December 3, 2020

Dear Medical Director,

I am writing regarding reference #206176411000. My I.D. number is #W1976 13603 and D.O.B. 07/27/1968. Upon learning that Aetna does not cover Ketamine Infusions, including but not limited to codes #96365, #96366, #99213, #96374, #J3490, #93042 and #99354, I submitted a request on Thursday, October 8, 2020 that my case be reviewed and approved for past Ketamine Infusion treatment as well as ongoing continued Ketamine Infusion treatment. Because there is no provider within the HCA realm that provides this service, I requested that a Gap Exception be made to have these services provided by Juan Carlos (Kit) Afable at Serenity Health at the highest benefit level possible and be covered as in-network. After two arduous months of the provider’s office faxing the necessary clinicals and Aetna continuing to maintain that they had not received them, I was finally able to get confirmation on Monday morning, November 30, 2020 that they had in fact been received, reviewed by the nurse and forwarded to the medical director for further review. I then received a call on Monday evening, November 30, 2020 from the nurse assigned to my case, Julie Berger, informing me that my request for coverage to be paid at the higher level had been denied. I expressed my sheer dismay at how my case could be denied with such a swiftness when I had just confirmed hours earlier that the clinicals had just been received. She suggested that I have my treating provider, Juan Carlos (Kit) Afable, call to schedule a peer review which he immediately scheduled without delay for Thursday, December 3, 2020. After a peer review with the medical director, my provider informed me that despite the evidence and studies that were presented, the medical director insisted that the decision to deny would stand based solely on the fact that Ketamine Infusions are considered to be ‘experimental’ and therefore not covered by Aetna. No other evidence, studies, records or extenuating circumstances were considered.

I am thereby appealing this decision and would like to submit my own letter to help you understand more clearly that my request is not solely in an effort to try an alternative or ‘experimental’ form of treatment, but is a matter of medical necessity due to serious health issues that began on 12/22/04. It is at that time that I began the difficult arduous journey of attempting to have my severe pain diagnosed. Over the past 15 years, I have been treated by numerous pain specialists and neurologists, and countless other specialists-all to no avail. I tried every conventional form of treatment that Western medicine could offer, and even countless forms of alternative treatments but all without success. My severe undiagnosed pain went improperly treated and incorrectly diagnosed for 1 1/2 years until finally after over 15 different doctors and a multitude of diagnoses, I was finally diagnosed with a rare debilitating neurological disorder called RSD (Reflex Sympathetic Dystrophy) or CRPS (Chronic Regional Pain Syndrome) by a Neurosurgeon, Dr. Gregory Nazar on 4/7/06. Even he in his 20 years of experience at the time had only seen one other patient with this rare neurological disease. He admitted that he did not have the expertise to treat me, nor did he know of anyone locally or even in this region who could treat me. Though relieved to finally get a correct diagnosis, I was devastated to find out that there were so few doctors who were familiar with RSD/CRPS and even fewer who were experienced in treating it. RSD/CRPS is disease effecting the small nerve fibers. It is where the sympathetic nervous system has malfunctioned and as in my case also involves spinal cord damage (CRPS II), which makes an already extremely challenging disorder even more difficult to treat. This disease has been coined, ‘the suicide disease’ and described as 'the worse pain known to man'. In fact, CRPS ranks the highest on McGills Pain Index. This rigorously tested scientifically designed chart that doctors use to measure pain ranks RSD/CRPS a whopping 42 out of 50, even above pain from natural childbirth and the amputation of a limb. It is characterized by indescribable severe burning, allodynia, skin mottling/discoloration, bruising, and swelling-just to name a few. After much intense distress and research my husband and I were able to locate a Neurologist in Palm Bay, FL, Dr. Masood Hashmi, who specializes in treating RSD/CRPS. Due to the rarity of the disease and the absence of capable doctors in this area, Anthem BC/BS gave consent that my treatment not only to be covered but to be paid at the higher level. Eventually, I was able to locate a knowledgeable doctor in Jeffersonville, IN. Dr. Michael Cassaro was not just a Critical Pain Management Specialist, but he was also a Neuro-Endocrine Modulation Specialist as well. Due to the complexity of my disease, the length of time that I have battled this disease and the widespread area that it effects my body (approximately 85%), the search for relief has been long and difficult. I treated with Dr. Cassaro starting in 2006 until his retirement in 2016. He put extensive effort into trying to help me cope with the symptoms of this horrific disease exhausting every means at his disposal.

Over the past several years, my conditioned has worsened in it's intensity if that is possible to imagine. In addition to the extreme burning that characterizes RSD/CRPS, I have also had ongoing long term episodes of not being able to sit normally, stand for any length of time, bend forward, or drive without enduring indescribable pain. This last episode started in October 2014 and has continued until now. This condition has seriously impeded my productivity in life and my ability to care for my family. It has resulted in me being housebound for much of the time and to a large extent, bed bound. Among the many procedures that Dr. Cassaro tried has been sympathetic nerve blocks, injections, epidurals, and root blocks to name a few. These treatments only aggravated my condition and caused me even more pain. Much to his regret, Dr. Cassaro felt that I had tried every conceivable treatment possible over the past 10 plus years to help manage my CRPS II with the exception of a spinal cord stimulator. Unfortunately, with CRPS, surgery is one of the worst things that I could entertain-as it has been known in most cases to advance the disease. In addition, the fact that I have had CRPS for over 15 years and that it is spread body wide, causes the spinal cord stimulator to be virtually ineffective. Another risk is infection. It is clear that if there is an infection as a result of the surgery, that my disease will worsen resulting in even more pain than I currently live with-which is unimaginable. Also, I would have to endure another surgery to have the device removed from my spine. I have since consulted with other doctors who agree that this treatment has not proven to be successful for CRPS patients. Having this as my last and only option has created tremendous feelings of hopelessness, depression and despair.

After Dr. Cassaro’s retirement, I sought treatment with several other doctors in hopes of relief. With one of your past denials, you recommended that I be seen by Dr. Adjith Nair, Kentuckiana Pain Specialists. Dr. Nair specializes in surgically implanting pain pumps to help patients cope with chronic pain that has not responded to any other conventional modalities. Once again, surgery of any kind has been shown ineffective for CRPS patients and has only proven to exacerbate and worsen the disease. But because of my desperation and ongoing battle to receive coverage for ‘experimental’ treatments with Aetna, I began treating with Dr. Nair in 2019 for a period of time to see what he could do to help bring my pain level down to a manageable degree. After much discussion in reviewing my medical history, Dr. Nair felt that I had tried practically everything possible without success and that there were very very few options available left to try. He finally convinced me despite the huge risks involved to proceed with the pain pump trial to see if it could help in any way. He attempted not one, not two, but three pain pump trials...all without success, and finally determined based on the results of the three fail trials that I should explore any and all other options and that he would not recommend a pain pump being implanted. Additionally around the same time, I was treated by a Dr. Michael Hibner at St. Joseph’s Hospital-Dignity Health, in Phoenix, AZ and underwent invasive exams, therapy and a surgical procedure. That surgical procedure included numerous (24) transvaginal Botox injections and nerve blocks. The recovery was long and difficult...and the pain continued. In addition, it was prescribed that I begin several months of invasive pelvic physical therapy. After over 3 months, there was no improvement so therapy was discontinued.

The ONLY treatment that has proven in my case to have any measure of success has been Ketamine Infusions. In September/October of 2014, from 9/21 to 10/2, I received numerous infusions from Dr. Glen Z. Brooks in the Financial District of Manhattan, NY. If you would go back in your archives and pull the EOB’s for these dates, (Claim I.D. #P9RTF08DZ00 and #PVABH2KZB00), you will see that not only were these services paid, but they were paid at the higher benefit level of 70%. I will be including with my letter super-bills, claims, and past EOB’s showing payment of these Ketamine Infusions. Also, I will be sending letters from past providers expressing the difficulty and complexity of CRPS. In December 2019, I received Ketamine Infusion with Dr. Jay Joshi in Vernon Hills, IL. This was another occasion that I pushed for a Gap Exception to be put in place. However, due to COVID my return trip for April 2020 was cancelled. It was at that time, that my husband was able to research and find that a Ketamine Center had opened in Louisville, KY-Serenity Health. Seeing proof that Aetna has paid for Ketamine Infusions in the past, how is it possible that the same exact services are now being denied with Serenity Health. At that time in 2014, there was no Ketamine Centers within a 1,000 miles of my home. Now, Serenity Health, has been in Louisville for the past 2 years-a Center only 25 miles from home when over the years I’ve had to travel to the ends of the earth to receive Ketamine Infusions. Due to the severity and length of time that I have battled this rare incurable disease, no other modality has or can even begin to provide ANY measure of relief. It is truly an injustice to penalize me or deny me treatment that has been PROVEN effective in helping me cope with the symptoms of my disease simply because it is considered alternative or "experimental". My condition has continued to digress and it is apparent that my condition will continue to digress or improve depending on the treating provider that I have in front of me. This disease is by no means common or easily treated, which calls for flexility in acceptance by Aetna insurance to cover modalities that do not fall into the "normal" guidelines. We are dealing with a rare, complex, incurable disease. Therefore, new and successfully proven modalities should not be discounted just because it is viewed as “investigational” or "experimental". Surgery carries a tremendous risk of being detrimental in my case. So it is only logical, in my view, that my insurance affords me the opportunity to receive non-invasive, less expensive therapies such as this. How is it that you continue to dismiss Ketamine Infusions as ‘investigational’ and ‘experimental’ when I am living proof that they are not. The treatments that I have been receiving from Serenity Health under Juan Carlos (Kit) Afable since August 11, 2020 until now have proven to be the ONLY treatment that has been able to stabilize my pain level and get it to a manageable level. It will be necessary that I continue receiving Ketamine Infusions as needed to maintain stabilization. It is unethical and unreasonable that my husband has been employed for over 15 years with HCA (Hospital Corporations of America) and over the years has paid thousands and thousands of dollars for exceptional health insurance. I am primarily the one in our family who is in need of medical insurance, and yet Aetna refuses to pay for the only treatment that has proven to be successful in my case. Over the years, I have acquiesced with every recommendation of treatment and provider that Aetna has recommended. Not one of them has been able to do anything to help manage my CRPS. Within the last three months, I have spent out of pocket over $6,500.00 for Ketamine Infusions. That is not including the hundreds of dollars that we have out of pocketed for our Aetna insurance premium in those same three months. To date, Aetna has reimbursed me a total of $52.00!

Therefore, I am writing to appeal the decision regarding reimbursement for Ketamine Infusions that I have received and already paid in full at Serenity Health as well as future ongoing Infusions that I will continue to need going forward. I ask that you please seriously reconsider approval for Ketamine Infusions to be approved and paid at the higher benefit level in the light of all the foregoing information that I have presented. I very much appreciate your consideration and prompt attention to this matter. I am hopeful that we can come to a positive resolution to this issue. Otherwise, I will be looking next to HCA’s HR department directly to give further attention to this critical matter. After many years and even many more resources, I have finally found a Provider who is fully knowledgeable of my rare disorder and has been able to effectively stabilize it and bring me a measure of relief. It is my goal to continue treating with Serenity Health, restore my health to the extent possible, and to a degree my quality of life that has been lost for so long. Once again, thank you for your kind and prompt attention to this urgent matter. My contact information is listed above. I look forward to your timely response.

Sincerely,

Caprena Richie

Enclosure