**Project Name: JAN221413 Policy PERC/NMS Engagement**

**Date: 09/06/2022**

**Segment: Session 2**

**[//Introductions//]**

**Wes P: I can see some familiar faces. Hey, Rebekah, how are you?**

Rebekah D: Doing well. How are you?

**Wes P: Doing good. Doing good. Did you have a nice long weekend?**

Rebekah D: I sure did. Lots of naps.

**Wes P: Great, I love it. Sounds wonderful. Good, thank for joining. And I see Greg too. Hey Greg, how are you?**

Greg J: Doing well.

**Wes P: Good. Good to hear.**

Greg J: Waiting for rain like everyone else.

**Wes P: It's gloomy here but it's much needed so, good to hear. And I see Rasheeda's on it as well. Hi Rasheeda.**

Rasheeda J: Hi How are you

**Wes P: Doing well, How are you doing?**

Pretty good.

**Wes P: Did you have a good long weekend?**

Rasheeda J: Yes, I did.

**Wes P: Good. Thanks for joining. And CJ's on too. Hey CJ**

CJ C: Hey, how's it going.

**Wes P: Doing Good. How are you doing?**

CJ C: Doing fine.

**Wes P: Good, good. Thanks for joining.**

CJ C: Thank you

**Wes P: OK, we should have two others joining us, but we're just going to get started for now. and if the others jump in we'll introduce them. So thanks everybody for joining today. Our session today is a Policy Cross PERC, so we're here to talk about issues that go beyond just individual diseases areas and PERCs. We're talking about policy obviously, with the name of the PERC. Specifically non-medical switching which we can call NMS, just to make everybody's life easier or switching whatever you prefer. Thanks everyone for jumping on. I'm going to jump right in. We have a two hour session with a five minute break right in the middle at the top of the hour. So, after that we'll have a few topics of discussion you can see here, and then we'll wrap up. Welcome everyone. It's great to see you all. I think I've met most or all of you at some point, but for anyone who hasn't met me I'm Wes Peters I'm a research specialist with CorEvitas Healthivibe. We switched our name, but you can call us either, it doesn't matter. And It's great to see everyone. I have a few slides here on general guidelines. I think you're all pretty familiar with these by now. So I'll just quickly go over them. Our discussion today is led by Janssen & CorEvitas staff, over here to collect your thoughts, opinions, and personal experiences, so there are no wrong answers. Just try to speak one at a time to make sure we can hear you. On Zoom sometimes if you've got multiple people speaking at once you might have some audio cut out, but if it happens don't worry about we'll just call on you one at a time. I mentioned before the discussion is going to last two hours today with a five minute break right in the middle. Now you can see in bold here, I have a request to avoid topics related to specific products or medications, or inquiries seeking medical advice. I have another slide coming up right after this diving deeper into that so I'll hold off a second from explaining that too much. Finally, just a reminder that our conversation is confidential. I think most of you have heard me say this a few times now, I like to tell my groups that that's a really positive thing. That this is a closed circle. So you can feel comfortable telling us your thoughts, opinions, beliefs knowing that it remains within this circle. I see it as a really positive thing. Finally, thank you all for participating. I appreciate you all jumping on, the day after Labor Day. It's great to see everyone. I mentioned that slide about safety reporting and adverse events. So you can see that here. Our intention today is not to ask for adverse events or product complaint information. So a few examples of what that could look like. I do want to point out because we're talking about non-medical switching today which tends to be related to medication, there's a good chance our conversation may lead towards specific brands or specific medications. So, I think the best ways we can avoid naming specific medications is to be as specific as possible. You can use a generic name, a molecule name, or you can use a non-branded name or a drug class. As long as you're not mentioning the specific brand of medication, that will avoid any of these issues whatsoever. But that being said, if an advert event or a product complaint does arise, it's not the end of the world. We're just required to collect it and if it's a J&J company product or device that's mentioned we would have to report that to the appropriate J&J organization for follow-up. So it's a pretty involved process; we like to avoid it when we can. So I appreciate you all helping out as best you can there. So, thanks, everyone.**

**Let's get through introductions. As I mentioned before we have a few individuals we're waiting on to join the call, so let's start with those who are on and go west to east. So Rebekah, your slightly more west it looks like than Lauren and Lauren also, I don't believe has joined us yet, so we're just going to start with you, Rebekah. Rebekah you're from our multiple sclerosis PERC and you're from Peoria, Illinois. You want to tell us how you're doing, introduce yourself and I do have an icebreaker for you. Tell us, if you had to have lunch with anyone real or fictional, a character or somebody you admire. Anything at all. From a movie or a book or someone from real life. Who would it be and tell us why? So, I'll let you go ahead, Rebekah.**

Rebekah D: all right. Hi everyone. My name is Rebekah. I am from Peoria, Illinois. So I am about two hours in between Chicago and St. Louis. I was diagnosed with multiple sclerosis, Spring of 2020, so still a - am I easier to hear if I pull it here?

**Wes P: A little bit.**

Rebekah D: I'm from Peria, halfway between St. Louis and Chicago. I was diagnosed with MS back in 2020, so it's still a relatively new diagnosis for me. If I could have lunch with anyone I would probably - off the top of my head, probably Stevie Nicks. I'm a huge Stevie Nicks fan. I'd love to pick her brain. See what that little Gemini brain is up to. So, that's who I'd have lunch with.

**Wes P: That's great. Thank you Rebekah. I'm a huge Fleetwood Mac fan, so I think I'd be there too. So, thank you. And Rasheeda, I'm going to jump over to you next. You're North Carolina. And Rasheeda is part of our ankylosing spondylitis PERC. Rasheeda, do you want to jump in and introduce yourself to everybody. Tell everybody how you're doing and who you'd like to have lunch with?**

Rasheeda D: Sure. Hi everyone. I am Rasheeda. I'm doing very well. If I could have lunch with anyone it would be one of my favorite authors Bebe Moore Campbell. She's actually deceased, but I would love to pick her brain and ask her about some of the books that she's written. She just has a really interesting perspective, just writing about historical events and even fictional events. Her characters are pretty dynamic. So I would like to have lunch with her.

**Wes P: Thanks Rasheeda. I'm writing down that name right now, so that's a good one. Thank you. So next up is, I guess CJ your slightly further west I think then Greg, so I'm going to jump to you first. In Manassas Virginia, CJ's part of our inflammatory bowel PERC. CJ, you want to introduce yourself? Tell everybody how you're doing and if you have anybody you would like to have lunch with and who it would be.**

CJ C: Hello everybody my name is CJ. I have posterous colitis. And somebody I would have lunch with would be probably David Goggins. Just because he's inspired me in a lot of different ways.

**Wes P: I'm not familiar CJ. Who's David Goggins?**

CJ C: He's a- I think he's a retired Navy Seal. He's done a lot of ultra-marathon races, and he's written a book as well. Motivational speaker as well.

**Wes P: Cool. Any ultra-marathon runner to me is amazing. I like to run but I have a limit. That's really impressive. Well, cool. Well, thanks for joining us CJ.**

CJ C: Thank you.

**Wes P: Yep. And Greg I'll jump over to you in Virginia Beach. Greg from our prostate cancer PERC. You want to tell us how you’re doing and anybody you would like to have lunch with. If you had to pick somebody. Oh, hang on Greg, you're muted.**

Greg J: Sorry. I'm an old fashion guy. I'd go for Julia Caesar. I think he'd be fascinating to talk to. He would have a world of stories. Literally and just all the things he was able to accomplish in his lifetime. I'm doping reasonable well. I'm still recovering from COVID. That was an ordeal. And breathing is still hard, but I'm managing.

**Wes P: Sure. Well I hope you feel better. I think everybody I know had it last month. So it's definitely going around again. But Cesar's a good one. I haven't heard that one yet. So that's, I can't think of anyone better who's seen most of the world like you said so, thanks Greg. Great. And last but not least. Thor jumped on. Thor is in our also in our inflammatory bowel disease. OK Thor, in Georgetown, Texas. You want to jump in? Tell everyone how you're doing. And then, We're doing an ice-breaker. If you had to choose any one person who to have lunch with, it could be a real person or fictional. Who would it be and why?**

Thor H: Cool. Hi, I'm Thor. I live in Georgetown, Texas, which is right outside of Austin. I have IBD. I'm doing OK. Not terribly, not super well that's kind of[INAUDIBLE] I think everyone could relate to that. I could have lunch. Oh, I also am recovering from COVID, but I got some meds early on, and it was surprisingly not that bad. So, some cool meds and shout out to whatever drug maker makes that stuff. But If I was to have lunch with anyone, I'm going to go fictional and go with Sherlock Holmes, just because I think it would be a wild time. He'd be like crawling on the ground like some crazy coked field guy writing everything down, which is I guess what Watson did. So pretty cool guy.

**Wes P: That's good. Nice - and also he's charming too, so you kind of have that as well in his own weird way. Good. Glad to hear you're feeling a little bit better from the COVID infection. Hope you continue to recover and feel better. Thanks for joining us. OK, so I think we're just waiting on one other person, but I think for now let's just jump right in, and then if Lauren joins, we'll introduce her later on. So we have another attendee slide, we have a number of people here today. I'm going to start with Aarti Patel. Aarti, you want to jump in a introduce yourself.**

**Aarti P: Sure hi everyone. My name is Aarti Patel, and I'm the Population Health lead for and I'm part of Janssens Scientific Affairs.**

**Wes P: Thanks Aarti. Any thoughts about who you would like to have lunch with if you had to choose somebody?**

**Aarti P: I'm saying Bridget [INAUDIBLE] and another one I really like is Indra Nooyi. She's an advocate forma of PepsiCo, CEO, and I think I find her inspirational for balancing work, life and just kind of, as a leader. So I would put her as together with the other one I'd probably put.**

**Wes P: Great, good answer. Perfect, thanks Aarti. And next up is Bridget Doherty. Bridget would you like to jump in and introduce yourself?**

**Bridget D: Hi everyone. My name is Bridget Doherty. I'm partners with Aarti and the rest of the team and Janssen Scientific Affairs. I do Health Policy Research, Economic and Health Outcomes Research Thank you for your time today. Last week Aarti and I were laughing because we had a session last week and we were both going to say Ben Franklin, but she took it from me. I'll also add Michelle Obama. I'll go a little bit more modern. I'm a little late to the party. I just read her book, *Coming,* and just find her inspirational.**

**Wes P: That's a good one. Thanks Bridgett, perfect. And Caroline is next. Caroline you want to introduce yourself?.**

**Caroline K: Hello, my name is Caroline Kerner, and I'm a gastroenterologist with Janssen Scientific Affairs. And if I could have lunch with anyone I think, right now, it would be Barack Obama. My four year-old is fascinated with President's, and her favorite is Barack Obama. So, I would bring her along and make her day.**

**Wes P: That's good. Thanks Caroline. We'll have the whole Obama family over for lunch. Thank you. And next up is Lisa. Lisa would you like to jump in and introduce yourself.**

**Lisa S: Sure. Hi everyone. Great to see you again. Lisa Shea, Patient Engagement Research Leader, and Janssen Scientific Affairs. I think laughter is the best medicine, so if I had to have lunch with somebody I think I would choose Michael Scott from the office, these days. Fictional character, I know, but it would just be fun and entertaining at the same time. So, thanks everyone for your time today.**

**Wes P: Great Thanks Lisa. Next up is Steven Zona. Steven would you like to to jump in and introduce yourself to everybody?**

**Steven Zona: Hi, Steven Zona, I'm based out of Dallas, Texas with Janssen Scientific Affairs. I'm on our Value and Evidence Scientific Engagement Team. So I work closely with Aarti, Bridgett as well as Lisa. If I had to have lunch with someone. I'm going to see Lady Gaga this weekend so I would say it would be great to have lunch with her prior to the concert.**

**Wes P: That's a good one Steven. I'm a little jealous you're getting to see her. So, it sounds like fun. And last up is Valerie. Valerie would you like to jump in and introduce yourself?**

**Valerie B: Sure, hi. Valerie Braz. I am a clinical research scientist with Janssen Scientific Affairs. I don't know exactly who I'd have lunch with, but one of the great historical Queens, whether it'd be maybe Marie Antoinette, Nefertiti, like Catherine the Great from Russia, somewhere along that line. One of the historical queens.**

**Wes P: That's good, Valerie. I just got finished watching the Great on Hulu which is just a really cool series on Catherine's life, so I really recommend it, if you're a fan of Russian history. Cool thanks for joining. And on the CorEvitas side we have Casey. Casey would you like to jump in and introduce yourself?**

**Casey: Hey, I am Casey Project coordinator with CorEvitas. I do know most of you. So thank you guys for being here. It's always great to see your faces and not just chat through e-mail and stuff so it's good to see you guys here. And I'm going to stick with who I said last time which is still Michele Nichols who are from Stargate and who also has been a huge advocate for woman and diversity in STEM and in Hollywood. And it's great to see you guys thanks for being here.**

**Wes P: Thanks Casey, thanks for jumping in. And next up is Lauren Durante. Lauren would you like to introduce yourself?**

**Lauren D: Yeah. Hi, I'm Lauren Durante I'm the Project Manager with CorEvitas. I work on the Cross PERCs Policy and a couple of our other therapeutic areas. So I've had the pleasure of meeting some of you already, so I'm looking forward to seeing you guys again, and then those who I haven't met, thank you guys all so much for your time today. I'm really excited to see your experience and learn from everything that you guys have already been through. I'm in Madison, Wisconsin. I'm a huge sports fan. I guess coming off of the US Open I think I'm going to have to go with Serena. I think I would honestly do anything to have lunch with Serena. I think she's one of the greatest people in the sports world, but definitely in our society. So, thank you.**

**Wes P: Thanks Lauren. I wonder if she'll be back. I have a feeling she might not like retirement.**

**Lauren D: Oh my god, I hope so. I hope so. I don't know what we'll do without her.**

**[//NMS Awareness//]**

**Wes P: I think it's hard to stay retired when you're the greatest, right? So, cool. Thanks, Lauren. And I introduced myself earlier, but I'm Wes, Research Specialist. It's my role to hear from you all and understand your experiences. So, I wanted to thank you in advance for taking the time to speak with me today. I'm really looking forward to it. You know it's funny, always ask these ice-breakers and I'm always so invested in what you guys are telling me that I forget to think about somebody for myself, so I'm going to go with The author who's writing the book I'm currently reading, his name is William Finnegan. He is a Pulitzer Prize winning journalist, but the book he wrote is called *Barbarian Days. And,* it's all about surfing, because when he was younger he grew up in Hawaii, California and he was into surfing back when it was sort of the surfing revolution. And he went all over the world and found all sorts of surf spots. His book is mostly about how unhappy he is that the rest of the world has found all the surf spots, because now they're all popular resorts, and they're no longer private, quiet places. Just a really great writer and just wonderfully detailed in the way that he describes his life. With that said, let's jump into the discussion. We are here today to talk about non-medical switching. It sounds like from the pre-work we sent out that maybe a couple of you have experienced a non-medical switch at some point. But for the most part, most of the people in the group haven't experienced this. So I want to start with those who haven't. Greg, I know you mentioned you have at some point experienced this but I'll ask I'll on you later on just because I want to hear from some of the folks who haven't to begin with. So, CJ, I guess I'll start with you if you don't mind. Just want to hear a little bit about your awareness about non-medical switching. Whether you've heard about it in the past. What you think it is? Tell me a little bit more about your thoughts.**

CJ: I have not heard about non-medical switching and have not had any experience with it either. I believe it has to do with insurance companies. It could be that the drug that you need is not covered anymore by that insurance company, or that you do not have enough money to pay for it. Yeah, that's what I believe.

**Wes P: Got it OK. So you haven't heard of it in the past but you think it's the insurance company not- maybe not covering the drugs. Or do you think, it's the price, it's if they raised the price is that what your thinking? Sort of move it out of a patient's price range because it gets too expensive.**

CJ C: Yes

**Wes P: OK. Got it. And when you read the definition in the pre-work did you have any sort of first initial response to what it was or do you remember?**

CJ C: I just thought it was insurance to be honest.

**Wes P: Yep. No problem. And we'll have more information on the next few slides about it, but I'm just interested in hearing sort of your thoughts. So you're thinking it's an insurance company, and it's involved with coverage of the drug in some way or financials. Any other thoughts or any first reactions to the concept?**

CJ C: Negative. It's always, I feel like, it ends up screwing the patient over. Could possibly end up making them worse because they are on a time schedule to get this drug, and if they don't receive it and they're fighting with the insurance company, it could be some time before they receive it again.

**Wes P: Makes sense. Another question for you. You mentioned that you haven't had direct experience with non-medical switching, but have you ever been in one situations where the insurance decided they weren't going to cover a drug or they made it more expensive? Anything like that?**

CJ C: No, sir.

**Wes P: Thank you. I have a few more questions, but I'll wait until later on. I'll save them. So thanks, CJ. Rasheeda, I'm going to jump over to you. It sounds like you also haven't had experience with the switch, is that correct?**

Rasheeda J: Yes, that's correct. I had never heard of it before. You introduced the policy to us.

**Wes P: What were your first thoughts? What are you thinking a switch is and what's your reaction?**

Rasheeda J: I try to imagine how I would feel if it happened to me, and I would just feel kind of powerless, and especially if the medication is necessary. I thought about corporate greed, just if that does happen, are there true reasons for the switch or is it just to increase their profits? And I just it would be unfair.

**Wes P: And when you say true reasons for the switch, are you thinking true as in sort of a medical reason for it? Is that what you're thinking or -**

Rasheeda J: Yes, correct. If it's unavailable or if there was a safety reason with the manufacturing or something like that, but I imagine that probably happens less often than more often.

**Wes P: So you're thinking it's more related to profit, then?**

Rasheeda J: Yes.

**Wes P: And another question for you. When you say the definition - or I'm sorry, tell me a little bit what do you think the switch is, who's asking for a switch? Is it insurance company or is it someone else? What's your perception?**

Rasheeda J: I guess I would need to understand it more, but it seems like it would be more the drug companies maybe.

**Wes P: Drug companies. And we do have a definition on the next slide, so I'll give you more information in a moment. And do any of these words, by the way, on the slide jump out to you in the word cloud? Anything sort of resonate with what you're feeling or surprise you or anything?**

Rasheeda J: The "Unfair" and the "profits" kind of resonated with me. Maybe "stressful".

**Wes P: Thanks, Rasheeda. Rebekah, I'm going to jump to you next. I know you mentioned you also haven't had experience with this in the pre-work, I believe. Is that correct?**

Rebekah D: Yes, that's correct, not personally.

**Wes P: Were you at all aware of the concept before you saw it on the pre-work?**

Rebekah D: I was aware of the concept, I just wasn't aware of the specific term of non-medical switching.

**Wes P: Where had you heard about it? Did you know other people who have experienced it or -**

Rebekah D: Absolutely. I have a partner who is on the state's health insurance card, so she has to jump through a lot more hoops to get medical care. And she often needs to switch between stimulants because she was ADHD that requires a stimulant prescription, so - and this is starting to happen to me, that often the controlled aspect of certain medications will either cause doctors to hesitate or to take you off or the insurance company will say, "You can't try this one, you have to try this one first," even though both the health care provider and the patient have agreed, "This one stimulant will collect the best choice," doesn't matter if you don't have this diagnosis or you haven't tried this stimulant, then you are not - you're not allowed to move forward. So that's resulted in a little bit of delay of care for both me and my partner.

**Wes P: And then, who are you perceiving as sort of responsible for the switch? You mentioned the insurance company. Is that who you're thinking is primarily responsible?**

Rebekah D: Sorry, I - sorry, did I break -

**Wes P: Sorry, can you hear me?**

Rebekah D: Hello?

**Wes P: Did we lose you, Rebekah?**

Rebekah D: Can you hear me?

**Wes P: I can hear you. I -**

Rebekah D: I think - could you repeat the question one more time?

**Wes P: Yes, sorry, sorry. I was going to ask - you mentioned the insurance. Is that who you're thinking is primarily responsible for the switch? Is that who you're thinking is sort of initiating it?**

Rebekah D: That and partially the FDA.

**Wes P: The FDA. Thanks, Rebekah. And any words in the word cloud really jump out at you as resonating or surprising?**

Rebekah D: I like the word "Unconscionable." That one jumps out at me, but also "stressful." It's just when - especially when you get on a good routine, and then all of a sudden, that routine is interrupted, sometimes it can take a long time to get back into a routine, which messes up so many things.

**Wes P: Makes sense. Thanks, Rebekah. And Thor, I'm going to jump over to you. Sounds like you also haven't experienced the switch yourself. Is that correct?**

Thor H: I have not experienced the switch. Typically, before anything like that happens, I switch insurance companies instead.

**Wes P: Have you - in the past, have you sort of - does that happen, where you anticipate it could happen and you've switched an insurance company or -**

Thor H: Well, so at the time, I worked for a really small company that had a small - there were 30 users of the health insurance and I had a bad year medically, and then the next year, they decided to triple our premiums, citing me and two other users on our plan. So we switched insurance companies.

**Wes P: The whole - the employer switched insurance companies?**

Thor H: Yeah.

**Wes P: So in that case, do you feel that that's sort of a - I guess my question is, when those prices - or when the premiums went up, would you have considered that in a way a non-medical switch because it would've been so much more expensive?**

Thor H: Yeah, it was a retaliatory - I felt like the insurance was pretty much retaliating against us and making it cost-prohibitive for us to continue to use them as an insurance provider. And not necessary medication, non-medical switch, but overall health care, non-medical switch.

**Wes P: Interesting, so the insurance company just wanted to make it too expensive to work -**

Thor H: They wanted to make it hurt for us, to continue to be that deal or to be on their plan.

**Wes P: And you - and did you look into how much your medication would've cost on that new plan had you stayed with them?**

Thor H: The medication would've stayed the same. It was still on the same schedule of copays, so -

**Wes P: But just the premiums were much higher?**

Thor H: Mm-hmm.

**Wes P: So what are your thoughts about non-medical switching overall? And do any of the words on the screen resonate with you? Anything -**

Thor H: All of them. I think "Bad-Faith" is probably my favorite one because up until - I've had insurance my entire life. I'm in my mid-30s. I've had a few medical issues, but overall, I've been a net contributor to insurance for most of my life. And then I have a situation where I actually need insurance, and their profits become the priority, instead of me being a user of insurance. So "Bad-Faith" is a fun one. I think when I took the quiz, I put "insurance" - or the pre-work I did. Insurance practicing health care [INSURANCE].

**Wes P: I have that. I'm just going to ask you a little bit - tell me a little bit more about your thinking there.**

Thor H: I think it's people who are not licensed to practice health care have made decisions that, a drug, because it is novel or does not have a generic or whatever the case may be, has become too expensive for them to continue to pay for it, so they institute step therapies, where you have to start out with this super cheap drug, also has a ton of side effects that are undesirable, and they want you to start out with that one, to see if that cures your problem, whether your quality of life is taken into account or not.

**Wes P: So it's sort of the non-medical part, it's really no basis in -**

Thor H: They're not practicing medicine. They're practicing finance.

**Wes P: Thanks, Thor. Greg, I'm going to jump over to you. I know you mentioned you've had experience with a switch in the past, that your doctor informed you of it. Can you tell us a little bit more about your experience?**

Greg J: Well, I had my blood pressure medicine changed, that was the subject. And I was doing fine on the old stuff, and they said, "You got to switch over to the new." And went through an adjustment period, but then I finally got used to it, and I'm still using it, so that's what happened to me.

**Wes P: So a few questions for you. When your doctor sort of let you know, in that case, how do you think -**

Greg J: I think - actually, I think the pharmacy let me know. The doctor did not.

**Wes P: My mistake. So the - so you went to pick it up at the pharmacy and they told you that there'd been a change at that point?**

Greg J: Right.

**Wes P: So what was your - what were your steps to sort of figure out what was going on there? Did you call your doctor? Did you call the insurance company? What -**

Greg J: The - a better description would be I renewed my prescription, I went to the pharmacy, the cost went from here to way up here, where I said, "Time out." Contacted the doctor, he wrote another prescription that was similar, but not the same, and I picked that up. It worked reasonably well, and I stuck with it. That's maybe a more comprehensive description.

**Wes P: That's helpful. So in that case, you had your original medication, you went to the pharmacy, they were - you had now a sky-high price, so you went to your doctor and got a different prescription for - is it - was it for a different medication, then?**

Greg J: Slightly different.

**Wes P: Slightly different. And then the costs weren't nearly as high with that, then?**

Greg J: Correct.

**Wes P: Was there any -**

Greg J: And to be honest with you, I look at the screen, these are much younger people. When you get to be my age, you kind of network and you talk to one another. And you probably say jokes about it like Saturday Night Live, a bunch of old folks, sitting around, rocking, and talking about medicine and all the aches and pains they have. Well, it does have some productive input from that, and you find out who's taking what and what they're paying, and this person's taking that and they're paying this. And you ask the doctor, "Well, can I take this over here? It's cheaper." And there's a little network you get to. And so in time, you'll probably find out about those networks. It's quite real.

**Wes P: That's helpful. Thanks, Greg. I have a couple of questions based on that. When your doctor prescribed the new medication, was that something that had learned from another person in the network about or in your sort of circle of friends and family and acquaintances that someone else was on that medication and you thought that would be a better solution or was that the doctor's idea, to put you on that?**

Greg J: Well, it was the doctor's idea that when you see a Z medication. I knew of that medication because I had a friend that used it. So it wasn't brand spanking new to me. I'd heard of it.

**Wes P: You'd heard of it. Was there ever any conversation with your doctor about other options? Going to the insurance company, trying to the appeal the change, anything like that?**

Greg J: No, we never considered going to the insurance company. Now, I'll tell another story. I had cancer, and I was on a chemotherapy and had other attributes to it. And the oncologist I had said, "It's going to go generic." Well, I called the company, said, "When are you guys going to go generic?" "We're never going to go generic. There's years and years and years to come." But guess what? In nine months, they switched generic. So I had a really bad feeling about the insurance company now and pharmaceutical companies. And what they told you may not necessarily be what the outcome is.

**Wes P: That's good to know. So in that case, did you end up switching over to the generic or -**

Greg J: Yeah.

**Wes P: You did. Thanks, Greg. And a couple more questions for you. I'm interested to hear more about your experience. Did - is this something - did you ever hear it referred to as a non-medical switch or is that not a term that you'd heard until you took this survey?**

Greg J: Well, I had not heard that term before. But in the group of friends I have, it's happened, where something happens, someone had to change medicine because there's - it's gotten out of reach and they did this over here and they finally got it worked out. So from my perspective, it's not unheard of. It happens, and you just have to deal with it and find another medication that you can take that does similar work for you.

**Wes P: Is that usually the strategy your friends take? You said they have similar situations. Are they usually looking for a medication or has anyone ever tried to go to bat with the insurance company and fight them on it?**

Greg J: I really don't know anyone's who's contacted with insurance company or a pharmaceutical company other than what I just described. And excuse me, ask, "Is there an alternative?" Usually, figure it out with the medicines that are available to you, take one of those. It's just, what tier they're in, if this medicine's in this tier, you try to catch a tier down here that does similar kind of work. And you are more careful with the medication and what tier they're in. They become aware of that.

**Wes P: Makes sense. Another question for you. I have - I feel like have 100 questions for you, so if you don't mind -**

Greg J: I can call back.

**Wes P: You're on the hot seat. Did they ever give you any reasons for why the price of your original medication changed, for the blood pressure?**

Greg J: No. I think, to be honest with you, people accept it and go on down the road. And it may not be - maybe if it we fought it, it wouldn't happen so often, but people tend to accept what they're told.

**Wes P: That was going to be my next question. And I think we can get into that further, so maybe I'll save that, is sort of the thought process behind wanting to fight that kind of change or not, so -**

Greg J: Well, you talked - was it the guy that you asked [INAUDIBLE] that's my middle name.

**Wes P: [CROSSTALK]**

Greg J: Is his name or something. I'm always going to take on a battle, but there's a limit to how may you can take on.

**Wes P: Did you have the feeling - when this happened, did you say to yourself, "What are my odds of winning this battle if I was to call the insurance company?" Did that ever cross your mind?**

Greg J: Yeah, zero and none.

**Wes P: Zero and none. Thanks, Greg. I'll leave you off for now. I appreciate you answering all my questions. And then CJ, I wanted to ask you one more time, because I guess I didn't have a chance to ask you about the word cloud. Was there anything that jumped out to you on the screen in terms of these words?**

CJ C: I'd say the word "stressful" and "insurance."

**Wes P: Insurance. And do you know anyone who has sort of experienced this? I know you said you haven't. Do you know of anyone who's gone through something like this before?**

CJ C: I believe I've had a friend whose regular drug got shot up, the price got shot up, and then it was to the point where just one dose was around probably eight K. So then she ended up just calling the drug company and they have this thing where they - you just pay five dollars and they send you it.

**Wes P: You mean a copay card or coupon?**

CJ C: Something like that.

**Wes P: Good to hear. And do you know - does that person call it a non-medical switch? Was it ever called that to them or do they just think of it as a price increase?**

CJ C: I think they just thought of it as a price increase.

**Wes P: Price increase. Thanks, CJ.**

Greg J: I did have a comment about that. I have a story to tell.

**Wes P: Please.**

Greg J: And I'm full of them. You can just tell me, "Greg, just go away." But I remember I was due for cancer, and the doctor said, "I've got some medicine that can help you, but it's on the pricey side." I said, "Well, let's give it a whirl." I was cocky. So I went down to the pharmaceutical area and I gave them my prescription. They said, "Your copay will be $10,000 a month." I went, "Holy crap." And your mind immediately goes into overtime, something like that. And pretty quickly, I said, "I am not going to pay that kind of money for medicine and wipe out my - our savings." I didn't - and I thought if I died and left her with money, that was the calculation I was going to make because I was not going to spend our life savings to save my life along those lines. I just wouldn't do it. And you can talk to people, and a lot of people have that same feeling. And I know of another family that did do that. He eventually died and then she was penniless. And that was just a horrible story. But when you have someone you've loved all your life and you’re partners forever, you'll do anything for them. And I was going to say, I'm not going to take it if I got to go through that, take her through it. You get into extreme feeling sometimes that go beyond just the mundane about a dollar more here or there. And you, CJ talked about $10,000, $8,000. And that keyed it. People can't do that unless you just won the lottery and not many people do that. That's just the truth. Thank you for listening.

**Wesley P: Great. Thanks, Greg. Question for the whole group, because it sounds like most people haven't heard the term non-medical switching outside of when we sent the survey. Is that correct? Has anyone else heard that term before elsewhere? No? OK. I see everyone shaking their heads. Rebecca, I was going to ask you, you mentioned that your partner has had situations where their medication has been changed. Do you know what they would call this or what it has been called in that situation?**

Rebekah D: I'm not sure if we have a - if I've heard a specific term for it other than just medication change. [CROSSTALK] insurance or scheduling reasons.

**Wesley P: Makes sense. Sure. OK. Thanks, Rebecca. All right. Thank you all. I want to jump to the next slide. We have a definition slide just to make sure we're all on the same page. And it's the same definition that you all saw in the pre-work so I'm going to read it out. I think we've talked about this at pretty, pretty, pretty good lengths thus far, but I want to make sure that we're all thinking of the exact same thing. The definition here is sometimes a patient who's stable on their prescribed medicine will change to a different medicine, not a generic of the same medicine, but a different medication, right? For non-medical reasons. This means the switch is made for reasons other than the original medicine not working or side effects or problems taking the medication as prescribed. Often non-medical switching results from changes to medicines that are approved or preferred by the patient's insurance company specifically within the formulary. For those of you who mentioned insurance, you were correct. Most cases, this is happening because the insurance company has made some change to coverage. Made it more expensive as some of you are already familiar with that situation or just changed coverage, so something's no longer covered. We do have two examples on the screen here and then two non-examples. I'll start with the examples. The first example is the prescribed medication is no longer approved by the insurance company, so it's no longer on the formulary whatsoever and it's been replaced by another medicine. And our second example, the out-of-pocket cost, which is the cost not covered by the insurance company for the prescribed medication has increased due to a formulary change. For example, $15 became $50, so the patient switches because they can't afford a $50 copay, for example. Now it's costing the patient more out of their pocket. And it sounds like we heard a few examples of that already. We have some non-examples here too. This is if a patient switches from a branded medication to its generic form. And Greg, I know you mentioned that switch from branded to generic. And then a patient is switched to a different medication by their provider - The patient is switched to a different medication by their provider because it's more effective or it has fewer side effects. There, obviously, there's a medical reason behind switching, so it wouldn't be considered a non-medical switch. I'll pause here for a second. Does this all resonate with anyone or does anyone have any questions based off of the examples? Anything like that?**

Greg J: Well, I have one funny story to tell. I have sister-in-law; takes heartburn medicine. I do too. And come to find out over-the-counter costs this much, but the generic prescription costs this much. Everybody I know that needs heartburn medicine, they get a prescription and get the generic to offset the over-counter. That does happen too.

**Wesley P: OK. So, the over-the-counter cost is higher than the prescription for the generic, so you'd rather have a generic in that case. Got it. Interesting. Thanks, Greg. Any other thoughts about any of these changes or does anyone feel maybe this actually has happened to them in the past? Anything like that at all? It's OK if not. I’m just trying to get a sense of the group.**

Greg J: OK. I'll raise my hand one more time. This always sticks in my crawl. There was a company that someone - I think, insulin or EpiPens and the guy bought the company and jacked the price 2000% and no one could afford it. That's just unethical and wrong. I had to say that. [CROSSTALK]

**Wesley P: No, it's fine. I got it. And I think that might be a little bit different than what we're talking about here because this is mostly insurance company; getting involved in changing the price. Whereas it sounds like that was more of the pharmaceutical manufacturer who may have changed the price. But I see what you mean. Price is becoming unreasonable. I guess my question is, it sounds like in your case, Greg, this second bullet under examples, the out-of-pocket costs increasing due to a formulary change. We have an example from $15 to $50. That sounds like that's what happened to you with the blood pressure medication. Does that sound right?**

Greg J: That's correct. I think the difference was higher than that.

**Wesley P: Got it. It was a much greater financial difference for you?**

Greg J: Yes.

**[////]**

**Wesley P: Got it. Thanks, Greg. All right. We have a break now. I think we're a little bit ahead of schedule, but that's OK. We have a lot to talk about when we get back. Let's take a quick five-minute break. I see it's 2:51 now. Let's just come back at 2:57. I think it's almost 2:52. 2:57 Eastern. So, just five, six minutes from now. And we'll reconvene. And if you're going to step away, just do me a favor; mute and turn off your camera and then turn it back on when you're back. Thanks, everybody. We're just going to give everybody a couple of more minutes then we'll jump back in.**

Greg J: I do have a story to tell. It's just me.

**Wesley P: Hey, Greg. Give it one minute because -**

Greg J: Well, I can just talk to you. It’s stories for you.

**Wesley P: Oh, stories for me? OK, go ahead.**

Greg J: Is there anybody on your team that are cancer people?

**Wesley P: Like core avatar, like our company team?**

Greg J: Yeah.

**Wesley P: Yeah. We might have a - Some people work on some of the oncology programs.**

Greg J: Well, just to let you know, I had stage four prostate cancer. It migrated to my lungs. I caught COVID, and guess what happened? The COVID ate the cancer.

**Wesley P: I think you've told me this in the past.**

Greg J: It might be. I wasn't sure if you heard or remembered or not.

**Wesley P: Well, I remember it because I remember thinking that's wild. But yeah, you went to the hospital, and then a couple of weeks later, they said that you were cancer-free.**

Greg J: Yeah. In fact, about now six weeks ago, I had a body scan, and the negative.

**Wesley P: Great. Love to hear it.**

Greg J: Yeah. That's two years.

**Wesley P: Whatever happened, I'm glad it worked. I'm glad it worked well.**

Greg J: I wasn't glad it happened. That was not a fun place to be in hospital for four months. I got raked over the colds.

**Wesley P: Oh, wow. It was that bad. I'm sorry to hear that.**

Greg J: Yeah.

**Wesley P: Well, at least it's good to hear you’re negative though. It's still negative.**

Greg J: Yeah, it is now. That was the tradeoff.

**[////]**

**[//NMS Taking Action//]**

**Wesley P: Right. Good. Well, I think I saw a few people jump back on. I see we're back. OK. Let's go ahead and jump back in and we'll let the others catch up once they get back. Our next slide is about taking action. I want you all to imagine what would happen if you were to get a non-medical switch for those of you who've never had one. What would you do? And then Greg, for you, since I know you've had one, I want you to think a little bit more about what went through your head when you got it and some of the options that you could have taken. But I'll wait to get to you Greg because I want to hear from some of the other folks first. I want everybody else to imagine if they did get a non-medical switch, obviously not a fun situation, what would your first thoughts be? Who would you go to for questions? What questions would you have? CJ, if you don't mind, I'm going to start with you again. Tell me a little bit about what goes through your head when you think about this kind of scenario.**

CJ C: I personally don't have insurance. I have healthcare with the VA. But if I did and I was switched, I would feel very frustrated and very stressed out because one, I fight with them already to get proper healthcare, and not even considering me and switching me out to something else; I have a problem with. And then two, I don't pay for medications as well, so it's free, but I'm only thinking about how this drug do my body.

**Wesley P: You're thinking about the new medication they would want to switch you to.**

CJ C: Yes. And how [CROSSTALK]

**Wesley P: Sorry.**

CJ C: No, I'm sorry. I was going to say and how it would affect me and if I could tolerate it or if it'll cause me any problems.

**Wesley P: Got it. I have a few questions for you about the VA insurance. Are they covering just specific medications or are they pretty much covering most everything? I guess that's my question.**

CJ C: I feel like they cover most everything.

**Wesley P: So, you've never been in a situation where you'd be worried about them not covering something?**

CJ C: Yes.

**Wesley P: Good to hear. Got it. But if you were in this situation, like you were saying, you would have to be thinking about how would this new medication work with you. Who would you go to with some of these questions? Would you be calling your doctor first or who would you be talking to?**

CJ C: To be honest, I have no idea. I would probably talk to my doctor first, see what he has to say. And then probably, my community, my IBD community, see what they have to say and then go from there.

**Wesley P: And would you have any - I guess my next question for you is, would you think about trying to potentially fight the insurance company or to more or less try to appeal the decision? You could see on the screen, it's called a challenge with the switch, where you call them and have your doctor intervene. Is that something that you would consider doing?**

CJ C: Yes. Especially if the drug is working for me.

**Wesley P: And how would you think about starting that process? Where would you start?**

CJ C: I would most likely set up an appointment with my doctor to talk to him in person and then go from there.

**Wesley P: You would want your doctor to take the lead on the challenge process. Is that what you're thinking?**

CJ C: Yes.

**Wesley P: And do you think your doctor would support your decision to want to challenge a switch?**

CJ C: Yes.

**Wesley P: Another question for you. I've got a ton for you. How long do you think a challenge could take? What do you think the timing is?**

CJ C: I feel like from weeks to months possibly.

**Wesley P: Would you be concerned at all during that period about your medication, how much you have, what's covered, what's not?**

CJ C: Yes, I'd be concerned if I'm not receiving my old drug, how long would it take me to receive my new one?

**Wesley P: Right. OK, got it. Thanks, CJ.**

CJ C: Thank you.

**Wesley P: Thor, similar questions for you. If you were to get a switch, what would your first thoughts be? What's your reaction?**

Thor H: Well, I'm feisty, so I would definitely fight it. I would be stressed. The first thing it would derail my day and probably my week, unfortunately. It's taken so long to get to where I am now. And I'm still not where I want to be. Any back step is not ideal. Yeah, I would fight it. And I actually have thought stuff with my insurance company several times. But that was more around frequency of dosage and not changing the medication itself.

**Wesley P: How was that process? Was that difficult? Were you jumping through a lot of hoops or was it [CROSSTALK]**

Thor H: Back to your first question, I just realized I didn't answer to that about who I would reach out to is I have an excellent relationship with my GI on past perks engagements. I've talked about how much I love him. And have even considered not taking a new job because I wasn't sure if he would be on the new insurance that the new job would have. You know what I'm saying? So, yeah, I feel like I would text my doctor and I feel like last time we did this, it took a couple of months to increase dosage and it took like four challenges, and on the fourth one we've hadn't got.

**Wes P: Gosh. That was around the frequency of dosage, sorry?**

Thor H: Yeah, from six weeks to four weeks.

**Wes P: But that took four months you said, did I hear you correctly?**

Thor H: All total, we've been getting denials very quickly, like within a week.

**Wes P: It can take a while.**

Thor H: Yeah. And I didn't do any of the leg work. I literally just told my doctor what was happening. The biggest issue I was having was with my - we were increasing dosage not necessarily because I medically needed it but because of the incompetency that my specialty pharmacy had, and they would require - I would get a blanket pre-auth at the beginning of the year. But every time it was due to fill, the specialty pharmacy would say we need a new pre-authorization every six weeks, and that would take a week. So I was inevitably a week late, minimum. I was on a seven-week treatment plan instead of every six weeks. So, which it was kind of like, it felt incompetency to save money because by the end of the year, I would have missed a total of one dose which the pricing of which is 20 grand or something like that. I'm like hey, what better way to improve your numbers then to not give people the medication they need. That's a tangent.

**Wes P: That's helpful to know. So in the past, it's taken a while but your doctor's doing the legwork. You're just waiting to hear an answer. Do you have a sense of, I guess, does your GI doctor have people in their office helping them?**

Thor H: Oh yeah, I don't think he's physically doing anything. I don't know what her title is. Her name is Kayla and it just says I'll get Kayla working on this today. I think she might be a medical assistant, but I feel like she's more than that.

**Wes P: And do you have a sense that these individuals have or that this individual Kayla, is this something that you think that they have?**

Thor H: I would not be surprised if that was her full-time job like within the clinic, within the GI clinic.

**Wes P: That was my question was around time and effort that goes into it.**

Thor H: I've spoken with her a few times just about her needing some things at get go, but she seems to be very well versed in challenging stuff.

**Wes P: Do you ever interact with her on anything aside from insurance issues, or does that really seem like her -**

Thor H: It seems like it's her full-time I think.

**Wes P: That's helpful just to how the office is set up and who would handle something like this. If this were to happen to you, if you were to receive a request, you would go through the same kind of hoops. You would think doc, go to your doc, have them deal with it, right?**

Thor H: Yeah, I have a feeling that I text him and he says, "Kayla, this is happening again," and then she challenges and then he signs whatever forms. That's really what it seems like.

**Wes P: That makes total sense. One other question for you. Would you consider also telling it at any point to your insurance? Do you think that could help?**

Thor H: Oh yeah, I have. I'd feel like I am less helpful than Kayla is.

**Wes P: Do you think it helps speed the process along at all or is it just [CROSSTALK]?**

Thor H: No, I really think it just is a wasted couple hours of my day. I don't feel like anything really changes. I've spent a lot of time on the phone with different insurance companies, like as I've changed over the past couple of years, and I don't really feel like anything ever has happened. Am I going to stop calling? I'm still young, I've got energy, but if I was like Greg, I probably wouldn't. I've got other stuff to worry about. I've got three kids and a wife who also don't want me on the phone either, but I think right now we all still have energy. [CROSSTALK].

**Wes P: No it makes sense. I think you answered all my questions, but I've got another question for you on the next slide, so I'll hold that for a second if you all want to wait. Cool. Thanks. Rebekah, I'm going to jump over to you. So I know you haven't experienced in the past but imagining that you did, tell me your thought process. Who would you go to first?**

Rebekah D: After hearing Thor's story I realized that I kind of had this happen where my disease-modifying medication was not authorized to be infused at the infusion center that I was previously going to, and they wanted me to go to another one with really bad reviews in a really sketchy part of town. And I struggle with routine so putting me in a different infusion center would have thrown me off a lot. So I got that letter from my insurance company and then immediately messaged my doctor on My MyChart, and was like hey, I got this letter. I know that my healthcare system handles all the appeals for me because I've had to appeal care retroactively. It was a whole thing, it was frustrating and weird. But I pretty much just messaged her and I was like, "Hey, here are my reasons for not wanting to do that. Please fight this as hard as you can," and she did, and it was fine. It turns out I just needed to go to a specialty pharmacy so that was frustrating. So my initial response was definitely indignation like, "How dare you. Like no, this is working, stop messing with it. Don't do that." But yeah, the first person that I had went to is my doctor because I knew from a previous incident that they do handle all of the appeals. But I was ready, though. I was like do I need to show up in court, do I need to find an insurance lawyer? I will do that, I absolutely will do that.

**Wes P: You were prepared to invest some of your time too, not just of the doctor and to read - So I have a couple of questions.**

Rebekah D: Correct. Because usually my first thought is did they code something wrong? That's usually my first thought. Because I knew a nutritionist who also submits things to insurance company. She's like, "If I code it as this, they won't take it. But if I code it as this, it's fine." Both are true, but I don't know.

**Wes P: It could be a small snafu on the insurance company's part or something like that that blows up. I guess another question for you. You mentioned your healthcare system appeals the decisions. I'm assuming are you referring to your neurologist? Is that who we're talking about here, your doc?**

Rebekah D: Yes.

**Wes P: Are they part of that healthcare system? Is it all one integrated system?**

Rebekah D: Yes.

**Wes P: Do you think when you're telling your doctor about this in your doctor's office, do you think it's the individuals in that office or do you think that it's another - somewhere else in the healthcare system, somebody else is making the calls and appealing them?**

Rebekah D: I am sure there is an insurance coordinator who's doing all of that. So how my neurologist has explained it to me for both work things and insurance things, she pretty much just writes up her opinion and sends it off to the powers that be and they take her word nearly for verbatim and plop it on there and send it to the other powers that be. It's worked pretty well so far.

**Wes P: And it sounds like it was pretty quick when it happened, you managed to - how long are we talking?**

Rebekah D: Less than a week -

**Wes P: Les than a week.**

Rebekah D: - I would say that we had figured something out.

**Wes P: Would you have the same confidence or do you think that an issue like this that we're talking about today could be solved that quickly? Or do you think it could be drawn out?**

Rebekah D: I think there's definitely a chance things could be drawn out just judging by how long my last appeal took, which was for retroactive service, so I was waiting to see if I was going to get a bill for 5K or not. So I'm not sure if I have much faith in anything else being resolved quite that quickly, especially if it were more than just, "Oh, you can just switch pharmacies." Especially if it's a bigger issue than that. I would think it would take longer.

**Wes P: Do you have like a maximum time that you'd be willing to wait? I guess my question is how long could the process get drawn out until you say I might consider another option?**

Rebekah D: I would consider another option immediately just because of the nature of my disease. I would not want to miss more than one dose, so I would probably wait for the appeal decision to come through on my infused medication and then ask my doctor for a temporary oral medication that I could just take until the infusion was approved.

**Wes P: You're looking for short-term solutions until they can figure out the picture?**

Rebekah D: Yeah.

**Wes P: That's really helpful, Rebekah. Any other thoughts on any of this? Some on challenging or appeals? Anything you feel we haven't covered?**

Rebekah D. I don't know. When I got my first letter telling me that my insurance denied the care, it was absolutely terrifying and then I saw all of the paperwork. And I was like, oh shoot, I am a writer. I could do this but this is so exhausting, so it takes a lot of time and it's a lot mental energy just to, all right, who do I need to call? Who do I got to talk to next? Or do I need it says here like there may be a court appearance, what?

**Wes P: I'm sorry about the background noise.**

Rebekah D: It's OK. It's really intimidating, it's kind of scary.

**Wes P: Agreed. That's helpful. Thanks, Rebekah. I wanted to jump over to Rasheeda and ask you the kind of questions. Rasheeda, what's your thoughts if you were to receive a request for a switch. What would go through your head? What do you think your options would be? Who would you go to first?**

Rasheeda J: I trust my physician, so I definitely would consult with her before making any type of switch in medication. And it would probably be a long consultation just because my current medication has worked for so many years. But yeah, I would rely on her opinion. Depending on the cost, if it was just a couple of bucks more, that's no sweat. But if you're talking hundreds or thousands more, I don't think I would have a choice but to fight to be able to find something that would be more feasible.

**Wes P: If it was a high enough cost change, you're feeling you don't have a choice, you've got to challenge it.**

Rasheeda J: Yes.

**Wes P: Have you ever had a conversation with your physician? You mention you have a good relationship with them. Have you ever had that conversation about if you ever had any insurance issues, what you would do anything like that?**

Rasheeda J: Well fortunately, when I first started the medication, there was already an advocacy program that worked with lowering the cost of my medication working with the insurance provider. So that hasn't been an issue as of yet. I'm dealing with a separate issue where I had to have some iron infusions, there was a savings program that I did have to jump a lot of hoops to try to lower the cost and it was a matter of thousands of dollars, and it was very cumbersome. I'm thinking about what Rebekah said just long packets of making sure everything's filled out specifically in the way that they require and then sending it ad resending it and getting on the phone having to make sure they've received it, and it can become very time-consuming as well as frustrating. But fortunately, that was just a one-time occasion, so I couldn't imagine if it happened more than once having to deal with it more than one time.

**Wes P: But do you think in this case your doctor and their office would be able to take on the brunt of the work and do most of it? Or do you think you would have to get involved as much as you did before?**

Rasheeda J: Yeah, it seemed like once they provided that option, it was up to the patient to take advantage of the savings program. with that one, I don't think I had an option to rely on any type of advocacy or support from that doctor's office.

**Wes P: But in this case, do you think you would have to get involved? Would you want to get involved? Would you want to call the insurance as well as your doctor and chime in, or would you let doctor handle it? I guess that's my question.**

Rasheeda J: Yeah, I would. To be quite honest, I've always just gone with the insurance that my employer has provided whenever I've signed up for any type of benefits. So just thinking about shopping around for insurance, that's never even crossed my mind. But if it was an NMS situation, I think I would have to. And now I'm just taking notes from some of the other participants like if it ever happened, I think I'd know the route to take now.

**Wes P: You would have to think about your options. Would you consider picking up the phone and calling your insurance and saying, "Hey, I know my doctor's challenging this. I also wanted to give you a call and get more information." What do you think?**

Rasheeda J: Yeah, now I would.

**Wes P: How long do you think this kind of challenge could take? How long do you think that process could be?**

Rasheeda J: Well I know with the other issue, it wasn't necessarily my insurance company, it was just I guess getting their approval from the savings program and that did take about two months, so I can only imagine it would take several months if I were to take on a challenge like this.

**Wes P: How long are you willing to wait for an answer? Do you have a short-term plan or a solution like Rebekah was kind of mentioning?**

Rasheeda J: For my condition, depending on if I had specific types of flareups, there are other options as opposed to taking the long-term medication, so I would have to rely on those. But even there would be a time limit as to how many times I could take those options if there's like steroid shots or something like that. Or if it's affecting my eyes or my lungs, then they would want me to stay off of my medication for an extended period. But if it was a matter of the cost, then I would just - and as long as I needed to.

**Wes P: Thanks Rasheeda. And Greg, last but not least. Thanks for being patient. I know you mentioned you've been through this process before, you've had your medication to become much more expensive, at a more higher out-of-pocket costs. Did it ever go through your head to think maybe I call the insurance or maybe talk to my doctor about challenging it. Was that ever something that you consider?**

Greg J: No, I didn't do that. But I do have a sad story.

**Wes P: Go ahead.**

Greg J: Duke has an advocacy group and I think it was something somewhere, and when I couldn't afford my medicine, they actually looked at grants to give me and so they are very strong and, if you will, took care of me and provided full service. So they're to be commended in many respects.

**Wes P: Were they successful in finding that?**

Greg J: Yes.

**Wes P: They were.**

Greg J: I wound up, I think I paid six bucks -

**Wes P: Six bucks, that's pretty good.**

Greg J: - on 10,000. You figure that one out.

**Wes P: That's great. I'm glad to hear that. There's advocacy, there's an advocacy group through your healthcare system that could help. If you were in a situation where you were receiving another non-medical switch request and you talk to your doctor, and you said, "Look, maybe we should challenge this, do you ever see yourself going through that process and asking your doctor to challenge it with the insurance company?**

Greg J: Who were you talking too?

**Wes P: Sorry, Greg, still you. Sorry about that. I guess my question is for you Greg, would you ever see yourself in a situation where you had gotten another switch and it was expensive again. Could you see yourself going to your doctor's office and saying, "Can we challenge this? Can we go to the insurance and try to fight them on it?"**

Greg J: Yeah, I would do that.

**Wes P: You'd do it?**

Greg J: Yep.

**Wes P: How long would you be willing to wait for a decision from the insurance company?**

Greg J: Several weeks. If it got two months, I think that's too much.

**[//NMS Effects//]**

**Wes P: Two months. I think that's all my questions on this slide. I wanted to ask a little bit about what kind of effects medical switching could have? So I realize most of you haven't had experience. Greg, I know you've had a little bit of experience with it. So I just want to hear about some of the things that non-medical switch could affect in one way or another. And whether you feel that there could be an effect. So you could see the first bullet here as the relationship with your provider. So I want to open this up to the group and see if anyone feels that a non-medical switch could impact your relationship with your provider at all. Thor, I know you mentioned you have a really strong relationship with your GI doc, you can easily get in touch with them. Could you see a non-medical switch at all impacting your relationship with your provider? And if so, how?**

Thor H: I think that I know interest by the doctor really well. And I think that he generally wants what's best for me. So if I am non-switching- If I am switching not because of it being better or something that he would advise product, I think that he would be on my team. By the way, I looked at Kayla's email signature from the last email I had from Mary Kayla, is a lead medical assistant. So she's just part of my care team like that. Just good at this I guess. I don't think it. Maybe in a really stressful moment, I could just be frustrated with him and that could be strainful or that could strain our relationship. But I don't think- No I think we're solid.

**Wes P: You're solid.**

Thor H: Yeah.

**Wes P: Good. Good to hear. Same question for the rest of the group. Does anyone else see any way in which this could impact your relationship with your provider? Change it at all, for the better or for the worse? And I guess I'm thinking a little bit about trust with your provider or communication, anything that could change at all.**

Rebekah D: I think for me a lot of it would come from the willingness from my provider to fight the insurance company. Which so far I have seen pretty good things from all of my providers as far as, if you want it, if you need it, we'll fight to get it for you. And some of my providers have even gone to say if we cannot get it for you, we will send you to wherever. We will refer you up to Mayo, we will send you out to wherever you need. So it would really depend on kind of their trajectory after that non-medical switch. So if they're just like, Well, that's how insurance goes, then I would definitely not be as nearly as trustworthy. But if they say, well, this is as far as I can take you on this road, now is the time for me to hand it off to somebody else, then to me, that's an indication of a good healthcare provider.

**Wes P: So it's the effort that's been made, it sounds like, that's helping build that trust. If it's not being made then maybe you're going to lose some trust in your provider. Versus if they do, you'll continue to have that strong relationship. Is that pretty much it?**

Rebekah D: Absolutely, yes.

**Wes P: Great. Thanks, Rebekah. So did anyone else feel the same about their provider? Is that sort of an important component of your relationship with your providers, how far they're willing to fight and help you in this kind of situation?**

Rasheeda J: Yes, advocacy is very important for me when it comes to my physicians, my rheumatologist. Like Rebekah mentioned, just how far they are willing to fight, the amount of information they provide, making sure that I'm well informed with the decisions that they make and why they're making them, and giving me enough information to make the best decision for myself. And then supporting me in that decision.

**Wes P: So it's multiple things. It's, you got to be well informed, they need to give you that equation, and how much are they willing to go to bat for you with the insurance company.**

Rasheeda J: Yes.

**Wes P: Makes sense. And if not, if they're not willing to do that, are you feeling less trustful? I guess that's my question.**

Rasheeda J: I think because of the relationship I've already built, I don't know if my trust would be easily broken. But if those things weren't met, which typically they always have been as far as the support, the advocacy, and the information. Then I probably would start to question, OK, is this the right provider for me? But even then I still probably would take what they- I would take what they have to say. I'll weigh it very heavily.

**Wes P: And that's- Would you say that's based on your already having a really trusting relationship with that provider? It's sort of, the foundation's there already?**

Rasheeda J: Yes.

**Wes P: Thanks Rasheeda. Any other thoughts from the group on that- this particular topic about healthcare provider?**

CJ C: Let's say for myself it'd depend on how I was doing overall with my health. If I was in a flare and they're fighting to change me off a medication, and my doctor's not fighting for me, then that's when I would kind of just lose trust and it will put a strain in the relationship. But if I was healthy and they're trying to switch me just for profit reasons, then I'd lose trust again.

**Wes P: So you would feel the same way either way. Even if you were healthy versus not being healthy. You're expecting your doctor's going to basically do everything they can for you no matter what?**

CJ C: Yeah.

**Wes P: Makes sense. So it doesn't matter how you're feeling, you expect them to absolutely do everything they can.**

CJ C: Yes.

**Wes P: And I guess as a follow-up to that what does that mean? Does that mean a lot of time spent helping or does that mean sort of keeping you in the loop about what's going on? Tell me a little bit about what you expect from your provider in these situations.**

CJ C: I would want to be informed on what's going on, like each step. Keep me in the loop and just making sure that we're doing the best we can to get exactly what we need.

**Wes P: Thanks CJ.**

CJ C: Thank you.

**Wes P: And the next question- the next two bullets here are kind of related. Stability on medication and health, quality of life. I think these things are all obviously intertwined. So it's kind of the same question. How do you think, if at all, non-medical switching could have an impact on your stability on medication? That's the first question. And then the second question is, could that have an impact on your health as well? I think we've heard a little bit about this already. But I wanted to hear- I wanted to ask it directly and hear. Is non-medical switching, do you consider it a threat to your stability, on education? Think about how long it took you to find the right therapy. Thor, I know you mentioned that it took you a very long time to get to where you are and you're still not quite where you want to be. So from your perspective, is it frustrating that what stability you've built up be sort of erased by a non-medical switch or at least hurt?**

.

Thor H: Yeah. It's-

**Wes P: Oh, hang on Thor you're muted.**

Thor H: Sorry. All of that and more. If I were to switch medications that better be for something really good. Something that's supposed to be even better than the one that I'm currently on. But I think my relationship with my provider would be the same. I would follow his lead there of course. I would of course have questions, a lot of questions before accepting. But I think our relationship would be fine. I think that I am generally stable on the current medication. So I definitely like on that six weeks cycle that I'm on, once I get to week five and a half, I definitely feel, not withdrawal, but I feel the symptoms of my disease intensifying. So when I'm on week seven I'm terrible. So I think the idea of not having the medication is something - it will need to be a Band-Aid situation where you're pulling the Band-Aid off or pulling the bandage off and putting the Band-Aid on. It would have to be some pretty seamless navigation there in order for it to not affect my health intensely.

**Wes P: And I have a- Go ahead, sorry.**

Thor H: No, I'm good.

**Wes P: I was going to say I have a question about kind of what Band-Aid solutions there could be. But I'm interested also in, you mentioned it took a long time to feel where you are now, which is quite mostly stable. Like you were saying. How long did that take? What was that process like?**

Thor H: So I've had Crohn's for 22 years. It started with a really bad flare and then kind of went into remission for a really long time. And then the beginning of the pandemic, like April 2020, I had a flare with an emergency surgery, but I ended up in the hospital with. And it was- probably it wasn't until 18 months later where I felt kind of normal-ish. Even then I can tell that the medication is definitely holding it all together. Like holding the stitching of myself together. At least in my abdomen. The Band-Aid situation would probably- I would expect it to, and I am very interested in missing. However not a physician and or much less a gastroenterologist. But I would assume that I would take both medications at the same time and wean off one, and replace it with the other, hopefully.

**Wes P: So question for you. During that 18 months when you said it took, post your hospital visit, for that flare, was there trial and error to finding stability? Were you- You were going through multiple medications or was it just one?**

Thor H: Yeah. So it started out with steroids. And then we had more targeted steroids and then dipped our toes into the biologic. And I also had complicating factors from the surgery. So they were very hesitant to put me on anything that would worsen that situation. So they were even hesitant to put me on the steroids for a little while. And my case is very unique. I haven't heard of a lot of people who have experienced the same thing. So take that with a grain of salt. But it just- We only ever tried one biologic. And after my infusion I felt significantly- I felt, within a few days like things were getting back to normal. For the first time since the surgery.

**Wes P: How long did that take to get to that point? Was that the full 18 months you said or was it a little-**

Thor H: No, that was probably, let's see, that was in October of that year. So that was six months later, and then after a year of being on the medication. It really started kicking into high gear and kind of in a cruising, in speed.

**Wes P: So like the second half of the year it started to get better and then like you said, after that year mark you're starting to feel a little bit more like yourself. Is that correct?**

Thor H: Yeah. It felt normal until- not like, I was diagnosed when I was 14 so I don't know if I remember bowel movements from before having Crohn's. But basically, I feel like where I was for about that giant gap of time where I hadn't had any issues of note. And that's where I'm at now. However, I still have a lot of fatigue and a lot of the other stuff that's associated with Crohn's. And meanwhile, I would like to get to what a normal person is. Not necessarily normal for me but normal person without IBS.

**Wes P: So I guess what I'm asking because- and I appreciate you giving me all the background because what I'm trying to understand is if you were to get a non-medical switch if this was to happen to you, do you think you'd be looking at another year or so of trying to find the right medication, do you think that's what would happen?**

Thor H: I think it would be at least a year.

**Wes P: A year.**

Thor H: Yeah. Because my doctor was very unwilling, as much as I trust him, he was unwilling to try to mess with anything before we had given it at least six months.

**Wes P: So you're kind of trying it out for a few months and then it's OK, let's see if it works. And so from your perspective, who has a year to give, right? Is that frustrating to you that that could happen? I guess it's my question.**

Thor H: It is this looming anxiety that I have in the back of my mind all the time, yeah. That's OK.

**Wes P: Thank you, I appreciate it. And I'm sorry to even bring up the possibility [INAUDIBLE].**

Thor H: No, it's fine.

**Wes P: Sure. Thanks, Thor. Rasheeda, same kind of question for you. Tell me a little bit about how long it took to- Do you feel that you've reached stability on medication? And how long it took to get there?**

Rasheeda J: Yeah. So actually, recently I've had periodic- I've had to take breaks on taking my medication with the birth of my daughter. Because it is a biologic and so whenever she has to have certain vaccinations, I have to stop taking the medication because I'm breastfeeding. And so it does have an effect on I guess my range of motion and how I'm feeling. So I can only imagine if I had to consider switching my medication, how it will have an effect on health. Because even just taking a break for four weeks or a month at a time it is- it does take a toll on my body.

**Wes P: Thanks Rasheeda. Rebekah, same question for you. How long did it take to find any stability, if you have it at all, on your medication? And what's your thoughts about potentially having to go through that process again if you were to get switched?**

Rebekah D: My stability from my infusions has not been great. Because I do travel quite a bit. So sometimes something will come up I'd like- The first time I had to get off of my infusion schedule was for a family emergency. So I'm still navigating what to do when that sort of thing happens. So really, my stability hasn't come until probably within the last two months. So even with the struggle of scheduling the infusions and going to the center, and coordinating it with work, and coordinating it with the car and all of the other things, that's been a big struggle. If I had to switch medication, or even wait for an appeal, I would probably switch to an oral medication in the meantime. And I am notoriously awful at taking pills. I cannot remember to take them. The brain fog, it comes with the MS or maybe I'm just forgetful, I don't know. So if you put me on a pill, I would not be very successful. I Would have a less than perfect patient use and it probably would not go very well.

**Wes P: So that's not a great option in your mind. That makes sense. So if in that situation where you're being asked to switch and you're looking for something in the meantime as a sort of temporary fix. Which is what it sounds like, the oral medication would be for you. Is that- I guess, tell us a little bit about your thoughts in that situation. Is that frustrating for you or not? Or is it difficult? Is it going to set you back several months because it took this long to find stability? Tell me a little bit about that.**

Rebekah D: It would be extremely frustrating. I would resign myself to the oral medication and do my absolute best. But then I would probably give myself a deadline and say, OK, after about three months. I'm guessing it would probably about three months. If I got a flare-up before then, it would be before then. But providing that I had no change in symptoms after about three months, I would start looking at the more aggressive therapies that are in a similar class. But those have side effects that I do not want, primarily a completely disrupted immune system, and we're still dealing with a number of now pandemics at the same time, so I would really rather not, not have an immune system right now. So it would be a really big choice of continue taking a less effective medication or give up my immune system and access to the world for a more effective medication. So yeah, that's what I'd be looking at, so I give myself about three months to make that decision and then see what else is out there.

**[//NMS Support//]**

**Wes P: So we do have one more slide, and thank you for the information and your thoughts and everything like that. I really appreciate it. We do have one more slide, it's sort of a short slide. Just about kind of- we talked a lot about the issues here. We talked about what's at stake. I want to hear what kind of support could be helpful if this process were to ever occur to you. Or Greg, in your situation, when it did happen to you, what could have been helpful, or what was helpful in terms of what you would need during that process? And what kind of support could make it easier to remain on the medication that you were originally taking? I'm going to open up to the group and see if there's anything that really pops out that could be helpful that you can think of at all to make your lives easier if this did ever happen to you.**

Greg J: Well again, I think conversing with friends who been down that road, and they can make suggestions is good. Of course talking to your doctor. He, my doctor, doesn't have an advocate like my oncologist does. It's a different kind of thing. The oncologist was wonderful. Primary care physician not so much he's about doctoring, not finding insurance numbers in my perspective. So the stories I heard were very encouraging that the doctors were able to do that for you. I had to say it's like sink or swim on your own to a point and if you're lucky and have friends that can help you along the way, then you're in pretty good shape. But it happens, and I wish there were a magical wand where they can do something, but I don't know what it is. It's business, and human feeling and business don't always go together.

**Wes P: CJ, I saw you were about to jump in. What's on your mind?**

CJ C: I was going to say just the doctors support. kind of hold my hand through this process. Guide me through it. Help me understand it better so that we can both make a better decision.

**Wes P: Got it. So you're looking for the doctor to help. And from your perspective, are you thinking the doctor could help you remain on the medication that he originally prescribed. Is that one of your ultimate goals here?**

CJ C: Yes.

**Wes P: So you want the doctor to challenge; you want them to get involved with the insurance company. Is that what you're thinking?**

CJ C: Yes.

**Wes P: What kind of support do you think could make it easier for your doctor to do that? for them to get involved with the insurance company. Because, obviously, every medical practice is busy etcetera. What do you think could make it easier for them to fight for you? I guess that's a big question for you.**

CJ C: Just having the right paperwork I guess. Just having their assistant actually help them as well. Because I know that a lot of the doctors they really be busy and have t heir assistance do a lot of their work for them. But if they just had that paperwork with them and they had somebody who could to tell them what's going on, and what needs to be filled out, and they could just go from there.

**Wes P: Do you have faith that your current doctor could or their office could handle a request like this, and successfully help fight for you?**

CJ C: Probably not. Probably not.

**Wes P: Tell me more. Did they seem understaffed or do you think they just don't have the right people? What do you think?**

CJ C: I feel like they're just doing their job. They're not really going up and above. I have to fight for just getting results for myself. And it's one of those things where it's just like if you guys say you guys are going to do something and get me my results, I kind of expect for that to happen.

**Wes P: So you kind of have to take the initiative on certain things, then?**

CJ C: Yes.

**Wes P: Thanks, CJ. Rasheeda, do you want to jump in?**

Rasheeda J: Yeah, I was sitting here thinking. Greg mentioned just having friends that he speaks to and they kind of give each other tips, but I don't have a lot of friends that have the same condition that I do. But if there is just like a peer support of I guess a network of people who have the same condition and I imagine they would share the same type of treatments and if it changes, if their medication changes for one insurance company, it probably would change for others. So just helping, having a peer support group helping navigate those changes or even just, like I'm a school counselor, so I'm just thinking how to navigate conversations with the billing or your insurance company, and we talked about how we would start or where we would start. So maybe just a navigation worksheet on where pink patients can- OK, well if this ever- and if NMS ever happens, this is what you can do. Maybe you could start with your physician and if they don't, if you feel like they're not giving you the support that you need, then you can go to this advocacy group. Whether it's something in your area or something nationally, because Greg mentioned he received a lot of support from Duke, Duke's Care Team, and I'm right here where Duke is. And I understand that the medical care in the area that I live is a lot different from the medical care that people in other parts of the country receive. So just something that where people can go if they have something that is local or if they just need something national to just find that support and that advocacy.

Greg J: I'm going to pop in for just a second. I would really recommend that you can even go to your church and talk to your pastor, and he may even know of someone else who has something similar. And get some kind of crisis group like that for you to get. If you will, some kind of support makes sense, but you talked about other types of support mechanisms, advocacy groups that are out there. Surely there's got to be one or two. And then your right, sometimes you can be in an area that's just medically poor. It happens my sister's in Martinsville, Virginia, which is north of Durham, but the hospital there in Durham, Duke, they're night and day. They're totally different. And you have got to really be your own advocate when it comes to fighting what you need to have done and fighting to make sure that you're getting support and the medical support you need. So be adventurous; be strong; and if you have to contact another doctor, I've had to do that myself. That I knew that path wasn't good, and I actually switched doctors and got what I needed to go. So have gumption; go for it.

**Wes P: Thanks Greg. Makes sense. I want to give Rebekah and Thor a chance to respond too. Rebekah do you want to jump in?**

Rebekah D: Yeah. During the NMS process, I think I would need to really understand what is going on and why these decisions are being made. So one thing that I noted that I would want is just the health insurance policy wording. Because I work in insurance, I read insurance policies all day, not health insurance policies, but I do comprehend that language. So I'd want to say, "OK, tell me where it says that this will not be covered, and if you can't find it, tell me the amendment or the update where this is." So that's something that I would want to kind of surf through. Whether that's looking at the formulary or whatnot, I would want to take a look into that. Other than that, I probably would just need therapy to deal with the stress of getting through whatever, however, my life may change. Because my life could very well change if I veer off of my medication in a very dramatic way. So I would definitely need some therapy, but as far as staying on the original medication, I know we talked about those co-pay assistant programs that are absolutely invaluable. I'd also need a better paying job; I just need one of those in general. But then, as Thor was saying about Kayla, I think everybody needs a Kayla. I think that personalized- The fact that you're able to give her name is a testament to the personalization and the connection that you have. So I definitely think that having someone who is familiar with patients, and familiar with their case files, and knows exactly what's going on in the appeals process, and is a dedicated person within the medical office to be that communicator and that advocate, I think would be very, very powerful.

**Wes P: Thanks Rebekah. And Thor, last but not least. Any thoughts on what could be helpful during this whole process?**

Thor H: So, a couple things. This might be kind of relevant. At one point I was on a negative pressure wound vac, which was great. It hooks a wound together to help it heal quickly. And at one point, my insurance company was like, "OK, we're done paying for this." And my doctor at the time, reached out to the rep and the rep said, "Hey, just keep him on it and we'll deal with the appeal." And they appealed it for a couple of more months and basically, they ate the costs. So basically, I got like a sample of a wound vac for a couple months, and then I got the final day where not going to pay for this any more. Which was fine, because by that point, I no longer required it. But that was insanely helpful and it was a super stressful point in time. So samples of 30,000.00 biologics would be cool. Also, samples of great cars would be cool, too. Samples. But in all seriousness, I work for a large hospital corporation now and it seems like every floor has a medical social worker and those people are geniuses. And if I could have one of those in my life for generally, I think that would be super helpful, or stuff like that.

**[////]**

**Wes P: So a professional NPWT, someone to help navigate this kinds of thing. Thanks, Thor. I think that's all my questions. I know we're a minute over time, I wanted to see if there were any questions from the Janssen team before we wrap it up? Anything at all from the team?**

**Lisa S: I don't have any questions left. I just want to thank everybody for helping for your time and input in making the case for Kayla, as part of the healthcare team. So thanks everybody, it's really nice to be chatting with you today.**

**Wes P: OK, well in that case, I wanted to thank you all for spending the time and just as always, you’re so informative, it's always great to hear from you. I do have a slide here with our contact email. It's janssenPERC@healthivibe.com we still have to update to the CorEvitas email, so if you have any questions or anything else pops up in your head as an idea, something you didn't get to share today, shoot us an email, we read it frequently. So anything at all is appreciated and if you have any questions we can get back to you too. So just want to say thank you all again. I hope you all have a great rest of the week. Take care, stay healthy, and will hope to hear from you soon.**

CJ C: Thank you

Rebekah D: Thank you guys.

**Lisa S: Thanks everyone, stay well.**

**Wes P: Take care.**

**[////]**