When we moved to Indiana in 2009 I could not find a PMP who would prescribe more than 220mg ER of morphine supplement oral tablets and 15 mg of IR for flares. Then in 2016, my PMP knocked me down to 120 mg of ER and 15mg for flares and handed me a two-page document which was the Indiana legislature asking PMP's to decrease morphine by 35% a year. I started lobbying for a morphine pain pump because my chronic pain levels were running my life. My quality of life was falling like a rock. I lobbied for more morphine but I could not find a PMP that would increase my morphine sulfate. After 18 months of experiencing pain in the 7 to 9 range every day, I finally found a neurosurgeon who would implant the pump if I passed the trial. I changed PMP's twice until I found a PMP would perform the trial. I passed the trial and 30 days later the neurosurgeon implanted a Medtronic pain pump in my right hip 09-22-2017. Then I discovered that it would take 6 months of fiddling with the pain pump to gain the full benefit of the pump. It has been a nightmare. I have gone through withdrawal for 15 years of morphine. Morphine is a fat soluble. Every time I lose a pound I go through withdrawal which is like having the flu. In Indiana, they won't prescribe methadone to help you ease off of morphine. You just do it cold turkey. I'm probably 30 days away from transitioning from oral to the pump. My brain is confused and it will take 3 to 6 months for my brain to accept the morphine in my spinal column. In August of 2016, I was diagnosed with an opioid-induced mood disorder. I have had the blessing of therapy CBT and now I'm doing DBT. I'm taking Lexapro and it has done a wonderful job improving my mood. In August I listened to Man's Search for Meaning, by Viktor E. Frankl and learned that we can't control suffering but we can choose how we cope with it, find meaning in it and move forward. I have found a meaning and purpose that's greater than my suffering and I'm doing well. Weak. Walking with a pain after transitioning from a wheelchair to walker to a cane. I am visually impaired but have learned how to convert my speech to type and my text to voice. I talk and listen for hours of my day to books, the Psalms, the New Testament and Christian, praise and worship music. God changes my focus from pain, self, and suffering to love joy, peace, patience, kindness, goodness, faithfulness, gentleness, and self-control. My AS is raging I'm taking all the Remicade as frequently as I can. Now every day is a bonus. When I wake I ask the Lord to help me be Jesus in someone's life. One of my friends wrote me this morning to say "Thank you, Larry, for ministering to all of us here on FB whilst 'naked and exposed in the public square'. Your light for Christ does indeed shine and we are all the richer for the encouragement you bring whilst in the midst of your trials. May God richly bless you and Karen through this one! xx" I will enter your name and situation in my prayer journal and pray for you every morning during my personal devotions. Ken Medema is a friend of mine. I hope this encourages you. Thank you for reading my story.

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To whom it may concern,

My name is Kristen Miller. I live in Midland Park New Jersey. I have been suffering from chronic pain since May of 2004 after being diagnosed with Lyme disease. The effects of this disease have devastated my body in ways no human should ever have to feel. It has set off many autoimmune conditions, has stopped my heart, has accumulated fluid in my lungs, has left me unable to function as a normal human being.  I have severe arthritis, osteoporosis, degenerative disc disease, spinal and cervical stenosis, seizures, gastrointestinal problems just to name a few.  I have had so many surgeries, I have lost count.

I was on opiate pain medication for a period of time and able to have somewhat of a normal existence. There was one particular occasion where my pharmacy did not have my medication in stock and could not fill my prescription. I went to another local pharmacy where they were able to fill my prescription. A few months later my primary care physician suggested I go to the hospital because I was having trouble with my heart and I was in a lot of pain. They admitted me and we're extremely hesitant on giving me anything to relieve the pain. When I finally saw one of the doctors she said she had gone over my records and seen that I was using different pharmacies to get my pain medication, so basically accused me of being an addict seeking out my meds.  I was also forced to change pain management doctors because my original one had stopped taking my insurance, apparently that was another red flag unbeknownst to me.  I never took more then I was prescribed, in fact I still have a half of a bottle of morphine sitting here from 8 months ago that has not been touched.

After being released from the hospital I refused to take the pain medication anymore because of the stigma and the dark cloud that it hung over my head. That is the last thing I am....a pain med seeking addict.   I am now living in constant agony, barely able to function even with everyday tasks such as showering, doing dishes, taking care of my children or being of any use at all.  I do not live I merely exist in a life of hell.

Nobody will ever understand this until it actually happens to them or someone close to them. There is no way to describe the pain that many people suffer with on a daily basis, it is literally inhumane. My daughter is studying to be a veterinarian and animals in this country get treated better than people do. It is unfair what is trying to be done to people that actually need this medication to function or in my case as well to even eat comfortably.

I understand there is a crisis in this country with addiction and abuse that needs to be managed, but it is also affecting the people that truly need this to survive.  Taking it away from the people that need it will only cause more consequences in the end. It wouldn't surprise me if the suicide rate increased, and it would not surprise me if people started seeking drugs on the street not knowing what they are getting and dying from that.

I do have a medical marijuana card, but in the state of New Jersey they make that unaffordable.....that is another HUGE problem.  I would gladly try it but for $120 CASH.....no can do as we are trying to live on one income with three children in one of the most expensive areas in the USA.

I am begging for change, not only for myself but for many others who suffer as I do as well as the families who suffer with them and watch them struggle on a daily basis to do what every other American takes for granted. I have learned to appreciate my small victories and to some, these victories are the smallest of things.  To me just being able to get out of bed in the morning taking a shower and making it through a day are considered a victory.  There are nights I go to bed and just pray that God have mercy and take me.  This is NOT depression....this is PAIN...REAL PHYSICAL PAIN. This is coming from a mother who gave birth naturally to three children and did not even ask for a Tylenol through the process nor after. I also had my chest cut open while wide awake to drain blood from around my heart due to a botched pacemaker insertion.....no meds.....NOTHING.   I would rather go through childbirth everyday for the rest of my life than live with this pain.

There is not a day that goes by that I think I would be better off not being here right now. When I look into my children's eyes and see their pain because they feel so helpless it makes me so angry.  My family is so undeserving to watch this control my life.  Pain medication does not take it all the way, but I am able to be a much more productive person.  I would never think to do anything to harm myself, but I think about it daily because the suffering in unbearable.

I am submitting this letter on behalf not only myself but also on behalf of my amazing husband and three children who want me back in some respect.  I'm also sending this on behalf of all the people that suffer from these invisible illnesses that are destroying them from the inside out.

I would like to add a text I received from my daughter about a year ago:

Mom, I can understand how much pain and discomfort you are in, and in a sense I feel the pain too because we are so connected.  I need you to know that no matter what has happened or what will happen you were and will continue to be the strongest driven woman I have ever met and could not be more proud to say I was raised by the best  mother in the world.  I would not be the strong woman I have grown to be if it was not for you. Just so you know, I live each day fighting to be happy because after watching you struggle through the pain and agony for so many years but yet still have the ability to push yourself to get up every  morning with that smile and positive outlook that there is hope.  I'm so proud of you and I love you with all my heart and I have learned to fight for my own happiness and a better life for myself.  Never feel like you were not there for me because you are an amazing strong mom who taught me to keep fighting and NEVER give up.  I love you.

This is only one of the reasons I continue to battle for my life everyday.....I have so much to live for and so much to be thankful for.

Sincerely,

Kristen Miller

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| |  | | --- | | **Danielle Franzi <dewad@aol.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |
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To Whom it May Concern,  
  
     I am writing this letter on behalf of myself and other Chronic Pain Patients because I can longer stand all of the injustices against us.  I have had Lupus, Kidney disease, Mixed Connective Tissue Disease and Cerebritis of the brain that was diagnosed when I was 19 years old.  I am now 43.  When, I was first diagnosed with these debilitating diseases I had no problem whenever I would need effective pain relief.  I can tell you that the presence of chronic inflammation in the body is extremely painful.  Throughout the years I would go on Opioids and go off Opioids depending on whether I was in a flair from the autoimmune diseases that were attacking every part of my body.  
     However, three years ago I started to flare with something that seemed like my life would be taken by the very insidious disease of Late stage chronic Neurological Lyme disease.  In addition to Lyme and Bartonella ( Lyme co-infection,) I also had Polymyositis (chronic inflammation and weakening of the muscles.) I also had Interstitial cystitis (bladder inflammation,) and Small Fiber Neuropathy.  My rheumatologist put me on Opioids because I was told that the immune system will not heal when your body is in the kind of pain that these diseases cause.  My body would continue to break down without proper pain control and in the end, they would prove fatal.  I was already on the maximum dose of Cymalta and Neurontin which did nothing to help quell the pain.  I could not take Lyrica because of unwanted side effects that it caused.  I asked my Rheumatologist, well what about pain management and she told me that I could try pain management but they no longer will give out Opioids because of the DEA and the CDC crackdown of Opioid medication.  However, I found it hard to believe that I would be turned away from a pain management doctor.  I called two different pain doctors and was immediately told, before even seeing a doctor that they no longer prescribed Opioids under any circumstance unless for palliative care.  I did manage to get one appointment for a pain doctor.  I was told after filling out all of my paperwork that if you are coming to see the doctor for Opioids to forget it because they are under barrage everyday from the DEA and other agencies and they were warned against prescribing pain medications.  They were fearful of being shut down from the government.  
    I live in constant fear of the government taking away my medications that allow me to get out of bed everyday and take care of myself.  Opioids do not make me high in any way, shape or form.  On good days, I can do some psychical therapy but on bad days I am home bound but still able to get out of bed.  I know in my heart that if the government takes away these life saving medications from me I fear for the quality of my life as well as my life expectancy.  Why is the government causing pain patients suffering on top of already suffering from these debilitating pain conditions.  I feel like we are being punished just for being sick.  Is this how the sick and suffering are treated in modern day America and sadly the answer is yes.  The addicts get medications to help with their suffering so why are Chronic Pain Patients being denied their proper medications!  
  
Sincerely,  
Danielle Franzi, NJ

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A society which allows people to suffer for any length of time, is understood to be a morally bankrupt society. It is inhumane and unacceptable to force suffering on citizens. Especially in America.  
  
No more 'about us without us'. Unless we are moving towards a Hitleresque society, you must include those of us who live with unrelenting, debilitating pain, AND our doctors in every conversation/policy. So far this government has allowed ONLY addiction special interests and other non medical personnel to control this conversation and all policies. Not once have any politicians even considered speaking to us and that must stop today.  
  
You MUST make intractable pain, surgical, cancer and terminal patients FULLY EXEMPT from any anti-opioid policies. And yes, even those dying in unspeakable pain are denied pain control.  
  
Controlling pain - easing the suffering of American citizens is a basic right. Forcing doctors to deny this right, goes against the oath they've taken and rips families apart. Again, it is inhumane, immorally wrong and completely unacceptable. I live with complex regional pain syndrome also known as the suicide disease. Untreated, we merely exist in pain no one can begin to understand or imagine. The anti-human policies created against patients and doctors will not stop addiction, but it is causing suicides among pain/cancer patients to skyrocket. And will also cause skyrocketing medical cost via unnecessary ER visits, doctor visits, tests, etc.  Much more cost effective to treat pain with opioids that are proven to work.  
  
All policies, guidelines and decisions that affect pain care on the federal, state and local level MUST include intractable pain patients and actual doctors who understand how dangerous untreated pain is. Our lives matter and it's time government understand that as well. We are not disposable. NO MORE ABOUT US WITHOUT US.  
  
IT IS THE MOST BASIC HUMAN RIGHT THAT NO ONE SHOULD BE LEFT TO SUFFER IN PAIN. IT IS TANTAMOUNT TO TORTURE. No government should ever decide policy that forces suffering on its own citizens. Relief of pain is essential so that all patients are able to function, engage, and have the best quality of life possible.  
  
You can ease suffering and get actual addicts the help they need at the same time. Pain patients/doctors did not start the addiction problem. Addiction has been around for thousands of years - and addicts will abuse anything they can get their hands on. It is unfair and criminal to deny pain relief to those who suffer just because 'some people abuse'. We are not criminals, yet we are now being treated as such.  
Thank you,  
Gayle Onnen, former mass fatality responder for the federal government

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Letter to President Trump

Dear President Trump,  
  
 I know you are a President willing to listen to the people, so on behalf of pain patients across America I would like to tell you our feelings on the opiate epidemic. I will be blunt, you are going about this the wrong way and unfortunately I don't think your advisors are giving you the information you need.

  Pain patients already have huge burdens under current regulations. We have to drive sometimes far distances to pick up prescriptions from our doctor's office because we can no longer have prescriptions called in or receive refills. Patients with limited mobility and limited incomes often find it difficult just to get their medications. Patients are being limited on the number of pills they can be prescribed, each patient is different and it should be between the patient and doctor to decide the most effective treatment and amount of medication they need. We also have a prescription drug monitoring program here in PA and I'm sure in many other states. This is not only a violation of our medical privacy, but also a violation of our 4th Amendment being there are no warrants issued to obtain this information. These medications are often our only means to any decent quality of life. Most pain patients do not abuse their medications. They simply want enough relief to have a life worth living.   
  
 Now when it comes to drug addiction and abuse something that is rarely, if ever, considered is the amount of addicts that are dual diagnosis (50%-80%). Dual diagnosis is when there is a mental health disorder along with addiction. As you know our medical system is failing. When it comes to our mental health care it is even more inadequate. Many people are going undiagnosed and/or untreated for their mental issues. When this happens many of them turn to street drugs to self medicate. They are looking for an escape from their mental disorder. You will find most addicts aren't addicts because they want to party and get high, they are looking for an escape from their own mind. We need to start treating the underlying condition (mental disorder) if we wish to truly make a difference in the drug epidemic.  
  
 It's time we start looking for common sense solutions rather than the same failed drug policies and policies that make it harder on pain patients and their doctors. I believe you are a man that can make the changes needed that will help Americans being failed by their Government and Healthcare systems rather than punish them for the shortcomings of our failing systems.   
  
 Please feel free to have someone contact me for more information. I would be honored to help create legislation and policies that would benefit all Americans and be Constitutional at the same time. I have a passion for America and the ideals on which our nation was founded. I'm involved in politics and I'm currently running for my Borough Council. I previously ran for PA State Representative and will continue running for elected offices so I can bring common sense to legislation and defend our Constitutional rights. Thank you very much for your time, Mr. President.  
  
Sincerely,

Denise Bedio

Dear Senator Miller and Rep. Amore My name is Claudia Merandi. I’m 49 years old and reside in East Providence with my daughters, 16 and 12. Since I was a child, I’ve suffered from severe Crohn’s Disease. I owned Merandi Court Reporting, was a successful court reporter, and had 15 amazing reporters on staff. Due to the severity of my illness, I was forced to go on disability. In a blink of an eye, everything I worked for was gone. I spent, well over, 400 days in Miriam Hospital. All of my surgeries were performed there and I receive my treatment in the Fain Building every five weeks. My children were raised in Miriam Hospital. Up until two-and-a-half years ago, I spent most of my time at Miriam Hospital due to severe dehydration, C-diff, flu, pneumonia, painful obstructions, fissures, and a myriad of other Crohn’s-related problems. Crohn’s isn’t just a “bathroom” illness. In 2014, I was introduced to St. Ann’s Pain Management in Swansea, MA. When I went there, I thought I had the wrong building. I was quick to pass judgment. But after spending time with my pain management doctor, an anesthesiologist, I was put on an opiate that I would take four times daily. I went aggressive with my treatment, started my daily pain meds, and my life changed. I was no longer held hostage to a hospital bed. However, with Crohn’s, when you have a flare and severe joint pain and 40 bowel movements daily, you will have breakthrough pain. That’s the time you have to seek help at the ER. I would dread those visits. They would be filled with anxiety en route because I knew I had the “interrogation” process ahead of me. Before I would go to the ER, I would call my GI so they could call ahead. I always followed protocol. In March 2017, I was treated horribly by a doctor, who, basically, told me how healthy I looked. After my port was accessed, he told me wouldn’t treat my pain because I have pain medication at home. He was inquiring why I would need pain medication when I had it at home. Now, any doctor who’s been trained in opiate addiction would know the difference between chronic pain and breakthrough pain. In a nutshell, I was flagged as a drug seeker. I called my mom because I was too sick to drive. I left Miriam Hospital that day without a shred of dignity left. Two days later, I was rushed in because I was suffering from a massive-sized kidney stone. My urologist was dumbfounded as to why this ER doc would neglect to treat my pain. Crohn’s and kidney stones are very dangerous. I had not one but two surgeries that week, two days after that miserable ER experience. When I went back for my surgery, I had to go through the ER. Another doc came in and apologized for what happened. He said all the doctors were on high alert due to the opiate epidemic and they can only give a certain amount of IV pain meds. I followed up with a letter to the Chief at Miriam. Due to the opiate epidemic, the lines have become blurred in regards to treating patients with chronic illnesses. While I empathize with this epidemic, “WE”, the chronic illness community, have our own epidemic. I’m an advocate for hundreds of people in RI, the US, as well as South Africa, Australia, and the UK. I simply cannot fight this battle alone. We need help. How could the government forget about the chronic illness community? PCPs and GIs can’t treat our pain because of new guidelines. Apparently, they can write scripts on an as-needed basis. My question to you is: HOW COULD THE GOVERNMENT FORGET ABOUT US? We have MS, Lupus, Cancer, Crohn’s, Colitis, Sickle Cell…we need pain medication to survive. If I can’t receive pain medication, my life will revert back to being a patient. I have people that are asking me to help them relocate to states that offer assisted suicide because they can’t receive pain medication in the state they live in. So, I decided to construct a bill and present it to the lawmakers in the State of Rhode Island. I figured, let’s first start with the ERs in Rhode Island. That’s really where we need it first. When we’re crying in pain, we seek solace at the ER. But the ER docs are fearful of retribution, I would imagine, because of the strict guidelines. This bill, “THE EMERGENCY ROOM COMPASSION BILL FOR THE CHRONIC ILLNESS COMMUNITY” is going to be endorsed and sponsored by Rep. Gregg Amore in January of 2018. What do I hope this bill could do? 1. When you enter an ER in RI, you would, perhaps see the logo. It would say: “THIS HOSPITAL RECOGNIZES THE CHRONIC ILLNESS COMMUNITY AND AND TREATS PATIENTS WITH COMPASSION. 2. Offer refresher courses in treating the chronically ill and not assume all are drug seekers. 3. Treat patients without retribution for their superiors. 4. All ER personnel should follow the SAME criteria when treating the chronically ill. Every lawmaker that you meet with, sit with, and talk with, has someone In their family who has a loved one with a chronic illness. That person may be you. I don’t know. But I do know that every fifth commercial is Crohn’s related. I’m not a doctor. I’m not a nurse. I’m just a girl with Crohn’s who got her life back and doesn’t want to lose it. We need help. I respond to calls daily from people crying in the ER, asking me to help them. Hundreds of people have left comments on my FB page and there are various petitions circulating regarding this topic. One petition has already went to President Trump. But I’m focused on the State that I live in because my 16-year old is now showing signs of my illness. My dad suffered from Crohn’s, me, and now my 16-year old. But as a mom, I can’t bear to watch her suffer the way I did. Please help us. Please bring awareness to the chronically ill people that desperately need pain medication to survive. Many, across the nation, have already begun to seek pain medication on the streets and many are discussing suicide. Surely, there must be a better option to help this community continue to receive when they need. We didn’t ask for this illness. Struggling with Crohn’s has obstacles that you cannot imagine unless you suffer from it…. but begging for pain medication at the emergency room is unacceptable and it cannot continue. Please help. I thank you

Very truly yours, Claudia A. Merandi 5 Chedell Avenue East Providence, RI 02914 401 523 0426

I'm 44 years old, this all started for me at 17 after a car accident caused me to suffer a broken back, unfortunately for me the breaks sustained were so weird that i was able to get up and walk...In pain but I could walk. I never received medical treatment directly after, I'd just wrecked my parents birthday gift, so when they came for my friend and I, immediately I said everyone is okay. I wasn't, but, needless to say. We were also moving at the time so I waited till we got to our new home and went to the doctor. Well, I explained to him everything that happened and how I hurt... Now, this is 27yrs ago, the doctor said to me, you're to young and you look ok to me...i dont think you have back problems!!! Yes, he did say that, and that was the beginning of four years of looking for help, just to EVEN correctly diagnosis me. See back then it was all about MRI's being so expensive and insurance not wanting to pay for them that the Drs. did everything they could to avoid them and the same for pain medicine, it was also impossible to obtain for relief then too. I bugged my dr monthly the first two years, and nothing, then finally i got him to refer me to pain management, i had been trying massage therapy, physical therapy, swimming, weight training, chiropractic and aerobic exercise...of course all of these things were done at a 10th of what you should do because of the pain I was in. Once going to the pain management dr. I discovered i was just being shuffled over to a "ultram" Mill. That medication did not help, i wanted and needed something that provided some real relief, i reslly, really needed to know what was wrong. Its been a couple years since the accident and both legs are so severely week, deteriorating, left foot drop...STILL have not gotten a MRI.. Im fed up at this point and feeling quite torn on what to do so I went back to my PCP and lo and behold he's not there anymore! There's a new Dr. already taking his patients and the first thing he does amazed me he checked my reflexes! NO ONE to date had done that one simple thing, needless to say, surgeries began right after that.  
My first was a Discectomy, failed, another Discectomy at two levels, failed, repeated and fail. After these I was now constantly having to take pain medication to try and survive one surgery to the next and continue to work as much as I could. Surgical intervention had failed, I was in need of a really good pain management place, but, i could feel something was not right right with my back, and when you live with pain 24/7 you become a wiz at knowing your body. My new pain Dr. suggested a Dr and you guessed it i went right back into yet another surgery, ok now Four years into this and this last final plea for help finds me in surgery and the Dr. finding that my backs been BROKEN ALL THIS TIME. Yea, all those 'ectomy surgeries no one else got the view and when i laid down the vertebrae that had broken would slide right into place at a bilateral (meaning both legs affected) setting so on the MRI's you couldn't see it, but when they put me upright on the table sure enough what was the broken piece was cutting into my spinal cord and he later said within 6mos i wouldn't have been able to walk! Thankfully he did catch it and all, he said there was a ton of scar tissue and nerve damage and that was way back then, I've been battling this everyday since. During that surgery I became the proud owner of titanium rods, screws, cages, etc and fusion in there, but the rest of my back is shot to. It may be these other conditions are with me because of just that area of my back or if i would've had the same problems if my back had been fixed earlier. Well, if it had been fixed earlier and not left to the "your too young for pain" mindset, i would not have half the problems I've got today and thats a fact. With the scar tissue and nerve damage more problems occur, more tests all the time, over the next few years i was also diagnosed with RA(rheumatoid arthritis), DDD(degenerative disc disease), RLS(restless leg syndrome)RSD(reflex sympathetic dystrophy)also called CRPS(complex regional pain syndrome), CELIAC DISEASE, SEVERE NERVE DAMAGE BILATERAL (MEANING BOTH LEGS), and last but not least, SCOLIOSIS…  
  
As I lay here on my side typing this out, I'd much rather be doing anything but! Its Sunday morning really cool out and I'm without ANYTHING for breakthrough pain. Whats breakthrough pain you ask? Four years ago my current and hopefully for a long time Pain mgmt Dr. installed a intra-thecal pain pump, which delivers the medication directly to the spine to help with all the severe nerve pain. That pump has a medication called Sufenta in it. Its a stronger medication, its stronger than the Fentynal patches, the delivery of the patches are NOT right, my body was using up the medication in the first 32 hrs when they were supposed to last 72 hrs! The way the medicine goes in also stops a lot of side effects because it doesn't run through your system. This has been a TREMENDOUS help! I still require medication though for breakthrough pain. Getting that small amount of medication to help with the other diseases/disorders that are taking me over is like pulling teeth, still, after all these years, its expected that these medications will be needed to help the pump do most of the work, but by golly the government STILL have Dr's so scared and wound up that we are getting swallowed up and tossed out with the bath water! How long must one prove they're in pain, show films, take blood tests', urine testing, pill counts at every visit from ALL your drs.! Its completely insane. You say, CDC, that chronic pain patients arent really affected by this, well think again, the majority goes to reputable Dr's, this is however our lives, and I means Lives literally and figuratively! We dont put ourselves through all this crap for a "high" First and foremost, that little feeling that addicts chase from these medicines, your real pain patient stops feeling that like instantly if they ever felt it to begin with, the pain so much outweighs the benefits, BUT, I'll take 35% relief versus nothing any day and thats sad, thats absolutely a shame that any pain patient has to live like this but we are, were making it, right now, and barely already, 27years and its no better its worse! For years I'd blame my age, my mood, my looks, my personality, my skin color, my gender, something there must be something about me that screams drug addict to them, that and what the hell is the attraction of this medication that makes them think Everyone wants it so bad, well I've grown up, I'm older I am a mother now and I get it, I can see why people are afraid. But, that by no way means that we should be looked upon and treated so badly because of the sterotyping your making. If my mothers blood pressure medication became popular on the streets, would you start limiting people from heart attack medication? How about the obesity problem in America are you going to stop sugars and carbohydrates from being allowed in foods and food products? What about alcoholism? I've now heard that someone actually was approved for DISABILITY because they was a alcoholic! Why arent you shutting down the liquor stores? Gaming has also started to become a crisis too now, so, they need to halt production of consoles..see that is just plain stupid. Dr/patient confidentiality, I guess were now supposed to let that go, cause our pharmacies already frown on us and look upon us like we a drug addicts perpetuating mayhem...no, now we have to tell them our life story and update to get our prescription and thats if they want to? Well, the one pharmacy thats already made that announcement just started me boycotting them sooner. I could beg and plead with you to not make our lives more hell than they already are, but, that would be a waste of my and your time. Just listen.  
  
Thank you  
Nyree D. Peterson  
Bremen, AL 35033

MY STORY

My story starts a long time ago when I was an active teenager and broke tailbone, back and several other injuries. As I became older these injuries started giving me problems. Then out of the blue my wrists started bothering me. Carpal Tunnel, surgery on right didn’t work. This ended my career at the phone company and has been disabled since 1993. I have always had Degenerative bone disease. So over the years things have gone downhill. I now have Fibromyalgia, Psoriatic Arthritis, Rheumatoid Arthritis, Osteoporosis to the worst end of the scale, shoulder problems from several injuries over the years, have had to had both thumb worked on due to arthritis. My back from top to bottom is in terrible shape. I have herniated discs in the neck and low to mid back and lower back I even have bulging disc on top of some of these discs. I have been given pain meds for the pain; I have done therapy, special exercises, chiropractor, and surgeries. Now because of the epidurals I now have what used to be rare but is becoming more prevalent Arachnoiditis. With all this I have tried to stay at the lowest pain dosage as I can but I still live with the pain it never goes away. I used to work I was a very active Jaycee, started a support group around 1991 for my husband’s National Guard unit in Maine. I also was active in Wic and Welfare reform at the time. Now because of all the pain in my body, my life has been totally changed. I have to pace myself with everything I do, Housework, yard work, trips and days of going out. It has been hard as I was raising my kids without being able to go a lot of places with them and just have fun. My husband was a truck driver.

So over the years I was being given epidural shots in the back to help relieve the pain and now because of that I have gotten Arachnoiditis which is the Dura in the spinal cord is inflamed. The pain is so much worse than the arthritis, broken bones and everything combined. So now the country is in this opiate epidemic making it that much harder to be treated. Most doctors, x-ray techs and more have not seen Arachnoiditis because it used to be so rare, not anymore and doctors don’t know the best way to treat it, they just say can’t do anything get a spinal cord stimulator which entails more pain and surgery and no way of knowing if it will work or cause more damage. Most of us are being under medicated. That leaves some of us no options to see if we can get pain relief from anywhere. If the correct dosage of the correct meds were given some this problem would be gone. The govt has made it their work to stop opiates from being given at all. These people are part of the problem- they have no idea of the real situation all they see is people get arrested or overdosing they don’t look at the whole person’s situation or care. If these people are going to make decisions on this issue they need to be educated. We have a chronic illness that requires pain meds to live would you stop heart patients from being allowed the meds they need.

So this is my story and my thoughts. Sarah Yerxa

November 7, 2017 Sandra Goshorn Mechanicsburg, Pennsylvania sandralgoshorn@gmail.com 717.512.6491 Hello, my name is Sandra. I’m a 45 year old Mother of 3. I also run my own daycare business out of my home and am responsible for providing care to my double heart attack victim fiance’ along with being the main financial provider for my family. In 2010 I was diagnosed with Thyroid Cancer. I had 2 small tumors and 2 massive tumors wrapped around the vocal cords in my neck. After a very painstaking delicate surgery to remove as much of the tumors as possible, I was thrilled to learn the surgeon had managed to save all my vocal cords and remove enough of the tumors that only minute follow up was necessary. Unfortunately, with losing a major functioning hormone to my body, I found myself very quickly gaining weight. My body completely seemed to change and despite what I did, I couldn’t seem to maintain a healthy weight. Wanting to be healthy and fit for my young toddler, my doctor and I decided on weight loss surgery. In January, 2012 I underwent RNY Gastric Bypass Surgery. It was a long road to recovery. Your body is put into a state of malnutrition and is unable to absorb vitamins easily. I was prepared for that and knew the first year would be difficult, but I persevered. Within 2 months of RNY Surgery, my Gallbladder went from zero gallstones to over 50 stones. My gallbladder needed removed immediately, so out it came. Within a few more months, I developed my 1st incisional hernia and gastric bleeding ulcer. Those 2 conditions would later prove to become chronic inflictions that have included 3 extremely rare Peterson's Hernias that only RNY patient's may develop, 6 incisional hernia’s and 6 years of extremely painful bleeding gastric ulcers. Between 2012 and 2015 I had to undergo 3 laparoscopic exploratory surgeries because my body seemed to be rejecting the new pouch and revisions to my gastroenterological body. I was in a constant state of extreme nausea and pain. The inability to absorb any nutrients or vitamins were taking it’s toll on me, even with vitamin infusions. I was diagnosed woth sensory and peripheral neuropathy and trigeminal neuralgia. It was if my entire body was shutting down, piece by piece. In 2015 my stomach completely failed and I had to have a 100% complete revision of my RNY. At this time due to all the scar tissue and bowel obstructions, I almost bleed to death on the surgery table. They managed to stop the bleeding once but after arriving on recovery, my gut became a geyser all over the staff. I became severely anemic and had multiple blood transfusions and still almost died. I ended up with a hematoma that covered 40% of my body. It was during this time and hospital staff keeping me as comfortable as possible, I managed to become severely burned over 10% of my body and was rushed to the closest burn unit. I spent another 2 weeks recovering from both the vast hematoma and burns. Within that year, I succumbed to 2 cases of severe orbital cellulitis where the infection are through the muscle, jaw, bone, tissue, sinus cavity, orbital socket and up into my brain. Not once, but twice, but 3 times. In the past 6 years I’ve had over 25 procedures and surgeries. I have chronic bleeding painful ulcers, repeated incisional & Peterson's Hernias where my bowel is slipping through my intestines. I have so much scar tissue and blockages that it causes constant pain. The blockages grow so rapidly that my bowels then become blocked and I could go 3 to 4 weeks without any bowel movement. I suffer with Gastroparenitis, Chronic Incisional & Peterson's Hernias. I’ve developed immunological disorders, 5 of them with constant repeated infections throughout my body. My liver has come close to failing, I now have early onset COPD with no reason for it, pelvic congestion disorder, spondilitis, Chronic malnutrition, esophageal disorders, the tube in my throat is under the size of a straw, which makes any level of swallowing painful, but I must eat and I must take my medicines. I most recently had another blockage so dangerous that no gastric acids were being released and my internal organs were turning toxic. Despite my doctor's due diligence, my body either didn’t react to cancer well or it didn’t react to rerouting my gastro system. My intestines are now completely disconnected and are just inside taking up space, as is 90% of my stomach. In case you were unaware, the intestines are where most vitamins, nutrients, and medications are absorbed. Because of this, I have an extremely high metabolic enzyme rate due to malabsorption Cytochrome P450. As quick as something goes in, it’s straight back out without absorbing the necessary minerals, nutrients and medications. Because of this, I have to take all of these nutrients and medications several times a day in order for my body to have the least bit effectiveness of them. Nitrous Oxide doesn’t work, novacaine doesn’t work, lidocaine doesn’t work. Dentists and anesthesiologists run from me. Despite all of this, there’s been one thing that has given me a semi-normal existence with tolerable enough pain to manage life. Granted I have my days that are so horrific, I dare not move, but I also have days that I can get right up and feel normal. But there is only one reason I’m still alive today, that reason is opioid pain management. I’ve been through all the tricks in the bag. The aquatherapy, gym membership, epidurals, massage, chiropractic, acupuncture, tens units, magnesium bath, salt room, prednisone, nerve blockers, gabapentin’s, antidepressants, anxiety meds….. nothing else works the way opioids do and even that is minimal at best. Because of opioid treatment for my multitude of disorders, I’m able to finally live. Run my business, care for children, care for my fiance of 8 years! Yes, he stuck around through all of it with me and I for him and his heart attacks. Last year I even managed to walk my through most of a 5k color run and I was my 7 year olds cheerleader coach. It was like despite all I had against me, I finally had a life back. Then it happened, the catchphrase of the decade, “The opiate epidemic”. “The War on Opiates”. All of a sudden, the one thing that finally helped me live life again, is at risk of being taken away. I pass all my drug tests, I comply with pill counting, I follow my pain contract, I never doctor shop, I never pharmacy shop. I do everything that’s asked of me and now I’m labelled an addict just because I have disorders that require treatment? I can’t begin to understand the travesty of this injustice. While I can sympathize with the issue regarding junkies and addicts, I refuse to be lumped into the same group as them. My medications are no different to me than blood pressure medicine or diabetic medicine or seizure medicine. What about mental health medicines. Those may become habit forming, are people that require them going to be cut off as well? Many doctors who previously cared for those of us with pain disorders are no longer treating pain because of scrutiny and pressure from the Drug Enforcement Administration. Many steps can be taken to improve pain care in America now. First, we must ensure that well-intended government policies and prescribing guidelines do not unnecessarily restrict the use of opioid pain medications for people who truly need them and use them responsibly. Please do not disregard the medical needs of chronic Intractable Pain patients due to the very small percentage of people who have substance abuse issues. Through no fault of my own, I have been stricken with disorders that causes extreme pain and is currently incurable. I suffer from malabsorption issues of Cytochrome P450 enzymes that affect my medication metabolism. Occasionally I need non-standard dosages of medication to achieve any analgesia. This can happen to anyone. I cannot take aspirin, nsaids or naproxin because they eat right through my pouch. There is no 1 pill fits all here and only skilled, trained physicians can make that determination. What we all need is trained, licensed physicians who are qualified, recognized as experts, and specifically enabled to prescribe whatever treatments or medications they deem necessary for intractable pain patients without interference from regulatory agencies, pharmacies, or insurance providers. Without such specialists, under treated patients will continue to suffer and some will die from the physiological impacts of living with inadequately treated pain. I'm personally asking for your help in 3 ways. First, please ensure that Federal agencies, state and local legislators, pharmacies, medical boards, etc... do not impose restrictive opioid prescribing guidelines that fail to address the medication needs of long-term chronic Intractable Pain patients. Second, please support exemptions for people like myself and others, who by no fault of their own do not fit the “one size fits all” model of pain care, and thirdly, provide training for physicians who can be licensed to prescribe non-standard dosages of medications, including high-dose opioids for chronic Intractable Pain patients who need them. Thank you, and remember… chronic Intractable Pain can happen to anyone. No one asks for this. I am counting on you to stand up for me and so many others!

Sincerely,

Sandra Goshorn

State: Florida

I am writing this letter because I'm very concerned about the current environment toward people who suffer with chronic pain. We are patients, not addicts. We are people who follow all the rules yet are being discriminated against because of those who don't. I have a master’s degree, I am an intelligent woman who can understand the risks associated with medications, and it should be my choice whether to take it or not.

My brother died of alcoholism and it absolutely broke my heart. I know well what addiction can do to a family. However I also know that because my brother made choices that eventually led to his death, it didn't make a dent in alcohol use in this country. We have bars on every corner. Alcohol is sold in many stores. Kids start drinking alcohol at young ages and this is somehow considered acceptable? Many people die every year due to alcohol but it's still legal and people haven't been told they can't drink for fun. Yet because we sadly have people dying due to drug use, which is mostly not prescribed by doctors, chronic pain patients are being told we can't have medication to improve our quality of life. Not for fun, but in order to function on a daily basis. How is this right?

I have severe erosion in my insides due to OTC medications and NSAID medications. My doctor now prescribes an extended release medication for me with no acetaminophen, Tylenol, or naproxen in it. I can no longer take those products for long term use. The extended release pain medication has given me the ability to work again after being isolated and alone due to the severity of my pain. I was hit head on by an elderly man driving. I was stopped at a stop sign on my way to work and my life hasn't been the same since. I am now a chronic pain patient due to several ruptured/herniated discs in my neck and back resulting from the head on collision. I didn't ask for this pain as no one suffering in chronic pain has. I've since been diagnosed with fibromyalgia which I'm told is common after neck injuries. I recently had an MRI and a Syrinx was discovered in my lower back. These conditions cause all over-wide spread pain making life very difficult. Thankfully I'm able to work and support myself but without the use of pain medication, in addition to other alternative treatments I've incorporated into my life, my career of over 30 years will end. Pain medication does not make me high. It simply helps to manage pain as it was designed to do.

My 84 year old dad suffers with debilitating arthritis and is finally taking pain medication to give him the ability to function and have better quality of life. My dad worked hard his entire life only now to be disrespected by pharmacists and insurance companies. Pharmacies have refused to fill his pain medication after he finally agreed to give it a try. (My dad was never a person to take medications). He is currently getting his prescribed pain medication and is able to function and have better quality to his life. He gets up, showers, and dresses himself every single day. He makes sure to walk as much as possible. If his pain medication is taken from him, he'll not only needlessly suffer more but the increased burden to my aging mother would be more than she can bare.

I'm writing this for both my father and myself. We are heartbroken over the loss of my brother, my dad's son. However we have never asked that someone else's right to drink be taken from them. I would like to ask that the same respect be given to us regarding pain medications. We take our medications as prescribed. We have never had an increase in our prescriptions. We have never sold our medications or shared them with others. Yet my father had been turned away at a pharmacy and my medications have been reduced to a bare minimum. I'm currently still working at age 53 and I don't want to be on disability. If my medication is taken or reduced more I'll have no choice but to stop working, sell my home, and live somewhere isolated again. Is that what our government wants?

Gov. Rick Scott of Florida, where I live, is proposing that pain medication refills be allowed for only THREE days at a time for both acute and chronic pain patients. As it is now, I have to drive to my doctor of over 10 years, who is almost 2 hours away, every month. What employer likes this? What employer would allow me to take off work every 3 days to fill a prescription that gives me the ability to continue working? I'm expendable and they'd absolutely get someone else to fill my position. No one else would even hire me.

I could write and tell you of the severity of my pain but I don't know that it would make a difference. I don't know that telling you my back and hips often feel like they're on fire would matter to you. I don't know if telling you it's difficult to walk some days would matter. I don't know if you hear the hurt. But maybe telling you that I'd become another statistic would help. Many people have committed suicide due to unmanaged pain. I'm in several support groups and sadly hear of this throughout our country. Many say they'd rather be dead then to feel the debilitating pain they have without pain medications to help. Would knowing that I'd be a drain on society by being another person on disability matter? Would you hear that? I can only pray that someone who has a voice in our government will listen to our stories and try to feel our pain. I can only take life one day at a time, not knowing if my medication will be further cut or even taken away. I pray you have the ability to hear that many, many people in pain are relying on you to understand that we are patients, not addicts, and by further regulating our medications you will be adding to the number of deaths in this country. Many will turn to unsafe street drugs and possibly die or even decide to take their own life. Chronic pain is pain 24 hours a day with relief as our medications provide. We are patients, not addicts. I humbly ask that you recognize the difference and allow our doctors to treat us appropriately in order to manage the pain we endure every day of our lives.  I humbly ask that you be our voice to speak in our defense and to educate others that we are here. We are doing everything we can, trying every treatment option out there because we want to live, not die. I humbly ask that you review statistics and recognize that we are not the problem. We are patients. We are not addicts.

I would like to remain anonymous due to the stigma against pain patients in this country at this time. I don't want to further jeopardize my employment. Thank you for taking time to read this. I pray you understand.

Sincerely,

A chronic pain sufferer, not an addict.

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| |  | | --- | | **Shannon Jones <wolfladi352012@gmail.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |
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A problem with few solutions

Just how often are hospice patients left in the lurch? Inspection reports, performed by states and collected by CMS, don’t give a clear answer, in part because hospices are reviewed so infrequently.

Unlike nursing homes, hospices don’t face inspection every year to maintain certification. Based on available funding, CMS has instead set fluctuating annual targets for state hospice inspections. In 2014, CMS tightened the rules, requiring states to increase the frequency to once every three years by 2018.

Often, promising to do better is the only requirement hospices face, even when regulators uncover problems. The Office of the Inspector General at the federal Department of Health and Human Services has called for stricter oversight and monitoring of hospice for a decade, said Nancy Harrison, a New York-based deputy regional inspector general. One problem, she said, is there is no punishment short of termination — barring the hospice from receiving payment from Medicare— which is disruptive for dying patients who lose service.

CMS records show termination is rare. Through routine inspections as well as those prompted by complaints, CMS identified deficiencies in more than half of 4,453 hospices from Jan. 1, 2012 to Feb. 1, 2017. During that same time period, only 17 hospices were terminated, according to CMS.

In Alaska, Patricia Martin filed a complaint against Mat-Su Regional with the Alaska Department of Health and Social Services six weeks after her husband’s death. An investigation concluded that the hospice failed to properly coordinate services, jeopardizing his end-of-life care. Hospice officials declined to comment about his case, citing patient privacy rules. In an email, Mat-Su administrator Bernie F. Jarriel Jr. said the hospice “strengthened our policy and procedures” as a result of the investigation, and “members of our caregiving team have been re-educated on these practices.”

In Minnesota, officials with the local Heartland Home Health and Hospice agency referred questions to its corporate owner, HCR ManorCare of Toledo, Ohio. Officials there did not respond to multiple requests for comment about Leo Fuerstenberg’s care. CMS documents indicate the nurse who missed 16 messages “was re-educated on responsibilities of being on call.”

In a 2016 study, the OIG’s Harrison and colleagues called for state surveyors to better scrutinize the care plans hospices outline for their patients. And they recommended that CMS create a range of different levels of punishment for hospice infractions, such as requiring in-service training, denying payments, civil fines, and imposing temporary management.

CMS has no statutory authority to impose those alternate sanctions, said spokesman Jibril Boykin. But it did work to increase transparency in August by launching a consumer-focused website called Hospice Compare that now includes hospices’ self-reported performance on quality measures, and, next year, will include family ratings of hospices.

Until that happens, there’s little information available for families trying to pick a hospice that will show up when it counts. Tucci, of the Hospice Foundation of America, suggests that families of ill or frail relatives consider hospice options before a crisis occurs. The agency recommends 16 questions families should ask before choosing a hospice.

Back in Alaska, Patricia Martin said she’s still waiting for officials with Mat-Su Regional Home Health and Hospice to answer questions about her husband’s poor care. She urges other families enrolling patients in hospice to be vigilant.

“It is my hope that no other family or patient will ever have to go through the nightmare that we did,” she said. “If they promise you they’re going to do something, they should do it.”

St. Stephen, Minn., Leo D. Fuerstenberg, 63, a retired U.S. Veterans Affairs counselor, died panicked and gasping for air on Feb. 22, 2016, with no pain medication, according to his wife. Laure Fuerstenberg, 58, said a shipment sent from Heartland Home Health Care and Hospice included an oxygen tank, a box of eye drops and nose drops, but no painkillers.

“They were prescription drugs, but it didn’t say what they were or how to give them,” she recalled. “I just panicked. I called the hospice, and I said, ‘We’re in trouble. I need help right away.’ I waited and waited. They never called back.”

For more than two hours, she tried desperately to comfort her husband, who had an aggressive form of amyloidosis, a rare disease that can lead to organ failure. But he died in her arms in bed, trapping her under the weight of his body until she managed to call neighbors for help.

“That last part of it was really horrible,” she said. “The one thing I promised him is that he wouldn’t be in pain, he wouldn’t suffer.”

Later, state investigators determined that Heartland’s on-duty hospice nurse had muted her phone, missing 16 calls for help. Hospice officials did not respond to repeated interview requests.

“They never followed their protocol, and I’ve never had anybody from there say, ‘We failed, We were wrong,’” said Fuerstenberg, a school counselor who said she relives her husband’s death daily. “If that had been me on my job, I’d be fired.”

Her account was among more than 1,000 citizen complaints that led state investigators across the country to uncover wrongdoing from January 2012 to February 2017, federal records show.

But the complaints offer only a glimpse of a larger problem, said Dr. Joan Teno, a researcher at University of Washington who has studied hospice quality for 20 years. “These are people who got upset enough to complain.”

Officials with the National Hospice and Palliative Care Organization (NHPCO), an industry trade group, said that such accounts are inexcusable — but rare.

“I would venture to say whatever measure you want to use, there are an exponential number of positive stories about hospice that would overwhelm the negative,” said Jonathan Keyserling, NHPCO’s senior vice president of health policy. “When you serve 1.6 million people and families a year, you’re going to have instances where care could be improved,” he added.

But even one case is too many and hospices should be held accountable for such lapses, said Amy Tucci, president and chief executive of the Hospice Foundation of America, a nonprofit focused on education about death, dying and grief. “It’s like medical malpractice. It’s relatively rare, but when it happens, it tarnishes the entire field,” she said.

How often hospices fail to respond to families or patients is an understudied question, experts say, in part because it’s hard to monitor. But a recent national survey of families of hospice patients suggests the problem is widespread: 1 in 5 respondents said their hospice agency did not always show up when they needed help, according to the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey, designed by the Centers for Medicare & Medicaid Services.

“That’s a failing grade,” Teno said. “We need to do better.”

‘It’s like they just didn’t do anything’

Hospice care in the U.S. got its start in the 1970s, driven by religious and non-profit groups aimed at providing humane care at the end of life. Today, however, many providers are part of for-profit companies and large, publicly traded firms. It’s a lucrative business: For-profit hospices saw nearly 15% profit margins on Medicare payments in 2014, according to the Medicare Payment Advisory Commission.

Most families are happy with their experience, according to the CAHPS survey. In data collected from 2015 to 2016 from 2,128 hospices, 80% of respondents rated hospice a 9 or 10 out of 10. Kaiser Family Foundation polling conducted for this story found that out of 142 people with hospice experience, 9% were “dissatisfied” and 89% “satisfied” with hospice. (Kaiser Health News is an editorially independent project of the foundation.)

Indeed, many people give hospice glowing reviews. Lynn Parés, for instance, gushed about her experience from 2013 to 2014 with Family Hospice of Boulder, Colo. When her 87-year-old mother cut her leg, staff came daily to treat her wound. In her last week of life, a nurse came every day. The hospice also provided family counseling, spiritual guidance, and volunteers who surrounded her mother’s bedside, singing old-time songs.

“They were in constant contact with us,” Parés said of the hospice. “It’s amazing to me how much heart there is involved in hospice care.” After her mother died, Parés and her siblings donated part of their inheritance to the hospice. “I can never say enough good about them.”

In 2015, the small, family-owned Boulder company was acquired by a large regional chain, New Century Hospice, part of a larger wave of consolidation in the field.

As the industry grows — hospice enrollment has more than doubled since 2000 — some companies are not following through on their promises to patients, according to the government reports. For instance, data show many hospices fail to provide extra care in times of crisis. To get Medicare payments, hospices are required to offer four levels of care: routine care, which is by far the most common; respite care to give family caregivers a break for short time periods; and two levels of so-called “crisis care,” continuous care and general inpatient care, when patients suffer acutely. But 21% of hospices, which together served over 84,000 patients, failed to provide either form of crisis care in 2015, according to CMS.

Other research has found troubling variation in how often hospice staff visit when death is imminent. A patient’s final two days of life, when symptoms escalate, can be a scary time for families. Teno and her co-authors found that 281 hospice programs, or 8.1% of hospices, didn’t provide a single skilled visit — from a nurse, doctor, social worker or therapist — to any patients who were receiving routine home care, the most common level of care, in the last two days of life in 2014.

Regardless of how often they visit, hospices collect the same flat daily rate from Medicare for each patient receiving routine care: $191 for the first 60 days, then $150 thereafter, with geographic adjustments as well as extra payments in a patient’s last week of life.

Overall, 12.3% of patients on routine home care received no skilled visits in the last two days of life, the study found. Patients who died on a Sunday had the worst luck: they were more than three times less likely to have a skilled visit than those who died on a Tuesday. Teno said that gives her a strong suspicion that missed visits stem from chronic understaffing, since hospices often have fewer staff on weekends.

In Minnesota, Fuerstenberg’s pleas for help went unanswered on a Sunday evening; her husband died just after midnight on Monday. She was appalled when she received a bill for care the agency said occurred on that day.

“When they got paid for nothing, it was like a slap in the face,” said Fuerstenberg, who filed a complaint with Minnesota health officials last year. She heard nothing about the case from hospice officials and didn’t learn it had been investigated until she was contacted by reporters for this story.

In St. Paul, Virginia, a small town in the Appalachian mountains, Virginia Varney enlisted Medical Services of America Home Health and Hospice, a national chain, to care for her 42-year-old son, James Ingle, who was dying of metastatic skin cancer. On his final day, Christmas of 2012, he was agitated, vomiting blood, and his pain was out of control. Varney called at least four times to get through to hospice. Hours later, she said, the hospice sent an inexperienced licensed practical nurse who looked “really scared” and called a registered nurse for backup. The RN never came. Ingle died that night.

Varney said she felt numb, angry and “very disappointed” in the hospice care: “It’s like they just didn’t do anything. And I know they were getting money for it.”

“They told me 24 hours a day, seven days a week, holidays and all,” Varney said. “I didn’t find that to be true.”

An investigation by Virginia state inspectors, which corroborated Varney’s story, revealed the hospice nurse changed the records from that night after the fact, altering the time she reported being at the home. The registered nurse was fired that February. The hospice declined to comment for this story.

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To whom it may concern,

My name is Kristen Miller. I live in Midland Park New Jersey. I have been suffering from chronic pain since May of 2004 after being diagnosed with Lyme disease. The effects of this disease have devastated my body in ways no human should ever have to feel. It has set off many autoimmune conditions, has stopped my heart, has accumulated fluid in my lungs, has left me unable to function as a normal human being.

I was on opiate pain medication for a period of time. There was one particular occasion where my Pharmacy did not have my medication in stock and could not fill my prescription. I went to another local pharmacy where they were able to fill my prescription. A few months later my primary care physician suggested I go to the hospital because I was having trouble with my heart and I was in a lot of pain. They admitted me and we're extremely hesitant on giving me anything to relieve the pain. When I finally saw one of the doctors she said she had gone over my records and seen that I was using different pharmacies to get my pain medication, so basically accused me of being an addict seeking out my meds.  I was also forced to change pain management doctors because my original one had stopped taking my insurance, apparently that was another red flag unbeknownst to me.  I never took more then I was prescribed, in fact I still have a bottle of morphine sitting here from 8 months ago that has not been touched.

After being released from the hospital I refused to take the pain medication anymore because of the stigma and the Dark Cloud that hung over my head. I am now living in constant agony, barely able to function even with everyday tasks such as showering, doing dishes, taking care of my children or being of any use at all.  I do not live I merely exist in a life of hell.

Nobody will ever understand this until it actually happens to them or someone close to them. There is no way to describe the pain that many people suffer with on a daily basis, it is literally inhumane. My daughter is a veterinarian and animals in this country get treated better than people do. It is unfair what is trying to be done to people that actually need this medication to function.

I understand there is a crisis in this country with addiction and abuse but it is also affecting the people that truly need this to survive.  Taking it away from the people that need it will only cause more consequences in the end. It wouldn't surprise me if the suicide rate increased, and it would not surprise me if people started seeking drugs on the street not knowing what they are getting and dying from that.

I am begging for change, not only for myself but for many others who suffer as I do as well as the families who suffer with them and watch them struggle on a daily basis to do what every other American takes for granted. I have learned to appreciate my small victories and to some, these victories are the smallest of things.  To me just being able to get out of bed in the morning taking a shower and making it through a day are considered a victory.

There is not a day that goes by that I think I would be better off not being here right now. When I look into my children's eyes and see their pain because they feel so helpless it makes me so angry.  My family is so undeserving to watch this control my life.  Pain medication does not take it all the way, but I am able to be a much more productive person.

I am submitting this letter on behalf not only myself but also on behalf of my amazing husband and three children who want me back in some respect.  I'm also sending this on behalf of all the people that suffer from these invisible illnesses that are destroying them from the inside out.

Sincerely,

Kristen Miller

Sent from AOL Mobile Mail

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A society which allows people to suffer for any length of time, is understood to be a morally bankrupt society. It is inhumane and unacceptable to force suffering on citizens. Especially in America.

No more 'about us without us'. Unless we are moving towards a Hitleresque society, you must include those of us who live with unrelenting, debilitating pain, AND our doctors in every conversation/policy. So far this government has allowed ONLY addiction special interests and other non medical personnel to control this conversation and all policies. Not once have any politicians even considered speaking to us and that must stop today.

You MUST make intractable pain, surgical, cancer and terminal patients FULLY EXEMPT from any anti-opioid policies. And yes, even those dying in unspeakable pain are denied pain control.

Controlling pain - easing the suffering of American citizens is a basic right. Forcing doctors to deny this right, goes against the oath they've taken and rips families apart. Again, it is inhumane, immorally wrong and completely unacceptable. I live with complex regional pain syndrome also known as the suicide disease. Untreated, we merely exist in pain no one can begin to understand or imagine. The anti-human policies created against patients and doctors will not stop addiction, but it is causing suicides among pain/cancer patients to skyrocket. And will also cause skyrocketing medical cost via unnecessary ER visits, doctor visits, tests, etc.  Much more cost effective to treat pain with opioids that are proven to work.

All policies, guidelines and decisions that affect pain care on the federal, state and local level MUST include intractable pain patients and actual doctors who understand how dangerous untreated pain is. Our lives matter and it's time government understand that as well. We are not disposable. NO MORE ABOUT US WITHOUT US.

IT IS THE MOST BASIC HUMAN RIGHT THAT NO ONE SHOULD BE LEFT TO SUFFER IN PAIN. IT IS TANTAMOUNT TO TORTURE. No government should ever decide policy that forces suffering on its own citizens. Relief of pain is essential so that all patients are able to function, engage, and have the best quality of life possible.

You can ease suffering and get actual addicts the help they need at the same time. Pain patients/doctors did not start the addiction problem. Addiction has been around for thousands of years - and addicts will abuse anything they can get their hands on. It is unfair and criminal to deny pain relief to those who suffer just because 'some people abuse'. We are not criminals, yet we are now being treated as such.

Gayle Onnen

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My name is Denise OBrien better known to my Grandchildren as Grammy.  I have Chronic pain.  I take pain meds not to get high but to enjoy my Grandchildren, with my meds I am not in bed all the time crying in pain.

I was diagnosed with Fibromyalgia in 2005 and in 2010 was lucky to have a doctor who was willing to help me, not because I was seeking drugs but seeking  relief from my pain  and to get my life back.

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# [**How the CDC Opioid Guidelines Affected Me**](https://www.painnewsnetwork.org/stories/2017/3/1/how-the-cdc-opioid-guidelines-have-affected-me)

[March 01, 2017](https://www.painnewsnetwork.org/stories/2017/3/1/how-the-cdc-opioid-guidelines-have-affected-me)

By Sarah Irvine, Guest Columnist

I'm 42 years old and have been suffering from chronic pain for the past several years. I was injured at work almost 8 years ago and, like many others, I have been affected by the CDC opioid guidelines.

I have herniated and bulging discs in my lower back, scoliosis and I ambulate with a cane. I have Protein C deficiency, a blood clotting disorder, and I am not a surgical candidate.

I live with excruciating pain and my pain medication, morphine sulfate, has been decreased from 150 mg daily to 45 mg daily. I also was recently prescribed Lyrica and baclofen, a muscle relaxer.

This does nothing to alleviate my pain. I'm becoming shorter, my spine is shaped like a serpent and my muscles are becoming more atrophied. Workers compensation refuses to pay for any more physical therapy and Medicare won't cover it either.

I'm certainly not able to pay out of pocket and at this point I'm in too much pain to function. Due to the Protein C deficiency, I should not take NSAIDs or steroids because they increase my risk of bleeding. I am also on a high dose of Coumadin for my blood disorder.

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What about interventional pain management such as a spinal cord stimulators or a pain pump? I had a pain pump placed in November and the quality of my life has changed so much I can't even put it into words except most people can't believe how much I have changed and that I smile and laugh again!

V8 months ago

Sara im thrilled that the pain pump helped you, but unfortunately for every one that it does help there are 100's it don't. Not to Mention being invasive and expensive I tried that all it did was make it worse and cost me thousands of dollars. I'm allergic to morphine so it almost killed me on top of it

I tried the spinal cord stimulator, tens units physical therapy I tried everything.

They don't help everyone, my pain journey started 17 years ago when I was rear ended while stopped. My first spinal fusion was a complete failure but because the doc I had was well Known and refused to believe HIS SURGERY NEVER FAILED he acutally told my husband that but no one listened to me. So while the bak cage continued to grew crooked into my spinal nerve roots the more damage was done, I finally after trying everything going to 22 yes I said 22 surgeon asking for help (not pain meds) I had nothing but road blocks until I found a doctor who not only listened but agreed there was something terribly wrong

After redoing the fusion he tried very hard to help me but the damage was done. He was afraid to remove the cages because it would have paralyzed me. Although now that might not be so bad as the pain I have is more than Anyone should ever have to bare . This witch hunt will soon include pain pumps because your using the same medication I tried a pain pump but like I said I'm allergic to morphine so that's not a option for me. Sadly there isn't any good ones, I'm just trying to hold on day to day.

I pray that these people who think they are helping save us from ourselves are happy, I lost a good friend last week he blew his brains out because the docs cut him off without any reduction even not Because he did anything wrong but because THEY DID he's dead gone for ever why because the dea cdc and allthe other puppets in government are making decisions for people they know NOTHING ABOUT . I'm done now im to the point I beg God to bring me home I hsve nothing to live for here but more pain .

Penny8 months ago

It's about the money. Follow the money. Insurance wants to reduce its loss in this category.

maryw8 months ago

  I agree Penny,100%,,,I went for 14 years,,1 visit a year,,cost thee insurance company NOTHING,, it was 250.00 a appointment w/my doc,,,which is our was part of our deductable,,NOW,, we alll know WHAT their FORCING us to do,,pending your MEDICINE,, u r forced 1 a month,,or every 90 days,,,and FORCED PEE TESTS,, that insurance companies are denying to pay,,,THEY HAVE MADE IT MORE EXPENSIVE,, not us,,its alll on purpose,,just another fyi,,,i did submit a case to my state aclu December 19th,,2016,,,,it takes 10 weeks for them to decide if they will help us or not,,Sooo,,,if I get a yes,,from my aclu,,to take on the federal government/and state government on this,WILLFULL torture/genocide/discrimination/abuse of ,''just power,''/falsification of data/abusing the public trust/coercion w/media outlets to spread propaganda/lieing to the public/CAUSING SEVERE PHYSICAL PAIN. onto a human being for a 3rd party for information/denial of effective medical care to reduce severe physical pain/Denial of timely medical care causing severe physical pain onto another humanbeing,,,,,,,I will let EVERYONE KNOW,,for all of u wanting to hop on a civil lawsuit are more then welcome!!!!!!!!!!!!

Im praying they will it's outrageous what they are doing and the latest numbers are showing even now more heroin deaths are occuring please keep us posted

Yay Mary! Thank you so very much - you are the best!!!

Shelley Norman Echtle8 months ago

I agree Sarah, the lower doses are inhumane. I suppose if we were animals, they would put us to sleep! But, we aren't pets, we are humans just like Debra Houry who wrote these ridiculous guidelines that are heralded as laws, but they're not! She did not take the time to think of chronic pain patients or she couldn't reflectively have sent this forward. She did not think of those of us who were on opiates that have a proven track record with our doctors! She didn't think of the many years our doctors studied and interned and the thousands of hours since that they've educated themselves to prescribe us our drugs. She didn't think of the 116 million pain patients that are in need of treatment. She just blatantly did not think. She got caught up in groupthink. She got caught in the loop of stopping the abuse. She got caught up in stopping overdoses, celebrity deaths and drug seekers. She ignored the facts of what it is like to be a chronic pain patient. Now, we the people, must speak out in the next 45 hours (central time) and let out voices be heard!!! The drug companies, especially Pfizer, are now pushing their Lyrica, Cymbalta, and Savella harder than ever! The problem is that approximately 63% of people can not take these drugs due to side effects and allergic reactions. I tried them.... they did NOT work! Now, we have to decide, will we lift our voices and demand dignity? Will we demand introspection? Will we demand to be treated with respect and humanity? Will the doctors demand their right "to do no harm!"? Every single person in the USA will eventually be affected by this.... it will start with the opioids, then it will continue to other medication choices! Every misconception that Ms. Houry touted, every collusion with the insurance companies, will now go down historically when American Medicine became manipulated by one ill-written white paper. Other countries will watch as our suicide rates sky-rocket; they'll see Americans crossing borders to get prescriptions; people will leave to go to other countries permanently; or lastly, our heroin addiction rates will become the highest in USA history... all because Ms. Houry did not take the time to think! I dare to say, that collusion of the insurance companies included a pay-off, but that I will not ever know. The damage is near... please, please, please write your email today! The time is NOW! It is imperative that we react with written word, and show, we want to make America great again! We want empathetic compassionate care that shows humans can relate even wheelie we suffer!

Shelley Norman Echtle

Pam8 months ago

Thank you for sharing your story. I too suffer from multiple debilitating incurable diseases that cause severe pain. Ten long years of it, years of PT, massage, chiro, accupuncture, epidurals, discectomies, facet injections, SI joint injections, trigger point injections, water therapy, every nonopiod medication that did nothing for my pain and i had horrible side effects from, two failed spinal fusions, steriods, nerve burned, and more. When I finally was put on opiod therapy, I was given a quality of life. Eight years on the same stable dose with success, until about a year and half ago, my dr lowered my meds to ineffective doses and took some away. For months now he has been making degrading comments at me, tells me to look into going to a detox ctr, i am furious!!!! I AM NOT AN ADDICT! I cannot help my body is ridden with debilitating incurable diseases, im just trying to have the pain managed so i can function! I suggest for you to join chronic pain support groups on facebook, many are coming together to fight back!

Anne Fuqua8 months ago

Sarah,

Reading stories like yours makes me so angry. The situation HAS to improve! I can't believe how much worse things have gotten in the past few years. Just since Christmas it seems like the avalanche has grown and is moving faster everyday.

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My pain story starts many years ago. I was diagnosed as being a type 1 diabetic at the age of 9. Fast forward to adulthood. Despite good control diabetes can be a terrible, debilitating disease. A few years ago I had to have a hysterectomy surgery did not go too well. Several years later I was dealing with terrible abdominal pain. I refused all offers of pain medicine because of the stigma attached and I also just wanted to know what was causing the pain, not just mask it. My OBGYN was wonderful she went to the hospital and went through my medical records because the doctor who did the hysterectomy was now deceased. She recommended that I have another surgery to go in and see what was going on. After the surgery she informed me that my adhesions were so bad that all of my organs and bowels were covered. She did not know how I was even walking around let alone functioning(I have two sons). She then told me that I would probably be on pain medicine for the rest of my life. I was on about 40mg long acting oxycodone and 10mg for breakthrough pain. I was referred to pain management. I was immediately taken off of the meds that were working and placed on medicines that did not work. I have gone to pain management for years and my current dosage is 5mg of oxycodone every 4 hours. I do like my pain management doctor as she gives me ideas that do not always involve medications. I do not like that at this point my current dosage is not working for me. I have the issue of the abdominal adhesions, terrible diabetic neuropathy, arthritis, fibromyalgia, migraines and back problems as well. I do not "look sick" and when people hear my story they are shocked and amazed. Everyone except for my family, who has been there for the pulmonary embolisms, mild heart attacks and everything else this cruel disease has dished out. I love my children more than anything on this earth but sometimes the pain is unbearable and they are the only thing between me and the end. It is that serious! I hate going to get my prescriptions so much my son now goes to pick them up for me. His liscense has to be scanned so will he now be labeled a "drug seeker" or someone who simply does not want his mom to feel bad anymore?

This issue is very serious. I had an uncle, I repeat had an uncle who is no longer with us. He was an asset to society, former military, went back to his small town to help others and married the love of his life. He was a chronic pain patient. I saw my uncle suffer. We will never know what killed him because my aunt declined an autopsy. Knowing what I know, suicide is possible. We must do something about thi. The same way I take my insulin, my Lipitor, my aspirin, I also need my pain meds to function and contribute to those I love. Not to get high. I have raised to great sons primarily by myself, while on pain medicine, not high. One works for Flow Automotive and one is on the management track for Chick Fil A. They have both graduated High School & moved on to college and have NEVER been in trouble. They are both well spoken, have great manners & complimented all of the time.

In closing pain medicine is not bad. Pain medicine is medicine.

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ALLISON KIMBERLY JACOBS

Age: 30

Allison Kimberly, age 30, of Colorado was denied treatment for her intractable pain from interstitial cystitis, and several other painful conditions. Interstitial cystitis can end in suicide from the failure to treat it properly as it is an extreme form of agonizing discomfort. It is said the University of Colorado emergency room in Aurora refused her treatment for her pain. Allison posted on Instagram describing how she was treated as an addict and sent away without pain medicine.

“I was rushed to the ER because my pain was so out of control I couldn’t take it anymore, I got ZERO help. After 7 hours I was discharged. The nurse has the nerve to say that my kind of pain shouldn’t be that bad and basically I was faking for medication. I am so beside myself I am shaking as I type this. Screaming and begging in pain, needing any kind of help they’d give me and I was just sent home. As soon as I am able I’m reporting my whole experience”

Allison did not have time to file a complaint against the hospital as she violently ended her life while her mother walked her dog, the animal companion that had made her anguish less lonely. No doctors appear to have been charged. The Colorado Hospital Association was in the process of piloting a no-opioid policy for the state. She died in June, 2017

Link to obituary:

<http://www.legacy.com/obituaries/denverpost/obituary.aspx?page=lifestory&pid=185902615>

More and more patients will die if our government continues its brutal War Against Chronic Pain Patients. We take daily opiates not because we want to, but because we have no other choice. Without proper pain management our lives are over. More and more of our brothers and sisters will continue to commit suicide if our pain is ignored and untreated. We deserve better than this.

Don't let the death of our sister go unanswered!!

Tell the government we are #PatientsNotAddicts and we have rights too!!

#CNN #CNNHealth #SuicideDue2Pain #POTUS #OpiateEpidemic #ChronicPain #WarOnDrugs #FLOTUS

# DAUGHTER SAYS UNTREATED PAIN LED TO MOTHER’S SUICIDE

Suicides are never easy to accept. Especially if they involve a loved one. Even more so if they could have been prevented.

Lacy Stewart says her mother never would have killed herself if she’d been given proper medical care for her chronic fibromyalgia pain.

“I feel angry about the way she was treated,” says Stewart, a registered nurse who believes the healthcare system not only failed to treat her mother, but drove Marsha Reid to suicide at age 59.

Her life was taken from her is the way I feel,” says Stewart. “I know it was. A person can only handle so much pain for so long. It takes its toll on every area — your mind, your body, everything. And she just couldn’t do it anymore. She’d had enough. Because nobody would help her. Nobody.”

Stewart says her mother was fit and physically active – handling all the chores at her 10-acre farm in north Texas — until she slipped on ice and landed hard on her face in 2009. Reid broke a few teeth and sustained nerve damage in the fall — injuries that evolved into the classic symptoms of fibromyalgia: chronic widespread pain, anxiety, fatigue, insomnia and depression.

Of course she sought out help. Searching for doctors that would take her on, she encountered road block after road block. Many doctor’s offices would just flat out say, ‘We don’t take fibromyalgia patients,’” recalls Stewart.

“So you take that and couple it with the fact that pain medication is often required for these patients and now the CDC has regulations that deter a physician from wanting to prescribe pain medication at all and you end up here. Zero help for a woman suffering day in and day out for all these years. She lost her job, her home, her independence.”

In January, Reid checked into a hotel room and tried to kill herself by taking a full bottle of Xanax. The failed suicide attempt left Reid even more depressed and her health deteriorated further. She started having hallucinations, hearing voices and seeing dead people.

In July, Stewart drove her mother for five hours to see a pain management doctor.

“I was appalled at the treatment from the physician. We explained the pain and the issues with her mind, and he said he could only treat one or the other. Not both! Not the whole patient! When I brought up pain medication you would have thought I had asked him for heroin,” says Stewart.

“I’ll never forget the conversation I had with him in the hall on the way out. I looked him in the eye and said the pain is so severe she will kill herself! It’s only a matter of time. He basically said his hands were tied because of the regulations and what I was asking was for him to lose his license! I was furious and felt betrayed by the field I loved, medicine.”

One treatment was suggested for her mother.

They wanted her to go to water aerobics,” said Stewart. “The woman could barely take a bath and they wanted her to go to water aerobics! I read in the CDC (opioid) prescribing guidelines that they wanted doctors to use alternative measures for pain relief such as water aerobics and physical therapy. They never spent a day in pain in their lives, obviously. Because then they would know that is ridiculous. It’s almost a joke to me, the guidelines that I have read.”

In recent months, Pain News Network has been contacted by **dozens of pain patients who say they are contemplating suicide.** It’s not just the difficulty in getting opioid pain medication. The growing crisis in pain care has reached a point where many patients are unable even to get a doctor’s appointment.

“I have been on a wait list for pain treatment for a year now. I am suffering needlessly and am questioning my ability to be able to live like this much longer,” said Isabel Etkind, a Connecticut woman who suffers from severe arthritis pain.

“I don’t want to die but I can’t live like this either. I know that many other people are experiencing the same thing, but knowing that does not really help! It is inhumane and cruel to treat people this way. If I were a dog, cat or horse, the animal rights people would be all over it, but torturing humans is OK. As is usually the case, the elderly, the military and the poor are suffering the most.”

Another woman, who suffers from chronic back pain, asked that we not use her name. She works in the emergency room of a hospital in southern California that recently adopted a policy of not prescribing opioids unless all other pain treatments have failed.

“Since November 1, we have seen a huge increase in overdoses from street drugs. Nearly all of these patients are chronic pain sufferers who are now getting their medications off the streets. A 33-year old fibromyalgia patient died from fentanyl overdose this week,” she wrote to PNN. “I understand the desperation these patients feel and try to educate the ER doctors about chronic pain from a layman’s point of view. This new effort to stigmatize and demonize chronic pain sufferers has got to stop!

“We have full time jobs, pay mortgages, raise families. All this, while in levels of pain that normal people couldn’t handle. We hate having to be chained to pill bottles and doctors and pharmacists. What other choice do we have? Curl up and die? I hope the new Trump administration will appoint people to DEA and CDC who will think of us as humans and help us instead of hurting us.”

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I'm writing to explain my day to day struggle with lupus SLE and RA. I was diagnosed with lupus in 2005 when I ended up in the hospital with a double pulmonary embolism in my lungs. I had struggled with severe pain in my knees, elbows, hands and feet. Most days I couldn't hardly walk up and down stairs without struggle and sometime tears from the pain. I worked in housekeeping and lost several jobs due to days I couldn't make it in due flare ups. In 2009 my rheumatologist put me on tramadol. I became a new person! I was able most days to get up and go to work, clean my house, play with my kids. Although I still struggle some days Tramadol really helps with day to day hurdles. I realize something needs to be done about the opioid epidemic but people who suffer everyday due to auto immune diseases need these drugs to feel a little better. I'm on a lower dose and my rheumatologist even have me a drug test! Why should we have to suffer due to other people's misuse! I hope that you'll consider ought stories and try to understand the pain w all suffer each day! Unless you've been in our shoes you have no idea how it feels. Thank you. Sincerely Kim from Stfrancis Mn

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I had scoliosis as a child, my back straightened as I grew older but the back pain never went away. Ten years ago, a doctor offered me vicodin, but I didn’t want anything that hardcore. My back pain worsened, as did my health in my early thirties. I was diagnosed with Mixed Connective Tissue Disease. My rheumatologist diagnosed me with Plaquenil, and when the pain didn’t get better Meloxicam and then Diclofenac Sodium . When the pain didn’t get better, tests ensued. An MRI showed that I also had degenerative disc disease and osteoarthritis, specifically in my lower back. Again, nothing more was offered to me or suggested. I pursued relief and was referred to a pain specialist. I have undergone two invasive cortisone injections which helped for a few days, urine tests every visit, and then I was given more Meloxicam and more Diclofenac Sodium. Of course, the pain didn’t get better. My rheumatologist suggested a drug, Etodolac which can raise blood pressure. I felt uncomfortable taking something with those side effects. The pain specialist then offered Cyclobenzaprine which also didn’t help. Now I am taking methocarbamol, I’ve since stopped the unhelpful prescription NSAIDS. They were backing me up, which stopped my appetite. I have had an exemplary record with not abusing prescription drugs. It shouldn’t be this difficult to get relief. I don’t understand why my pain doesn’t matter. I cannot function like I used to. I can’t walk, sit or stand more than a half an hour without being in pain. I’m only 35. Why am I being given random, harmful medications instead of actual beneficial medicine?

Catrina Morris-Kurylak

# [**How Chronic Pain Killed My Husband**](https://www.painnewsnetwork.org/stories/2017/9/4/how-chronic-pain-killed-my-husband)

[September 06, 2017](https://www.painnewsnetwork.org/stories/2017/9/4/how-chronic-pain-killed-my-husband)

By Meredith Lawrence, Guest Columnist

So much has been written about the opioid epidemic, but so little seems to be out there about what living with true chronic pain is like. My husband, Jay, lived and died in incredible pain at the age of 58.  As his wife, I lived that journey with him.

Jay is no longer here to tell his story, but I want the world to see what I saw.  I want you to know how he went from working 60 hours a week doing hard physical labor, until his pain grew worse and he could not even get out of a chair on his own.

I want you to know the deterioration Jay went through over the last ten years. I want you to know what a good day and a bad day is like when you live with chronic pain.  I want you to know exactly what happened when the doctor decreased his pain medication. And I want you to know how my husband finally made the decision to commit suicide.

I want people to understand that when chronic pain runs your life, eventually you just want the pain to stop.

First a bit of history.  I met Jay in 2005, when we both stopped drinking.  Two years later, Jay began to lose feeling in his legs and started having falls, as a result of compressed nerves in his spine. The pain was so bad Jay had to stop working and go on disability, which started his depressive episodes.

Jay had a series of lower back and neck fusion surgeries.  This was when he was first prescribed painkillers, antidepressants and anti-anxiety medications.  From 2008 to 2011, Jay tried various treatments to control the pain that lingered even after a third back surgery.  These included steroid shots, nerve blocks and a spinal cord stimulator.  Ultimately he had a drug pump implanted that delivered morphine, in addition to the pain pills he was being prescribed.

In 2012, Jay was diagnosed with trauma induced dementia.  I believe that diagnosis was right, based on his symptoms, but not all of the doctors agreed.  Some believed the confusion was due to high doses of morphine and/or his sleep apnea.

By 2016, Jay’s confusion and memory issues were increasing. He was on a steady dose of 120mg morphine daily, in addition to the medication he was receiving from his pain pump.

Jay’s depression seemed to come and go, depending on the day and his pain levels.  He was weaned down on his Xanax to 2mg a day to help him sleep. He was aware of the risks of combining Xanax and morphine.

Let me tell you what a good day was like before they changed his medications. I worked a full time job from 2 pm to 10 pm five days a week. I would get home, and Jay would have my coffee ready for me at night.  We would stay up and watch TV until 2 or so.  When it was time for sleep, I went to bed and he slept in his recliner.

We started sleeping apart after his first surgery in 2007. He was more comfortable sitting up in the chair, but could never sleep more than three hours at a time.  He knew sleeping in bed would just keep me awake.

A good day always meant it was not cold or raining.  On a good morning, he would be up first and get coffee started.  He would take our two miniature pinchers outside in the yard on their leash for potty time.

We usually had at least one appointment a week, but if not we could have a nice quiet morning.  That meant coffee in front of the TV.  After a couple of hours of that, he might switch over to playing his computer games, but he was never far from his chair.

A typical adventure for us would involve going to Walmart.  Jay was not able to walk through the store, but he hated using the handicapped carts. I could always see a look on his face when he had to do it.  After going to the store, we might have lunch or an early dinner at Steak n Shake or Cracker Barrel.  It always needed to be some place familiar and comfortable for him.  More than once we sat, ordered and then took our food home because he was in too much pain.

In the summer we might walk the dogs after dinner.  Just a quick two block walk, but a lot of times he would have to stop halfway and go back home.  A couple of times I had to go get the car and pick him up because his legs just would not support him anymore.

A bad day was awful for me to watch, and absolutely horrible for Jay to live. It meant no real sleep, just catnaps in the chair whenever he could.  He always made coffee for us, but on a bad day he would forget to add coffee to the coffee maker and we would just have hot water.  The pain was so much he was just distracted.

On many bad days, I would look over and see tears just running down his face because he was in so much pain.  It also made Jay’s depression worse.  We spent many cold winter nights talking about how much pain would be too much and would make life not worth living.  It is the most horrible feeling in this whole world to hear the person you love most talk about ending their life.

In January, 2017 Jay’s pain clinic decided they could no longer prescribe the high doses of morphine he was on.  In addition, they were not going to continue seeing him if he decided to stay on Xanax.  The Xanax was prescribed by another doctor, but they did not care.

I begged the pain doctor -- yes, literally begged -- for some other option. The doctor said that if Jay continued the Xanax he would no longer see him.  He would not give another option for medications, and at one point even said that most of his patients with pain were “making it up.”

The last thing the doctor said to us will stick with me forever.  He said, “My patient’s quality of life is not worth losing my practice over.”

When we left that day, we were barely in the car and I knew what Jay was going to say to me.  I will never forget how sad his voice was when he told me this was it for him. He was not going to continue to live like this.

Mercedes McGuire

Mercedes McGuire of Indiana ended her life August 4th, 2017 after struggling with agony originally suppressed with opioid pain medicine but reappearing after her pain medicine was cut back in a fashion after the CDC regulations. She was in such discomfort she went to the ER because she could not stand the intractable pain by “learning to live with it” as suggested by CDC consultants. The ER gave her a small prescription. She went to the pharmacy where they refused to fill it “because she had a pain contract”. She went home and killed herself. She was a young mother with a 4 year old son, Bentley.  Bentley, will never get over the loss of his mom.

Link to Obituary:

<http://www.tributes.com/obituary/show/Mercedes-Kirsten-McGuire-105071405>

Link to GoFundMe for Bentley:

<https://www.gofundme.com/Bentley-s-future>

How many more children will have to lose parents? Or parents lose children?  All because our government is placing value on someone else's live over ours.  It is possible to treat chronic pain and addiction at the same time!!  It never has to be one or the other!!  We deserve proper treatment for our chronic, debilitating medical conditions.  We deserve better from our government.

We are #PatientsNotAddicts and we have rights too!!!

#CNNhealth #CNN #OpiateEpidemic #ChronicPain #WarOnDrugs #POTUS #FLOTUS #GivePainAVoice #WashingtonPost #60Minutes #SuicideDue2Pain #CivilRights #Activism #ShameOnYou #Addiction #PatientRights

BOB MASON

Age 67

Bob Mason, age 67 of Helena, Montana was denied pain medicine to treat his chronic pain after losing access to his pain control doctor and finding no one else, took his own life in January of 2016. He tried to “deal with his pain” as is recommended by the new pain minimizing CDC consultants. He tried for 7 days to deal with it.

According to Mason’s daughter, Mieska, the last couple weeks up before Bob passed away, there were a lot of tears everyday on the phone,” she said, “between the pain and really just the sadness of not being able to walk his dog, but, I’m sure it was more than that. There would be tears, then he would joke,” she said, “then he’d call back an hour later and be teary and in pain again. He didn’t like the drugs, but there were no other options.” His suicide became the other option.

HOW MANY MORE OF OUR BROTHERS AND SISTERS HAVE TO DIE BEFORE OUR GOVERNMENT REALIZES THAT THEY ARE KILLING US OFF BECAUSE OF THEIR WAR ON OPIATES. WE ARE THE COLLATERAL DAMAGE LEFT BEHIND TO LIVE TORTUROUS, PAINED EXISTENCES OR KILL OURSELVES.  WE DESERVE BETTER FROM OUR GOVERNMENT. THEY SHOULD NOT BE ACTIVELY TRYING TO KILL CHRONIC PAIN PATIENTS TO TRY AND SAVE ADDICTS!  YOU CAN SAVE BOTH!!

We are #PatientsNotAddicts and we will not silently go away to die like the government wants me to. We will fight for our right to proper medical treatment!!

#POTUS #FLOTUS #ChronicPain #OpiateEpidemic #Addiction #GivePainAVoice #CDC #DEA #VA #CNN #CNNHealth #JimmyDore #TYT #Activism

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Good evening. I am a 50 year old chronic pain patient. I have debilitating pain due to diseases affecting my spine, joints and bones as well as injuries from a MVA.  
  
I am prescribed narcotics for severe pain as well as physical therapy. I have endured years of epidural steroid injections, taken many anti-inflammatory medications, nerve pain medications such as gabapentin, and an antidepressant that also helps with muscle pain. I use a tens unit and have tried massage therapy. I have seen multiple surgeons, neurologist, and been to pain management. I have been told by all that with my disease processes there is no surgery that can alleviate my pain. The ESI’s stopped working after several years plus the steroids were not good for my diabetes. I tried as many options as possible other than pain medications to try to maintain my quality of life.  
  
I see a psychiatrist and licensed professional counselor on a regular basis to manage depression. My psychiatrist agrees that managing my pain is vital to maintaining my quality of life.  
  
My current pain medication does include an anti inflammatory and is not the highest dose possible of the medication. My doctor is cautious with prescribing narcotics and requires adherence to strict policies be followed for their use.  
  
I would not be able to maintain my quality of life without the medications to help control my pain. I am not an addict nor am I someone who abuses drugs.. I have never used illegal drugs. I have no criminal record and have never been arrested for any crime.  
  
I do not feel it is fair to group chronic pain patients with drug addicts and drug abusers. I have never abused medications nor have I ever overdosed. I am just a woman with multiple medical conditions for which there is no cure..  
  
My appropriate use of pain medications is what allows me to spend time with my family without being in excruciating pain. My husband, son, daughter, grandchildren and other family members all appreciate spending time with me and understand my limitations due to my illness.  
  
Please consider patients like myself who are good law abiding citizens trying to live life with chronic pain. I take pain medications but I do so cautiously and I follow the rules for their use (not abuse)  
  
Thank you for your time and for considering patients that need medications to function that are not addicts or drug abusers.  
  
Kind regards  
Kerri Waits  
  
What we do for ourselves dies with us, what we do for others and the world remains and is immortal.  
By Albert Pine

# [**Pain Warrior: A Tribute to Sherri Little**](https://www.painnewsnetwork.org/stories/2016/7/4/pain-warrior-the-life-death-of-sherri-little)

[July 04, 2016](https://www.painnewsnetwork.org/stories/2016/7/4/pain-warrior-the-life-death-of-sherri-little)

(Editor’s note: This week marks the first anniversary of the death of Sherri Little, a 53-year old California woman who took her own life, after years of struggle with chronic pain and depression. Suicide is a difficult but important issue to address in the pain community, and our story about Sherri’s final days [***(“Sherri’s Story: A Final Plea for Help”***](http://www.painnewsnetwork.org/stories/2016/3/3/sherris-story-a-final-plea-for-help)) touched many readers. Tina Petrova was a friend of Sherri’s and wrote the following tribute to her.)

By Tina Petrova, Guest Columnist

Sherri L. Little was a stunningly beautiful, diminutive blonde with sparkling, mischievous eyes. We became fast friends on Facebook, united by our common passion of pain patient advocacy.

She initially reached out to me after hearing that I had a film in development on chronic pain [**(“Pandemic of Denial”**](http://www.pandemicofdenial.com/)), saying, “Do I have a story for you!”

And indeed, she did.

Sherri was one of those rare people who could light up a room upon entering. She possessed charisma in spades and emanated a childlike wonder and joy

During the all too short time I knew Sherri, her key focus was advocating for pain patients, speaking up, and getting involved. Her search for treatments for her own painful conditions (occipital neuralgia, fibromyalgia and complicated IBS) took a back seat to her passion to help others.

I had the pleasure and honor of hosting Sherri in Toronto, Canada in May 2015. She made the long trek from Mexico where she was staying, to New York City to participate in the 2015 Caterpillar Walk for fibromyalgia, travelling onwards to me.

I drove her around to my own treating doctors, hoping she could benefit from those who had greatly helped me. We filmed a short interview with her, which is to become a key centerpiece in our upcoming documentary.

It was Sherri’s final wish that we tell her story to the world.

Despite sleep deprived nights and painful days, she took delight in all the small activities I had planned during her stay with me, such as lunching at a vegetarian restaurant.

It surprised me that such small gestures could be so impactful for her, until she explained that her adult relationships thus far had not supported her pained life. She shared with me that she longed for deep, authentic connections.

Sherri was to return to Toronto in September 2015 to continue the interview process. Sadly, this was not to be.

Sherri was found dead on July 7, 2015, after a July 4th weekend attempt to get medical help at a hospital in Los Angeles. Unable to eat and drink for four weeks, she had taken a solo train trip to L.A. from San Diego, hiring a patient advocate to champion her rights.

Her last ditch hope with faltering health was that she would gain access to the specialists and treatment she so badly needed to live her life with any quality. For reasons her family and I still cannot fathom or piece together, Sherri left the hospital and checked into a hotel room across the street, alone and in pain. We will never know for certain what transpired in those final hours.

Having a previous diagnosis of [Clostridium difficile colitis](https://en.wikipedia.org/wiki/Clostridium_difficile_colitis) and suffering from severe abdominal pain, she had been unable to keep food down for over a month and was existing solely on raw juices.

Her mom told me she had driven down to San Diego to take her daughter to the hospital on more than one occasion for horrible bowel pain and dehydration. After giving Sherri an IV drip in the ER, they released her home on each occasion.

In honor of Sherri’s courageous battle with chronic pain, we will be dedicating “Pandemic of Denial” to Sherri and her fight for better pain care for our community.

Sherri’s laughter will no longer echo in the halls of life, but I’m sure she’s busy keeping the angels on their toes in heaven with her loving heart and her shining soul of activism.

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To who it may concern,

        I would like to thank you for letting me have this opportunity to tell you a little about my life as a chronic pain patient. It might be similar to others but we all have our own families and struggles everyday. I feel that amid the crisis that heroin and opiates are causing in America there are many successes when opiates are managed effectively. Very rarely do I see that side of the story told in the news.

      I was in a car accident in 1989 that did not cause me to have any broken bones but it did cause my life to change forever. I was twenty-eight years old then, now I am fifty-seven. I had a whip lash injury that effected not only the muscles in my neck and back but my jaw joint was dislocated. I have misplaced disc in my jaw joint that gives me severe headaches. This has changed my life, I cannot eat hard food or speak for long periods of time. I cannot raise my voice at all without getting severe headaches. I cannot even cry without expecting a telltale headache for a few days. This is not even my worse pain, the car accident left me with soft tissue injuries. That is tissue that holds up my spine, and can no longer do that job effectively. I have developed arthritis in my spine that leaves me with back pain. I have sacral ilium joints that become inflamed. Additionally, my spinal canal in my lower back has some narrowing that causes sciatic nerve pain down both of my legs. My legs are becoming weak and some days I cannot walk.

      I have been in and out of physical therapy for over twenty years.  When I was younger, before I developed arthritis, I could get by with exercise, heat and ice, and muscle relaxers. Now that the arthritis has set in there is only so much those treatments will accomplish. I began going to pain management three years ago, and started with a low dose of hydrocone twice a day. It really helped me to have a life again. Not an exciting life but a life where I could do my housework and take care of my family. My thirty-five year old son is single and lives with me and my six year old grandson stays at my house on the weekends and in the summer. I have to get up and out of bed everyday. I have to go grocery shopping and do errands. I have to babysit my grandson when my son works. I have a house to clean and food to cook. These are just necessitates. surely people with chronic pain deserve to do things of enjoyment if we are able. I would like to take my grandson to the park and be more active again. I am not married and my son does help me but he has to work.

         My pain management doctor has increased my medication because of the sciatic nerve pain. I will be having an operation to try to make the narrowing of my spinal column larger. I am dreading it but it is my only chance of being able to go back to the lowest level of pain that I had before. There is only an 80% chance the operation might help. The surgeon said it will not help my back pain but it can decrease my leg pain. The nerve pain is hot and it feels like my legs are swollen when they are not. I have bad muscle spasm in my legs now. The pain travels into my feet. Without my pain medication I would be uncomfortable simply laying in bed.

       I go to Centra Medical Group Physical Medicine & Pain Management Center in Lynchburg, Virginia. I have a pain contract. I can only get narcotic medication from pain management unless I am in the emergency room with an emergency. They cannot prescribe me any narcotics. I have to have random urine test. They send it off for fairly extensive lab work. They test for unprescribed medication. They test to make sure I have my pain medications in my system at the levels they are suppose to be. I can only use one pharmacy to get my pain medication. I have to bring my medications to my office visits and they are counted. I have to get a new written prescription every thirty days. I have Medicaid because I am disabled and they will only cover so many tablets a month per the written prescription. I cannot get my pain medication earlier if I run out.

       My state of Virginia has one of the lower rates of opioid overdoses in the country. That might be because of the pain management practices. It is wrong that people who live with chronic pain should be denied medication because of other people who abuse it. It has helped me to be able to get out of bed everyday. I am hoping that with surgery my use will go down. There are many more people like myself. I hear their stories and it saddens me to think that we are being targeted for crimes that others commit. I am not saying that addiction is a crime but bad prescribing practices and illegal use are effecting people like myself. Now, CVS might not be able to give me but only ten days of my pain medication. That would be fine if I was healthy but making chronic pain patients leave their houses every ten days is not right. Thank you for being willing to read my story.

Sincerely,

Sharon Primerano

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I am one of the millions of American citizens battling chronic pain.  I’ve had three back surgeries and deal with chronic pain daily.  I get steroid injections, radio frequency ablation and any other treatment that might help.  I take Vicodin four times daily.  Without the Vicodin, I would have no quality of life at all.  I’ve never taken more than the doctor prescribed and I keep my Vicodin in a safe.  Please don’t make it even harder for us.  Don’t let us be forgotten in this war against opioids..  I’m 65 years old and I want to enjoy the time I have left.  
  
Thank you

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I am 44 years old, I have several diagnosis that qualifies me for chronic pain. I am an opiod dependant patient, I have tried to go to a clinic that offered me to become opiod free, by giving me Suboxone until I could have an ablation injection of the facet joints believed to be my main source of pain. I had an extreme adverse reaction to this medications and was treated unfairly. It nearly killed me being judged as just another withdrawal case, while my kidneys and liver shut down over the course of the next few weeks this clinic attempted to put me on buprenorphin sublingual version, in which at the lowest dosage still made me horrifically sick. I am on the lowest dosage of opiod 5-325 twice a day, no where close to the guidelines for redundancy. After 6months of brutal treatment being degraded like a herione street addict, which I've never been. I was rescreened through my GP and went back on the dosage I have maintained for nearly a decade. As my body has progressed symptoms increased my pain I have lost the abilities to do daily stuff like house cleaning, bathing and day to day things because of the severe pain. Daily stretching and what little medicine I receive prevent me from any quality of life. Surgery isn't an option, injections don't help, I cannot take Nsaids. Please revise the current status and guidlines needed to help our chronic pain victims with little or limited choices to obtain medicine that keeps us active in our lives, and families lives. Treating patients like criminals shouldn't be second choice or even apart of this country!

Heather Bowling

Missouri resident

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My quality of life has been diminished about 17 years ago I had fibromyalgia I was in so much pain I struggled to find a way deal with the symptoms I was put on medication to control my pain without it it would be impossible to work I work full time and part time 12 hours a day then as the years went by I injured my spine about a year ago I went to a spine specialist to find out what is happening to me to find out my entire lumber collapsed from the arthritis and dealing with chronic migraines and clusters from this and I have 15 bulging and herniated disc and dealing with sciatica pain has been awful pain medication the I am on is a opioid one I never abuse it I been on it for years now it has given me a least a life I can live it not perfect but I struggle everyday I workout as best as I can lost a lot of weight now facing multi surgeries I do the best as I Can I had injections already it help a little bit I deal with glaucoma thyroid problems ibs, now diabetes , my brother also suffers from this issues as well without this medication life would be be almost impossible  
Diane Oppelt  
  
Sent from my iPhone Pain letter My name is Jennifer Hart, I am a 36 year old wife, mom, and Registered Nurse from Oklahoma. I have a genetic condition called Ehlers Danlos Syndrome. It causes frequent joint dislocations, subluxations, joint pain, and widespread muscle pain and spasms. I have also been injured in 2 separate car accidents and and some of those injuries never healed. As a result, I have 12 chronic pain conditions (Spinal CSF leak, Chiari Malformation, Craniocervical Instability, Chronic Migraines, TMJ, bulging cervical disc, Tendinitis, Trochanteric Bursitis, SI joint disorder, Carpal Tunnel syndrome, Scoliosis, and Peripheral Neuropathy). All but 2 of my conditions are inoperable, so I have had to learn to live with the pain. The car accidents triggered my Ehlers Danlos Syndrome symptoms, so I was healthy until I was 28 years old. My symptoms began 8 years ago, after my first car accident, when I was hit by a teen who ran a red light. For the first 3 years after the onset of my symptoms I tried every other alternative to Opioids. Physical Therapy, Acupuncture, Acupressure, Cognitive Behavioral Therapy, Chiropractor, alternative medicine, massage, essential oils, anti-epileptics, antidepressants, muscle relaxers, NSAID'S, injections, blocks, & surgeries. I even had a neurostimulator implantm. My physicians all agreed that I at least needed to try Opioids as part of my treatment plan as a last resort after my 2nd car accident where I was hit by a distracted driver. After much research, prayer by a distracted driver. After much research, prayer and the need to return to work, I decided to give it a try. I'm so glad I did because the medicine allowed me to return to work, serve at church, serve as a house nurse for a sex trafficking safe house, & function in my responsibilities at home, running a household. I have been in pain management 5 years and abide by all the rules and conditions put in place by my Dr. My pain was controlled until earlier this year when my Dr announced he would be tapering my dosage down by 75%. His reasoning was because of the CDC guidelines. Even though the guidelines are intended for primary care physicians, my Dr is fearful because of the high dosages I am on. He admits I am not at risk for addiction or abuse, however has seen too many physicians lose their practices because the quantity of prescriptions they are prescribing. So, he is weaning me down to below 100mme. This is against my will, I have expressed how out of control my pain is and that I'm bedridden 20 of 24 hours a day, & the 4 hours I'm upright are severely limited as to what I can do. I am only upright to spend time on the couch with my husband & children in the evenings after dinner. The rest of my upright time is to eat, drive my children to & from school, bathe and get dressed. He says his hands are tied and will not put me back on my previous dosage. I'm fearful I will be completely bedridden by the time he completes tapering my dosages down. With my medication, I am able to run my home, run errands, light exercise, light housework, cook, go on date night with my husband, & attend my children's date night with my husband, & attend my children's activities. I am not the only one suffering. Because of how under-treated my pain is, I have had to pull my children out of sports & activities because I cannot get them there consistently & my husband works long hours to to compensate for my not working. My disability does not cover our bills. Without my medication, I will be bedridden. Thank you for taking the time to read this letter. I am fighting very hard to improve my condition, but feel at this time I have been abandoned by the medical community. In 2 weeks, I will travel across the country to Los Angeles to prepare for surgical repair of my CSF leak. I have spent unthinkable amounts of money to try to improve my condition as I have a lot of living left to do. I just need access to my medications to be able to do the rest. Sincerely, Jennifer Hart

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Hi,   
My name is Kelly McCord and I'm writing to you from Wisconsin to ask you to help patients with painful Chronic Conditions. It's crucial that we do not lose access to beneficial treatment. With the recent CDC guidelines, it's become more difficult for patients to have access to their prescription opioid medications. Doctors, specialists, and pharmacists are all making it more difficult for patients to have a good quality of life as the guidelines are being imposed upon patients as law. Many patients have had their otherwise valid dose reduce or discontinued entirely. Others were non-medically switched to Buprenorphine. These guidelines were imposed upon medical professionals by the government, again, not by law. The DEA and CDC clearly has a hold over the medical community. At what point are they interfering with the doctor-patient relationship? I'd urge you to review US Code Title 42, § 1395.   
  
Opioids are beneficial medicines that are used to treat severe pain. They are the last step on the pharmaceutical ladder and when other treatments have failed or are not possible, opioids have safely and reasonably given so many people with unbearable pain conditions the ability to be productive and minimize both cancerous and severe, malignant pain.   
  
Making Rx opioids unavailable would be harmful to millions of Americans with Chronic Pain conditions including Cancer-related pain, Ankylosing Spondylitis, the Ehlers-Danlos Syndromes, Congenital and acquired spinal defects or spinal degeneration, Osteoarthritis, Interstitial Cystitis, Fibromyalgia, Complex Regional Pain Syndrome, Sickle Cell Anemia, HIV, and many other disorders and illnesses. Many of these disorders or diseases are incurable, meaning the patient can only be treated symptomatically (pain included). These illnesses often come with many complexities and comorbidities, which are also often painful in their own right; combined with other disorders, a patient can be overwhelmed by layers and types of pain. Some levels of pain can be minimized with anti-depressants or neuromodulators, but that does not take every patient or each variable into account. Patients always begin with over-the-counter medicines to treat pain, but some are not effective for the severity, or some medicines are not appropriate for certain conditions. (For example, one may have taken nsaids to address pain only to result in GI distress, bleeding, ulcers, and polyps. Now nsaids are no longer are viable option.) Opioids can be safe and effective for this demographic with complex pain.    
  
Both patient and provider can show responsibility and accountability. So many of us have demonstrated that we can be functional, responsible, contributing members of society due to integrating opioids into our treatment plans. Yet we're conflated and associated with addicts and judged harshly simply for working with our doctors to lessen our pain and improve our quality of life.  
  
Living with intractable pain is the biggest challenge of my life. I was diagnosed with Ehlers Danlos after many years of painful dislocations, slipping ribs and patellas, early osteoarthritis. My body continues to crumble from the inside out. I've got comorbidities of Mast Cell Activation Syndrome, CRPS, Dysautonomia, Degenerative Disc Disease, Adult Onset Scoliosis, congenital heart defects and painful congenital spine defects. I experience both chronic and acute pain daily; EDS is unique because in addition to having both types of steady and intermittent pain, patients like me also experience different types of pain, like nerve pain and musculoskeletal pain. These types of pain are succinctly different, yet we're told they can be managed antidepressants and anticonvulsants. Unfortunately, these do not have the same effectiveness on musculoskeletal pain as opioids, which work well for me and other data demonstrate effectiveness on this nociceptive pain. EDS, like many chronic disorders, is a complex issue that deserves attention, less simplification, and more focus on the variables among each patient.   
  
It's quite humbling, actually, to be someone who once worked, gave birth, walked around the world for days on end, and now, at times, I find it difficult to walk across a room as my feet crunch and pop beneath me.  
  
Nothing will change my diagnosis or fix my body; there is no cure for EDS. However, opioids are a valuable tool in a multi-modal approach to severe, complex pain. Making these medicines unavailable will only mean that legitimate patients deserving of care will be forced to needlessly  suffer and many will die. Right now we really need to see people in positions of strong leadership make decisions that will help people who have largely been responsible, upfront, conscientious, and compliant; however, as the opioid epidemic was declared and more attention was drawn to addiction, we've been disparaged, our authentic stories overlooked for sensationalism. Chronic pain patients are conflated with addicts, assumed to be liars. All opioids are said to be bad. No stories of success or redemption are told. This has to stop. We need someone to stand up for pain patients' rights, for the right to live with less pain. Many of us know this life exists as we've been fortunate to have experienced this through the science of prescription opioid painkillers. When taken responsibly, as prescribed by a physician, patients can, in fact, have positive, healthy outcomes, even in the long term.   
  
I hope you will consider my words and think of the millions of Americans living with untreated chronic pain.   
  
Sincerely,   
Kelly McCord

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Sent from [Mail](https://go.microsoft.com/fwlink/?LinkId=550986) for Windows 10

My name is Christy Miller from West Virginia and I am a chronic pain patient. I have suffered with pain since a work related injury in 2011. I am no longer able to work to support myself or contribute to my families income. I went through back surgery to remove one herniated disc to try to help the pain and stop the progress of cauda equine syndrome. After the surgery I still had some pain but not as bad as before. I went through physical therapy where my back was re-injured and has hurt worse then before the surgery.

I not only suffer with pain every day. I am numb from my waist to my toes, have issues with my bladder and bowels due to the cauda equine syndrome, fall frequently, and  have lost my interest in sex-if you can’t feel it what’s the point? I have issues getting dressed and combing my hair etc due to pain. Some days I don’t want to take a breath because it hurts to bad. I have quit doing all the things I love to do because I just can’t do it anymore.

My doctor is currently dosing me off of my pain medication due to all the new guidelines and the strictness they have to follow he is no longer going to prescribe them at all. He said he is sorry but he don’t have time to entertain all the red tape it takes to have them come in and check all his charts etc all the time to make sure he is doing his job correctly when he writes out our medicine. It’s a sad day when somebody who sits behind a desk seems to know more about a patient than the doctor who is treating them.

I understand there is a drug problem in the world. I have family members who have died from it but not everyone is an addict and those who are overdosing are not getting it from the doctors. My cousin just passed away in September from a drug overdose and it wasn’t from a doctor prescribed medicine and he had never been given any from one either. He had always used street drugs and sadly they took his life. I support doing something to fight the epidemic but denying pain patients their medicine is not it. I have seen some who have lost their medicine from their doctor in my area not be able to find another doctor go to street drugs to get relief. How is that helping the problem?

Since my medicine has been cut my quality of life has went down hill. I have had days where I can’t get out of bed at all. It took me over an hour just to get out of bed to use the rest room. When you have issues with the bladder and bowels that causes problems. My back still has discs that are messed up as well as degenerative disc disease and arthritis. I also have rheumatoid arthritis which is taking a toll on my body. I have diabetes as well. I can’t even get the Neurontin to help with the neuropathy anymore due to it being considered a “bad” drug too. What are you supposed to do to get some relief? Please don’t say therapy, ibuprofen, and, injections because even my doctor laughed at those and said they didn’t help me before so he didn’t hold out much hope of them helping me now. Actually my neurosurgeon said no to anymore therapy unless it was water therapy and insurance won’t cover it and neither will workers comp and the only place near me is over two hours away.

I fight depression daily. It’s a struggle to get up and face the day knowing you are going to be in pain. I feel like I am no use to anyone when I am not able to do anything and it is only going to get worse next month when I have no pain meds at all. Everyone likes to be able to do something and when you can’t it makes you feel worthless. To go from working every day to not being able to do anything really take a toll on your mind and your finances. Don’t get me started on the lovely social security that I am fighting. I will likely die before I see that get granted. So I sit and worry about how to feed my family and pay the bills all while some idiot sits behind a desk and tells us how to manage out pain. I pray they never end up in the type of pain that I have.

Dear Honorable Paul Mitchell,

My name is Katelyn Dekoski, I live in Michigan’s 10 Congressional District; and I am writing you to ask for your attention to a matter that affects thousands of people in your district, tens of thousands in the state, and millions across the country. I am asking for a change in attitudes towards people in pain, who live in chronic pain, and who need improved access to treatments. I’m writing because I want my voice to be heard when actions are taken to curb the opioid abuse problem.

We who suffer need your help. I myself, suffer from Hydrocephalus (excess fluid on the brain treated with a shunt) among other problems, when my shunt malfunctions or isn’t working properly I get the worst headaches in the world. The only way I can think of to describe is that I feel like someone has shot me in the head. Even if my shunt is only temporally plugged which happens often enough, I have gone to the local ER for pain control because my Neurosurgeon is 2 hours away and my Primary Care Provider doesn’t know what to do for me. Anyway, the last time I ended up in the ER I was in very bad pain, my blood pressure was very high. They gave me a migraine cocktail and decided to do a CT and series of x-rays those all came back fine so I was sent on my way still in pain, I asked if I could have a shot of something else and was told no that opioids are no longer given in the ER. I don’t daily take opioids but I do count on them for relief when my shunt is failing, or I am having a problem, even after surgery, after my brain surgeries a 7-day supply usually isn’t good enough, Tylenol is still ineffective against the surgical pain at that point.

I think it important that we focus on the fact that most people abusing prescription drugs are not chronic pain patients and people after surgery. Those who abuse these medications do so because they get a “high” feeling. I myself don’t like to take these strong types of drugs, they do help my pain. I have never felt high, I usually get tired and sometimes it scares me, there have been times in the hospital when I needed pain control so I didn’t have a stroke but I was scared because I didn’t have control of what was going around me, most chronic pain patients are like this we like being able to live life without pain but we hate the numbing of other senses.

Thank you for your attention to this matter and for reading my story,

Sincerely,

Katelyn Dekoski

To Whom It May Concern,  
  
There is a war being waged on American soil. It is a war that we see talked about every day on the news and in political circles. It is not ISIL but our own government and medical institution that has indirectly declared war on chronic pain patients all across our nation. People who have done nothing wrong, who have never abused their medicines, nor who are addicted or diverting medicines, are being stripped of their rights. They are being forced into contracts signed under duress and coercion, with the direct threat of not receiving needed and beneficial medicine. They are being denied needed medicines for real medical conditions that cause pain. All of this is happening because of the declared ‘OPIOID EPIDEMIC’.  
  
My own history with this opiate hysteria began after a neck injury I sustained while doing tree cutting on our property. I sustained 3 herniated discs and could not move from a sitting position for 3 months. I was put on low dose opiates and muscle relaxants. Over time got to a point where I could function, not to the level I was at prior to my injury but I was able to lie down and engage in modified daily activities again with a very low dose of medication.   
  
I was told cervical spine injections and surgery was the only other treatment for my injury and so after researching all my options I decided that medicine offered me enough relief and held the least potential risks. I was on opiate pain relief for a year or so when I was presented with a ‘pain contract’. I was told that it was a new Kaiser policy and that I would no longer receive the medicines that were helping me unless I complied by signing the contract and agree to submit to a drug screen that day. My doctor told me that she was afraid of losing her license and that she was under threat by the DEA. I was also told that the drug screen was just to measure levels of the drug she had prescribed and make sure that I was at a safe level. That second part was not totally true. I was also tested for other illicit drugs which I only learned later.  
  
I was presented with the contract, given a cup to pee in and told to go down the hall to the nursing station. I walked out with cup in hand and when I got to the nursing station I was shown to the bathroom by a medical assistant. When I went to go into the bathroom she stopped me with her hand and told me that I could not take my purse or my coat with me and would have to leave it with her because, ‘people try to cheat these test all the time’. I was also admonished that if I couldn’t pee I would have to sit in a chair in her view and drink water until I could so I should be sure I could urinate before I went in. I gave her my purse and coat, collected the sample, got my prescription and left. It was all beyond humiliating. I left the office in tears and drove the 30 miles home swearing that I would never go through that again, no matter how much I was suffering.  
  
Less than 6 months later I called for a refill. They told me that I would have to be seen by my doctor to get the refill. I made the appointment and when my doctor walked in she went right to the computer and without looking at me told me that I would need to submit to another drug screen before I left if I wanted my medicines. I told her that it felt like she was accusing me of something and asked her what the first drug screen showed. She said it showed I was taking the medicine as prescribed to me and that I was not taking any other illicit substances. I told her that it was what I told her to begin with and she responded with ‘people lie’.  
  
I told her that I was uncomfortable continuing to drug test and also told her that I felt that I was forced to sign their ‘pain contract’ that basically signs away a patient’s 4th and 5th amendment rights, with the direct threat of not receiving my medicine. (Just to clarify a bit, these contracts include submitting to random drug screens, random pill counts, limiting a patient to one pharmacy, and limiting a patient to one prescribing physician, among other restrictions and privacy violations.)  
  
She shrugged, still looking at the computer and told me that she was sorry to hear that but if I didn’t submit to the test she would not refill my medication. She stated that if I didn’t have anything to hide she didn’t see why I would object as people who don’t have anything to hide don’t have anything to worry about. I told her that her veiled accusation and subsequent actions were exactly the kind of thing that my 4th amendment rights are designed to protect me from.  
  
She then stated that she was uncomfortable anyway just prescribing medicine and told me that in her opinion I needed to have surgery. She commented that she was starting to believe that I didn’t want to help myself, then told me that she felt that I should look for a different PCP as I wouldn’t agree to the surgery she recommended, and told me she was referring me to a pain clinic that was an hour and a half from my home.  
  
I asked her to please look at me, as she still hadn’t looked at me once this whole time. She turned to me dramatically and stared at me. I asked her if she even knew my medical history and why I didn’t want to undergo the surgery. (I was born with an immune dysfunction and have a chronic health illness. I am prone to infection and poor healing.) She said she didn’t need to know my medical history as she knew about my injury and that she had thousands of patients and couldn’t remember every one anyway. She stated that she had a similar surgery and that it helped her.  
  
Anyway, I left that appointment and filed a grievance with Kaiser Permanente. I was eventually put on the grievance hamster wheel, which is designed to weed the weak willed and computer challenged out quickly, and eventually was basically told to get lost. They told me that chronic pain is not life threatening and therefore doctors are under no obligation to treat pain. Kaiser’s legal eagles also told me that if I didn’t like their policies or want to abide by their pain contract then it’s a free country and I was free to find care elsewhere.  
  
Initially I contacted the ACLU, government officials, media agencies, and contacted lawyers, all to no avail. Nearly everyone responded that they could not help me and finished with a statement along the lines of, didn’t I know ‘we are facing an opioid epidemic’. Since then, things have only gotten exponentially worse for people who are already suffering day in and day out. Not only that, but acute and post surgical pain control guidelines have also been affected. Now opiates are denied or drastically limited in those cases as well. Another nightmare reality I became painfully aware of, figuratively and literally, more than once over the last 4 years.  
  
Needless to say there is much I could tell you about the dismissive attitudes, the disregard, the lack of compassion, and the blatant contempt being carried out by doctors, pharmacists, and ancillary staff on patients suffering horribly with chronic illness and pain. I could tell you stories that would make you cringe about what happened before, during, and after I had surgeries for various serious emergent health issues in this regard. But all that would fill many, many pages and I’m not even sure you’ve actually made it this far.  
Just another aspect of this insanity is that I and other patients with chronic illness and pain are now feeling we have to tell very personal stories and give out private medical information to perfect strangers in order somehow prove that we are in physical need of these powerful but beneficial opiate medicines. We do so to enlighten people on the suffering that is happening to those for whom opiates help, to try and fight back against the one sided false narrative regarding opiates. You see, the truth of the matter is that addicts take drugs to escape life, while people with pain take them to function and be a part of life again.  
  
To add insult to injury, the overdose deaths have increased despite restrictions on prescribed medications because addicts still get drugs for escapism, more dangerous and deadly ones too I might add, while people in pain are basically being tortured. Some patients are in so much agony that they are now taking their own lives. But we’re not hearing their stories due to the stigma of both opiates and suicide.  
  
Yes, there is a war happening in America and pain patients are evidently the acceptable collateral damage. It must stop and we are counting on those in positions of authority, people who propped up the guidelines and opiate restrictions in the name of saving addicts, to put an end to these inhumane policies and practices. These policies and practices are causing needless pain and suffering for millions of innocent Americans.   
  
Sincerely,

Arianne Grand Gassaway

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| |  | | --- | | **Ashley Reber <wnchydroangel@hotmail.com>** | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |
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Dear Honorable,

My name is  Ashley Reber. I am writing to ask for a change in attitudes toward people in pain who need improved access to care. I want my voice to be heard when actions are taken to curb the opioid abuse problem.

I need your help I am a chronic pain patient, advocate, and writer. I understand the fears of growing heroin and other opioid pain abuse on the streets, and I believe there are ways to both treat the chronically pained and those afflicted by addiction. Just so that you can get a bit of background, I am a 31 year old woman​​. I began developing major health issues after ​developing “growing pains” in 1993. That's when my health started to decline and pain issues started!​  My grandmother was unable to get me properly diagnosed. I started going to a pain management specialist when I was 16 after I crushed 2 disks in my low back,in a snow skiing accident,  where I was put on opioid medications and I became​ functional, coherent, started ​working, ​and was ​engaged with family, friends ​and​

in life again! I felt alive again!He knew medically exactly what I needed, what my body could and couldn't withstand. When my doctor was approached by some of my family members about the high dosages, He said he would rather see me comfortable, living life to the best of my ability. Rather then curled up in ball, in bed 24/7 in agony just waiting for my journey to end naturally or from suicide!!! When I was 30 I was also diagnosed with Ehlers Danlos Syndrome an extremely painful connective tissue disorder. It affects all your joints and organs made of collagen. It causes joint dislocations on a daily basis.

So the higher doses of medications  were and are essential for me to sustain any kind of relief from my horribly depleting body.  The pain gets so bad my muscles tense up and start to spasm in my legs and feet. My toes and feet curl up so bad it takes a hardbound book and two very strong individuals to place them at the bottom of my feet and push forward. At that point it freaks out who's doing it, because it sounds like all my bones are breaking. High pain levels has led to many ​hospitalizations which I would assume effects insurances bottom line. And anybody who knows about hospitals knows that the worst place for somebody who's immune deficiency (immune system is compromised)​ ​would be the hospital leaving my compromised body open to a ​g​ambit of other conditions / ailments... I could obtain!

I represent​ the​ millions of patients ​with​ similar conditions, some of whom are unable to obtain ANY pain medication, because of the increasing restrictions surrounding opioid pain medications,. Others receive inadequate care. In the land of the free, where we are supposed to have the right to Life, Liberty and the Pursuit of Happiness, millions of Americans are being denied this simple privilege, because when you live in chronic pain twenty-four hours a day, every day of your life and there are legal medications which can help you to live quality life, but you are denied them, you are now being treated as a second-class citizen by your own country. I receive emails, phone calls, etc., from at least ten to fifteen people a day who are on the verge of resorting to street drugs or suicide because their lives are no longer worth living. Please consider speaking with me and some other pain advocates, in order to attempt to help both pain patients and addicts to get the treatment they deserve.

It is scientifically proven that legitimate pain patients do not experience the feelings of euphoria that drug addicts do, and that they are highly unlikely to abuse or divert their medications, I have written you regarding this issue numerous times. As someone who has done a significant amount of research on this topic, I feel that I could be of valuable resource to you and your team, when you consider laws which limit the care of patients like me.

Thank you for your time and consideration. I look forward to speaking further with you about the ways in which patient and lawmaker communication can help lawmakers to understand better how they can better serve their communities, and how we can come together to improve the lives of all citizens.Please contact me to set up a meeting to learn how to help us pain pains.

PAIN IS RELENTLESS, CRUEL, NON-DISCRIMINATING, CONSTANT IT STARTS TO DESTROY YOUR BODY, MIND AND ULTIMATELY YOU... THE WHOLE YOU!!!

Sincerely,

Ashley Reber

Greetings-

I have been disabled with Lupus of the Central nervous system and brain, an extremely painful and debilitating illness.

I moved to be with family from California to New Mexico two years ago, Oct 2015. I brought 15 years of records with me, I have been disabled in since1993 at the age of 22.

When I moved I was told by all my new specialist and primary care doc I would be given no pain meds. I was shuffled around the state to see pain specialists and docs who all said they would not treat any pain that could not be cured. I walked myself off opioids I had been taking for many years to avoid withdrawal, as no alternative to sudden withdrawal was made available to me. I was then started on many different new meds in an effort by the docs to find an "alternative to pain treatment". I repeatedly said I was bedridden due to the untreated pain, I was literally told "it doesn't matter."

I have never abused my pain meds and have always been fully compliant with my docs.

2 years have now gone by. I have been forced to fly back to California for treatment by my old Neurologist. I now have issues with the DEA and Walgreens in New Mexico withholding my prescription. After 2 months had gone by, they said It was okay, but could give no reason or steps I should take. Now they are withholding them again, with no explanation as to when I will receive them. I had also been forced to walk myself off opiods again to avoid withdrawal, as my meds were essentially withheld with no reason given. I have been told "maybe I should move to another state", which is not an option for someone living with a severe disability.

The damage done to my body from untreated pain over the last 2 years is permanent. I have had a great decline in health, mobility, and ability to function with tasks of daily living. I am now fully disabled due to this.

I feel my value to society as a human being is less than zero. I have essentially been told "Go away and die."

My human rights are essentially nonexistant, and I beg you to listen.

Sincerely-

Russell Carl Kline

https://ssl.gstatic.com/ui/v1/icons/mail/images/cleardot.gif

From: **Kevin Mooney** <[kevinmooney61@gmail.com](mailto:kevinmooney61@gmail.com)>  
Date: Thu, Oct 26, 2017 at 8:19 PM  
Subject:   
To: Stacey Fields <[fieldsie62@gmail.com](mailto:fieldsie62@gmail.com)>

Hi! I'm Kevin M. I'm a chronic intractable pain patient due to a low back spine fusion with hardware implanted, I have a fractured disc in the thoracic area of my spine, I live in constant excruciating pain every day and opioids are the only medication that gives me similarly quality of life and will to live, if that's taken away from me it would be cruel inhumane torture.

Regards.

Kevin

---------- Forwarded message ----------  
From: **Brian Harris** <[Banthony03@outlook.com](mailto:Banthony03@outlook.com)>  
Date: Thu, Oct 26, 2017 at 6:40 PM  
Subject: ACCESS TO PAIN MEDICATIONS AS A HUMAN RIGHT  
To: "[fieldsie62@gmail.com](mailto:fieldsie62@gmail.com)" <[fieldsie62@gmail.com](mailto:fieldsie62@gmail.com)>

Chronic pain is one of the most significant causes of suffering nationally and worldwide, and a common symptom for both cancer patients, chronic pain patients, and people living with HIV/AIDS.  Chronic pain has a profound effect on quality of life.  It effects sleep, mobility, a persons ability to interact with loved ones, and even the immune system.  It can even have a negative influence on disease outcomes.  Many chronic pain patients have relied on effective pain medications to alleviate these symptoms.  The World Health Orginization, along with other various national bodies, recommends the administration of analgesic medications such as morphine to treat HIV/AIDS patients living with moderate to severe pain.  It even includes morphine and codeine on its Model List of Essential Medicines.  Nearly 50 years ago the UN adopted the Single Convention on Narcotic Drugs (1961), to combat the illicit trade and manufacturing of narcotics while ensuring the availability for scientific and medical purposes to alleviate pain and suffering.  Yet, despite the existence of these international human rights laws, our own government has failed to ensure that people who have chronic pain have access to adequate pain treatment by adopting strict restrictions and guidelines.  These new unreasonable restrictive policies and guidelines are a violation against the obligation to protect Americans from cruel, inhuman and degrading suffering.

My name is Brian Harris.  I am a completely healthy person living in the state of Mississippi with undetectable HIV, but also live with chronic pain.  I’ve also been diagnosed with fibromyalgia, osteoarthritis, and osteopoikilosis.  What started out as tolerable pain developed into debilitating pain that has impacted every aspect of my life.  From my mood, appetite, emotional stress, and my overall outlook on life.  I’ve spent many nights with little-to-no sleep where the only thing I could focus on was how awful I felt.

Pain is a subjective experience, but for me it can be described as severe, excruciating, and downright debilitating.  Pain effects every aspect of my quality of life.  It effects my ability to participate socially, to work, do to simple household chores, and even to care for my loved ones.  My suffering not only effects myself, but those around me.  For when I suffer distress, anxiety, and depression associated from being in pain, they to experience distresses.  What is frustrating is that there is no standard metric developed to describe the pain burden for people with HIV related pain or chronic pain.  This may be do in large part because of the different stages of the disease and also the fact that people experience pain differently.

For me my pain has no consistent pattern,  however, it usually is more prevalent in my lower back, my neck, my limbs, joints and my muscles.  I experience everything from sever stinging, burning, and tingling.  At times it feels as though someone’s pricking me with several tiny needles in my hands and feet.  I get a numbness/weakness in my muscles, which constantly seem to have spasms and fits of uncontrollable twitching.  I get headaches that range from mild to severe.  At times they may only feel like mild pressure/dull aching, but can develop into heavy throbbing.  I also experience sever joint and bone pain.  Most times I’m reluctant to express just how bad the pain is and how miserable I truly am feeling.  This may be due in part by me not wanting to be a complainer, out of fear of not being believed by my doctor, or could possibly be from my own fear of what might be causing some of my symptoms.

The sources of my chronic pain have taken me many years to untangle, and even today can feel so overwhelming, complex, and even mysterious.  My causes are not only from my HIV related illness and it’s stages alone, but from my other underlying health issues and even from my antiviral medications.   Not only have I had to deal with the physical symptoms from my pain, I’ve had to deal with psychological effects as well.

The goal of my pain control has never been to cure my chronic pain disease, but to manage it.  Allowing me to function effectively as possible, minimize my pain, and improve my quality of life.  Part of my pain management over the past 10 years has been the use of a nonsteroidal anti-inflammatory creams, older types of mild antidepressants/anti-seizure medications, hydrocodone(10/325), and a long acting morphine sulfate (100 mg ER).  Due to my HIV status and my viral meds, I am limited to what I can take.  Most all injection medicines used to treat pain are steroidal, which adversely effect the immune system.  Also, I have to worry about the interactions that most other medications have on my current regiment.

As a result of the “War on Opiods”, new CDC/AMA guidelines, and the current political assault on opioid prescribing, my doctor began reducing my hydrocodone about four years ago.  I went from 4 daily to now just 30 monthly (to use “only when needed”).  I went from being on a stable dose of 100 mg morphine, to now just 30 mg.  A reduction of 70 mg in just two months.  He stated that due to resent changes in opioid prescribing laws here in MS, he could no longer prescribe pain medications unless I had cancer, or was an end of life patient.  He is being forced to wean me off completely.  As if somehow my chronic pain is supposed to magically disappear.

I have struggled with daily chronic pain for over a decade.  I have tried other therapies, remedies, and medications but found little to no relief.  I have responsibly relied on pain medications as a means to help me manage my systems.  Yet due to the current anti opioid prescribing limitations to curb opioid abuse, and my physician’s reluctance to prescribe those medications, I have found myself in a position of being denied access to the very thing that can help relieve my suffering.  These new prescribing “dosage” limitations are causing me harm and are interfering with my patient-provider relationship.  There has to be a balance between both prescription drug abuse and the treatment of chronic pain, one that doesn’t only fixate on one problem at the expense of the other.

I am one of over 100 million chronic pain patients in the US.  I am not an addict or drug seekers.  I depend on a stable high dosage of morphine sulfates for pain control, and have never taken more than I absolutely needed.  I get no “high” from these medications.  My pain has since returned to a level that is truly unbearable at times, my daily life has since been reduced significantly, and for the first time I feel absolutely hopeless.  I’ve reached out to my ID physician, several organization, and other legislators with no eval.  What am I to do?  I can’t believe that I may be faced to just except this new reality.   A reality that if current legislation and perceptions of treating people with a chronic pain do not change, I (along with many others) will be forced to simply suffer.  Restrictive standards for prescribing opioid medications to people like me are condemning millions of pain patients to a life lived in complete agony.  Some will seek street drugs, others will commit suicide, and the fictitious “epidemic” of death will go on.

I urge you to help the voices of chronic pain patients be heard.  CDC practice standard must be withdrawn from state boards, the demonization of drug companies who produce pain medications must stop, and chronic pain patients should not be looked at as addicts.  Pleas help stop the war on chronic pain patients!

Sincerely,

Brian Harris

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Shannon Tuten

477 Jeter Street

Edgefield, SC 29824

My name is Shannon Tuten, I am a resident of Edgefield County, South Carolina and am writing to you concerning actions being taken by the Drug Enforcement Agency, in their attack on the “opioid crisis”, I do not doubt there are persons who abuse drugs at a high rate, I know it to be true as I am a retired paramedic with over 20 years of service both as a paid and volunteer medic in my community. I have always served my community in some shape or fashion from enlisting in the US Navy to deploying with the Medical Reserve Corp following Hurricane Katrina, and as a member of the US Coast Guard Auxiliary Flotilla that serves Lake Thurmond, I had a life, I could function and I used opioids to allow me to function, to serve others, to live, That is until now,

In 1993 I developed severe abdominal pain, nausea, vomiting, it persisted and I was in and out of the hospital over 100 times in the next 3.5 years, over 300 days as an inpatient, I was diagnosed with Chronic Pancreatitis due to a ‘divisum” which is a birth defect in the main duct of my pancreas, I had additional diagnosis of Sphincter of Oddi disorder, Gastroparesis, and Interstitial cystitis, All of which are extremely painful conditions on their own, add them together and you get someone who ceased to function, The recurrent hospital admissions lead to bouts of sepsis including a kidney infection that went undiagnosed until it attacked my cardiac pacemaker causing endocarditis, In other words, the recurrent admissions were killing me, I was one admission away from a drug resistant sepsis that I could not fight off,. During this time I was trying to find an answer to my pain management at home so I could manage some of the flares at home and not require admission, if I could get the pain under control then I could fight it off at home with the same steps used in the hospital, withhold foods, clear liquids slowly advancing diet, So I requested an appointment with pain management, and the trials and errors began, We tried non drug therapies to include a TENS unit, breathing exercises, physical therapy, even acupressure and essential oils, I even tried homeopathic cures to include turmeric, magnesium, all to no avail, they were miserable failures and I continued to get sicker and sicker, and more admissions, 5 days in the hospital, 2-3 days home, repeat, it was no life, We then tried nerve blocks, we tried them on 3 different occasions, and with 2 different anesthesiologist just in case one physician had a better technique, Nothing, not even a small glimmer of hope, It was then my GI doctor at the Medical University of South Carolina sat me down and told me that I should not be ashamed to take long term narcotic medications if it saved my life, I was allergic to most or had severe adverse reactions to others, Morphine caused such severe itching that it took 50mg of Benadryl just to counteract the itching, that meant I was knocked out and slept for most of the day then awoke with a drug hangover, It was no way to be able to function, and I couldn’t,. Lyrica, Cymbalta, Gabitril all non opioids and used to treat nerve pain were all out, as they caused severe reactions in my parents so much so doctors refused to even try them with me, dangerous reactions, Lyrica caused my mom to lose any idea of where she was going, what she was doing, to the point she pulled out a weapon to see if it was loaded- from a locked box- and pulled the trigger, she shot herself in the abdomen rupturing her spleen, she died 3 months later from complications, So excuse me if I refuse to try any medications in that class. I did try Gabitril one time and I was admitted for memory loss I have no memory of the 18 hours after I took the first dose, I was walking around trying to take my shirt off outside and cursing out anyone who tried to help me, In all we tried either as a patient in the hospital or as an outpatient the following medications, Morphine, Nubain, Demerol, Dilaudid, Percocet, Ultram, Stadol, Gabitril, Oxycontin, I could not take any of them, none I was quickly running out of options, I tried the fentanyl patches and they literally burned my skin, I tried removing the adhesive and using paper tape same thing my skin would not tolerate them at all, they burned to the point of leaving blisters where the patch was on my skin, not just the areas with the adhesive, That meant I had one option left for long term relief, Methadone, I used it and it helped tremendously with no bad side effects, but I continued to have severe breakthrough pain throughout the day and when eating, we tried an anti spasmodic such as Bentyl. Which helped somewhat but my abdominal pain continued to increase and I needed something to STOP the breakthrough pain, so we went back to Fentanyl and tried the lozenges, which are marketed under the trade name of Actiq. It was an instant relief with ZERO side effects, no itching, no sleepiness, no dry mouth, all it did was relieve my pain to a manageable level so the methadone worked even better, They were the perfect one two punch and with them I managed to stay out of the hospital, My admissions were so often, my condition so dire that the SSA approved my SSD on the first request. So I am legally disabled, That was ten years ago, In the last ten years my doctor never had to increase my dose we did change once to four times a day with the Actiq which is still well under the recommended dosage schedule.

When Actiq (transmucosal fentanyl) was placed under the new TIRF (REMS) program the FDA stated that it was not to be prescribed except by oncologist, My pain management physician refused to continue my cocktail of methadone and Actiq and I was forced to try another medication,- Oxycontin, which did absolutely nothing for the pain except make me itch, profusely, I contacted the then director of the FDA via email and explained my dilemma, because of their new rules I could no longer get a prescription that had literally saved my life, (see attached correspondence) I was told that that was not the intent of the program to stop opioid dependant patients from continuing to receive their medications, I then explained I was concerned that this would place my PMD in the situation of being investigated for his continued prescription of this medication, I was told again that was not their “intent”. With that information in hand my doctor allowed me to go back on the Actiq. That was UNTIL last Monday, when this administration decided that chronic pain patients must suffer and die, We are not worthy of proper pain management,

I received notice via a phone call that he will no longer prescribe the medication because of the DEA”s war on opioids, and information relayed in a medical journal Pain Medicine News entitled *DEA Begins Targeting Off-Label Prescribing of TIRF Products* (included). In the article they note the FDA has once again narrowed who can allegedly receive this medication, it appears only cancer patients are entitled to long term pain management, and there is no legal way for my doctor to certify that he will only prescribe the medicine for cancer pain when I do not have cancer. According to the article “*While there is no law or regulation forbidding a physician to use Subsys off-label for noncancerous breakthrough pain, as described below, the DEA has drastically increased enforcement action against those who prescribe TIRF medications “off-label.”* ***The crux of the government’s position appears to be that the express wording of the TIRF provider agreement requires a physician to certify that she or he will only use TIRF medications for approved purposes and that any unapproved use is a breach of the TIRF provider agreement.*** *However, such an interpretation runs contrary to the wealth of federal case law that recognizes the government’s interest in permitting physicians to exercise independent judgment and prescribe medications “off-label”(*e.g., *Weaver v Reagen*, 886 F.2d 194, 198 [8th Cir. 1989]).

That means because of government interference in MY healthcare, I can no longer receive a legal prescription medication that has shown to be beneficial to my overall health, and well being, In essence the DEA and FDA have signed my death certificate.

So why am I writing my US senator, what can you possibly do to help me, Guidance, I respectfully submit to you by copy of this letter and additional documentation my health information concerning the role of opioids in my treatment plan, I have followed all of the rules I used one doctor, one pharmacy, and only ONE increase in my medication regime in 10 years. I have never had a positive drug screen and any event in which I received any other pain medication as in during kidney stone surgery, was documented and the records transferred in case of such an instance, I am asking that you contact the DEA and or FDA and ask for guidance on cases such as myself, As technically there are ZERO medications approved by the FDA to treat long term chronic pain, therefore ALL narcotic prescriptions are ‘off label” use, This will set a dangerous precedent for those of us in the chronic pain community, Is it there intention to go after doctors, such as mine, Dr John Downey. DO, US Army retired, and board certified in pain management, for prescribing a legal medication to a patient who is out of options and has shown beneficial results from its use, a patient with no history of abuse, and a long history of compliance.

What are chronic pain patients supposed to do for pain control, I am not in this fight alone I am one of thousands. We deserve to have our rights defended and preserved, this over reach by the DEA is not only what I feel illegal but highly unethical ,and will result in an increase in suicides in the chronic pain patient,. We are already seeing that effect in states that have limited dosages according to the CDC guidelines, or forced doctors to refuse to write any opioids to long time patients because of the Gestapo tactics being used by the DEA by arresting and going after their license for prescribing a legal medicine to a legitimate chronic pain patient, In the case the United States vs., Caronia, the court stated:

*“The most recent enforcement action against prescribers of TIRF products appears to be a policy shift and an encroachment on the exercise of independent medical decision making. Historically, the FDA does not seek to regulate how physicians use approved drugs. Courts have traditionally held that prescriptions written for off-label uses serve legitimate medical purposes, including for TIRF products* (see *United States v Caronia*, 703 F.3d 49, 153 [2d Cir. 2012]).

In fact, courts have gone so far as to say that “off label use is an accepted and necessary corollary of the FDA’s mission to regulate in this area without directly interfering with the practice of medicine.”10 ***Medical ethicists agree that “physicians may prescribe FDA-approved drugs … for any therapeutic use that is appropriate in their [independent] medical judgment.”11 Until recently, federal agencies have not sought to disrupt the independent judgment of physicians who prescribe medications for off-label purposes. Legislation that interferes with the independent medical judgment of a physician has grave consequences, such as decreased patient care and a chilling effect on the use of alternative therapies. Yet, it seems that the DEA is circumventing the FDA’s abstention from regulation of off-label uses by declaring the off-label use of TIRF products contrary to the vaguely worded requirements of the Controlled Substances Act.12***

Please advise me Senator Scott and my physician on how to proceed, I request that you or your office contact the DEA and ask for clarity on cases such as myself, Is it there intention to go after doctors ALL doctors who use fentanyl products off label regardless of the circumstance, If it is NOT then how do we get around having to certify he will not use it off label, as per the CDC TIRF certification, it seems to me to be entrapment, and easy “gotcha” for the DEA, and again a highly unethical. Move by the FDA, a ‘trick” to keep patients such as myself fromk being able to use a product for pain control, I guess only cancer patients deserve chronic pain therapy. As I understand this policy shift comes about because of the actions in ONE county where doctors were over prescribing Subsys- a fentanyl product,, that resulted in the deaths of several persons. Think about this, ONE county out of 3141 total in the US, As a firm believer in the 10th amendment, that believes in small government and states rights, that issue should be left to the state, NOT to the FDA and DEA to throw everyone in the entire chronic pain community away, because of the actions of a few. It would be like telling all hunters to throw out their guns because someone used one to kill people in Las Vegas, the gun did not cause the problem, the person that CHOSE to use the gun did so, and immediately thereafter the tragedy people began using it to call for more strict gun control, Except that we know by looking at places with strict gun laws it has not decreased violent crime, in many places it has increased and with it the illegal market of firearms, So then why do we apply this same failed logic to drugs, this isn’t about the ability to hunt or personal protection though, this is about life and death, for those of us cursed with chronic diseases through no fault of our own. I advise you to do your own due diligence on this matter and not what the lobbyist by persons like PROP spoon feed. The people of SC are depending on you to stand up for those in your state, not for the right to take an illegal drug, but for the right to humane treatment, with legal medications.

I apologize for the length of this letter but as you can see it is a subject that is very important to me, in all honestly, my life depends on the answer, There is zero doubt in my mind that without the Actiq, my pain will increase and my quality of life will decrease, I will once again end up a prisoner of the hospital system with flares that could have previously been managed at home and will succumb to a hospital acquired infection as shown by my previous medical history, I hope that you can get some clarity to this issue with the FDA and DEA, as to how doctors such as my own are to proceed and what patients as myself are to do for an answer to our pain, If the DEA holds a magic wand to take it all away, then I am more than willing to try that technique as well. To my knowledge Hogwarts and magic do not exist, and it is not an available treatment option, I look forward to your response, Should you wish to meet in person to discuss this matter I am more than willing to do so,

Attached:

<http://www.painmedicinenews.com/Policy-and-Management/Article/10-17/DEA-Begins-Targeting-Off-Label-Prescribing-of-TIRF-Products/44733>.

Correspondence between Shannon Tuten and FDA concerning REMS program and Actiq,

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From: **Pam Hawthorne** <[hawthornep@hotmail.com](mailto:hawthornep@hotmail.com)>  
Date: Mon, Oct 30, 2017 at 7:07 PM  
Subject: My CPP Letter  
To: "[fieldsie62@gmail.com](mailto:fieldsie62@gmail.com)" <[fieldsie62@gmail.com](mailto:fieldsie62@gmail.com)>

I have had moderate-to-severe rheumatoid arthritis throughout my entire body for 9 years now.  Compared to the other autoimmune diseases I have, rheumatoid arthritis is a very painful condition that I now live with 24 hours a day, every single day.  I had to go on Social Security Disability, because I cannot depend on my body’s ability to do just normal day-to-day activities consistently.

My first flare-up in 2008 affected multiple joints all over my body, so I was prescribed 3 medications to lower the inflammation and joint degeneration.  Since it actually takes at least a month for the medications to start working, I was prescribed Percocet, which is an opioid.  It gave me enough pain relief to continue working part-time and still lead a productive life.

When the inflammation lowered about 6 months later, my condition was considered to be moderate again.  However, the pain never did completely go away.  It lessened and the pain in my joints was a dull ache, so it slowed me down and brought fatigue like I never had before.  I was surprised and told the doctor that I had expected to feel no pain at all.  He told me that some patients are not able to reach full remission, so I may have to continue taking opioid medications for pain relief for the rest of my life, when the pain becomes intolerable.   When the disease is moderate, I still require opioid medication when I have a project requiring stronger use of my joints or when I am unable to sleep due to the pain.  Opiates never bring the pain level to zero, but it does lessen the pain enough to allow me to function every day.  There are days when I can go without opioid medication, so I never have considered myself to be addicted.  However, I am dependent on opioid medication to relieve the pain just like I depend on insulin to allow me to maintain my blood sugar levels to normal ranges.

In 2010, I had another flare-up mainly in my wrists and hands, so I continued taking Percocet to control the pain.  However, each year it has become increasingly difficult to get pain relievers:

1. Most doctors absolutely refuse to write prescriptions for pain relief now.  They have told me that it is due to federal guidelines that they must follow.  I found that the only doctors that would do it were my rheumatologists.  When I moved to California in 2014, my rheumatologists refused to treat my condition with what had been prescribed for 6 years previously and reduced my dosage to half.  My capabilities have been significantly reduced.
2. No refills are allowed even though I have a chronic condition that requires it.  The inconvenience and high costs of having to see a doctor to get a prescription every month is completely unnecessary and very stressful, which only adds to the pain.
3. Now, I must pay for a visit to the rheumatologist as well as a Pain Management Specialist just to get the prescription, so my medical costs have increased tremendously.  The Pain Management Specialist knows nothing about my disease, nor is he really an expert on pain management.  His expertise is the spine, but I have to pay him just to get the prescription for opioid medications.  I am treated like an addict with continuous urine tests and have had to try numerous medications that either haven’t worked or caused injury to me just to prove that they will not work, so that I can continue using what previously worked to lessen the pain.
4. Pharmacies refuse to fill a new prescription if it hasn’t been at least 1 month since the last one was filled.  You are treated like an addict because you are told how many pills you should still have in your bottle.  If you just happen to be in the store a couple days earlier than 1 month and want to pick up the prescription for the sake of convenience, it isn’t allowed.

5.    Insurance companies don’t trust prescriptions written by actual doctors now.  All pain medications are questioned, and in many cases, a Prior Authorization is required, which causes a several days delay.  Step therapy has also been required before I was allowed to use an opioid medication that I had been using for many years.  I suffered through the extra expenses and inconvenience, as well as a concussion and stitches as a result of a fall from the affects of one of the medications I was forced to try.

There have been no improvements in combating the opioid crisis, even after the federal and state governments put extreme limitations in place to make opioid medications difficult to obtain.  Not only have overdose deaths increased, but now, in addition, there are many suicides by chronic pain patients with undertreated pain.

It’s time to try something new and effective, which will also stop making chronic pain patients, who need opioid medications and use them responsibly, stop suffering.

My mom had rheumatoid arthritis, and she passed away in 2006 from a brain tumor, which was a side effect of the RA biologic medications seen advertised on TV all the time.  Rheumatologists actively promote and prescribe those types of medications that can be so dangerous to our health, yet they now will not prescribe opioid medications that actually help us live our lives in a more productive way.  My mom used Vicodin for over 20 years without becoming addicted.  It was her other RA medications that caused her death!

Recommendations:

As per Dr. Thomas Kline MD PhD, “The [CDC] Guidelines need to be recalled immediately as harm is present and evident, until the illegal attempts at federal medical practice revisions [42 USC 1395] are scientifically verified outside the structure of the CDC and its anti-pain consultants, including the three “authors” of the federal government guidelines for medical practice who have publicly written, or spoken favoring pain and pain medicine denial. None of the 12 guidelines has been proven, has any support from the medical literature, the most dangerous provisions were disproven prior to publication of these flawed restrictions on pain medicine (only opiate medicines work for pain).”

“Stop all raids on doctors offices conducted without probable cause and substitute requests for records with letters.”

“Begin to work directly with the addiction community to develop point of service spot tests for fentanyl contamination and spot tests for diamorphine (Heroin) purity. Perhaps with some immunity for possession only, work with the addiction community to track down the very dangerous fentanyl being manufactured and distributed by the cartels.”

**“**Physicians will not respond to the new Opioid Refugee Crisis without new financial incentives. We suggest a temporary CMS allowance for maximum billing codes to create a new “Certificate of Medical Pain Disease”. This would be an hour long intensive history and physical to establish and certify the need for long term medical pain medication and why. Once done this certificate can be presented to other doctors, pharmacies (where refusal to fill valid prescriptions has already lead to suicides), insurance companies, benefit managers, hospital ER’s, hospital surgical services, Medicaid, and Medicare, that a valid need exists and to honor physician prescribed pain medication at any dosage level, as established in the comprehensive evaluation for the “Certificate”.

“Begin public health education for families and for junior and high school students to stop addictions where 90% of them start, due to the opiate naive population being subjected to their first and possibly addiction triggering dose. Although rare, 4/1000, each person snatched from the jaws of addiction can lead a normal life with this genetic disease.”

The Opioid Commission was created without any representation of Pain Management Specialists or chronic pain patients.  How can decisions to limit or stop availability of effective medications for our treatments be made without our representation?

Having the facts is crucial in solving the opioid crisis.  Yet legislators and a lot of the other governing bodies have been making decisions based on incomplete and inaccurate information spread by a lobbying group and the CDC Guidelines.  There are ways to help those who are addicted without punishing those who rely upon opioids for reducing their physical pain caused by diseases and permanent injuries.

Please start listening to doctors and patients that really know the truth about opioids.

Pam Hawthorne

Roseville, CA

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---------- Forwarded message ----------  
From: **Ellie Kacik** <[e.Kacik2@aol.com](mailto:e.Kacik2@aol.com)>  
Date: Fri, Oct 27, 2017 at 4:43 PM  
Subject: I am a chronic pain patient through no fault of my own  
To: [fieldsie62@gmail.com](mailto:fieldsie62@gmail.com)  
  
  
  
  
Sent from my iPad. I am a chronic pain patient suffering from the huge decrease in my medication making it ever so difficult to function in my activities of daily living.   Suffering through 6 hips surgeries that were botched by the surgeon, I cldn't even sue.  PM came to me in the hospital & told me I wld never get better & placed me on pain meds accordibgly, however as of the new CDC guidelines in which my PM has chosen to abide by I am on les than 50% of my previous medications even though they declare I need them to function.  What kind of medical treatment is this?  I intend on fighting until my dying day,  I am not an addict but a human being reliant on the correct dosage of meds.

From: **D Tessi** <[dtessi1@gmail.com](mailto:dtessi1@gmail.com)>  
Date: Sun, Oct 29, 2017 at 2:29 PM  
Subject: Letter for CPP  
To: [fieldsie62@gmail.com](mailto:fieldsie62@gmail.com)

To be clear, chronic pain patients and opioid addicts are two distinct groups, both of which deserve care and support. Treating pain patients as addicts can lead to denial of care, which may actually increase the number of opioid addicts.  
  
I am a 17+ year compliant chronic pain patient. 2 failed back surgeries with fusion, hardware removal and finally laminectomy. Without the medication I have safely used for over 15 yrs., I would have no life. At at 49, I have tried ALL of the alternative options and chose to have no further invasive procedures done to my body. My opioids give me a semblance of life. I do not feel high. I am able to get up and do things like a "mostly" normal person.   
I have extensive medical records, showing the degenerative nature of my disease. It WILL get worse as I age. There are other things chronic pain sufferers do to relieve pain. In an effort to distract ourselves we meditate, pray and have hobbies like polymer clay, cross stitch and reading. We do many thing to take our minds off of our pain, We attempt to stay positive even when it feels impossible. A short relief from pain helps. Pain medicine helps us function, at least for a short time, in a way that most people take for granted. When our pain is adequately managed, We are not holed up in our houses with the drapes closed, clock watching our next dose, or crushing, snorting or injecting our drugs. WE WANT TO LIVE!  
We CPP's all agree that there is a problem with opioids. There is no reason that any patient who has a tooth extraction, broken arm or acute short term injury, should EVER receive more than a 3 day dose of meds. That is acute pain, expected to end in a short period of time. We CPP's don't have that luxury. We are broken, damaged and not expected to heal. The damage has been done, and age will only exacerbate the problem. We are responsible, we are accountable, and most of all...we are human, and deserve to be such.   
Thank you for your time.  
Diahn Escalante   
Oregon, USA

To Whom it May Concern November 2, 2017

I recently became aware of the growing concern about the misuse of opioids and the misinformation that is circulating more and more about what is really to blame. It has become synonymous with pain medication because I guess the word opioid is used. When in reality and speaking from experience it isn't pain medications causing the problem but rather heroin and illegal fentanyl . I say this because prescribing pain medication has gone way down yet statistics say overdoses continue to rise. How can that be? Except for the use of black market substances that junkies were replacing with the easy to access medication we use to treat chronic pain.

 Now that the pill mill days and easy breezy prescribing is over, they go back to the street drugs and we the chronic pain patient are left in pain with little or no recourse for our conditions.

 Maybe some of those overdoses are caused by pain patients abruptly cut off from treatment for pain and in desperation trying heroin themselves, not knowing what they are doing, they are dying. I don't know this for a fact. But it sure seems plausible.

 Pain will drive you. It will make you desperate. It will also left untreated kill you. Or cause you to kill yourself. I know when I first started battling it, death seemed more desirable, but as a Christian I couldn't come to terms with it. I did pray an awful lot and still do. Because as one of the millions of people whose lives are somewhat more bearable because of the use of opioids, I am scared that I like so many others will find themselves deprived of the only medication available that has made my life livable, allowed me to continue to work and consider death something that will only come later when I am much older.

 I am 62. A mother, grandmother, great grandmother. I work full time. I own my home. I pay taxes and bills and vote in every election. I have severe degenerative arthritis of the spine which makes sitting or standing for more than 30 minutes very painful. So I medicate. And move a lot sitting, standing, throughout my day. But I don't want to stay home lying in bed useless, which I was before. Not that my doctor didn't try everything else first I exhausted my savings after insurance on treatments I took nsaids until stomach bleeding stopped that. I do PT yoga and stretching, but I couldn't do those without help. Opioids are that help. Why would you want to take something away from so many that is only improving their lives? Why not take on Tobacco, it kills millions and offers no quality of life in return...alcohol...what about that? Why this? What is really going on here? Can we not separate the patient on medication from the junkie trying to get high, and treat them both, according to their need? There has got to be some middle ground here. Can we work towards that? Or do I just wait until they come for me?? Am sure you've heard the poem. Not one to stand by, I am advocating for myself and with others, please hear us.

Sandie Hamilton

Community Care Coordinator.

Hope Outreach Ministries

(580) 237-4800

Catherine Kuckuk 2205 9th Street Monroe WI 53566 To Whom it may concern, I am 54 yrs. old. I suffer from chronic migraines, Fybromyalgia, severe neuropathy in hands and feet from chemo damage, chronic post cancer pain, sleep disturbances, severe disc degeneration, stenosis of spine (WITH more than 1 surgery), anxiety and am currently winning a fight against stage 3C Inflammatory Cancer, one of the rarest and most insidious forms of breast cancer. Before all of this, I was raised by two parents, sent to private parochial schools, and very successfully finished high school. I went to college, got married and worked as a collections and loan officer at a prominent bank. I had two children. I was a well loved and highly successful, involved stay at home mother. I was a leader and money maker for my kids PTO, and I was very involved in volunteering with every grade-school and middle school that my kids attended. I had some back issues and migraine issues throughout my 20-30-40's but it was not chronic nor debilitating. I managed pain episodes as they came. Sometimes even with a very short prescription of opioids! Once I got diagnosed with cancer in 2008 and received many rounds of the "red devil" chemotherapy and extended radiation, things changed drastically. I had a double mastectomy, too. Before that, many cuttings and biopsies and "ectomies". I also had some lung explorations regarding a lung infection. My husband of 15 years found a fresh healthy gal and divorced me early during my treatment, which I finished alone. I then fought a 2 year long custody battle at the same time as fighting for my life. All the while my anxiety about dying kept growing and my ability to keep the chronic painful issues "at bay" began to fail. I developed all over, massive pain. My bones felt as if they had acid rubbed on them. My skin hurt to touch. My scalp hurt to wash. My teeth hurt, and are still falling out. I cant afford dental insurance, nor care. My headaches became daily and high migraine levels with numbness in my face and eye and neck, came often, sometimes daily. I couldn't see in my left eye when these would happen. My lower back pain morphed into episodes of breathtaking intensity. I would drop to my knees at any moment if I moved or reached the wrong way. The emergency room, at first, thought I was passing stones. My left upper quadrant has lost 60% use and most mobility from the cancer treatment, but gained mega pain that is only relieved by opioids. My spine started over-compensating for all the pain pulling me apart 24/7 and began to permanently misalign in response, as well as degenerate because of the constant chemo I am kept on daily and monthly to keep inflammatory breast cancer at bay. My bones are literally crumbling inside me. Headaches-way beyond what tylenol can touch, and daily pain rack my body. Since then, I have seen rheumatologists, oncologists, heart specialists, neurologists, rehab specialists and physical therapists. I have begun swimming rehab. I have begun physical rehab. Stretching whatever I can move. For 3 years I would fill my calendar with rounds to these specialists to try and correct what was going haywire everywhere in my body. I exercised. I swam. I ate greener. I took supplements. I ate loads of tylenol and ibuprofin around the clock till my kidneys ached. Nothing worked. Most Exercise made me have more pain, even with a hospital instructor working with me. I was finally approved to see a pain management center an hour from my home, when my back pain prevented me from my last available outlet; gardening. I could no longer bend over, wipe myself properly after visiting the restroom, shower my body properly, or get dressed in my normal attire without some aid from my kids. I was found to have severe disc degeneration disease, severe stenosis, and bulged/protruding disc disease, and promptly received pain blocking shots in my spine. Along with migraines and neuropathy, I also received steroid shots in both knees for years. I still get them. After a new pain doctor diagnosed me with Fybromyalgia and degenerative disc, My first pain specialist decided my migraines weren't really migraines, but that I was having opioid induced headaches from the oxycodone I was on for my cancer pain, and he wanted me “off all of them”. So I went off all opioids. Pretty quickly. He didn't believe Fybromyalgia nor migraine headaches nor even the post cancer pain were helped by opioid use because thats what the CDC data suggested, and he took them away and he tripled my neurontin, savella, and depression pill amounts. After this point I was unable to get around without a cane, and sometimes not much at all even with one. Now Im taking loads of prescribed neurontins, ssri's, beta blockers, heart meds, and anxiety meds, and I packed on 112 pounds, unable to exercise at all now because of severe pain. I had no opioids to ease any of the pain from any issues… and I had not one single drop of motivation to work through that pain without any relief, anymore. I also quickly began having severe memory loss from the higher dose gabapentin. I forgot where I dropped off my child one day. I couldn't remember simple words. I forgot where I was driving to in my car. I couldn't form sentences, and it became a game of charades to discuss anything with me. I had lists and memo stickers everywhere. My kids began to lose faith in me as their leader of the home. I was more depressed, and in so much more and more pain daily with no pain medication. I finally asked to be switched to a different doctor in the only pain mgmt. center available to me, an hour away from my home in Madison. You know what they did? They accused me of “drug seeking” and said I had to stick with my present doctor or leave the center. I had never asked for any drugs and actually went off ALL of my pain medications at his command 6 months prior, but they all gave me the stink eye and were very condescending to me after I asked to switch docs. I didn't feel he was helping me and as fact, I was getting so much worse I wanted to die. My knees eventually gave out. I am now qualified for double knee replacement surgery, too. My "pain doctor" found, after 6 months with no opioid medicine at all, that I was worse off with pain scale ratings and my mobility was down to a 0-1. He then decided that my chronic pain and headaches “might not be caused by opioid use”. He very reluctantly re-prescribed a 5mg ocycodone supply, which allowed me to hobble to the bathroom in the morning and get into the shower, do the basics, but the level of short term use oxycodone wasn't helping my whole body pain. 5-6 pills per day went fast, even though it seemed to be a lot of medicine when I looked at the bottle. That’s 1 pill every 4 hours, with one extra for break thru pain. Eventually I couldn't stand my situation any longer. Even as a single mother of two great and awesome children who I fought for two years in a contested custody court while going through the toughest cancer treatment I could ever imagine...I was ready to give up the fight. I could not take the pain. Not one. More. Day. I was ready to Give in and just make it all go away. I had nothing left in my tank. There was no single joy that could break through the constant array of different pain my body so easily forked over, day after day after day. I couldn't take one, more, minute. I cried every day. My regular primary doctor upped my depression medication and sent me out of office with another year of pre-authorized papers to continue the counseling I had been in since my divorce. My neurologist gave me more and more non-opiate drugs to try to stop the horrific head pain and migraines and nerve pain. My counsellor kept listening. I kept crying. My body was a traitor. I hurt so badly. Everywhere. My rheumatologist and orthopedist told me to hold out as long as I could on the knee replacements, because even though surgery might help my knee pain, I would need another in less than 10 years because of my age, and the expected mobility used on the replacement knees. He told me to "get some exercise and lose weight". (As if I haven't been trying to do that in the last three years.) To swim more. (I had to quit after pain meds were taken away) He signed off on my disability papers and gave me a disabled parking pass application. I swam. I stretched, and It hurt bad. The day after a swim I spent in bed from extra pain. I kept on being a mother and doing what I could, working through the pain as best as I could. I used everything I read about homeopathically, and found out what worked for others so I could ask about those treatments in the many offices I visited each month. I took my little 5mg oxycodone religiously, saving 3-4 of them each day for when my kids got home from school at 330 so I would be able to care for them better. So I could do something with them when they were with me. I slept or laid in bed almost all day without any pain medication. My counsellor kept listening. I kept crying. My body kept on hating me. Then 3 years ago my old, cruel pain management doctor left the office and moved to another city! I was able to switch doctors without being called and labeled a drug seeker! I chose a woman instead of a man, and her name was Dr. Kim. I began seeing her immediately, and she poured over my thick stack of records. We had hours and hours of discussion. We talked about my family, what I couldn't do anymore since opioids were taken away, what I wanted to do, needed to do and how I was feeling. Goals. She tracked my pain scale, and poured over my history some more. She listened. I cried. I don't know if it was because she was listening without judging me or because I felt hope, but I cried. A lot. She never ever once gave me the stink eye. My counsellor kept listening and smiled for the first time. After my new Dr. Kim decided to take my case on, she advised me about all the options available to me. She talked a lot about what failed, about what she wanted to retry, and what might fail again, anyways. She told me we would be going on a journey together but it would not be a fast fix. She said you may become physically addicted to opioids if that is what ends up working for me. I clearly Understood the dangers and eagerly accepted them if that was what worked because it would be better than wanting to die each and every day the moment I opened my eyes. We agreed on a plan, and started that day. I cried that day, again, in gratitude and relief and with great and all consuming hope. I cried the whole way home, singing along with the radio at the top of my lungs, clutching my new, starting prescriptions in my hot, sweaty tingly hands that I could barely feel. I cried with hope that I could possibly walk my son to school again, and get out of the hotel room when we visited the Dells for their birthdays, and stand in the snow and cheer them on when they were sledding, skating, or snowboarding. I might be able to be present with my kids, instead of barely hanging on to the fragile string that kept me alive. Trading in that string of guilt for a scratchy, thicker rope, made of hope. I started on a long acting opioid called oxycontin. Eventually that didn't work out because I need too much to be successful, and she changed it to patches and other narcotic medicine combinations. After 9-10 months we eventually found a combination of long acting morphine working with short acting oxycodone, that I used to get most of my pain under control right away. My neurologist also concurrently worked hard enough with my insurance for me to get Botox approved and my chronic migraines are -for now- beginning to be under control. I sleep at night, despite waking up 2-3 times because of pain and numbness that can't be controlled with all the drugs, but I do get sleep now. I have reduced my depression medication. I have un-tripled my Gabapentin and SSRI's and can now converse with anyone again, especially my kids. And I now remember where I drop them off. The last two years I have been able to be helped in and out of a sit-on-top-kayak and have fun on the water with my children! With assistance, I can canoe, I am able to sit or stand most times for short periods sometimes without a cane, and even fish, or drive for almost an hour, or take short vacations and walk out to the beach for the first time! This ability has been brought ONLY by the specific opioid combination found by my new pain doctor Kim who took the time to know me, who I am, build a trust, and become secure enough in my personality to not abuse what I have been given. I do get drug tested. I always pass. It has brought me such joy and good memories, I am able to cling to them when the pain does breakthrough and get bad, and not get me so depressed. I don't cry so often anymore. I am present and accounted for with my children. I am a new person! I wake up and I CAN hobble in massive pain to the bathroom, knowing my opioid medicine will enable me to get through each day and do what I have to do to care successfully for two growing teenagers and myself. I am so thankful to have a life again because of opioids. My children are so happy to have a mom again. The only reason they have a mom is because of my drug combination of two narcotics. I am so thankful I am crying right now, thinking of all the silent sufferers out there who are NOT getting access to the pain relief they need because of their doctors, or the DEA, or the CDC, or whomever their state representatives are who have never felt like we have. They don't recognize or cannot imagine the massive pain we suffer with, for whatever reason. I look absolutely fine, I still dress, and shower and even get haircuts. People don't see my pain because I can only go out when I feel up to it! They don't see me when Im in bed, crying or shaking in pain, waiting for the pills to work or for the time to pass when we can take another pill. We have invisible illnesses that have put us on disability, or into early retirement, or even worse, UNCONSCIONABLY kept us in bed, isolated, in our homes, all alone. We are literally Crying for help with no-one to even hear us. We have all gotten that "stink eye", that drug seeker look, and had notes made in our files that we can never change!, when we have asked for relief of any kind, or any drug at all for any modicum of relief, or some drug that mainstream people without chronic pain think of as "so bad" "you must want to be high...". But we don't feel high. From opioids, we feel the absence of pain. When you hurt so bad you cannot take it one more second, you WILL ask for something. You will ask for relief. Please don't make us look for it on the streets. Or from places that are illegal. Or tie our pain doctors hands so damned tightly they are unable to help us without getting into trouble themselves. The government and the DEA should not be in charge of our lives and what is available to us for pain relief. Sometimes opiate drugs are the only option left to us. Just to have even portions of a life. Do you blame us for asking for opioids when we can literally not stand living anymore? Do you think some government board who has no ability nor time to look into our lives should be in charge of the drug prescription guidelines? Or should it be put in the hands of capable doctors who have the time to get to know us and find the best way to help? Please, Give them that ability. Without Dr. Kim I am certain that I would be dead, and my children, mother-less. I am certain of that, just as I am certain of the millions of people out there, mothers, grandmothers, grandfathers, fathers, uncles, nieces and nephews and children, who need the help of narcotic drugs to get through their lives because of some qualifying cause. Let the doctors do their jobs and find relief for those causes, and treat them without being forced to degrade us by making us feel like we are "less than" for not being able to rid our own bodies of massive pain without narcotic use. If some drug works, why cant we have that choice? It’s a crime to me that medicine a few misuse is taken from us who need it. What about alcohol? Millions abuse that and I don't see there being an alcohol state of emergency?! Chronic pain is a severe hardship, it's insidious, and it's invisible. These things all add to our stigma of being drug abusers, because people only see us out and about when we feel ok. Or people only see us when were able to get to a doctor. So when we 'look ok' and are walking around and driving a car and shopping or doing whatever mundane thing we do, people say "oh, she looks great! I don't see a thing wrong!" But those are the times when our medicine is working. Our opiate medicine is what enables us to get up and live. Our medicine —those narcotics—are what gets us out the door and living. I have to say that if it weren't for a handful of good doctors who were willing to listen and learn about my treatments and issues I would no longer be here today. If it weren't for Dr Kim at my pain clinic, opening the door to real physical relief from that massive everyday pain, my life would have ended over 3 years ago. My kids wouldn't have a mom right now. I don't know how to convince you we aren't all addicts. I don't know how to convince you we need our voices to be loudly heard. Sometimes I feel as small as the Who's in Who-ville, with no one ever to hear our plight. What I do know is how pain has made me feel, and what is has taken from me, and its not a pretty story. But I also know that the way those doctors and some medical profession treated me when I begged for relief was just as bad as feeling that pain, and if telling you my story helps out at all, then I will keep telling it. So thank you, for listening. Im not crying much anymore. My body still hates me. My narcotics work for pain and allow me to live. My counselor is still listening, and smiling.

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I have had moderate-to-severe rheumatoid arthritis throughout my entire body for 9 years now.  Compared to the other autoimmune diseases I have, rheumatoid arthritis is a very painful condition that I now live with 24 hours a day, every single day.  I had to go on Social Security Disability, because I cannot depend on my body’s ability to do just normal day-to-day activities consistently.

My first flare-up in 2008 affected multiple joints all over my body, so I was prescribed 3 medications to lower the inflammation and joint degeneration.  Since it actually takes at least a month for the medications to start working, I was prescribed Percocet, which is an opioid.  It gave me enough pain relief to continue working part-time and still lead a productive life.

When the inflammation lowered about 6 months later, my condition was considered to be moderate again.  However, the pain never did completely go away.  It lessened and the pain in my joints was a dull ache, so it slowed me down and brought fatigue like I never had before.  I was surprised and told the doctor that I had expected to feel no pain at all.  He told me that some patients are not able to reach full remission, so I may have to continue taking opioid medications for pain relief for the rest of my life, when the pain becomes intolerable.   When the disease is moderate, I still require opioid medication when I have a project requiring stronger use of my joints or when I am unable to sleep due to the pain.  Opiates never bring the pain level to zero, but it does lessen the pain enough to allow me to function every day.  There are days when I can go without opioid medication, so I never have considered myself to be addicted.  However, I am dependent on opioid medication to relieve the pain just like I depend on insulin to allow me to maintain my blood sugar levels to normal ranges.

In 2010, I had another flare-up mainly in my wrists and hands, so I continued taking Percocet to control the pain.  However, each year it has become increasingly difficult to get pain relievers:

1. Most doctors absolutely refuse to write prescriptions for pain relief now.  They have told me that it is due to federal guidelines that they must follow.  I found that the only doctors that would do it were my rheumatologists.  When I moved to California in 2014, my rheumatologists refused to treat my condition with what had been prescribed for 6 years previously and reduced my dosage to half.  My capabilities have been significantly reduced.
2. No refills are allowed even though I have a chronic condition that requires it.  The inconvenience and high costs of having to see a doctor to get a prescription every month is completely unnecessary and very stressful, which only adds to the pain.
3. Now, I must pay for a visit to the rheumatologist as well as a Pain Management Specialist just to get the prescription, so my medical costs have increased tremendously.  The Pain Management Specialist knows nothing about my disease, nor is he really an expert on pain management.  His expertise is the spine, but I have to pay him just to get the prescription for opioid medications.  I am treated like an addict with continuous urine tests and have had to try numerous medications that either haven’t worked or caused injury to me just to prove that they will not work, so that I can continue using what previously worked to lessen the pain.
4. Pharmacies refuse to fill a new prescription if it hasn’t been at least 1 month since the last one was filled.  You are treated like an addict because you are told how many pills you should still have in your bottle.  If you just happen to be in the store a couple days earlier than 1 month and want to pick up the prescription for the sake of convenience, it isn’t allowed.

5.    Insurance companies don’t trust prescriptions written by actual doctors now.  All pain medications are questioned, and in many cases, a Prior Authorization is required, which causes a several days delay.  Step therapy has also been required before I was allowed to use an opioid medication that I had been using for many years.  I suffered through the extra expenses and inconvenience, as well as a concussion and stitches as a result of a fall from the affects of one of the medications I was forced to try.

There have been no improvements in combating the opioid crisis, even after the federal and state governments put extreme limitations in place to make opioid medications difficult to obtain.  Not only have overdose deaths increased, but now, in addition, there are many suicides by chronic pain patients with undertreated pain.

It’s time to try something new and effective, which will also stop making chronic pain patients, who need opioid medications and use them responsibly, stop suffering.

My mom had rheumatoid arthritis, and she passed away in 2006 from a brain tumor, which was a side effect of the RA biologic medications seen advertised on TV all the time.  Rheumatologists actively promote and prescribe those types of medications that can be so dangerous to our health, yet they now will not prescribe opioid medications that actually help us live our lives in a more productive way.  My mom used Vicodin for over 20 years without becoming addicted.  It was her other RA medications that caused her death!

Recommendations:

As per Dr. Thomas Kline MD PhD, “The [CDC] Guidelines need to be recalled immediately as harm is present and evident, until the illegal attempts at federal medical practice revisions [42 USC 1395] are scientifically verified outside the structure of the CDC and its anti-pain consultants, including the three “authors” of the federal government guidelines for medical practice who have publicly written, or spoken favoring pain and pain medicine denial. None of the 12 guidelines has been proven, has any support from the medical literature, the most dangerous provisions were disproven prior to publication of these flawed restrictions on pain medicine (only opiate medicines work for pain).”

“Stop all raids on doctors offices conducted without probable cause and substitute requests for records with letters.”

“Begin to work directly with the addiction community to develop point of service spot tests for fentanyl contamination and spot tests for diamorphine (Heroin) purity. Perhaps with some immunity for possession only, work with the addiction community to track down the very dangerous fentanyl being manufactured and distributed by the cartels.”

**“**Physicians will not respond to the new Opioid Refugee Crisis without new financial incentives. We suggest a temporary CMS allowance for maximum billing codes to create a new “Certificate of Medical Pain Disease”. This would be an hour long intensive history and physical to establish and certify the need for long term medical pain medication and why. Once done this certificate can be presented to other doctors, pharmacies (where refusal to fill valid prescriptions has already lead to suicides), insurance companies, benefit managers, hospital ER’s, hospital surgical services, Medicaid, and Medicare, that a valid need exists and to honor physician prescribed pain medication at any dosage level, as established in the comprehensive evaluation for the “Certificate”.

“Begin public health education for families and for junior and high school students to stop addictions where 90% of them start, due to the opiate naive population being subjected to their first and possibly addiction triggering dose. Although rare, 4/1000, each person snatched from the jaws of addiction can lead a normal life with this genetic disease.”

The Opioid Commission was created without any representation of Pain Management Specialists or chronic pain patients.  How can decisions to limit or stop availability of effective medications for our treatments be made without our representation?

Having the facts is crucial in solving the opioid crisis.  Yet legislators and a lot of the other governing bodies have been making decisions based on incomplete and inaccurate information spread by a lobbying group and the CDC Guidelines.  There are ways to help those who are addicted without punishing those who rely upon opioids for reducing their physical pain caused by diseases and permanent injuries.

Please start listening to doctors and patients that really know the truth about opioids.

Pam Hawthorne

Roseville, CA

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I've been suffering for years from by something called ankylosing spondylitis (AS) It is a very painful autoimmune disease which causes inflammation in many joints and can include organs such as eyes, heart, or lungs. Doctors have tried many medications, most of which have failed to work. Leading up to this diagnosis, I was treated very poorly by many physicians. Comments went from "you're just depressed" to "go home and exercise."  I know autoimmune diseases are difficult to diagnose, but it does not give them the right to say things like that to me.

I've been through many medical procedures and even surgeries since then, some related and some not. To treat some of my pain, I was at times prescribed small amounts of oxycodone. I always took it as directed and only did so when absolutely necessary. I did not want to become addicted and did not.

When my back pain increased dramatically from the AS, I sought the help of a back/spine specialist. He sort of listened to me then said I just need physical therapy. At my own suggestion, he reluctantly prescribed an MRI. I then asked for short term pain meds to help me get through. He said "oh this is not a case for Percocet" (that's the only thing that didn't make me nauseous). He exited the exam room so quick after that and I couldn't even finish my questions.

A few months later I saw my primary care physician. Due to some problems sleeping and pms symptoms getting worse (I was going through beginning of menopause), I asked for a continued script for Xanax. My gynecologist originally prescribed it.  My pcp told me she had to go through a special database with all my prescription history first. And if not, she could lose her license. She proceeded to read all of my meds from a computer that I've been on in the past year or two. I sat there feeling like the scum of the earth as if I was in fact a drug addict. When in reality, I had just been through a ton of health issues. After reading them, she rudely said "no wonder they cut you off!"  I could not believe what I was hearing. I just mumbled something like "yeah, I've been through a lot."

Like most chronic pain patients, I do not want to have to take any meds (especially pain meds) in the first place. However, knowing they are available for times that get particularly bad was very comforting.  For many of us, they take the edge off the pain so that we can participate in life. By taking them away, our hope is going away as well. That is wrong on so many levels. To make someone feel hopeless is criminal and ruthless. Please stop taking hope away from pain patients. They deserve to live too.

Sinc.,

Someone who matters

Hello, my name is Kate and I’m 28 years old. This is my chronic pain story.

I am a twin, born 2 months prematurely. My sister was in trouble and ended up passing away at the age of 13 months old. I had my own serious complications. I was born with what they called “a massive AVSD”. But in simple terms, I had no walls or chambers in my heart and the valves were just “flapping in the breeze” as my mom likes to say. In addition to that, both of my lungs were partially collapsed for the first 2 years of my life. I underwent multiple major surgeries, the biggest lasting over 23 hours. I am now 100% pacemaker dependent and have 4 active arrhythmias as well as a few other cardiac complications.

What does this have to do with chronic pain? Well I’ll tell you. Children born with CHDs or Congenital Heart Defects/Diseases historically didn’t survive into adulthood. In fact the specialty of doctors called “Adult Congenital” has only been around for a few years. Science is now finding that people born with these CHDs who do survive into adulthood are usually developing more problems later in life; which really does make a lot of sense. Think about it, if our hearts didn’t finish forming in the womb, what else didn’t finish? I, for example, had failure to thrive, I couldn’t gain weight and I didn’t get enough oxygen for over 2 years. Two years of critical development time, I spent very, very ill.

Fast forward a bit, I had a somewhat normal childhood. Sure I had more doctor appointments and surgeries than the children around me, but I didn’t know I was different at that time. That changed in high school. As I grew, my heart changed, arrhythmias became more apparent and I had to miss out on a lot of activities. Two years in a row I ended up in the hospital during band camp. My senior year I only got to perform with the colorguard once, because I would turn blue on the field and my coach didn’t want to risk me passing out. Also around that time I got a job as a cashier at a local car wash. I quickly realized I was unable to stand for long periods of time. I would suffer severe back pain and my legs would swell. I ignored it. Time went on.

I entered a nursing program after high school. This is when I realized the extent of my disability. I was unable to handle the workload. Physically, I didn’t have it in me. I couldn’t carry the books without pain and shortness of breath. I couldn’t wake up every morning and get to school. I was exhausted and running myself into the ground. I ended up in the hospital. I missed an exam. I was promised an “incomplete” for the semester so I could make up my work. I was given a D and forgotten about. The world doesn’t care if you’re disabled. I learned that then. I dropped out of school, defeated. But my parents were there. I collected myself and tried again. Unfortunately, again, I ended up in pain and ill. I gave up for a little while, but then I went to school again. I got certified in CPR, EKG, Medical Assisting and Phlebotomy (blood drawing). I quickly got a job at a local hospital. I was thrilled. I loved, my job. But the pain, the pain was severe. I would come home at night crying. My back was screaming, my knees on fire, my hips ached, my feet throbbed and my neck and shoulders begged me to stop. I fought through it. I worked 5 or 6 days a week, 8 hours a day. I worked that way for a year. Then gave in and had to go on temporary disability. I worked to identify the pain I felt. I failed. I went back to work part time. I worked that way for another year before ending up in the ER. At that point, I was told not to return to work. I was crushed, absolutely heartbroken. But my pain continued, even off the job. I filed for disability. I was denied twice. But I was finally approved. I have been on it for about 5 years now.

I finally found answers. I have Scoliosis, a dislocated rib, degenerative disc disease, severely pinched nerves, Fibromyalgia, Endometriosis, Polycystic Ovarian Syndrome and possible Lupus. I never have a pain free day. I have a very strict main management regime that I follow. A regime that I just recently seem to have perfected. I take an anti inflammatory once per day, a muscle relaxer up to 3 times daily. I’m on gabapentin as well. I also use Lidocaine ointment, even though the patches work better, insurance won’t cover them. I use vitamin supplements too, I take magnesium, turmeric and CBD oils to help with muscle pain and inflammation. I go to physical therapy, acupuncture, a chiropractor, and massage therapist multiple times per week. I go to the gym to walk on the treadmill 5 days per week. I wear wrist braces and a back brace, my shoes have custom orthotics, I occasionally need a neck brace and a cane. I do everything possible to keep my pain under control. Sometimes I still need more. I have more, currently. I also have a prescription for Percocet 10mg. I only take that when I can no longer tolerate the pain. I have had this ‘script for years. I’ve never needed to increase my dosage. I’ve never taken it unless absolutely necessary. Yet I am still made to feel badly for needing it. Why? Why does needing a stronger medication once a month or so make me a bad person? I recently moved to another state. I am terrified because the new doctors want me off the medication that literally keeps me able to live my life. I am not alone in these fears either. Many of my friends have lost access to their medication, their lifelines, due to this “opioid crisis”. These ridiculous new “guidelines” are only hurting the real patients. It won’t do anything for the criminals and addicts. The suicide rate in the chronic pain community is rising. We do not deserve to suffer. We deserve peace, support and understanding. You are in a position to help us. What will you do

 

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| |  | | --- | | Dana Brutsman <twinkle72@msn.com> | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |
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Will start off by introducing myself.. My name is Dana Brutsman. I am 45 years old and live in Kansas City Missouri. I have been married almost 22 years and we have 2 boys that are 20 and 17. Most of my life has been pretty normal. Got married had 2 children. I didn’t really have any issues health wise. Was on the go all the time. Being a stay at home with 2 boys will do that. Cooked cleaned helped at the school. Even went running a mile or so a few times week with my husband. I was able to keep up and do it all. One day I was at my doctor’s office and mentioned how my hands and feet hurt sometimes and they will swell. That was the start of my journey with many auto immune diseases. At first the symptoms I had could be dealt with on my own. I still kept doing what I did. As time went on new and more symptoms began happening. I broke out in hives when I was out in the sun. All those things I use to do the everyday now made me hurt. Started seeing more doctors and all the tests started. They would put me on a new medication to try but one of my symptoms I had developed was also with my stomach. Most medications would make me vomit, very nauseous, or break out in hives. So far they have diagnosed me with Sjogrens, Arthritis, Raynauds, Peripheral Neuropathy, Hashimoto’s Thyriod Disease, Fibromyalgia. Every time my blood work comes back elevated for Lupus and Rheumatiod Arthritis and even though I have some symptoms I don’t have enough for an official diagnosis. I still go to many doctors and do tests. I tried physical therapy even tried to just walk that mile I use to run. Nothing was helping. It came to where making cookies or cleaning just the dishes would cause pain. Shooting pain. My hands or feet would lock up. It hurt to touch anything. I get neck pain which causes the base of skull to hurt and that pain there is no pain chart for. Even to lay down and have the pillow touch my neck is too much on those days. Gripping my phone or steering wheel causes pain. Simple things that you do everyday now cause me pain. The pain has taken over my body. It wasn’t just my hands and feet and wasn’t just the burning from the neuropathy. It is pain to where its hard to just get out of bed. One day I could be walking up the stairs and my knees or hips would hurt so bad it makes it hard to walk. My life had changed so much and I wasn’t living it because I was hurting. So a doctor one day years ago started me on pain medication. To be honest I had mixed feelings about it. I knew the risks and warnings of taking it but I also wanted some relief from pain. I have been on Hydrocodone since. I know without them I would miss out on so much. You know its not even doing the everyday things that matter. Its those moments in life I cant get back if I miss. In July our youngest son became an Eagle Scout. A very proud day for us. Without my pain meds I would not been able to attend his Eagle ceremony. He is a senior this year and know for me to be able to attend his graduation I will need my pain pills. Without them I would miss out in these special moments in my children’s lives. As a mom you feel guilty when you miss an event in your child’s life because you hurt too much to get out of bed. Even with the pain meds I have bad days but always look forward to the ones that are not as bad. There is no cure for all I have going on. All the doctors can do is treat my symptoms and try to give me some kind of quality of life. One way is with pain pills. I go to my doctors appointments like I am supposed to. I take my medication like I am supposed to. I plan ahead for busy days or events just so I can make it through them with as little pain as possible. Thank you for taking the time to hear my story.

Dana Brutsman

Hi.

My name is Karen Pool. I'm 36 yrs,old. For the last 6 yrs I've been living with chronic pain every day. Since my illness began 6 yrs ago, I have been told that there's nothing really wrong with me (despite xrays & MRI'S showing severe arthritis, degenerative disc disease, bone spurs, bulging discs & more), that fibromyalgia is just something Drs diagnose you with when you're in pain, but Drs can't find anything wrong.

As a result of the opioid epidemic, Drs are being scrutinized, fined & sometimes even losing their licenses for prescribing pain meds. Leaving Drs afraid to prescribe pain meds to anyone, regardless of how much pain they are in.

I've been out of pain management for a year & half now. Life with no pain meds is a nightmare. Every minute of every day I'm in agonizing pain to the point of feeling like I'm going to go crazy from it. The pain never stops. It's there when you wake up in the morning & it's there when you go to sleep at night. My kids have seen me cry numerous times from being in constant pain.

Here in Tennessee where I live, the opioid problem is really bad. So many Drs have stopped seeing patients for pain medications that it's next to impossible in Tennessee to get in to see a pain management Dr. I've gone to numerous Drs & asked them to help me get in to see a pain management Dr. Only to be told that they can't find anyone within 100 miles of where I live.

I know this isn't just a problem in Tennessee, it's everywhere. I know a system needs to be in place to make sure that pain meds don't end up on the street for sale. I also know that the current system is accomplishing nothing except making it next to impossible for people like me to get the pain meds they need.

Please expose this for the national crisis it is. Please help get the word out nationwide, that a system that actually works needs to be put in place. Not one that keeps people with chronic pain from being able to live in their own bodies. People are suffering needlessly. Many to the point that they feel committing suicide is the only way to stop the pain.

So many in this country are giving up. Their suffering in silence. Turning to alcohol, street drugs, taking their own lives in a desperate attempt to find relief. Leaving behind so much heartbreak for the loved ones left behind, who know that it didn't have to be this way.

Thank you for taking the time to read this.

Karen Pool

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Hello my name is Christian Manouse I am 21 years of age and have had acute on chronic pancreatitis for 6 years. I suffer daily excruciating pain and malnutrition due to my disease. I live in a small town in Connecticut, the closest city to me has two hospitals. One of those is called Waterbury Hospital. I showed up to Waterbury Hospital in Waterbury Connecticut rolling around in severe pain from what I later found to be another attack of acute pancreatitis. I told the doctor my story, he saw my agony, I explained that I have chronic pancreatitis and I’ve had it since I was very young, he could contact my specialist anybody he wants I just needed help. What did he do? He put me down as opiod dependent (even though I had NO OPIODS in my blood test that evening) and had mental health speak to me... needless to say I was stuck with acute pancreatitis nobody was helping.... I was blatantly neglected at Waterbury Hospital in Waterbury Connecticut. I am sure now my pancreatic function has, once again, been compromised due to receiving improper medical care. Thank god for Hartford Hospital where they immediately acknowledged and treated my pain, diagnosed acute interstitial pancreatitis, and showed support. This has to end.... innocent Americans... sick Americans... are being judged, harmed, neglected, and left to suffer daily. In an age of modern medicine where better treatments exist than ever before we should NOT be denied what care we KNOW we need...I am young and want to have a family some day and work a steady job, be a productive member of this society not a twenty one year old bed ridden with severe pancreatic pain. I have so much to offer to this country, to this world. Negligence and judgement of Americans with chronic pain is inhumane and NEEDS to stop. This is a despicable act against the sickest of Americans and nobody cares because everyone holds these WRONG judgements that the chronically ill are LAZY, ADDICTED, or UNINTELLIGENT. This is far from true, we want to be just like everyone else but because we have medical conditions we make the best of every day despite limitations and agony.  
Please help us!  
Help us please.  
Thank you.  
  
  
Christian Manouse

To whom it may concern,

My name is Karen Knudsen and, while I have not been in the “mainstream” employment cycle recently, I have not remained idle.

Upon completion of my college career and following a stint as a lifeguard and Guest Relations Manager at Walt Disney World, I was employed as a Medical Assistant for some of the most caring and giving medical professionals in Orlando. I loved being able to share what I had learned to help make others’ lives better. I had this privilege for many years. Eventually, I met my husband and we were married.

A year later, after learning I was pregnant with my son Jonathan, my husband, James, and I made the decision to focus on the raising of our child to the best of our ability. While some may consider this a sacrifice, I felt it was my duty to make certain this boy had all the tools he would need to make his way

My husband and I always looked for ways to enrich the life of our young son but also our own in the process. We have provided Jonathan myriad experiences to learn about the world around him through travel and volunteerism. We regularly work at several agencies to feed the homeless, work with Habitat for Humanity building homes and working with mentoring children in educational environments.

As my son grew older, his demands on my time were reduced. This gave me the opportunity to be more involved with the local community. For the past few years, I have spent every third Monday cooking meals for the residents of Coalition for the Homeless in downtown Orlando. Several times a year, usually in Easter, Thanksgiving and Christmas, our friends and family will take over the kitchens at a local shelter, residential facility or Meals on Wheels in order to give the regular staff the day off. These have been some of the more rewarding efforts in my life.

I also became a certified spinning instructor and began teaching spinning at a local community center. This provided me with the chance to stay in shape, pass on some important fitness information and have fun at the same time.

So when some say I was just a homemaker, I reply that I am an educator, trainer, physician, counselor, travel consultant, mentor, financial planner, scheduling coordinator, media analyst, nutritionist, accountant, diplomat and chauffer. All this while enjoying my life and the lives of family.

With our son is well on his way, my husband and I are looking forward to the next adventure in our lives. I feel I have a rare skill set that can best be utilized sharing the things I have learned in helping your clients.

Thank you for your consideration in this matter.

Sincerely,

Karen Knudsen

Before I begin I felt it was important to include my cover letter from my resume in 2014 prior to being diagnosed with CP

Let me start by saying that I am not alcoholic and I maybe had a glass of wine once a week!

Two years ago I was having the most awful pain on my left side that landed me in the ER. I was rushed up to a room because my lipase were so high they were unable to count the levels! I was than given pain medicine in my IV which I slept for 2 days. I woke up in the middle of the night with the worst stabbing pain I could hardly breath. I called for a nurse and she stated “you people have to just get used to it !”

My husband than found out I was placed in a rehab unit for alcohol and drug abuse.

Thankfully I have a friend who is a doctor and he got my room changed. I wound up staying in the hospital for 2 weeks.

I am fortunate that I did not another attack for a whole year. I was on a trip to Israel when my second attack hit. I unfortunately had to end my dream vacation short and fly home one week early. When I finally (10 hour flight) got home my family rushed me to the ER I was told that if I could make it thru a long flight I must not be that bad! They sent me home with no pain meds and told me to just be on fluids!

I spent two weeks in bed crying not eating and very depressed.

I thought I finally am “cured” of this awful disease until 2 weeks ago. This time the attack was worse . My husband took me to the ER they refused to give me any strong meds stating they don’t have them in the ER. I was finally admitted to a room and was given the proper pain meds. I was unable to eat for a week and was given they chose of a feeding tube in my nose or one in my stomach. I opted for the feeding tube in my nose. I returned to my room and stated to the nurse that every time I breathed in my throat hurt and it was very hard to catch my breath. She didn’t check me and said its not time for your pain meds just try to relax. The next morning they tried to start my feeding tube with saline when they injected the solution in me I chocked and almost coded,my husband looked in my mouth and discovered the feeding tube was coiled around the back of my tongue and esophagus. Since I refused the other feeding tube I was discharged with a one week supply of pain meds! I than went to several ER’s only to be sent home due to the fact that they are unable to help me.

I recently had a doctors appointment at University of Florida with the head of the pancreatic division. I was told that my pancreatic is due to a genetic mutation. I was given a script for tramadol 50mg and I was only given a one week supply!

Let me make this perfectly clear I am not a drug ,seeking addict! This disease is very painful and these meds are only taken when needed in times of flare ups.

I am a 55 year old very active women that enjoys playing tennis, yoga, spinning, and my job teaching babies to swim.

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To whom it concerns. I became disabled in 1992 from a drunk driver hitting my veh. at 125 mph. Impact. It changed my life. My life left my body & I swear God put me back ib my body! Went thru 3 years of lil surgeries ect. Ended up having more precedures & surgeries on back,spine etc. Neck & spine still feel all messed up& hurts all the time

 Then my joints hurt thruout my body. I have too many problems to list here. I just know that I got cutoff my fentynl unfairly. I did not abuse the med. It is the only med that worked for my pain.

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To whom ever this may consern:

In June of 2009, I was a wife to Michael for 29yrs, a mother to Jeremy then 21 and living with my 2 men and Brooke who is married to Jeremy then for 1yr., was enjoying a wonderful career as an Executive Assistant for a world-wide evangelistic ministry called [www.livingwaters.com](http://www.livingwaters.com/)[www.wayofthemaster.com](http://www.wayofthemaster.com/)

involved in a motorcycle ministry to outlaw clubs along with my family and community members, leading a weekly Women's Bible Study for over 10years, and attending church as our busy schedules permitted.  Life had its challenges, but I loved living.   I had been working on a manuscript entitled, FROM VICTIM TO VICTOR - Leaving the Shame Behind,  writing several devotional gift style books and contributing freelance articles on many occassions; with writing being a great passion of mine.  Have contributed articles to THE INTERMOUNTAIN CHRISTIAN NEWS.

     In mid June, I underwent a same day Gall Bladder Removal surgery and a female procedure in Long Beach Memorial Hospital's Same Day Surgery Center.  Following a long weekend of rest, I returned to work, was back on my motorcycle and it seemed the surgery just caused very minor pain and inconvenience.

     Within days, it appeared to me that my Asthma was becoming exascerbated, but I continued working until fever, chills, weakness and my difficulty breathing worsened.

Long story short, after many visits to my doctor, accute care clinic and emergency rooms and being misdiagnosed; the medications that had been prescribed to me were not working.   My breathing became very bad and a fill-in Accute Care Clinic physician from Las Vegas finally cultured my sputum and diagnosed me with an uncommon pneumonia called ACINO BACTOR BAUMANI which was brought back from the Middle East by our courageous military members who had been infected by it.  Unfortunately for me, I had contracted it during my same day surgery!

     I was immediately hospitalized in Isolation at Long Beach Memorial Hospital where I contracted MRSA, CEPTCIS and INVASIVE ASPERGILLOSIS.  The last disease was nearly a death sentence, with growing fungus within my already damaged lungs causing them to end up appearing like swiss cheese...

     Only about 5% of people receiving this diagnosis recovered.  Many many medications were tried, and my infectious disease specialist, Dr. David Hirota began treating me with VORACONAZOL (V-FEND) even before the results of the ASPERGIIOUS culture came back.  This, I believe saved my life.  However, this journey continued over 4+ months where I nearly died several times, broke a blood vessel in my lung and began counghing up blood and was put on life support in a medically induced coma.

     I had to learn to walk, deal with a tracheotomy and overcome terrible pain which began in my toes and feet.  My nerve endings were dying and as they were firing off, as was one of the many serious side effects of the V-FEND.

     This was just the begining of my wretched road of CHRONIC INTRACTABLE PAIN.  Though I was finally released from a nursing home in October that year and had tried to return to work slowly on a part time basis, my pain began spreading as a result of the invasive infections that had struck my body and immune system and I ended up being symptomatic of Centralized Chronic Pain Syndrome.  I had been on heavey doses of morphine in the hospital which then changed to both opioids and nerve pain medications like Gabapentin.   These serious medications also have major side effects that come along with them.. One of them which began the death of my career, even when I tried so hard to work from home; was the fact that I was very quickly loosing my short term memory and had developed PTSD from the entire life changing crisis.

     My position demanded so much more than I could give and as my legs began to beat like a migrane, my hips burned with fire, my toes and feet throbbed, tingled and burned feeling like cold spikes were being pounded into the tips, my back became constantly weak with muscle pain and my tailbone feeling like it was growing spines pushing out of my flesh.   Even my head felt the peripheral neuropathy which had attacked my toes, feet, legs, fingers and hands.  The back right side of my skull feels like there are red ants crawling around biting my brain!  On January 31, 2012 to my bosses sorrow, he was forced to let me go.

     I had lost all abilities to care for myself, cook, clean, organize my meds, walk more than back and forth to the next door which was our rest room.  I was forced into a wheelchair outside of the house and my depression because of all the many losses began to take its toll, which even deepened my physical pain as I ballooned up over 400lbs being practically bedridden for month after month.  The passion I had to write choked out and died during this season... filled with agony and grief.  I no longer slept at night and was awake during the day following the crisis.   But instead, my sleeping is done in shifts.   Sometimes every hour on the hour I awake and need to apply my Voltaren Gel to my toes, feet, legs, hips, lower back, shoulders,  wrists and hands.  At times, my husband cannot even cope with coming to my doorway because of the strong odor of my pain gel.  Needless to say, I have been forced to sleep separated from him because of my pain, I will move my feet and legs to try and shake the pain away.  I am up and down so frequently that I wake him up...We have slept in the same room under 20 times since 2009!  We will be married 37 years next month.  My lover was forced to turn into my Care Taker.  And though we are near our children again, since June of 2015... they are limited in the assistance they are able to offer.

     In December of 2014, I underwent Gastric Sleeve Surgery, as I knew if my weight continued as it was; I was doomed!  The pain on ones bones and pressure upon ones heart & lungs with being so morbidly obese,  is unexplainable.  The pain never ends and sleep is the only retreat.  Though the opioid medications worked and continue to work enough to take the edge off, to save my life from suicide...they come along with their own set of symptons which I must battle daily.   Such as my bowels becoming impacted daily.   While I utilize several helps, this is so discouraging.   Though I have lost over 150lbs to date...my body hurts all over and I am unable to endure this kind of pain without some kind of relief that helps me to rest.

     This past April, I began Water Walking and Aquatic Excercise.   It has helped me tremendously!  Not with the nerve pain, but some of the muscular pain as well as helping me to endure more standing and walking a longer distance.   But distance remains relative to my abilities.   They are unique to me, according to my pain and breathing.  I am still oxygen dependent as I developed COPD as a result of my crisis.  I have been Disabled by Chronic Intractable Pain and Breathing Difficulties since December of 2009.

     We now live in poverty, owing approximately $50,000.00 which we could have easily paid off if I was still able to work.  I feel like a miserable failure because my health has ruined what little we had.  We depend upon the kindness of local food banks and purchase almost all of our grand daughters clothing, toys, ect...from our local Facebook Classified Groups.  I am embarrassed and following a terrible family crisis last December, we do not even have the means to help our children.

     PAIN HAS CRIPPLED MY BODY, STOLEN MY BEAUTY, NUMBED MY ABILITY TO LOVE AND ACCEPT LOVE, STOLEN HOPE CONSISTENTLY; BUT, FOR MY FAITH IN MESSIAH, I WOULD BE DEAD....

     After relocating to Helena, Montana in June of 2015 to be near our children...our eyes were opened to the atrocity which is the Un-Declared War on Chronic Intractable Pain Patients by the CDC, DEA, LAW ENFORCEMENT AND THE MEDICAL INDUSTRY!  I was force weaned, refused medical care, treated like a crimminal and an addict.  I had spent over 30yrs in Southern California and had no idea about the sufferring of patients like me, as we are made vulnerable and treated worse than we treat our pets here in the United States!  I even filed suit against a doctor who had finally accepted me as a patient, then turned arouns and coldly refused me care...even though my records from CA accompanied me.  The Montana Board of Medical Examiner's is Currupt and totally out of touch with the severity of our plight.  They can care less about the suicides from Chronic Intractable Pain Patients who have been abandoned and refused what is a Basic Human Right: ADEQUATE PAIN MANAGEMENT!

     Patients like Robert Mason, who after over 15yrs of agonizing back pain, had been abandoned by the medical industry except  for one lone "pain warrior and our Advocate": Dr. Mark Ibsen.

     We saw Bob when we attended a Witch Hunt at The MT BOME hearing who suspended our only doctor helping Chronic Intractable Pain Patients in the Helena area.  At that time, we testified about groups of Pain Patients being forced to travel outside of the state to receive adequate care from Dr. Forrest Tennant in West Covina (at 87 has finally retired).

     All Robert Mason needed that day besides pain relief...was his shoes tied...and a chair that was accessible to his broken body.  The MT BOME staff treated him worse than a dog!  Two days later, Bob wrote several notes...Put a gun to his head and stopped his physical pain.  I place the responsibility of Bob's death squarely upon the Montana Medical Association and MT Board of Medical Examiners.

     My best friend has had more than half of her pain medication robbed unjustly by one of Montana's prejudiced physicians.  She will soon be unable to do her job.  If that happens, I have no doubt whatsoever that she will follow Bob Mason and Chronic Intractable Pain Patients committing suicide daily.

   We have been unjustly targeted, simply by the nature of our conditions, we are so often too sick to write, to call, to be interviewed.

     I will include several photos after 3 hours of "prep-time" and my normal days....I do have photos on my Facebook [Judy Massey Notchick] of my 2009 crisis ....Judy's Journey.

     DOES OUR PRESIDENTS DECISION MEAN LIFE OR DEATH TO ME AND OVER 110-MILLION CHRONIC INTRACTABLE PAIN PATIENTS!?

With all sincerity,

Mrs. Judith (Judy) Notchick

#MTPAINEDLIVESMATTER

**My back feels like it’s breaking: A pain patient’s journey**

I am tired. No, exhausted. And I’m starting to lose hope every time I read the news. But I’m one of the “fortunate” ones: After years of pain from two herniated discs and an additional diagnosis of myofascial pain syndrome (a fancy word for daily muscle pain – imagine waking up and feeling like someone’s punched you all along your spine the night before), I was referred to pain management in the state of Virginia at age 33. I am prescribed low dose Vicodin (10 mg of hydrocodone to be used 1-2X a day). I can’t tell you how much this medication helps relax my muscles and soothe the nerve and bone pain that come with disc disease, enabling me to get my work done daily (and keeping me off disability), allowing me to go grocery shopping, letting me go see a band (standing room only) and actually hang out with my friends, etc.

Prior to receiving my prescription for Vicodin, I had tried everything: painful trigger point injections in my muscles, chiropractic care for a decade, multiple bouts of physical therapy, and an epidural steroid injection in my spine (that was fun!) I had also met with my primary care provider and a surgeon about the issue: Both told me I was “too young for surgery” and referred me to pain management.

I can’t say that my experience in pain management has been easy, particularly when it comes to getting my prescription. Let me summarize it this way: There is a certain “hushed tone” and worried expression that pharmacists take when pain patients bring in our prescriptions that we all know too well. My situation only got more complex though when, in April of this year, my husband and I decided to have a baby and I became pregnant. I knew that being pregnant would be especially hard for me in the third trimester as I got bigger and more strain was placed on my back, but I was promised verbally by my pain doctors that they had no issue with prescribing low dose opiates in pregnancy, as they are the safest and most effective medication a pregnant woman with chronic pain can take. These doctors assured me that all I needed to do for them to continue prescribing was to present letter from my OBGYN assuring them that she was OK with the treatment as well.

As soon as I got pregnant, I brought this letter in to their clinic. Well, they dropped me quicker than a hot potato, citing a “new policy” that they had created just that month that forbid them from treating pregnant women with medication. I was appalled! I told them that I *never* would have gotten pregnant and risked getting bigger and bigger with ongoing back pain if they had told me this before! I managed to stutter between tears that I felt like they had abandoned me; that I was “free falling without a parachute.” As I walked out of the office I read the headlines in a major paper laying in the waiting room: “Opioid crisis leads to widespread death toll!” Where was my story though? What of all of those people who opiates had helped? Were we going to be tossed aside, collateral damage in a crisis we did not cause, too much of a hot-button “political risk” for our doctors to touch?

Over the next couple of months I had to beg my OBGYN to prescribe me the dose of Vicodin I was used to in order to keep me stable and functioning at work. This particular doctor, thankfully, used to work in Methadone clinics with heroine users, so she knew that my prescribed, rationed use of the painkiller, along with my stellar track record –passing every urine drug screen, taking tests at the pain clinic to assess my (very low) risk of addiction – meant that I was not a risk. Thank God for this scientific, sensible doctor who felt confident in prescribing, knowing that the stress of chronic pain is far worse on a pregnant woman than low doses of opiates ever could be.

Still, it’s not the responsibility of OBGYNs to be prescribing monthly doses of pain meds to patients like me, and she encouraged me to find another pain management doctor. Her office was even called by my pharmacy after the pharmacy’s computer system flagged me for receiving Vicodin from both her and my past pain clinic doctors in the span of months. (I’m writing this to emphasize that the system works: If I were doctor shopping, the doctors would have been alerted!)

In order to find another pain clinic, I had been encouraged by the previous pain clinic that dropped me to “just call and ask the front desk receptionists if the doctor is willing to prescribe painkillers to a pregnant woman.” Well, I can’t begin to stress how badly I was treated calling and asking that question! To the front desk people, it looked like some random person exhibiting “drug seeking behavior.” I even had one woman scoff at me, laughing, “A pregnant woman?! Are you serious?!” Why yes, yes I am: I am not a vessel. I am still a human being with pain; even more so than before!

Finally, after much worry and many tears, after being treated like a “junkie,” I found a reputable clinic that would take me! Their doctor was a female herself and, as it turned out, also pregnant. She had sympathy. I remember crying in her office, telling her about how I could only stand for 5 minutes without my back feeling like it was breaking; how I had gained weight over the years due to the pain and loss of activity; how I was trying hard not to gain too much in pregnancy; how worried I was and how I missed my life as it had been before the disc pain entered my life a decade prior.

Yes, this doctor agreed to see me. Yet this should not have been so difficult! And fortunately, this doctor is still treating me, but for how long? I am going into my third trimester now. My hips and back feel like they’re being torn apart when I walk (and I still try to walk some each day, I don’t want to “lay down and give up”). But every time I read the news I wonder, will this woman, like so many other doctors, decide that I’m not worth the “political risk” and drop me when I need her the most? If she does, will I be able to type letters like this, advocating on behalf of myself and other people, when my back muscles have hardened into excruciating rocks sitting at the computer desk? Will I be forced onto disability and have to abandon my professional, paid job as a consumer advocate, helping low-income and disadvantaged populations learn how to avoid financial scams, bad mortgages and other predatory practices? I am a contributing member of society, with over a decade of experience working in the nonprofit realm. I am getting my Master’s degree in public administration. Eventually I want to start my own nonprofit to help address critical social issues.

Please understand that pain patients like myself do not use opiates to “get high.” (We would run out way too quickly if we did that, and pain doctors would catch on immediately.) If we were taking illegal drugs, the urine tests would also show that. And please understand that for the vast majority of us, opiates are the last remaining solution to our pain. We have tried everything from acupuncture to new age crystal therapy (boy does that one not work!); from months of physical therapy to yoga to swimming to chiropractic care and more. Some times these more conservative measures help us, but what we and our doctors have determined helps us the most (in many cases) is opiate-based medication. It stops the pain from the inside, it helps us TAKE that yoga class that we would otherwise be in too much pain to take, it keeps us employed, and it saves us from hopelessness and in some cases suicide.

I hope that you are reading this and that you will enact sensible legislation to help those who are addicted, while being careful not to scare doctors and pharmacists away from prescribing opiates even more. Please address pain patients and their (legitimate) doctors when you’re speaking on the issue. Those doctors are literally doing God’s work! They are not the ones that should be intimidated or punished. Please let us know that you care about all of your constituents and that you DO see the benefit in sensible, controlled opiate use.

Lauren H.

Fairfax, VA

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I am a retired officer from nyc...I am 45 yrs old..I have chronic abdominal pain...I have difficulty eating, EXTREME pain that radiates to my lower back. To make this worse doctors after almost a year are just now discovering MALS..A PAINFUL COMPRESSION OF THE MEDIAM ACURATE LIGAMENT CAUSING VOMITING INABILITY TO EAT, EXTREME PAIN..I served my city faithfully for 20 years...When I seek help for the pain I am treated like a drug addict.  Pain is so intense that I have fainted and have had numerous trips to the ER. I can barely be a mother or a wife.  I was supposed to move on happily to a new life.. now I am trying to manage pain.. I should not have to fight with doctors for pain relief... I can't get out of bed most days. I was strong beautiful and athletic...Now just a broken shadow.  My pain pills allow me to at least get out of bed and try to have a life.. Narcotic pasin relief for me is the difference between being in the hospital or being home...  They say a picture is a thousand words.. this was over a year ago...

I was strong, athletic and beautiful.. 18 months later I don't look like me anymore.. This is what pain does to AMERICANS WHO PROTECTED AND SERVED. I am in a bed on my back praying for a miracle. Hoping my pain management team will provide me pain meds until I can have surgery.  THIS IS NOT ANYWAY TO TREAT AMERICANS...FATHERS, MOTHERS, HUSBANDS, WIVES, CHILDREN, BROTHERS AND SISTER,....

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To whom this may concern,

 My name is Christy Noullet. I am a mother, wife, animal advocate and volunteer for my community as I am able. Recently I have learned that the things I am able to do on a volunteer basis will be taken away from me due to a crackdown on the medications that keep me semi functioning.

 Yes, I am a chronic pain patient that takes opioids and other medications to function in my daily life. I am not an addict, or a junkie. I do not deserve to be treated as such. Not only am I being treated as a junkie. I am forced to pay more for urine tests and medications that are already difficult for a one income family to pay for. Now, I am being told that I might have to go to the doctor more often, and pay extra co-pays to get my much needed medications. Many times, I have a hard time making the once a month appointment. How am I to make it more often? Financially, and physically placing a burden on citizens that aren't criminals is evil. When we voted y'all in. No one thought you would become an everyday part of our lives. You are not my doctor, or a doctor at all. You don't have to live with my pain, and you shouldn't be involved with any of it. Not to any degree.

 This war on innocent Americans is a travesty, and a complete overreach of the government.

 How often are you drug tested for your medications? You aren't even drug tested for your job! Yet, you all have to nerve to get involved in my health care.

 I am sorry there is a drug problem. It's not new. Your method of punishing Amercian, chronic pain patients will not help. If you really want to help the drug problem. Focus on education, and rebuilding the importance of stay at home moms, and the family unit. I hope you all have a plan to pay for the thousands of new fully disabled people. If my medications are not available. I will not be able to continue to be an active member of society. I'll go back to being nothing. A shell of a human that looks forward to death. A person that craves for the end of their life because of chronic pain. Stay out of our medicine cabinets, and focus on the real problems. We aren't it.

Sincerely,

Christy Noullet

Columbus Georgia

Ps. My day is now close to over. Not because it's bedtime, but because I spent my precious time, when I am able, to use my arms without severe pain to type this email. Please read the spoon theory. It might help you to understand what a day is like for folks with fibromyalgia, and other chronic pain problems.

<https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>

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Hi. My name is Jodi. I am from Illinois. I have had arthritis since I was a little kid. I remember going sledding, like all my friends were doing, only my dad used to have to carry me back up the hill. My legs were so painful. Now as an adult I still have arthritis in about every joint. Then I developed fibromyalgia. That causes terrible pain throughout my body. The worst happened when I went ahead and had my knee replaced at the age of 38. My pain became worse and worse in that knee, and the orthopedic said oh you will be ok, your young, sometimes it takes younger people longer to heal. I continued physical therapy for 6 months until finally the therapist said your doctor is not responding to either of us. So he sent me to see another orthopedic that specializes in knee replacements. After one week of seeing him, I found out that I had an infection in my new knee and the surrounding bone around it because it had 6 months to spread. Within a couple weeks I was in the hospital having my knee removed and having an antibiotic cement spacer being put in my leg for my knee for a few months. I was also sent home with a picc line and IV antibiotics. I was not allowed to put weight on my leg and had home health come in 3 days a week because I couldn't leave my house. Then they aspirated my cement knee and it came back with no more infection. So back to the hospital I went to get my new knee put in. It was a very long surgery because they had to saw off more bone than they expected. I remember waking up after that surgery screaming. I worked hard the next year trying to get stronger, but the knee was just not being accepted by my body. I also had horrible burning pain inside that leg along with bone pain. So after one year that orthopedic sent me to a higher specialist who thought I had another infection in there, so he did surgery and had planned to do everything all over again. Luckily I didn't have an infection, so he cleaned it up and replaced some plastic parts. Back to physical therapy I went, still in terrible pain. He did finally diagnose that I had CRPS in my leg from all the surgeries. 8 weeks later, something went wrong again. This time I again got sent to a higher up doctor. They found out my kneecap had died and crumbled in there (called avascular necrosis), so he had to do another surgery to remove all the kneecap pieces and shaped one piece into a tiny kneecap so my quads had something to go across. It never helped with the pain still, but he did say I definitely had CRPS from the multiple surgeries. I went back to physical therapy again and my regular doctor took over because the specialist was to busy to approve additional physical therapy. After about 6 months I fell because my replacement would give out all the time. I landed right just perfectly to screw up my good knee. I tore the patellar tendon and broke a bone. Apparently it should have been hard casted because it may have healed on its own that way. The orthopedic said he won't do any surgery in that knee because of the other legs issues. So still today I sit with my leg in an immobilizer and have to use a walker to get to even the bathroom. I have a prescription for a low dose opioid. It helps it so I can get out of bed, cook dinner for my family, pick up some around the house. My daughter's and husband have to clean, get groceries, do too many things that I should be able to do. I have severe pain in my leg. It feels like someone is frying bacon inside of me. I can't hardly wear pants because it hurts to touch my skin. I have tried many different medications to help the nerve pain. I have suddenly become allergic to a multitude of things this past couple years. Lyrica actually caused neurological problems so bad, that it's been a year and the issues haven't gone away. I am currently going to get lumbar sympathetic blocks that are unsuccessful, in fact they have made my CRPS spread all up my leg into my hip. I am trying to not have to take an opioid. The thing is, that so far I have had incredibly bad luck. Without the opioid that I take, I could not even get out of bed. I try to take as few as possible. Some days are worse than others of course. I still have fibromyalgia and arthritis to live with. There are times I ask myself why am I even still here? Pain is unbearable most of the time. I cannot do anything. I can't walk but a few feet with my walker. I haven't been to a grocery store in over a year. My husband has definitely lost his wife, at least the one he married. He has to take care of me and I'm not even that old. What is going to happen with me being immobile. My heart is eventually going to go because people need exercise. I tell myself I wish I had never had that knee replacement everyday. I have way more pain now than before. Taking away opioids from people who legitimately need them is barbaric. I do acknowledge that our country needs to do something about heroin or younger people who are looking to get high for some reason. We need to work on drug cartels and people who sell drugs. My doctor has done about everything he can do. Some people are going to need opioids to live. I have heard of so many people who are committing suicide because they are getting their medication taken away. Some doctors aren't even tapering their patients which could actually cause a heart attack. Please don't take away our medications. I will gladly continue taking drug tests monthly to prove I am not abusing anything. Thank you for hearing my story.

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My name is Summer Stephen's. I am a mother to 3 little girls ages 11, 8, and 6. I started having problems with my neck 3 years ago. It took me going to 5 different doctors before finding out what was wrong, that took almost a year before they discovered I had a ruptured disk in my neck, between my C5 and C6. I had a cervical anterior diskectomy and fusion surgery 2 and a half years ago. I was told before surgery that I would be able to go back to work 2 weeks post op. It took 12 weeks before I forced them to release me to go back to work so I wouldn't loose my promotion. That was in September of 2014, I ended up quitting my job in November. I had nerve damage because of the surgery and my hands go numb, the surgery was also not successful because I am still in pain today from it, so I have what you call fails back surgery syndrome. I was diagnosed with degenerative disk disease, spinal stenosis and anklyosing spondylitis.  Basically my spine is collapsing on top of itself. I depend on my pain medication for everything that I have to do. I have to get my kids ready for school everyday, I have to clean the house, I have to do the laundry, I have to get groceries, I have to cook dinner, I have to give them baths. If I didn't have my pain meds I would not be able to get out of bed! My quality of life is very minimal as it is. I have developed TMJ, where my disk slips out of place and makes it where I can't close my mouth so I can't eat anything but soft foods and  the sides of my face hurt so bad that I can hardly talk. My husband works out of town and is not here to help me do anything so my children depend on me to fulfill their needs. I don't know what would happen to them if I was unable to move and was bed ridden and bound to a wheelchair. I don't think it's fair that because people abuse pain meds that everyone who actually needs them gets punished for it. That's like grounding all your kids because one of them did something wrong. Drug addicts are going to do whatever they can to get their hands on drugs. If you ban them it's not going to stop them from obtaining them illegally. That's why there is a heroin epidemic. There are millions of us who suffer from chronic pain, there are probably more of us than the people abusing them. So, please take what I've said and so many others like me, into your consideration before making this decision that affects so many of us.  
  
Thank you,  
Summer Stephens

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To Whom it May Concern:

My name is Alyssa Forss. I’m a resident of Calumet Michigan. Today I’d like to share with your my struggles in managing my chronic illness & chronic pain and how the Opioid Crisis has affected my health care and quality of life.

I have a severe form endometriosis that has lead to chronic pelvic pain. I was diagnosed in May of 2006 at the age of 17. I had laparoscopic surgery to get my diagnosis, as endometriosis doesn’t show on any imaging technology, and they burned off the endometrial lesions on my pelvic wall. We knew they’d come back so I started on a series of high dose birth controls to hopefully slow the disease. For a while that worked. But in the spring of 2013 my symptoms came back worse than ever. I could hardly walk, stand or sit because of the constant pain. I lived most of my life curled up in the fetal position. We tried several different birth controls to see if it would help, none did. March of 2014 I had my second laparoscopic surgery where they found endometrial lesions all over my large intestine, including a very large one on my rectum. This had been my main source of pain but when I woke up in recovery I was told they were unable to remove it as burning that area would damage my rectum irrevocably. That’s when I first heard the words “chronic pain patient”.   
  
It didn’t sink in at first that my life would be entirely changed. That I would struggle for years to be functional enough to work. I was blissfully ignorant as is everyone who’s never had a disability. In the 3 years since my diagnosis I have worked hard to improve my health as much as possible. In April of this year I tried the last treatment option available to me to treat my endometriosis, leuprorelin (Lupron). This drug stops the body from producing all estrogen by affecting the pituitary gland. This is an extreme option only given to patients when nothing else works. It induces a severe form of menopause as the therapeutic level of this medication is to get you to 0 estrogen. I suffered from constant joint pain, hot flashes, erratic emotions, and insomnia. I lasted 4 months on the treatment before I had to stop. It was more disabling than my pain was. My physicians agreed that my response to the treatment was too severe to justify continuing, but that left me with no further treatment options to fight the disease. All we can do now is treat the symptoms; the foremost being my chronic pain.

I had the misfortune of becoming a chronic pain patient in an area where the closest pain management clinics are 2+ hours away, and they won’t treat my type of pain. The nearest pain clinic that will take my insurance (expanded Medicaid), and treat my type of pain, is lower Michigan’s U of M. A 7 hour drive away. Sitting for long periods of time is unbearable for me so I need a driver. My primary care physician is heartbroken that she can’t treat me herself due to fear of the CDC guidelines. I’ve been waiting for 3 weeks to get a call from U of M just to set up an appointment. They are booking out 3+ months in advance. And in the meantime? I suffer and wait. I’m unable to work, can barely perform basic household tasks, and all I desperately want to do is be a productive member of society. But without proper pain management, I’ll have to file for disability.

The regulation of opioids is absolutely necessary, but pain patients and pain management physicians need to be a part of the conversation. 100 million Americans suffer from chronic pain, yet there are less than 4,000 physicians specializing in pain management. We need to come up with a better plan than leaving millions of Americans in healthcare limbo to suffer.

Thank you for taking the time to read my story. I hope it helps give you a different perspective on the issue of opioid regulation.

Sincerely,  
Alyssa Forss

Calumet, MI

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To whom it may concern;

My name is Jonathan Schrier and I am writing you in regards to the opioid issue that is currently prevalent in the media and political arena. I am a United States Marine veteran (honorable discharge) who suffers chronic back, neck, knee and ankle pain due to my service.

To date I have managed my pain without painkillers but due to the degenerative nature of my injuries it will eventually take a much greater toll on my quality of life than it does currently and I will require pain medications to continue being a contributing member of society.

I fear when I reach the point in my life that this is required the option will no longer exist. I urge you to carefully consider the millions of people who have legitimate need for these medications not just the thousands who ruined their lives with poor choices and lack of self control.

Sincerely,

Jonathan P. Schrier

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| |  | | --- | | Anne Mathews-Schrier <aemathews@hotmail.com> | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |

To whom it may concern;

 My Name is Anne Schrier and I am writing you in regards to the current political hot topic, opioids. I have a condition called Interstitial Cystitis also called Painful Bladder Syndrome. I have lived with this disease since 2013. It takes my quality of life and when I have a flare it can immobilize me entirely. I, like many other chronic pain sufferers sometimes require the opioids that have been so vehemently demonized by the media just to be able to accomplish my daily tasks of taking care of my family.

 When I first became sick it took the doctors months of me being in excruciating pain before they finally were able to positively identify my disease and begin treating it with any success. In those months the only thing that kept my will to live going was the pain relief I got from the opioids that I was prescribed in an ER visit. I have never abused these medications, nor would I. They are a last line of defense against the debilitating pain I regularly suffer.

 While I understand the damages that are being done to individuals who choose to abuse these drugs, I urge you to carefully consider the millions of people across the country who use these life saving drugs (and pain management is life saving) before making rash decisions about regulations that could affect those who truly need them.

Sincerely,

Anne E. Schrier

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I had a doctor insist I was an addict when I wanted pain relief for what turned out to be a subluxated shoulder not that she helped me figure it out. At the time I had a diagnosis of unspecified connective tissue disorder, arthritis in my spine, scoliosis, hip dysplasia and several others for almost 6 years about 3-4 times a year my shoulder acted up no one pieced it together but the worst time I was around 26 I was on tramadol for pain related to the arthritis and it wasn't helping. I asked for something else and she refused instead sending me to pain management,  psychology and reducing my access to tramadol. That went on for 6 months. I was stuck coming up with ideas to try help I wasn't picky I just wanted relief. In the past I wad given vicoden and I would do pt at home to work with the joint to ease the pain. Without the vicoden I had trouble moving the shoulder, was losing range of motion and struggling to function. I stumbled across an ortho that figured out I had subluxated my shoulder and that it's common with Ehlers-danlos I got into massage therapy and finally after 6 months I got relief but I can't help  but be frustrated that a doctor was so certain that I'm depressed, that I'm wanting the pills that she didn't see the injury.

I deal with chronic pain and acute pain because of EDS and I can't always explain how I got injured just that I did and I need extra relief for it because with my EDS I have a strong tolerance to meds. I'm still scared that something like that is going to happen again.

I rarely go asking for just pills, or have my mind set on pills even back then I wanted relief whatever works is good. But if you only see a drug seeker then you don't go looking for another problem and without knowing why someone is in pain you can't treat it.  I had a plan that worked repeatedly until a doctor decided I'm drug seeking.

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My name is Sabrina Dale. I had my first back surgery in 2001, followed by my 2nd in 2004, and my last back surgery with fusion in 2005. I have had continuous back pain  ever since.  I have had several MRI, CT scans,  Mylograms. In between all my surgeries, I had several nerve blocks, and nothing has helped. I worked 2 jobs up until about 3 years ago, when my left leg and  back hurt so badly, I had to stop. I went to the  doctor  (Neurologist) and asked hhim what was wrong, he told me I had Arachnoiditis. I had never heard that word before. He said, it would progress and there was NO cure.

I now walk with a cane, I have severe numbness in my left leg as well as pain that radiates from my spine all the way to my toes . At times, I am in a wheelchair.  My pain management,  who I have been with for over 2 years has put me on several different medications. Oxycodone, Gabapentin,  Lyrica, Cymbalta, Morphine, Requip. And just recently I  was put on the Fentanyl patch because nothing else is helping my pain! I cry all the time because I  hurt so bad. Finally, the Fentanyl patch  is helping me to not hurt as if I'm on fire.

Please do not take the pain medications away from those of us who  legitimately  need them to help manage our pain. We do not use these drugs  to get high, we use these medications to actually be able to walk across the floor and not scream in pain. Getting rid of  these medications  will only hurt us more, the druggies  will just use something else to get high from.

Thanks so much for your  time and consideration  in this matter!

Sabrina Dale

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I am writing because my daughter suffers from chronic pain from her illness. Without pain meds she can not work, eat, even get out of bed. She is a productive member of society with her meds. She is being denied meds because of other peoples abuse. This makes many pain patients who have not abused their MEDICINE, not drugs, suffer. These issues must be separated. As a mother, I have seen my daughter suffer so much. Please take up this cause and protect pain patients. A Mother's Plea.

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I have been sick with Pancreatitis since 1985.  It became Chronic a few years later.  When I first got sick I had 3 young children to take care of.  The pain was relentless and the doctors started me on different pain medications. The medication made the pain bearable so that I could function and take care of my children.  It also allowed me to be able to eat without having agonizing pain.  Chronic Pancreatitis causes inflammation of the pancreas every time a person eats.  It's very painful and opiates make the pain bearable.  In December 2016 I had a flare that lasted 6 months!  I was admitted to Mather Hospital in Port Jefferson, New York.  My doctor wrote orders for pain medication which was half the dose that I normally take and treated me like a drug seeker.  I know he didn't believe my pain was real because he released me 2 days later.  This was the first time a doctor didn't take my complaint of severe pain seriously.  This diagnosis of Chronic Pancreatitis is worse than being diagnosed with Pancreatic cancer because those with that horrible disease usually pass away within a year.  Their suffering ends.  Those of us with Chronic Pancreatitis never get the relief we need.  The pain is never ending and the pain medication helps us live as normal as possible.  
  
We are not to blame for the epidemic in this country!  Restricting our access to these medications isn't going to curtail the opiate crisis because the majority of those abusing opiates aren't getting them legally.  It will just punish the ones who really need and depend on them.  Thank you for reading my letter.

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My name is Dawn Adams.  I have degenerative disc disease and now chronic pancreatitis.  I am a single mother of two that has worked very hard all my life until now.  I demanded independance, which I received through working hard.  I worked so hard I further damaged my back.  Recently,  I was in the hospital all summer,  dealing with getting diagnosed with chronic pancreatitis.  I lost 80 lbs from April to August.  I was unable to take care of my kids, so I had to sign off temporary custody to my mother.  I now go to pain management which has been a life saver.  I am prescribed oxycodone.  With being on the oxycodone, I have been able to slowly build up my strength and can now do light housework.  Thanksgiving break, I will be bringing my kids home.  I live in Florida and my kids are with my mom in Virginia.  So we are far away and I miss them so much.  They need me as a capable mother to take care of them.  I would not be able to do that without my pain medicine.  I try to only take it when I need it, but if I don't, I cannot even get out of bed.  My fiance even hand made our couch to be made with two twin mattresses so that I can comfortably lay down and still be with the family.  I still don't go anywhere but the grocery store or doctor appointments.  I cannot handle more than that.  Even that deserves a nap.  Every time I eat, I feel a thousand knives in my rib cage. I cannot eat without my pain meds at all. I still feel the pain, but I can bare it with my medication. Only with my medication can I even fathom the idea of raising my kids. Their father is not involved and honestly,  my mother is disabled too so she's barely making it helping me for now.  So my kids would probably end up in the system if I we're unable to take care of them.  This idea more than breaks my heart.  These diseases alone are scary enough to deal with, but then you add on all the side effects of not only physically, but life wise and it's unbearably scary.  It's going to be a forever road of dealing with both, my back and my pancreas.  I have to have my medication to make the most out of my life that I can while I'm here.  Not only do I NEED my medication,  my children NEED me to have my medication.  When they see me without medication;  they are scared.  I need medication just to cook dinner for them.  Or to do their laundry.  I know you cannot truly understand unless you live with someone with chronic pain,  but we fight everyday just to fake smile.  We fight just to make it through the day,  not just for us, but for our families.  Tons of us live off of antidepressants from chronic pain.  It causes that much damage to one's life.  Not only are we in need of pain medication, but our families depend on us being on pain medication for being there for them too.  If it weren't for pain medication, I honestly can say I would have ended my life already.  The constant pain is that unbearable.  If you decide to take away my right to pain medication, I want you to find my children and explain to them why their mother isn't around anymore.  I want you to do it personally, so you can see what you have done.  I need my medication.  It is my right.  Do not take it away from me, PLEASE.

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I was diagnosed in 1990 with fibrositis (which is what they called it back then).  I had never heard of it but the Doctor said there was no treatment and I just had to live with it.  The way mine has gone is it started out slowly, I was 46 when diagnosed and I'm 71 now.  Over the years it has progressed to my entire body and very painful.  In the last 6 years or so, it has become debilitating as it has affected my arms and legs.

My primary Care Doctor by the name of Dr. Thomas Hanna in Sandwich, MA refuses to order anything for pain. He finally ordered a "few" Tramadol but it's not something that I can take every day.  He only ordered 20.  He said this office does not order pain medication.  He then sent me to a Rheumatologist and that doc refused to order it as well.  They all say the same thing.  Opioids just make Fibromyalgia worse.  They are both under a larger organization called Cape Cod Healthcare which is setting the rules.  In fact, I fell and broke my arm in May of this year and had to have a 3 hour surgery to fix and the hospital was giving me a hard time on my 1st day post op for pain meds!  I had to argue with them.

It is so exhausting.  I don't know why the opioid addiction crisis is affecting us chronic pain patients.  I asked my doctor why he couldn't differentiate between the 2 groups?  I have never been addicted nor abused them when I was able to get them.

I've tried everything from natural stuff to massage to acupuncture to PT and on and on but I just cant' afford it and it never helped anyway.

I've had chronic pain for 27 years and I'm totally exhausted from it.  I have no social life and every little thing is hard to do.

Donna Lori

Massachusetts

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| |  | | --- | | Audrey Jennings <atjinla2013@yahoo.com> | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | https://mail.google.com/mail/u/0/images/cleardot.gif  https://mail.google.com/mail/u/0/images/cleardot.gif |

My name is Audrey Jennings and I live in Louisiana. I am 60 years old and the mother of three grown children and nine grandchildren.

I want to write my story as thoroughly as possible. So I guess I’ll start back in 2004 at the age of 48 when my problems began with the bones in my right wrist. I have always worked with my hands on computers my whole life. Eight hours a day five days a week for more than 30 years sitting at a desk and on computers.

Arthritis runs in my family and both my parents had it. So that’s probably where I got it from.

Back in 2004 I was having serious problems with my right hand and wrist. The pain was the worst pain I have ever had other than childbirth. It was at a point where I couldn’t hold onto things and was dropping stuff and pain was constant. I just assumed I had carpel tunnel syndrome because of the symptoms I was having. I probably went a year before I actually had my hand/wrist checked out by a doctor. As soon as the orthopedic showed me the x-rays I could see exactly what the problem was. I had a dead wrist bone right smack in the middle of my wrist. That’s when I was told that I had keinbocks disease. I had never heard of such a thing. I had a very good orthopedic at the time.

Kienbock’s disease, is a rare, debilitating condition that can lead to chronic pain and dysfunction. It happens when one of the eight small carpal bones in the wrist, the lunate bone, becomes damaged because there is no blood supply. It is also known as avascular necrosis of the lunate or osteocronosis of the lunate.

There is no cure for Kienbock's disease, but there are treatments options that can help restore the blood supply and maximize wrist function and reduce pain. If it’s not to the point of Stage 4.

Problems with arterial blood supply. Most people have two blood vessels supplying blood to the lunate bone, but some have just one.

Blood does not drain away properly through the veins. Trauma may affect blood supply, for example, a single blow to the wrist.

There may be skeletal variations, for example, an abnormally shaped lunate bone.

Diseases that may increase the risk include lupus, cerebral palsy, sickle cell anemia, and gout.

One study found that 9.4 percent of patients with cerebral palsy also had Kienbock's disease. I did not have any of these previous list of illnesses though. Mine was from only having one source of blood flow through my wrist. The fact that I use my hands eight hours a day every day, was pretty much the Trauma that caused me to get this disease and the fact that arthritis runs in my family. I was at stage 4 where there is no cure or ability to restore the blood because the bone has completely died. I had to have surgery to remove the set of three bones that run between my hand and where my arm starts. I did not get the fusion where they fuse the hand to the arm. Because I still needed to work and I needed as much mobility in my hand and wrist as possibly able. The surgery I had was where they actually remove the three bones and set my hand down upon the arm bones and it healed in that position. I have about 60% mobility in that hand/wrist. To this day I can never lift anything over 20 pounds with my right hand. If I do, I’m risking breaking it to the point of no repair.

Of course during this time I had to be put on pain medications to help me get through the day and have the ability to work. After the surgery and recovery, I still had pains for up to a year afterwards. Just when I thought my life was going to go back to normal And I was back working even with a partial right hand, I was able to work.

In the year 2009 Without any warning whatsoever, my right leg decided it did not want to work anymore. It just did not work! It was like dragging around a dead limb. I had been going to doctors to figure out why my leg no longer worked. At the same time, I was having severe neck pain, severe burning inside my neck and I could only get relief if I lay down, which meant it was hard to do my job sitting at a desk. It took one year and many MRIs, X-rays and CAT scans for the doctors to pinpoint the problem that was causing my leg to not function. Come to find out my neck, cervical spine had several bulging discs and narrowings in the spine and I have degenerative disc disease. The first cervical fusion I had was from C-2 to C4 thru the back of my neck. It was totally unsuccessful. My leg never did get back to working and I progressively got worse. The pain was chronic. Exactly A year later another neurosurgeon did a complete cervical fusion from C-2 to C-7. He explained it to me that in order to prevent the “domino effect” from happening in my spine this was necessary. Whatever he did, it worked! The first time I got out of that hospital bed after surgery my right leg was working again. It was very weak but with almost a year of physical therapy, I’m walking on it again. I still have to this day some problems with that leg. It has spasms and much weakness. Sometimes when my brain tells it to pick it up and walk the leg doesn’t want to listen and I can trip and fall very easily. I literally have to keep my mind on the fact that I want to raise my foot to walk and I will. I do not take walking for granted anymore.. Even with all this and even more surgeries in my future, the pain never goes away. I believe once you have surgery on your spine and the nerves involved they are never prepared back to normal and all kinds of nerve damage happens throughout the body along with chronic pain. Since that time, I have had a complete knee replacement, which was a nightmare in itself and lower back fusion from L2 to S1 which was just two years ago, unfortunately the lower back fusion failed. The bone did not fuse Around the metal hardware. So I am walking with a failed back fusion and I am always in severe pain. My complete knee replacement it’s over three years ago and the pain is still there. I’m not talking about a headache, or a toothache, or a cramp.. I’m talking serious chronic pain. Kind of pain that just goes through your whole body takes everything out of you just to deal with. I’m 60 years old Now and I am under a pain management specialists care. I need the pain Medication because if I don’t have it, I can’t get out of bed. I can’t function like a normal person. I can’t even take a shower by myself. I’m not an addict. I don’t look for a high with my medication. I am able to function fairly normally when I have my pain medication. I’m able to walk fairly decent, I am able to cook a meal, wash clothes take a shower and sometimes even venture out to visit my grandkids. If I wasn’t on my pain medication, I would probably just lay in bed living a debilitating life and wishing I would die. What the government has been doing with this so called opiate epidemic, is truly scaring so many real chronic pain patients to the point that they don’t know what’s going to happen from one day to the next. We are able to function in life fairly normally when we have our pain medications. With all this scare tactic news coming out about this so called opiate epidemic, I even decided to get off of my meds because of the fear of becoming addicted.. I was scared to that point. I stayed off of my medications for six months and I was still recovering from my lower back Fusion when I did that. Even after it was completely out of my system, I could not function on my own. The chronic pain was debilitating and always seem to be any level 10 pain level. I have had enough! I went back to my pain management doctor and get back on my medications. I even went as far as getting the shot in my hip area for the excruciating pain that was running down my hip into my leg and down to my foot making it very hard to walk. I went into the hospital as an outpatient and receive the shot which caused my insurance company $11,682. The medicine that was injected into my body only gave me two days of pain relief and now my pain is back just as bad as before. What a waste of the insurance companies money. So you see I have tried everything outside of pain medication to help relieve me of my pain. Nothing else works. The Government is scaring doctors into not giving their patients medicine or cutting them off completely without any type of withdrawl assistance. The government is causing more deaths this way for those who truly suffer chronic pain then for the addict on the street who is looking for a high. You could take all the opiates in the world away but if there is an addict out there looking for a high they will find it whether it’s opiates or something else. We are not like that. To chronic pain patients with terminal illnesses that are incurable and cause severe chronic pain we are just looking for some relief so that we can live a fairly normal life. I am under a pain management specialists care and I follow all the rules, take the drug test and do everything I am told to make sure I am able to continue keeping my pain medication. But I am reading stories of people who are worse off than me that are getting their medications taken away cold turkey and with no withdrawl assistance. People are committing suicide because as much as they have tried everything to relieve the pain nothing works. I’ve done everything, physical therapy, water therapy, body massage, I’ve even gotten the epidural shots. It’s scary waking up every morning not knowing if you’re going to have the pain medication that helps you get through the day and function a fairly normal life. If I didn’t have the degenerative diseases, osteoarthritis, neuropathy, type two diabetes, cardiovascular disease, and several other conditions, I would love never take another pill as long as I live. Pharmaceutical medicines are killing us, it’s not just the opiates. It’s the statins, the blood pressure medicine, diabetes medicine and everything else in between that is poisoning us way more than opiates. I live in daily chronic pain. If I have a day where I am not in pain, I think I have died and gone to heaven. How nice it must be to live life with no pain. I haven’t known that for over 10 years. All I want to do now is live the rest of my life as comfortable as possible and able to take my pain medications so that I could feel fairly normal. Society is making us out to be drug seekers. That is the furthest from the truth. Everyone of us would give up every medication we take if we thought we would know longer have debilitating chronic pain. Please don’t take our medications away. That would be barbaric and insane. The elderly are the majority of this country and this country needs to take care of their elderly. I live on Social Security disability and can no longer work. This is not how I expected my retirement years to be like. To have to beg my government to not take our medications away was the last thing I ever thought I would have to do.

From: "sylvia"   
Sent: 01-Oct-2017 18:30:09 +0000  
Subject: Chronic Pain letters

to whom it may concern

you need to understand that ppl with pancreatis need these opioiods for their pain you got to exclude them

and make these pharmacies stop punishing them my son suffers with this disease and it makes me mad as a mother

to see him suffer because the government wants to stop ppl from stealing and whatever else they do since when did

we as a nation make ppl suffer --well that is what is happening to my son these pharmicies are reducing their meds too and half the time the pharmicies wont carry them --so in youre fight against opioiods you need to think about these ppl with this disease and their are thousands who sure terribly

mother of a pancrestis patient

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| |  | | --- | | Jennifer Nelson <thaliajen1@icloud.com> | | https://mail.google.com/mail/u/0/images/cleardot.gif |  | **https://mail.google.com/mail/u/0/images/cleardot.gif**  **https://mail.google.com/mail/u/0/images/cleardot.gif** |

I'm 48, a mother, wife, homeowner and voter. I'm also a Chronic Pain Patient. I've had RSD for over 20 years. The pain has been managed all that time by the same dose of Opioid medication that I took 20 years ago. Without the opioids, I'm unable to walk well, unable to do housework, unable to care for my son.

You must know that in each state the laws being passed, the misguided CDC Guidelines and more, are causing pain patients to lose their jobs, their homes, and their lives. I'm praying that you'll stand up for Chronic Pain Patients.

In 20 years and 5 months, I've been on the same dose of opioids or lower. I've never failed a spot urine test, I see my Pain Management doctor every month, and I've never taken a pill out of order or misused my meds. 20 years. While you ponder that, please read forward.

There is a subgroup of opiate users who are being forgotten. We are chronic pain patients. We are being treated terribly because of people using illegal drugs. While I'm glad to see that you're making strides and helping people with their addictions, we would like to know what you're doing to help those of us who actually need opiate medications in order to have a life. We use the medication for severe pain, which is its intended purpose.

My name is Jennifer Nelson. I was diagnosed 20 years, 5 months ago with RSD of the left foot and leg. Now they call it CRPS. Upon diagnosis, I begged the physicians to amputate. I had never felt such pain, and nothing seemed to work. My doctors refused to give up, even when I had. I spent weeks out of my mind with pain, trying treatment after treatment, medications, TENS unit, Biofeedback, PT, etc. At one point, this good girl from Wisconsin who brought A's home from school, won many golf tournaments, volunteered where needed, didn't drink or smoke or disobey, sat with a cleaver, wondering if I could chop enough of the RSD foot off so the doctors would have to agree to amputate. I haven't admitted that to anyone until just now. One of the residents at the clinic knew someone with RSD and I heard him say that I'd be in a wheelchair by the time I was forty.

That angered me. I had plans for my life. A few days later my doctor switched my medication. I had already started on a few opioids but the doses were off or I just didn't respond to them. When my doctor finally found the right opioid and the correct dose, the 2 biggest pieces of the puzzle were solved. The cold- burning pain let up. I'm never 100% pain free, but with opioids I can live a very full life. The third piece of the puzzle was finding the proper muscle relaxant for the RSD "snake spasms" as I call them.

I was 28 when diagnosed. After educating me about the medications I was taking, my doctor told me to go out and live my life. I did as I was told. I returned to work, I met & married the man I love, we bought a home, traveled, adopted our son. And in all that time, I've never made a mistake with my medications. 20 years & 5 months, and I've never had to increase my dose. I've never taken too much, never come close to overdosing. 20 years, 5 months. When I read that there isn't enough info on long term opioid use, I want to scream, "Here I am!"

My life with the aid of opioids is good. And now this "Opioid Crises" threatens this life. What do I tell people when uninformed and reactionary crusaders achieve their goal of limiting the medication that allows me to live? Would you take insulin from a diabetic? What do we tell my 8 year old son when Mommy can't bear to get out of bed? Who does  my job? And what about my husband? Does he just abandon me to a darkened room where I scream? He's never known me without proper medication.

I'm sure you're receiving so many of these letters, and thinking that I have other options. Please know- I don't. I've tried it all. It's been 20 years. My Pain Management Doctor tells me that the disease is in my body and amputation will not help. All this time I thought at least I had that option. But no.

I am a mother, a wife, a homeowner, a voter. I see a PM every month and submit to random urine tests, pill counts. My PM required his patients to see a psychiatrist specializing in pain. Before seeing him, he had the psychiatrist assess me. I took the MMPI test and talked. I didn't mind doing these things because I know that I have nothing to hide.

According to the National Institute of Health only 5% of people prescribed opiates during the course of a year become addicted. 5%. Who are the problems here? Do you ever wonder why there's more overdoses even though the amount of opiates prescribed has declined since 2010?  Do you think if you were able to get all legal opiates banned that the drug crisis would end? No, because you cannot get heroin, carfentanyl, cocaine, crack, PCP, ecstasy, and all the other illegal drugs off the streets. Addicts will find a way.

 We are aware of the lies told by the CDC and Doctor Andrew Kolondy. This IS a conflict of interest as Dr. Kolondy is an addiction specialist who wants more addiction clinics and more Americans on Suboxone. I was told point blank that Suboxone wouldn't work with RSD. It also would interfere with problems I have with multiple kidney stones that require lithotripsy procedures. So where are the Pain Management doctors in this debate? The ones who actually care are more than willing to talk. If you're targeting CP patients, you should be talking to doctors who treat diseases and injuries of people living with debilitating chronic pain.

Please, talk to chronic pain patients and an actual pain specialist who isn't cowed by government and insurance pressure. Learn the truth about diseases that cause chronic pain. We, as chronic pain patients should not be punished for the sins of addicts. We seek light and life, and we take our medications so we can LIVE those lives. Addicts take drugs to hide. CP patients take medication to live.

We are a community seeing our brothers and sisters become suicidal with pain. The hysteria over this "Crises" has gone way past common sense. Please, when considering how to move forward, remember us. Don't allow anyone to tell you that we'll be fine. We won't. In my house alone we will lose a wife, a mother, a human being. I use that term because severe, terrifying pain such as RSD encompasses, makes one feel inhuman. I don't ever want to feel that again. But if we adopt CDC Guidelines or laws are made to stop opioid prescribing, CP patients are the very first to suffer. Addicts can buy what they need. But law abiding Pain patients won't.

The pain can also adversely affect the body's endocrine, cardiovascular, immune, neurologic, and musculoskeletal systems and require aggressive treatment of the pain as well as the resulting complications.  So not only does this affect our personal lives, but it also affects our health.

Throwing CP patients into the statistics is a disastrous move. Don't ever assume that we are like addicts. You'll never find a more law-abiding group of people. You see, we know that our physician can withhold our medication if we break their rules. We know that insurers are chomping at the bit to find a reason to stop paying for our meds. We happily follow the rules. If I abused opioids, I couldn't work, run a household, raise a child. But now, after 20 years of proper medication, I need to worry. Every month when I see my PM doctor, I worry that he's going to tell me that he's adopting CDC Guidelines, or worse, quitting his job because this government is putting too much pressure on him.

Don't throw the baby out with the bath water. Restricting opioids won't stop addicts. Addicts will continue to buy what they need in the street. But by legislating which doses are allowed, you're playing doctor with a patient you've never met. There's nothing wrong with educating people about pain medication. As the mother of a son, I'm all for that. Just please, use the correct information. Not everyone who uses opioids is an addict or on their way to becoming one, unlike some speakers' opinions at the Washtenaw Sheriff's meeting on Opioids.

Some of the restrictions I've heard about astound me. What if it is YOU getting emergency surgery? In some states I'm hearing that you can only have 4-5 days worth of pain meds. Who is legislating this? Opioids are not the problem. The problem is addiction. Addicts. People for whom one is never enough. This applies to all the drugs people abuse, including alcohol.

The CDC Guidelines started this mess. Even PM doctors were confused. Then insurers got involved. I don't think it's a secret to say that they were not worried for their patients. Money, in not covering our prescriptions, is their bottom line.

So to whom do we turn now? We, as a group, are frightened. None of us asked for these injuries or diseases. We have no spokesperson, no leader. We write to appeal to your humanity, to your common sense.

The Opioid Commission's suggestions to the White House are terribly worrisome. The numbers in 2015, as reported by the CDC, also include heroin and illegal Fentanyl, 33,000 deaths. The problem is that we don't know how many were from illegal drugs and how many were actually from prescribed medications. It's more than a good bet that street drugs caused the most deaths. Remember, 5% of CP patients abuse. Only 5%.

It was also said during this meeting that opiates have a place when necessary. As a CP Patient, I need clarification on that. I'd like to know who is going to decide which patients get opioids for their pain; what is the dose? The CDC Guideline dose is a one size fits all mess. For instance, would you prescribe the same dose for a broken arm and a patient recovering from heart surgery? Would a tonsillectomy get the same dose as a dying cancer patient? And please note that the level of pain from RSD  is measured as one of the most severe on the McGill University Pain Scale. Higher than terminal cancer pain.

We DO have a problem here. Addiction is serious. But lumping CP patients in with addicts is not just logistically wrong, it's morally wrong. You're causing physicians to leave the Pain Management specialty because they fear reprisals for properly treating pain. That leaves a lot of people without meds, suffering and dying. When you can't even yawn for fear of making the pain worse, your quality of life is near zero. I'm tired of reading about my fellow CP patients taking their lives because someone took their only lifeline.

I agree that any addiction is sad. I agree that something needs to be done about all drug addiction. But you don't need to cause harm to do it. CP patients only want to live their lives. Our doctors know this! Please, stop this craziness. You do not need to punish law abiding, tax paying, voting citizens in order to address this problem. In 20 years I've never had to increase my dose or switch to a stronger medication. Any doctor can tell you that it's impossible for me to be "getting high" on the same dose. I'm insulted that anyone would even assume it. Leave the prescribing to the PM docs. They really do know what they're doing. Please don't lump them in with the few who were illegally operating.

Please, put yourself in my shoes. In our shoes. Don't punish people who are already suffering. We need an answer to this mess, an assurance that CP patients will be left out of the guidelines, laws, and mandates that are sure to come. We do have the right to happiness, or at least the pursuit of it. Please do the right thing.

Sincerely,

Jennifer Nelson