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

**Date: 09/01/2022**

**Segment: Session 1**

**[//Introductions//]**

**Wes P: [INAUDIBLE].** **Hey, Gabrielle.**

**Gabrielle G: Hi.** **Sorry I’m a few minutes late.**

**Wes P: No problem.** **We’re just letting everybody in.** **We have five of our six. And the sixth will be joining in a few minutes. I see Gabe. Hey, Gabe.** H**ow are you doing?**

Gabe H: All right. How are you?

**Wes P: Doing good.** T**hank you and hey, Jed.** H**ow are you doing?**

Jed F: Oh, I’m doing OK, doing fine. Thanks for asking.

**Wes P: Good to hear.** **Thanks for jumping on.** **And Clarence is here, Hey, Clarence.**

Clarence W: I’m doing well. How is everybody?

**Wes P: Doing good.**

Clarence W: Perfect.

**Wes P: Thanks for asking.** **And hey, Allison.** **How are you doing?**

Allison D: Hey, I’m good.

**Wes P: Thanks for joining.** **And here’s Alex.** **Hey, Alex.**

AL. Hi.

**Wes P: Hi, there.** **Thanks for jumping on.** **So that’s five of our six, and the sixth person is going to be running a couple minutes late.** **So I think we’re OK to start.** **Thanks, everybody, for jumping on today.** **It’s great to see you all.** **Today, we’re talking about policy in a cross PERC.** **So we have members of all the different PERCs here today.** **So really, a variety of individuals.** **And we’re just interested in hearing your thoughts on non-medical switching.** **So I know you all had a chance to complete the pre-work.** **Thank you for doing so.** **Let’s go ahead and jump right in.** **We’ve got a two-hour session today, with a break in the middle.** **So around 4pm Eastern, we’ll take a five-minute break and then wrap up after that.** **So welcome, everybody.** **Again, it’s great to see you all.** **I‘ll go over some of these general guidelines.** **I think we’re all probably pretty familiar with them.** **Our discussion today is led by Janssen CorEvitas.** **Just so you’re all aware, HealthiVibe is now CorEvitas.** **We had a rebranding.** **But it’s the same people.** **Nothing else has changed, just the name.** **So we’re here today to collect your thoughts, opinions, and personal experiences.** **So just know there are absolutely no wrong answers whatsoever.** **Just try to speak one at a time, to be sure we can hear you.** **Our discussion, as I mentioned, is going to last about two hours.** **And please try to avoid topics related to specific products or medications, or inquiries seeking medical advice.** **I think you’re all aware.** **I have a slide on this next.** **So I’ll save my spiel, momentarily.** **And just as a reminder, our conversation today is confidential.** **I always tell my groups this is a positive thing.** **This is a closed circle.** **You can feel comfortable sharing your thoughts, opinions, ideas, knowing that it stays within this circle.** **So thank you all in advance for that.** **And finally, thanks, everyone, for participating.** **It’s great to see you all.** **I’ll go through this next slide relatively quickly.** **Our intention today is not to ask for adverse events or product complaints.** **I’ve got a few examples of what this looks like on the screen.** **Today, we’re talking about non-medical switching, so obviously, it’s related to your medication.** **So there’s a good chance that you may want to tell us about your medication, and the fact that you were switched, or you weren’t switched off of it.** **I do want to just ask that you try to use a generic name, or a drug class name, instead of using the specific branded name of the medication, if possible.** **If it does come up- and it happens.** **It’s not the end of the world- we’re just required to collect the information if it’s a J&J company product or device that’s mentioned in relation to the adverse event.** **And that would have to be reported to the appropriate J&J organization, for follow-up within 24 hours.** **So it’s really a pretty involved process.** **We like to avoid it when we can.** **So thank you all in advance for working with us on that.** **Let’s do our introductions.** **We have a number of folks on the call today, all across the country.** **So what I’m going to ask is each member jump in, introduce themselves.** **And then tell us, if you had to pick any one book, television, character, or real-life person that you would want to have lunch with, who would it be and why?** **So Gabe, I’m going to put you on the spot.** **I don't know.** **Maybe you haven’t had enough time to think that one through, but at least you can introduce yourself, and tell us how you’re doing.**

Gabe H: Hi. My name is Gabe Haggard [ph]. I have MS. I’m out here, in Los Angeles. I would think the one person would probably be Jesus. I think that would be a pretty cool lunchtime conversation.

**Wes P: That sounds like a pretty intense conversation.** **I like it, though.** **And he might turn your water into wine, too.**

Gabe H: So it would be cheap. It would be a cheap date. It would be-

**Wes P: No, that’s a good answer.** **That’s a good one, Gabe.** **Thank you.** **And thanks for going first, too.** **I appreciate it.** **Cool.** **And then Alex, I’m going to jump over to you, from our pulmonary hypertension PERC, also in Southern California.** **Alex, how are you doing?**

Alex F: I’m OK. How are you?

**Wes P: Doing good.** **Have you had any [CROSSTALK] about who you want to go to lunch with?**

Alex F: My grandmother. I just miss her so much, and it’s been more than 30 years since she’s been gone. And I would just love to talk to her.

**Wes P: Absolutely.** **Thank you, Alex.** **I like that one.** **Next up, I’m going to jump over to Jed, from the ankylosing spondylitis PERC.** **Jed, do you want to jump in and introduce yourself?**

Jed F: Yeah. Hi, I’m Jed Finley, in the ankylosing spondylitis PERC. And TV star, it’s got to be Kermit the Frog. I think he has seen a lot, a lot of experience throughout the years. And met all types of celebrities, so I’m sure he has plenty of dirt to spill.

**Wes P: That’s a good one, Jed.** **Thanks.** **My dog- we named him Muppet because he jumps up like the Muppets do.**

Jed F: I could see that.

**Wes P: It’s always great to have a fellow Muppets fan on the call.** **I like Kermit.** **That’s a great choice.** **So thanks, Jed.** **And then next, let’s go over to Clarence, in Memphis, Tennessee.** **Clarence is part of our prostate cancer PERC.** **Clarence, you want to introduce yourself, tell us how you’re doing?**

Clarence W: Yeah. I’m Clarence Williamson, and I’m a survivor of prostate cancer. And I thought about- after Alex stated her person, I had a thought about my dad. But I decided I’d love to have lunch with President Barack Obama, to tap into some of his brilliant mind. So that would be the one I’d love to have lunch with.

**Wes P: That’s a good one, too, Clarence.** **I like that.** **You have to think he has so much going on in that head, right?** **So much to share.** **So thank you.** **And last but not least, Allison, also from our pulmonary hypertension PERC.** **Allison, you want to jump in and tell us how you’re doing?**

Allison D: Yeah. So I just finished the book *When Breath Becomes Air*. And it’s about a neurosurgery resident who’s diagnosed with lung cancer. And despite all his treatments, he decided to go back to doing neurosurgery. And I think that would be really cool because I feel like our stories are kind of similar in some ways. So I would love to meet him. His name’s Paul Kalanithi.

**Wes P: That’s a great one.** **Thanks, Allison.** **I read that book years ago, and it’s heartbreaking.** **But he’s such a great writer, so definitely recommend it, too.** **Thank you.** **Thanks for jumping in.** **Are you doing good, Allison?**

Allison D: Yup. All is good. I actually just came back from the barn. So just got to hang out with my horse for a little bit.

**Wes P: That’s great.** **Love to hear it.** **And we do also have Jessica, from our multiple sclerosis PERC joining us.** **But I think she’s a couple minutes late.** **So when she jumps on, I’ll give her a second to introduce herself.** **In the meantime, I’m going to jump to our next slide, which is our other attendees.** **And so, from the Janssen side, I’m going to hand it over to Aarti Patel.** **Aarti, you want to jump in and introduce yourself?**

**Aarti P: Sure.** **Hi, everyone.** **Thanks for your time today.** **Was glad to hear your insights.** **I really find these discussions so rewarding and insightful.** **I’m, again, Aarti Patel, and I am part of the real-world evidence team, and I focus on health equity research.** **Nice to meet you all.**

**Wes P: Thanks, Aarti.** **And do you have any thoughts about who you’d like to go to lunch with?** **Any ideas?**

**Aarti P: I was thinking, actually, that- I was reading this book about Ben Franklin.** **So I’d really love to have a conversation with him.** **He’s so just innovative, and just some of the things that he’s- never would have thought until I started reading this book.**

**Wes P: That’s a good one.** **Thanks, Aarti.** **Perfect.** **And next up, Bridget Doherty.** **Bridget, do you want to jump in and introduce yourself?**

**Bridget D: Sure.** **Hi, everyone.** **My name is Bridget Doherty.** **I also work in Janssen scientific affairs, and I do health policy research.** **So thank you again for your time.** **Aarti took my person because I’m from Philly.** **And so Ben, of course, is intricate.** **But if I had to think of somebody- and frankly, I want to meet Obama.** **I want to meet Kermit.** **I want to meet everybody.** **But I then would have to go for Alexander Hamilton, to see if he’s anything like portrayed by Lin-Manuel Miranda.** **So anyway, that’s-**

**Wes P: That’s a good one.** **A lot of founding fathers on the call today.** **I was going to say, being from Philadelphia, you can’t get very far without seeing Ben Franklin’s name.**

**Bridget D: No, he’s everywhere.** **But as Aarti said, he’s also an extremely interesting human being.** **So he’d probably be a lot of fun to have lunch with.**

**Wes P: Definitely.** **Well, thanks, Bridget.** **And next up is Gabrielle Geonnotti.** **Gabrielle, I’m hoping you’re not also going to say Benjamin Franklin.**

**Gabrielle G: I wasn’t, but as a fellow Philadelphian now, I feel embarrassed that I didn’t go straight there.** **Hi, everyone.** **My name is Gabrielle.** **I am the member of the Janssen scientific affairs patient engagement team.** **As you know, we are the lucky ones who get to work across all of our different PERCs.** **I, in particular, work on a whole bunch of different ones.** **So I see some familiar faces, and some new people, as well.** **So it’s nice to meet and see all of you again.** **I think- I’ll stick with the history theme, but I’ll go with Leonardo DaVinci.** **I think he’d be fascinating to meet, and hear about all the different things he had his hands in.**

**Wes P: That’s a good one.** **Thanks, Gabrielle.** **Perfect.** **And now let’s jump over to the CorEvitas team.** **Casey, do you want to jump in, reintroduce yourself?**

**Casey C: Yeah.** **I’m Casey.** **I am one of the project coordinators with CorEvitas.** **I almost said HealthiVibe.** **I’m so used to it.** **I do have the pleasure of knowing a lot of you guys that are on the call, and some of you that I haven’t worked as closely with.** **But I am one of the project coordinators that does a lot of our PERC member face and connections.** **So a lot of the emails that you receive, and coordinating those things for you guys.** **For who I’d like to have lunch with, it’d have to be Nichelle Nichols.** **If you don’t know her, she was the original Uhura on *Star Trek*.** **And she was also just a groundbreaking advocate for women and people of color, not only in acting, but in STEM.** **She was a huge push- and advocate for diversity in STEM, which I love.** **Especially for women in STEM.** **So I’ve met her twice, or I had before she passed away.** **And I’d love to spend more time with her.**

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

**Wes P: That’s really cool, Casey.** **It’s nice you got to meet her, as well.** **Thank you.** **Thanks for sharing.** **And then last, but not least, I’m Wes, a research specialist with CorEvitas.** **I think I’ve met just about everybody on the call, in one meeting or another.** **So it’s good to see you all again.** **And it’s my role to hear about your experiences.** **And so again, I want to thank you for joining today.** **I’m really excited to hear from you.** **If I had to pick any one person- I’ve been watching the Beatles- the *Get Back* documentary that’s on Disney+.** **And never was a huge Beatles fan, but now I’m starting to get the appeal.** **So I’m thinking maybe I’d love to have lunch with Paul McCartney.** **I feel like he’s been pretty much at the top of the music scene for the last 50 years.** **It would be so great to hear his experience.** **Plus, I just think the British accent is always just charming.** **So anyway, that would be my choice.** **So thank you all for humoring us with the exercise, there.** **Let’s jump into our discussion.** **So we’re here today to talk about non-medical switching.** **We can call it NMS, if that’s easier.** **It seems like a number of you guys are familiar with non-medical switching.** **And even a few of you have experienced it.** **So before we begin, I want to make sure that I have everybody’s experience correct.** **I believe that, Alex, you said that you have experienced a non-medical switch in the past.** **That’s correct.** **And Clarence, you have, as well?** **Got it.** **Has anyone else, by show of hands, experienced one?** **Has anyone encountered this?** **Jed, you’re kind of on the fence.** **I’ll be interested to hear your experience in a second.** **But I want to hear from Gabe and Allison first, since they haven’t gone through the process.** **Hear a little bit about what your guys’ thoughts are, whether you’ve heard about this elsewhere.** **So Allison, if you don’t mind, I’ll start with you.**

Allison D: So I personally have not experienced a non-medical switch. Probably more because I have great insurance, versus I am very opinionated and will make sure that they won’t do something like that to me and my healthcare. And I have the resources to make sure that can’t or won’t happen. And I have experienced it with patients, on the other hand. And it’s just a really frustrating experience when the doctor says they need to try one medication. And they’re like, “Well, try this other thing.” And it’s just like, “Well, we would have recommended that if we thought that it was the best course of action.”

**Wes P: And when you say other patients, are these other individuals you’ve just met, or through support groups?** **Who are you usually talking to?**

Allison D: That, and personal patients. I’m a nurse.

**Wes P: Oh, that’s right.** **So you’re speaking to individuals regularly, who-** **How often do you hear about this experience?**

Allison D: I’d say less now, because I’m more on the inpatient version of it, especially with kids. So a lot of things aren’t covered or considered FDA approved for kids. So it’s just harder, in a sense. But we kind of get our way, because, again, there’s nothing that’s proven to work. So I feel like, in my current role, less. But it’s ebbed and flowed.

**Wes P: So you also mentioned that you have resources to- if you ever were given a non-medical switch, you would have the resources to challenge it.** **Can you tell us a little bit more about what that means?**

Allison D: I am very good at telling pharmaceutical companies that, “If you make this decision for me, I will die,” in a sense. And I’m not afraid to push that out there. And really able to know who to ask. My physicians would be really good, especially physicians who aren’t necessarily physicians, and more of my friends, at this point, who also work with the disease significantly. So I’d definitely pull in all of my resources. My current team is absolutely amazing, and they would fight for me, if this were to happen. So it’s really just not being afraid to be bold to these companies, as the patient. And then having more information, as also a provider.

**Wes P: So you mentioned the pharmaceutical companies.** **Is that- are you thinking that’s where the non-medical switch request typically comes from?**

Allison D: No. Definitely more from the insurance companies. But the person who unfortunately has to deal with it is the specialty pharmacies- generally get the most of my wrath.

**Wes P: Got it.** **So you’re pretty familiar with how this goes, then.** **Makes sense.** **And so you’ve already given us some of your insights into how you feel about it.** **Do any of the words in the word cloud really jump out to you, on the screen, as resonating, or anything like that?**

Allison D: I’m not sure if I was the one who wrote Frustrating and Annoying, but those are the two that come to most in my head.

**Wes P: That’s helpful.** **And just frustrating from your perspective because it’s- tell us more.** **Where’s your head at?**

Allison D: Just because a provider would not prescribe a medication if they didn’t think it was the best course of action for this patient. And it’s really frustrating, especially- I’ve heard things of- they prescribe one class to the patient, and the insurance company wants them to try the other class, which is not necessarily the first-line treatment. And just having them try to go around what actually is best for the patients. Especially with pulmonary hypertension. It’s such a serious disease. And if insurance companies want to dictate how you treat someone with severe pulmonary hypertension, that would not work, in comparison to someone with very mild pulmonary hypertension. Which is generally what these non-medical switches happen. They want to do the cheapest drug that’s most available. While, really, some of these patients need the most aggressive treatment if they want to live.

**Wes P: Got it.** **And in your role as a nurse, have you ever gotten involved with helping to challenge a non-medical switch?** **Has anyone ever asked you to get involved?**

Allison D: That’s generally not what my role is. I’ve definitely helped patients get coverage for a medication, but not arguing a non-medical switch.

**Wes P: Got it.** **That’s helpful.** T**hank you, Allison.** I**’ve got a number of more questions for you, but I’m going to hold off until the next slide.** B**ut thank you.** G**abe, I’m going to jump back over to you.** Y**ou also- you haven’t received any non-medical switches in the past.** C**orrect?**

Gabe H: That’s correct.

**Wes P: Got it.** **Were you aware that this existed?** **Had you ever heard of it before?**

Gabe H: Yes. I am aware of it. I have heard of it. I don’t recall if I know anyone intimately that has dealt with it. What it brings up in my mind, for me, is a number of situations where, at the outset, a provider has told me, “Well, we’re going to try a generic,” or “We’re going to try this, because it will be more cost-effective.” But it has been my experience- it has been my personal experience that we have gone into it with the understanding that, “Hey, this is something we’re going to try for a financial reason. And we will move on from it if it’s not advantageous to your health.”

**Wes P: Interesting-**

Gabe H: But I haven’t experienced it after the fact. Someone saying, “Hey, now you’re going to take the blue pill instead of the red pill.” I haven’t experienced that.

**Wes P: So do you think that sort of approach that the provider is taking with you, going for that most cost-effective medication first- is that a strategy, you think, from the provider’s part, to avoid trouble down the line with the insurance company?** **Is that sort of what you’re thinking?**

Gabe H: In my experience, in my perception, it has been due to, perhaps, the variety of copay that I might be responsible for, in the situations I’ve been involved with. And it has been, in a manner of speaking, a holistic approach to, “Hey, we’ll give this a try because it has some things going for it, such as cost. And we believe it will still help in the same way. If that’s not the case, then we will adjust.” And so it has been kind of an overarching thing, that it has been a journey with my provider.

**Wes P: Have you- in the past, has that most cost-effective first option- has it worked, or has it not worked?** **Have you had to move to less potentially cost-effective options?** **I guess that’s part of my question, not worked? Have you had to move to less potentially cost-effective options? I guess that's part of my question.**

Gabe H: It has worked, and I haven't had the situation where I've had to go back to my provider and say, "OK, it's time for the real deal or the big guns or the next one or the brand." I haven't had to.

**Wes P: OK, that's helpful. And what are your thoughts overall about bond medical switching? Who do you think it comes from and what's the reason? Do you have any ideas around that?**

Gabe H: Not too much, it's more just hearsay. I think there's a reason why insurance is the biggest one. I feel from what I've heard that that has been one of the biggest motivators as the insurance company is looking for more frugal way of taking care of this. But again, like I - banking on my experience. It hasn't just been an insurance thing. It has been a collaboration with the provider and the - with the physician and with the patient in terms of, hey, what's going to work for your - for our situation? And part of that situation is whatever financial means you may or may not have. So, yeah.

**Wes P: Got it. And tell me a little bit more about that collaboration. When you say it's a collaboration with the provider and the patient, trying to figure out what's going to work. That's - you're not thinking that there's also the provider could be collaborating with the insurance company too on that or is that - it's separate? I'm sorry, tell me about your thinking.**

Gabe H: Yeah, I wasn't thinking that. I was thinking the - it's appeared to me that the provider is like, "Look, this is what the insurance company's going to try to do."

**Wes P: Right.**

Gabe H: This is what they're going to be more willing to greenlight. And then, and the physician speaking, in my opinion, it will probably work. And it's going to save you money. And so, we can try it. But if we need to change, then we can go to bow. And then, we'll be on firmer footing to present to the insurance company, "No, XYZ did not work. We have to get ABC."

**Wes P: Got it, that's helpful. So it's building the evidence in case you do need a more costly option, right? You can say, "We tried the generic." Right?**

Gabe H: Yeah.

**Wes P: Got it, OK. That's helpful. Any of the words in the word cloud really jump out to you as meaningful or surprising?**

Gabe H: Frustrating. I very much become a creature of habit. And so, I hesitate to say - to use unnecessary or words like, “fat.” But certainly, frustrating, stressful, annoying, puzzled. Those are certainly something that I would associate with it when you're trying to solve an issue, and then, there's a peripheral concern like that, which isn't - which in my estimation, isn't always completely irrelevant, because cost is cost. So, it's not necessarily always irrelevant but it is certainly frustrating, annoying, stressful, puzzling, yeah.

**Wes P: Got it. OK. So, yeah, it's that - it sounds like it's puzzling, it's frustrating. There could be an element you're thinking where maybe it's not totally unnecessary just because of the financial side of it. Is that what you're thinking?**

Gabe H: I think that's what I'm inferring, yeah. And again, but also, I understand that, in my inference, is a magical land in which the insurance companies are acting in good faith.

**Wes P: Right.**

Gabe H: Which may or may not be the case.

**Wes P: Right. So, that's helpful. Again, I have more questions. But I think I'll give you a break here, because I have asked you enough for a moment. But thank you, Gabe. We'll get back to you. Jed, you said you were on the fence about maybe experiencing this in the past. Want to tell us more?**

Jed F: Yeah. So, when I was thinking about when you asked me was I don't know if it was so much that insurance was switching me because it was less - because it's more cost effective for them or if it was whatnot. But, a lot of my non-medical switching has been my insurance company switching me to a different provider. And that provider being not even close to as good as what I've been working with. The difference of going from a small family owned, a couple offices around the mid-west pharmacy to a just multinational like, “we take 72,000 calls a minute,” kind of place and you can't get the best service. Because that's happening quite a bit where insurance, they've just signed a new contract and said, "All right, you're leaving this pharmacy and you're going to mega corp." And then, it's like, I have one place that I had to use the insurance. And every time my prescription ran out, they'd mark me as, “deceased.” And after I call them up and say, "I'm still alive." "Yeah, sorry. It's a glitch in the system. We'll get it worked out." And then, they never would. Every three months, I would die again. And - but again, it's like if this was the small pharmacy, I legit could've driven down to them and said, "Hello." The same happened with my CPAP supply where, again, small company, local, got me everything I needed, if I didn't like it, I could call them up and I - they could say, "Come by the office and get it." Multi gigantic corporation, and they sent me the most sub-par equipment ever. And I was like, "I hate this, can I go back to the brand I was using before?" "I'm sorry, this is what we supply." So, it had nothing to do with medicine. It just had to do with what was the business choice that time and their contract was with this company, not this company. So that's happened to me a couple times. And then, and of course, when I first got prescribed my biologic, nobody really wants to pay for that. I did go through the typical, "Have you tried this, this, this, this, this, this and this?" And they mentioned massage. My immune system is attacking my body and you think massage is going to help? OK. So, but fortunately, at that point, my doctor had an office at the hospital. Their whole job was just to go, "No, no, no. Seriously? No." So they sped up the process where I only had to wait a month and a half where a lot of people with my condition have to wait three or four months to finally get that, “yes,” and actually try other things. So, yeah, I think I wanted to just get it out all there, just whoop. The FDA also caused me trouble where I, at first, I was approved to use a certain dosage a certain amount of times. And the FDA changed their - the restrictions and said that, "No, you don't need that much anymore. You need less." And less was not good. So, I had to switch to a different medication because less of what I was on before, which was great, wasn't cutting it anymore. So again, not medical, just something else. It was I have to switch my meds.

**Wes P: Right. Just sounds like you're familiar with policy decisions, insurance decisions impacting your care. I'm interested to hear - so you mentioned that often - or when this has happened to you, it's been more on the medical care side, your provider's getting switched. Is it a case for you getting a notification that says,, “this provider's no longer in network, go find another,” or are they telling you, “you're going to have to see a new person?”**

Jed F: Yeah, they switched - I may get a letter in the mail, but it's an automatic switch. Either the company was bought out by a different company or insurance signed an agreement with a different company. But yes, it was never a choice of like, "You could go find a new place." It was, "This is who you're using. This is where you get the medication from or your CPAP supplies or whatever else."

**Wes P: Right, OK. Interesting. So, in terms of the non-medical switching, we'll be talking about medication, but it sounds like you've experienced this in a different way, right? You've -**

Jed F: Yeah.

**Wes P: Been compelled to switch care before.**

Jed F: Right.

**Wes P: And tell me a little bit about - so let's talk a little bit about specifically medication, right? It sounds like, so you're familiar with how this process goes. Do you have any thoughts or questions? Anything unclear about a non-medical switch for medication specifically from your perspective?**

Jed F: No, I understand typically what they're saying where it's that - it's not that the drug wasn't working, it's just the business, for whatever reasons, more cost efficient. There's some other reason why they want you to switch. And I know sometimes that can work out, like going from a name brand to a generic, sometimes it's fine. But, no, I get the idea of what we're going for. Just putting a little bit of a variety to the table.

**Wes P: Right, OK. Thanks, Jed. That's helpful. It sounds like, so again, you're pretty familiar. Do any of these words really jump out to you as resonating or surprising?**

Jed F: Insurance bureaucracy, that's a good one. That's typically that's really what it is. It's just some faceless businessman signing a paper and that changes everything. "But we have to do it, sorry."

**Wes P: Yeah, right. So again, that brings up another question I have for you. You mentioned it's a business decision, it's a business person making a decision. Do you - so from your perspective, you're not thinking anyone medically trained on the insurance side is looking at this? Is it - you're thinking it's just a business decision?**

Jed F: Yeah, I really feel like it's always business.

**Wes P: OK.**

Jed F: They may tell someone on the medical side that, "Hey, we really think you should approve this." But I'd like to think in my - that someone with medical training and medical degree would sit back and go, "No, I don't think so. Let's just stay at the chorus." I really think it's just someone in finance who's making these decisions.

**Wes P: Got it, OK. Thanks, Jed. I'm going to jump over now, Clarence and Alex, you both mentioned that you have experienced this. I'd love to hear about your experiences. Alex, I'll start with you, and then, I'll jump over to Clarence. Alex, do you want to tell us a little bit about your experience? You mentioned you received a letter in the mail, right, about -**

Alex F: Yeah, that was just recently. And they weren't going to let me take the medication that I was on. And according to them, I was off of it for three months. But, a friend of mine whose wife passed away with the condition have extras. And so, I was on it for all that time. But then, I was thinking about, in 2001, I was diagnosed with panhypopit, my pituitary gland partially [INAUDIBLE] nothing works. So, each time that I switched from state to state, they kept telling me, "You already take the generic. You can't do that when you take the generic." Then the doctor says if you need it or not. But every time because I went from Texas to Maryland and down to California. And every time, they did that to me.

**Wes P: Yeah, right. So anytime you moved, anytime you crossed state lines, pretty much that's happened to you?**

Alex F: Yeah.

**Wes P: Interesting. And this most recent time, were they also asking you to go to the generic? Was that the switch they requested?**

Alex F: They wouldn't want give it to me at all, I was on the generic already.

**Wes P: Yeah.**

Alex F: But they didn't want to give it to me at all until I had a test.

**Wes P: Wow. Do they have any substitute for it or do they have any -**

Alex F: No.

**Wes P: Different medication?**

Alex F: No.

**Wes P: Wow.**

Alex F: They just wanted me to get off of it altogether.

**Wes P: Gosh, OK, that's scary. So but you had - so you mentioned three months. Was that the supply you were able to get from your friend just to give you enough time to get the test?**

Alex F: Yeah.

**Wes P: Wow, OK. Got it. And so, then, tell me a little bit. So once - I have a number of questions for you. When you first got the letter in the mail, what was your first thought? Who did you go to? Did you ask any questions? Tell me a little bit about that.**

Alex F: I, first, I was scared because the medications for PH are life sustaining. And so, I really did get scared and upset. And called the doctor's office. And they sent me to get a voicemail. And then, I sent them a message through mychart, and they finally got back to me, but they were like, "We have to have a right heart cath before we can figure out what you're going to get." And according to them, I was off for three months, yeah.

**Wes P: Wow, OK. Got it. So did it take them three months to get you in for right heart cath?**

Alex F: Yeah, I did. It did, yeah.

**Wes P: That's crazy.**

Alex F: And I did pulmonary function test and I did a six minute walk. I had a CAT test. And I had some other ones as well. I had an echocardiogram and that sort of thing for them to say that, yes, I am actually have this disease and I haven't been playing around for 24 years.

**Wes P: Right. Wow. So, I have a couple of questions for you.**

Alex F: OK.

**Wes P: Did you ever reach out to the insurance? Did you try to give another call too?**

Alex F: I didn't. The doctor's office told me that if I wanted to fight with them, that would be fine. But that we just needed to wait those many weeks to get the right heart cath and anything else taken care of. And they said that it would be better if I just left it alone.

**Wes P: Wow, OK. So, they didn't recommend even trying to talk it out?**

Alex F: Yeah.

**Wes P: Got it. And when you talked to the doctor's office and they mentioned that they wouldn't be able to get you in for three months, did you express your concern that you were going to run out of medication and that this was, obviously, this could lead to progression or worse?**

Alex F: Yeah. And I did tell them that. But when they had the schedule, that was what they had. I would imagine if I was in patient or at the ER that they would do an emergency one or something like that, but I was still at home and -

**Wes P: Yep. Would you have considered going in to get an emergency test if you weren't able to find that extra supply?**

Alex F: Yes, most definitely.

**Wes P: Sure. OK, wow. So, really a pretty urgent situation, yeah.**

Alex F: Mm-hmm.

**Wes P: And so, now that you're able to get the test, you're able to prove you have PH, right?**

Alex F: Yeah.

**Wes P: Were you able to - but the insurance company accept that, then continue to fill your medication?**

Alex F: Yeah, my doctor is adding two medications and taking me off the sildenafil, so I have three medicines. Actually, my pulmonary pressures have increased and I'm now in heart failure. So, but I've done this before. So I know what to do and the doctors are monitoring me very carefully and that kind of thing.

**Wes P: OK.**

Alex F: Still scary, though.

**Wes P: Yeah, absolutely scary. I hope you to do well and the doctors are able to help you, yeah.**

Alex F: Thank you.

**Wes P: Thanks, Alex. I have - I think I have more questions for you, but I'll save them for the next slide.**

Alex F: OK.

**Wes P: If you don't mind. So, thanks for sharing your experience.**

Alex F: Mm-hmm.

**Wes P: Clarence, last but not least. Do you want to tell us a little bit about your experience? You mentioned you went to fill your prescription, right? And you learned that the formulary had changed?**

Clarence W: Right. It was for asthma symptoms. I wasn't clear whether that was the problem, but it was for asthma symptoms. Years and years ago, I worked in a chemical manufacturing plant. And they were extremely dangerous chemicals that we worked with. But that was like 15 years previous. But chemicals have residual effects that may not show up till later. So I didn't disagree with the diagnosis. But originally, I was put on a single medication. And it wasn't working fast enough for my improvement. I was - the breathing. And so, the doctor prescribed another medication that had a two in one med, which was, I guess, they call them, “a bad medication.” [INAUDIBLE] this was a bad. And the cost was more than a single medication. But the following year, at the end of the year, it changed the formulary and they move it to another classification and the cost of medication doubled. It went up to $300 a month for this med. And I had to realize that $300+ a month is a lot of money for one single man, because I'm taking other meds for my cancer and everything else. So, I bought it first, after that, I contacted the doctor and we went back to just - after the next month, we went back to the single med. And I'm on Medicare. So - and I've got a supplemental plan that takes care of all my medication. So, I went back to the single med about a month, two months later, and it did not work. It went back to not doing the job. So, I made phone calls to the - I contacted the insurance company, the supplemental, and as it turned out, the pharmaceutical that they're purchasing from wants to change the formulary and they don't ask questions or opinions before they make these changes. It was changed. The price increased, the cost was a different level. And that was it. So, I went on and bit the bullet and took these meds for six, seven months. And my condition began to get better. And with my doctor's permission, I slowly start cutting back rather than every single day, every other day, as needed. And eventually, the condition got better but the formulary change was the cause of this medication needing to be switched, because of the cost. So, but my prostate cancer support group, they haven't been - that had been switched medications and I'm really not sure whether it was non-medical or not. More likely it was medical. But as soon as I learned about how the formulary changes periodically, generally every year and I understood why the price of medications go up and down and this is behind-the-scenes decision.

**Wesley P: I have a couple of questions for you. You mentioned you found out at the pharmacy that the price had gone up that day. And you mentioned you contacted your doctor. Did you consider ever reaching out to the insurance company at that point? Or was that only later on that you called them?**

Clarence W: That was later on. That was only later on.

**Wesley P: Was it ever an option or ever something you and your doctor thought about doing, was maybe challenging the change?**

Clarence W: No, it wasn't an option. We didn't discuss that. The doctor didn't seem willing to challenge it. She's just, it is what it is basically. And the only thing that could be done is if the insurance company made a special compensation for me personally. And I'm not wanting to - if I need to pay for what I need and I've got the resources, I go ahead and do it. And then I work with my doctor on how we can work our way around it. And it's fortunate that that condition was not life-threatening. If it was a life-threatening condition, it would've been a whole different ball game.

**Wesley P: Right. Different story.**

Clarence W: Yeah.

**Wesley P: Just one or two more questions for you. You mentioned after being on that single med for a while, so you switched onto the single med, but it wasn't really doing the job. You were doing worse. At that point, you contacted the insurance company and you mentioned there was something about the pharmaceutical company who was selling the drug to the insurance company. Can you tell me more about what happened there? Did you get more information about what was going on?**

Clarence W: No, I didn't. And that was an assumption that I made as to how the business goes. And we are learning more about pharmaceuticals and how they wind up to the general public. There's a lot of steps in between. And my assumption was that the supplemental insurance company is willing to pay what the formulary is and that's it.

**Wesley P: Makes sense. After that point, you talked to the insurance company. Did they give you any help or did they pretty much just say it is what it is?**

Clarence W: They didn't give me any help. I went over the formulary and looked at the different other drugs that were used for my condition, but I didn't want to make a decision and change the drug myself because it was lower cost. I didn't want to do that.

**Wesley P: At that point, you said, I'll go back to the double med or the bi med and just pay for it [CROSSTALK] a month?**

Clarence W: Right.

**Wesley P: Got it. Thanks, Clarence. I have more questions for you, but I'll hold off for a second. I did want to ask you, do any of the words in the word cloud really jump out to you?**

Clarence W: Yeah. Insurance company bureaucracy is the first one. Profits was the second one. [INAUDIBLE] was the main too. It wasn't frustrating. Well, it wasn't stressful, but it was a little frustrating for me.

**Wesley P: And from your perspective, I asked Jed this too. Do you think that - is this decision at all, does it have any medical basis, do you think, or is it pretty much just down to the money? That's my question for you**

Clarence W: Down to the money. That's it.

**Wesley P: When you called, did they give you any medical justification or did they just say it's just more expensive?**

Clarence W: No. You mean the pharmaceutical? They just said that they changed the classification. Once they moved it in the formulary, they moved up and others moved down, but my particular drug was one that moved up.

**Wesley P: And that was the insurance company who said that, right?**

Clarence W: Yes.

**Wesley P: OK. Thanks, Clarence. Appreciate it. I want to thank you all for sharing your experiences. Especially, I realize this really frustrating situation for multiple of you who have experienced it, so thank you for sharing it. Our next slide is a definition slide. And so, it sounds like most, or some of you are pretty familiar with the topic, but I just wanted to make sure that we were all on the same page. We have quick definition. I'll read it. Feel free to stop me if anything's unclear. Our definition is sometimes a patient who's stable on their prescribed medicine will change to a different medicine not a generic or of the same medicine 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. And so, often, non-medical switching results from changes to medicines that are approved or preferred by the patient's insurance company or the formulary. A number of you have mentioned the insurance company, and as you're pretty aware, it's often the insurance company who are making these changes that prompt the requests for the switch. Now, we do have two examples of what the non-medical switch could look like. And then we have two non-examples, so examples that aren't technically a non-medical switch. I'll go over the examples really quick. One example is your prescribed medicine is no longer improved by the insurance company, so it's no longer on the formulary and it's been replaced by another medicine or the out-of-pocket cost. That's the cost not covered by the insurance company for the prescribed medicine has increased due to a formulary change. For example, $15 to $50, so the patient switches because they can't afford a $50 copay. You're forced to switch to a different medication because the more expensive medication is just not possible. Clarence, it sounds like that may have been the case in your situation where you were presented with an almost unaffordable price tag so you felt like you had the switch. Two examples that we would consider not examples of a non-medical switch is if a patient - I'm sorry. If a patient switches from a branded medication to its generic form or a patient is switched to a different medication by their provider because it's more effective or has fewer side effects. There, you see more of a medical reason to it as opposed to the non-medical reasoning. With all that said, and I do want to give us time for a break. In a minute or two, we'll take a quick break. Are there any questions about the definition or any of these examples? Does this gel with what you guys were picturing for a non-medical switch? I’m seeing a couple of nodding heads. Anything at all unclear or any questions that you have right now? I think we're going to cover a lot more after the break, but is there anything that is a question mark in your mind about this process? No? All right. I think we're all on the same page then. Let's go ahead and take our break now. We have a ton of content to cover when we get back, so I want to give us enough time. It looks like it's 3:54.**

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

**Let's just come back at 4:00 PM Eastern; at the top of the hour and we'll keep going. If you don't mind, if you're going to step away, just mute your microphone and turn off your camera. And then when you're back, turn your camera back on and we'll see you in five. Thanks, everybody. I’m going to give everybody another 30 seconds to come back on. Thanks for coming back. Let's jump back into our discussion. Our next topic is about taking action. Sounds like a number of you have experienced this in one way or another in the past. And so, I think you've given us - started to give us a picture of the actions you took and what you tried to do to resolve the issue. I think my question now for you is, imagine you were presented with this situation again or something similar. What would you do differently or what would you do the same? And in an ideal world, what would be the easiest way to resolve the issue? That's my question for those of you who have experienced the switch. And then for those of you who haven't, and there's a few of you who have not, who have never received a request, I want you to imagine that you were. Obviously, not an ideal scenario. And tell me a little bit about how you would respond to it, what your first action would be, who you would go to, what your questions would be. Let's jump into the slide. And I'm going to start - Allison, I hope you don't mind. I'm going to start with you. You mentioned that you haven't received this switch request in the past. Tell us a little bit about if you were to receive one, what you think your options would be, where you would go, what would your first move be.**

Allison D: Yeah, it's hard. I feel like the first one would be. I would go straight to my doctors and be like, is this something that you would consider an appropriate switch or a safe switch? And if they said that they don't believe it's safe, then escalating it with my insurance company. I've actually screamed at them enough times that I actually have a person that knows me well enough and helps me deal with my problems the best. I just ask for her and figure out what - I feel like my course of action in my brain versus what she thinks is the best course of action to deal with this and really just escalating it to the right people. I know prior authorizations along with whenever they deny these prior authorizations and these appeals are very, very popular. Although like my doctors are also not afraid to be like, if you do this, she's going to die. They've told me that as well, is that - we use the same language and make sure that everyone understands that this is completely inappropriate. I feel like that's just mainly what I would do.

**Wesley P: And you've had this conversation with your doctors before where you've told them in this situation what do we do? And then have they walked you through the steps of how it would go or?**

Allison D: Not really. Not in this - and we're talking about - I guess the only reason we've had this conversation is because my insurance company didn't want to cover a necessary test. It feels like it would be a very similar pathway except we're probably going to deal with the PDM rather than the insurance company.

**Wesley P: Yep. That makes sense. Got it. I guess part of my question is, you're prepared - who could be prepared for a situation like this? But you seem to have an action plan. Tell me for - because I know you've also interacted with patients as well. You mentioned you're a nurse. Do you think if they were to receive a non-medical switch, your typical patient, do you think they would know to go to their doctor or their insurance company? What would you think they would do?**

Allison D: I feel like it depends on which providers we're talking about. The providers I used to work for in pulmonary hypertension, they were very good at making the patients know that their physician is their biggest advocate. And I feel like a lot of people aren't that lucky, especially with these physicians and specialists that are completely overwhelmed and may not have the time or the resources, or even the want to deal with things like this. I feel like very fortunate in the pulmonary hypertension community. You actually have to care if you want to take care of these patients for the most part. They really know these insurance companies and these pharmaceuticals very, very well and how to go around it. I feel like we're just in our little bubble in the pulmonary hypertension world, although not all centers are the same, but fortunately, I've been very lucky

**Wesley P: A big part of this is the fact that your team has the time and the resources to deal with it. Do you know, have they dealt with it with other patients? Have they ever talked about something like this?**

Allison D: I haven't asked them directly, but I'm sure I've seen a lot on the pulmonary hypertension support groups about people having non-medical switches and some of their providers will fight for them. Others, they're just kind of defend for themselves.

**Wesley P: But your plan would be also to directly call the insurance and escalate. And I'm assuming you would challenge too, right? That would be your line of thinking would be -**

Allison D: I have been told more times than once that it's not my job or responsibility to be arguing this with an insurance company by the insurance company saying that the doctors need to call, but I've done this enough in my life and worked enough that I know the right lingo and know what things to look up to fight my case.

**Wesley P: And in this case then it would be like a double approach where both your doctor and you are on the phone with them, right?**

Allison D: Mm-hmm.

**Wesley P: And in your experience, that's been more likely to be successful than if it was just your doctors is what you're telling us?**

Allison D: I feel like they would probably be able to be capable and doing it on their own end, but I like pushing them from both directions because they feel like things go a little faster.

**Wesley P: Yep. That makes sense. Thanks, Allison. I appreciate it. Question for Gabe. Same question. I know you've never directly received a request to switch. Imagining that you did, where would you go first? Who would you go to?**

Gabe H: I think our conversation would begin with my doctor, with my primary. And then it might go from there. I've had not the same situation, but a little bit of experience with speaking with my insurance company as well if I had a question about X, Y, or Z. I think that I would begin with my doctor and then move on to the insurance company as needed. And then not the same situations, but in similar or in different medical types of situations, I've often gone to - I would seek an alternate opinion. Because at times, my doctor might say, well, we can't do this because of that. And then my instinct would be to go get a second opinion. Like if this doctor, this insurance -

**Wesley P: Gabe, sorry to interrupt you. Your audio is going in and out. Can you hear us?**

Gabe H: Yeah. [INAUDIBLE]

**Wesley P: For some reason, it seems like your mic's dropping in and out. Maybe I'll come back to you. I'll give you a minute. But hold that thought. Sorry. I'll let you figure that one out. Jed, I wanted to go back to you. Similar questions. I know you've experienced this with your provider where you've been switched. And obviously, that's a slightly different situation because it's hard to call your old provider and say, can you help me? When they're the one who's being switched - you're being switched from them. Imagining you’re now in this scenario where it's your medication and you've been switched, where do you go? What are your first thoughts?**

Jed F: When the FDA regulations changed and I switched biologics because of that, that went straight to my doctor. He informed me of it and he said, look, I can try to win this for you, but I'm not going to win. He just switched me into a different medication. He said this one is practically the same. You are able to use this weekly, so let's just give this one a try. And it was fine. That one was. For me, if I'm put in these situations where - honestly, I would talk to my doctor first and probably get the same answer of no. I would want to call insurance next. For the most part, insurance, they've at least seemed helpful about it. About certain things that I've had to call them about. Otherwise, very friendly, and very oh yeah, absolutely we’ll help you out. And then I find out a month later that nothing actually happened. But let's hope it doesn't happen again. I would talk to insurance. And then step number three would be curl up in a ball and just cry a lot because I'm not really the - I can get in people's faces, but I feel like I always go a little bit too far. So, I want to stay away from any controversy and I'm the hopeful one that I just - I want things to just be better without me really having put down the hammer. But if it was - if they told me I wasn't able to take any of my medication ever again and it was like here, have sand, I would definitely have to. I would have no choice, but to get really emotional because I need these medications. If I don't take them, my disease progresses like crazy. And my disability goes from here to here almost in a week. That answers these questions.

**Wesley P: Yep. Makes absolute sense. And I can understand where that confrontation could be. Not necessarily a great thing, but like you said, the medication is so important. You have to really let them know just how important it is, but I'm wondering when you think about this, right? And you mentioned you would go to your doctor first and then your insurance company. Do you think that conversation with the insurance company from your perspective, is that the final yes or no that you're going to get, or do you think there's anything else that you could do after that? That's my question.**

Jed F: Yeah. They're the ones with the money, so typically, the buck stops here. But I am connected with a ton of bulldog advocates who all they do is just call up Washington, call up insurance companies, march, do protests and whatnot, and get paper signed and whatnot. I would definitely talk to them. That probably would not be the end and say, hey, who do you know that I need to talk to? Because there's probably a nonprofit out there that is willing to take on these fights. And so, again, I did a speech at this conference one time. All patient advocates have our position. I am not the march on Washington guy. I'm the guy who brings - who runs support groups. But I do know plenty of march on Washington people and they're scary, so I would call them up.

**Wesley P: Got it. You've got a network. You know people.**

Jed F: Yeah. I'm connected.

**Wesley P: OK. Here's another question. Let me frame it this way. You mentioned you feel like calling the insurance company. That's where you're going to have the battle of yes or no. And then after that, you may have to, like you said, call the people you know if, imagining that the challenge process, because you can see on the screen here it says, considering a challenge. And this is sort of for everyone to think about. If the process for challenging is your health care provider is actually going to be the one who's going to be calling the insurance company, fighting this battle for you, going through the process of justifying why you need the medication, does that- Jed, for you does that make you feel better, like you don't have to necessarily have to do this all alone, that you're not the only one who's going to be on the phone?**

Jed F: Yes. And as for me, I trust all of my healthcare providers. So all my doctors, I believe that they would do the best. I've have doctors in the past where they probably would've just take my recommendation and throw it in the trash and say, "Hope he doesn't come back again." But from- everyone I'm with right now, it would be good. Like I said that, when I first got approved my biologic, it was my doctor's office, and they had a whole department of people who were just supposed to annoy insurance and just say, "No, it doesn't work. No, that doesn't work. He needs exactly what was prescribed." Until they give in. So yes, that is comforting and especially since I don't want to fight- if there's someone who's willing to do a little bit more educated fighting for me because they have- probably have more answers than I do. At least they know better or worse than I do. So that's good and considering the challenge I would like to- if they're with me I'm all for challenges. I just- I just hope it wouldn't take months and months and months and months because I'm in the process right now, it's been going on since February and it's a billing thing where one of these new provider- one of these suppliers they must on the first day of school because they had no idea how to properly bill insurance, they messed up, and he just pass the bill on to me. As that makes sense. So I'm fighting back since February. So it's- sometimes it can go for a while.

**Wes P: It can definitely drag out. So how long is too long? How long are you willing to deal with this kind of fighting for your failing condition?**

Jed F: This thing I'm in right now, with the billing, I'm ready to drop them right now. I'm willing to - it's my CPAP supplier, and I'm willing to go without CPAP for the rest my life if it means that I don't have to deal with them anymore, but that's not good again, that's- so it's- If it was like my AS treatment I would not have waited this long. If they were- if they were trying to short me on medication I wouldn't have put up with that but definitely 6 months depending on the- depending on what it is, I think 6 months is probably the longest. You should stay quiet until you really bring in the big guns.

**Wes P: That makes sense. Another question for you, would potentially trying a switch to a different medication be at all an option for you if that's what the insurance company wants you to do or is that out of the question in any situation?**

Jed F: As long as the same basic type of medication I'm willing to try anything, especially a lot- there's a lot of AS treatments and it's- it's unfortunately a lot of trial and error. What works one- great for one person, won't work at all for another person. So I think I'm on a good treatment right now but I'm also fully aware there's probably something a lot better but I would have to try it first, and then- so I'm always open. I'm always open, I want to trust the doctor that if they say something is good I'll give it a try because I can always stop if it doesn't work, but the problem with biologics is once you go off of it it's really hard to go back on to it because your body builds antibodies to it. So eventually it'll just, "We don't have to fight anymore. We'll put up a wall and they'll never come back in again."

**Wes P: So messing- messing with that is always a risk?**

Jed F: Yes, you don't want to stop if you don't have to.

**Wes P: Makes sense. Got it. Thanks, Jed. Thank you. Clarence, I'm going to jump back to you and so I know you've been through this process and the formulary change prompted you to try a different medication. Tell me a little bit about your thought process when you saw the new price tag and once you talk to your doctor what was your thinking? Did you think should I consider fighting this at all? Did that ever crossed your mind or did you think maybe I'll just try the single med instead?**

Clarence W: Well, no. It never crossed my mind to fight it. So what I could understand the- I didn't think that once the formulary changed that it could be undone. That was- that was my assumption and I pretty much thought I was right. So my response if this has to happen again was I would- I would go back to my doctor immediately and not just say I'll go back on this previous medication. I would inquire and want to know more about other medications between these two because there might have been something available that would've work the same as this double med works and we never got into that and that was my fault. This was a doctor I had no relationship with, I was referred to this pulmonologist by my primary who I trust a lot, but I get a referral, I go in, I'm a new patient. So we didn't have a relationship of how we work together. It was she saw me, she did all the testing, I fell in this category as far as my ability to breath and she prescribe meds. That was it, and then prescribed a better med that was working, and then when the formulary changed they started to go with everything else changing. So I would go back to my physician first and be more forceful and work with her, work with them if possible and maybe hopefully they would call the insurance company and something might happen that way, but it was in- if I couldn't work with my physician I would call the insurance company myself, and then if it was necessary, if I couldn't afford his medication that works I would have maybe look for another doctor. That's one of the things that we learned in that support group is be your own best advocate and if you're not satisfied with the physician, find another one. We don't owe physicians anything.

**Wes P: So quick question for you then, from your perspective the relationship you have with your doctor could- could help determine whether or not you would want to challenge something like this or even think to ask. Is that what you're telling me that having a better relationship with your doctor could lead to that conversation? Is that what you're thinking?**

Clarence W: Yes. Yes, a better relationship could lead to being challenged and especially if my doctor was part of instituting the challenge. My doctor can probably get a lot more done than I can.

**Wes P: Do you- do you wish that your doctor- when this happened, do you wish that they had told you that it could've been challenged or would that have been an option you would've considered at the time?**

Clarence W: Yes. If that information had come to me I would have considered it, yes.

**Wes P: Thanks, Clarence. And Gabe, I wanted to get back to you see if you have any luck with the microphone, to see if you sound any better? It still sound- I don't know what's up. It's still- still kind of like half muted. I don't know if pulling the- if going without the headphones could help maybe or if that's an option. If not it's OK. Maybe give that a shot because we can't barely hear anything you're saying and I can give you a second too if you need to test it out.**

Gabe H: Test, can you hear me?

**Wes P: Yes, much better.**

Gabe H: So I think that- I think in terms of considering challenge or timing of challenge I think it was- it was really kind of very depending on what the medication is and what- what my time horizon is, what's going on, what are my symptoms, what are- what is the situation would kind of dictate how quickly or how- and how aggressively I might choose to take action.

**Wes P: Got it.**

Gabe H: So I think it's just there are kind of a lot of factors in it and could because you might find yourself in certain situation where nothing- where no action is too much. You need- you need your medications so you need to make something happen.

**Wes P: And would you- would you be a help I guess in that situation where it is severe? Would you be concerned at all about sort of running out of medication while you're waiting for a decision to happen? Would that be on your mind?**

Gabe H: That would be, absolutely. Yes, that would be a big concern.

**Wes P: Makes sense. Now you mentioned when- when you would receive this response hypothetically if you did get it, you would start with your primary care doctor, but imagining that this was for your MS medication would you then go to your urologist I'm assuming in that case?**

Gabe H: Yes, absolutely. So I guess- I guess I would probably begin with the provider that prescribed it to begin with.

**Wes P: That makes sense. Would it have crossed your mind that the provider could initiate a challenge and be the person who's sort of fighting this battle over the phone? Or would you have thought, “I need to be the one who's calling the insurance company?'**

Gabe H: Actually, I would think that, and I certainly at least would rely on them, and again, if I was at an impasse with my provider I might seek a second opinion, would try to find a medical advocate that would be willing and able to go to battle with me, to address the situation. Would be to try to build the medical necessity of it, and then can approach the insurance company like that.

**Wes P: Makes sense. Thanks, Gabe. And Alex, I wanted to ask you the same question. So you told us about your situation, where you were told you needed to provide a test to prove that you have pulmonary hypertension. You mentioned you called the doctor's office, they told you that there weren't many options. I want you to imagine another hypothetical scenario where you were given another request to switch your medication to something else, and you felt- tell me a little bit about what your thoughts would be whether you would consider challenging it, would you go to your doctor to challenge it? What's your thinking?**

Alex F: I would definitely go to the doctor to challenge it because I don't think insurances have any right to butt into my medical affairs. I don't- and I would leave it to the doctors to challenge it. I would have done it myself if I didn't have my friend give me more meds this three months, otherwise I'd have been on the phone constantly and I know he wouldn't gone to the office but when I was first diagnosed I totally did leave everything up to the- up to the doctor's office so that they can get the insurance covered and everything else.

**Wes P: Did that- did that- was that a successful strategy letting the doctors take care of it or do you wish that you would also been on the phone? What's your thinking?**

Alex F: Back then I would not have known the difference. I wouldn't even know that I could call. I was 28 years old and I would've totally- If I remember correctly I had asked my doctor if- who was going to take care of the insurance part and I don't think I would have even known to call myself back then.

**Wes P: Interesting. Whereas today you would be on the phone? You sort of-**

Alex F: Yes.

**Wes P: And so what- what makes the difference there? Is it that you think you have a better chance of succeeding if you yourself were on the phone too like Allison was saying or if that would speed the process a little?**

Alex F: I would hope it would speed the process along. I don't know about them deciding either way because I call, but I do feel like it would- it could help. It could help, but with them being the big pharma's or insurance- I don't even know what I'm saying, I'm sorry. I guess they would listen, wouldn't they? But whether that was put into action or not I don't know.

**Wes P: So one question I have for you. You mentioned pharma, would you consider calling them as well? Would you think that they would have maybe something either to do with it or something that they could help you with?**

Alex F: I would- Yes, I would call the pharma and say that the insurance- for me the insurance is inpatient, outpatient, and- but of course I have- I do have prescriptions with Medicare but I would- I would call them both, try to figure out what's going on, but thankfully I was able to be covered with my friend and I wouldn't- if I hadn't, I would.

**Wes P: You would've. And if you would gotten a request like this, would your first thought have been this is the insurance company or would you have thought, "Maybe the pharmaceutical company is involved with this." Or even, "Maybe my doctor is involved with this." And would any of those have crossed your mind?**

Alex F: Yes, definitely the doctor because it took so long for him to even suggest a right heart cath, but not really the makers of the drugs but the pharmacy as far as them giving me the medications. Is that makes sense?

**Wes P: The pharmacy- them too. So you would- you would call the pharmacy as well?**

Alex F: Yes.

**Wes P: Got it. Got it. That does makes sense. Thanks you, Alex. I guess another- I think that's a question for the group too. When you would receive this request, would anyone think to call- I think we've heard the insurance company from everyone and we've heard that you would call your doctor, but would anyone think that maybe the pharmaceutical company was at all involved in the decision or that their doctor themselves was involved with the decision? What would your gut feeling be about receiving a request?**

Alex F: I don't- I wouldn't think about the manufacturers of it because it would- it would be Medicare part B that would be dealing with the medications. So I guess insurance. That's what I- how I see it is that that's who I would- who I would speak to as well as my doctor.

**Wes P: And does everyone else feel the same way? Does everyone else- is the first entity that pops in your mind always insurance or does anyone else have a gut feeling that maybe someone else was involved with this? Jed, go ahead.**

Jed F: Insurance all the way because if the doctor does it would be non-medical.

**Wes P: But so I guess my question is when this would happen to you it wouldn't necessarily say non-medical switch, you could just say your prices have increased or your formulary has changed. Would you- would you know that it was just the insurance? I guess that's my question for you.**

Jed F: Yes, the insurance or you've been switched to a company that insurance works with. It's- it's basically been there for me, it's all the insurance didn't want to pay or insurance sign a new deal with different pharmacy.

**Wes P: Got it. Got it. Thanks, Jed. Clarence, I see you put your hand up. Did you want to talk?**

Clarence W: Yes, I agree with Jed it's the insurance probably, not always but quite often this probably the insurance and by Medicare then it's this supplemental is regulated by Medicare. So but the formulary changed, I don't think Medicare gets into the insurance, changing the formulary level of different medications, but I really- I really doubt if it's the pharmaceutical companies because they're- they're handed it off previously to different groups before it gets to me. So I'm looking at the insurance companies almost all the time increasing this, making that change.

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

**Wes P: Thanks, Clarence. So I want to get to the next slide. We have about half an hour left. I want to make sure we get through everything. So our next flight is all about the effects of non-medical switching. So now I want to switch gears a little bit, think about what could non-medical switching impact in your life, in your care. And so you'll see the first bullet there is your relationship with your provider. Now I want to hear from the group, does anyone feel if at all a non-medical switch could impact your relationship with your provider long term? I know it's sort of an open ended question but I want you all to think a little bit about how this could potentially impact your relationship with your provider for better or for worse. So I'll open that up to the group, does anyone have any feelings or any ideas about if that could be the case?**

Gabe H: I feel like it would depend on how it was introduced to me. So it might be something the type of situation that would strengthen my relationship with the provider if- depending on how it was presented.

**Wes P: Sorry, go ahead.**

Gabe H: So if they came to me would say, "Hey, look. Who's this? What's happening? This is being switched for a non-medical reason. These are the reasons it's being switched and these are from a medical perspective, these are the outcomes I'd anticipate." Then that could be, "He's- he or she is being honest and straightforward." And if it didn't go in a positive way, the communication was not done in a positive way, whether it's a good communication or a bad communication, it could damage that relationship.

**Wes P: And I guess another question for you, tell me a little bit about the ways in which that relationship could be impacted? Like you said, if it wasn't approached or handled in that appropriate way like you said, and if that communication wasn't done well- first of all, tell me a little bit about how- what would that look like, is that them not telling you what- I'm sorry is that your provider not telling you that like you said these are the medical outcomes you can anticipate, this is what the insurance company is sort of requesting. You're expecting that from your provider right off the bat, correct?**

Gabe H: I believe so, yeah. I would expect or I would want that, and if it wasn't happening then I might try to find someone who I could expect it from.

**Wes P: If your provider was telling you "I'm a little bit worried about the outcomes that could happen". So imagine this conversation is happening, your provider is telling you "these are the reasons they want to switch you I'm a little bit worried about it, would your expectation be then the provider to say let's challenge this, let's get on the phone and try to solve this? Are you expecting the provider to kind of initiate that process?**

Gabe H: That would be my hope.

**Wes P: If they didn't would that then- like you said would you then say well maybe I should go find somebody who will fight for me, is that what you're thinking?**

Gabe H: I think so yeah.

**Wes P: Got it so you're kind of expecting the doctor to take the initiative, the provider to really have the initiate in this situation correct?**

Gabe H: Again, whether the doctor is going to take the initiative or not going to take the initiative, I am going to take the initiative to find the doctor who will because I don't have the medical expertise but I am going to take the initiative in my care so I am going to go find the medical expertise that I feel is necessary to then challenge.

**Wes P: Makes sense, absolutely thanks Gabe. Clarence, I wanted to ask you the same kind of question because you mentioned that the particular provider you were working with when this happened that you didn't necessarily have a strong relationship with them. Did it impact at all your relationship afterwards, the fact that this provider was sort of just being able to help and if not did you feel that impacted your relationship?**

Clarence W: It didn't. I didn't get a positive feeling for the way the whole situation wound up going. By seeing this doctor just initially one time, I wasn't sure and I didn't know what to expect from this doctor as far as this medical condition since it wasn't as serious a medical condition as most everybody else are experiencing and whether it's like my cancer treatment. I would look at that entirely in a different realm if something like that happened because other than the dollars being much higher, the consequences of not having the right med would be much worse. So I would be fighting that to get the medication that I needed in this case. I can say that if the doctor responded in a helping way and gave me information that I didn't have like other meds in between, the single inhaler and the one that she prescribed to me, if we had discussed other options I would have appreciated that and I would have known that they were involved and was concerned about my treatment and making sure I had the right med to make me improve my condition. If that happened then it would increase the likelihood that I would remain with that doctor and would have a good relationship. It could have gone in the other direction if she, I should say if they I shouldn't keep saying she because I don't want to offend anybody, the difference between a he or a she but the relationship really could have went south if we didn't have a small conversation about going back to the med that was working in the beginning. It's pretty much remained a neutral relationship after it was all over and I was OK with that and I assume she was too.

**Wes P: So you broke even total got it thanks Clarence. Alex I wanted to ask you the same question. Did you walk away after your experience recently, did you feel your relationship with your provider had at all been impacted by the situation where you had this request from the insurance company for the test?**

Alex F: No because they weren't the ones making that decision, I believe.

**Wes P: So I guess I'm just wondering because it seemed like the provider wasn't able to get you in for a few months, and you were put in a [INAUDIBLE] situation. Was that at all a source of any unhappiness on your part that the provider wasn't really able to get you in in a timely fashion? I guess that's part of my question.**

Alex F: I see, probably after the fact yeah just a little bit I guess but I know that hospitals are constantly busy and you got to sit there and wait for several hours to be seen and that sort of thing.

**Wes P: That makes sense, thanks Alex, any other thoughts from the group about the way in which your relationship with your provider could be impacted at all for better or for worse?**

Allison D: It brings me back to this one situation where I had an issue with a prior authorization and I was talking to my nurse practitioner and she told me that it wasn't her job to fight it so I feel like that immediately lost all of my trust in that facility and that should have been my biggest red flag to leave. I actually stayed there for a couple more years after that and really they didn't impress me further. So really having a team that'll advocate for you, a prior authorization is someone's job. You can't just tell me it's not your job without pointing me to the direction of the someone whose job it actually is. I think that's just one of the bigger things. If they're not willing to fight for you- I understand, I work in the health care system I understand how short staffed we are but really not taking that time can really make or break a relationship.

**Wes P: That's a really helpful perspective. Do you feel is that trust that you lost in that situation or is it just- tell me a little bit more about how that relationship was changed after that.**

Allison D: I absolutely adore her and love her because I just have that relationship with nurse practitioners but it just left me- if I didn't push it and advocate for it, being like if it's not your job whose job is it and really knowing those resources and finding those resources, I could have went without that medication for a long time. Again, it's just really frustrating and I'd never go back to that facility again just because of one of many things that has happened there.

**Wes P: Got it thanks Allison, the next bullet point is stability on medication and the last bullet point is effect on health and I think the two are related in their own way. Jed you had mentioned with biologics that your concern was stepping off of a biologic, switching that can impact the way that your immune system reacts and you may have a loss of efficacy in the future. Is that something that when you hear non-medical switching is that something you're worried about in terms of having to switch, losing that stability on medication?**

Jed F: Well now it does. I was thinking about that when whoever was talking. I would hope that they would always, no matter who's making the decisions, that they'd always put me on some biologic which there's still many more I have not tried. However, if it was this stuff is way too expensive we're not willing to pay for this anymore, here's your NSAID and a DMARD and you're set that would really scare me because I'm going to feel bad at least a week later if not sooner. Just knowing that the longer I go the harder it's going to be to get back on a treatment like this, I would definitely feel like I'm against the clock and I might have to even skip work just to focus on getting this figured out. In those kind of situations, if me being off this for a while means that my body won't accept it anymore I can't risk that and then I'd have to go all bulldog on them and like I said I don't want to do that.

**Wes P: Got it, that's helpful thank you, any thoughts about other sort of challenges that could happen in that situation? Say you need to taper off of a biologic or something like that; is that a process that you would be worried about in that situation?**

Jed F: Honestly I've never really had those big reactions. I don't think I've ever gone cold turkey off something really big but honestly it probably wouldn't have crossed my mind. I just would have thought about the next few weeks and how that eventually my AS would catch up with me and my spine would start fusing together again without that treatment.

**Wes P: So it's that progression that you're worried about?**

Jed F: Yeah.

**Wes P: Makes sense, thanks Jed. Gabe similar question for you, is this a concern for you about stability on medication and having to switch? I think you touched on this earlier before but how would this impact the way that you're currently stable on medication and your health overall?**

Gabe H: That is certainly something that would be very concerning to me and would also play into that, we talked about that when to escalate, when to bring in second, third, fourth opinion, when to call, who, when to drive down there, when to take action. It would certainly be the stability on medication; again all of the above if you look at the bottle and half the time it's do not suddenly stop taking this medication. You have to taper off so many of these medications that you don't have a lot of time. Now with MS, a variety of the medications have long timer horizons. Your next dose isn't for six months at times so you have a while but still you want to know where your next meal is coming from and be confident in that. So that's definitely a concern for me that I'm concerned with would be stability.

**Wes P: Got it thanks Gabe, any other thoughts from the group about stability on medication or the effect on your overall health that this could or could not impact?**

Gabe H: Well it's just the stress that would come along with that, stress is so often definitely with my condition but I would imagine with most all serious health conditions. The side car of stress that comes along with so many of these situations can take a very real and very negative effect on your health.

**Wes P: Makes sense thanks Gabe. Alex, I saw you were going to chime in, do you have something to add?**

Alex F: Yeah if I hadn't have been on the medication, would my condition have progressed so much worse it totally could have had a bad effect on my health.

**Wes P: So for you stability is so important, if I'm understanding you correctly, you've got to remain on your meds. You've got to be adherent, you're taking it every day, missing doses is not an option for you. Would you say that's fair?**

Alex F: I'm not very compliant but I do try to take it as much as I can especially on my depressed days.

**Wes P: Well that's another question for you too. Gabe just mentioned stress and mental health. Is that also something that you would be worried about? A request for a switch, could it impact your mental health and impact your stress like Gabe was saying? Do you feel the same way?**

Alex F: I think so yeah definitely because I'm already feeling the effects of what I was told yesterday and I felt it before but I didn't pay much attention to it. If I would have been out for those three months I was thinking about that just now, it really would have been not good.

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

**Wes P: Makes sense thanks Alex, any other thoughts from the group on this topic? I know we've covered a good amount but I want to make sure we hear from everybody. Thank you all, last slide a bit of an open ended one, I want to hear about support. So we have two questions on the screen here. Thinking about for anyone who might face a non-medical switch in the future, what do you need during the non-medical switch process to feel more supported and like you have the resources you need and then also the second question here is what kind of support would make it easier to remain on the medication that your provider originally prescribed if you were given a non-medical switch? What kind of support would you need? So the two questions I think are sort of related, it's just about support overall. I'm going to go around the group here and hear from everybody and so Clarence if you don't mind I'm going to start with you. I know you've been through this process. What kind of support would have been helpful during the process and what kind of support might have helped you stay on the medication that you were originally prescribed?**

Clarence W: More support from my physician might have helped but to a larger degree some support financially, not money in my pocket but financial support for lowering the cost of the medication to a point where I could better afford it and take it on a regular basis and treat the symptoms in the best way possible and get rid of them and then come off the meds. For me it was kind of a long term, stretched out further than I think it should have been so financial compensation or dispensation in some way would have went a long way.

**Wes P: Got it and you're still paying for the bimed that's so expensive; you're still paying for that mostly out of pocket?**

Clarence W: No my condition got better and I slowly was weaned off of it and today I'm not taking it but in the back of my mind is what if this comes back again and then I'll be in the same place I was before. I'll have to attack it in a different way if it happens again.

**Wes P: Makes sense got it thanks Clarence. Allison I'm going to jump over to you. What are your thoughts on some of the support that would have been helpful or that could be helpful in the future if this ever happened?**

Allison D: I guess just knowing your resources. I feel like having a strong physician or a nurse practitioner or even a very strong nurse coordinator is super important dealing with this and just having people that you know that you can talk to and get support from without being judged or feeling like it's a waste of their time.

**Wes P: Sure and you mentioned a nurse coordinator, is that someone who you've worked with in the past to get support for similar issues?**

Allison D: Yeah I feel like my nurse coordinator is the first line of action generally because if you ask my physician anything about insurance or something like that he would just look at you with a blank stare. He's just that kind of guy. He's very intelligent in certain things but not when it comes to medications and insurance companies so she's definitely one of my biggest proponents when it comes to dealing with insurance companies and she's very good at her job.

**Wes P: So that's really interesting. Actually I want a quick show of hands from the group whether others feel the same way that their MD wouldn't necessarily be the person to turn to but rather maybe someone else in the practice, a nurse practitioner or a nurse coordinator as Allison mentioned. Does anyone else feel the same way? Jed hand up, got it, anyone else feel that way, Alex so a few individuals. Allison sorry I didn't mean to cut you off, any other thoughts about what could help you remain on the medication you're originally prescribed if this ever happened to you?**

Allison D: No I feel like that's pretty much it, just a strong network of people who will fight for you.

**Wes P: It sounds like you have that. It sounds like you're prepared in case something like this ever happens, hopefully it never does but good to be prepared so thank you. Jed, same kind of question for you; what kind of support is most helpful for you if this process ever were to happen to you for your medication?**

Jed F: I'd want to reach out to someone who's had this happen before and see what they did. I believe that some of my more bulldog type friends, if they have not had it happen to them directly that they would know someone and just find out what they did. I only get so much energy a day so I don't want to waste my energy on something that's not going to get anywhere. I think about all these times where I've just gone crazy just to fix something and then I found out oh there's an easier option, I should have just looked at that. So I would want to find someone who's done it before or who knows who's done it before. You asked about not the doctor but the nurse practitioner, my co-lead of my support group in Saint Louis, she's a nurse so she should know and she's got spondylitis just like I do so she'd probably have some ideas as well so I would definitely look to them, just anyone with experience so I'd know if my steps were the right steps.

**Wes P: Makes sense and any thoughts on that second question about what would make it easier to remain on the medication you were originally prescribed? I know you mentioned it was so important to stop the progression, anything that could really help you maintain the medication that you currently are taking?**

Jed F: I think the only thing that would help me is if my doctor managed to convince insurance or whoever was trying to make the change that it wasn't worth it because for me it's not a financial thing. I pay nothing for any of my drugs, a few of them I do, not the big ones. It wouldn't be that I'd need financial support or anything but just someone who's making the calls to say no we can't do this, seriously think about it.

**Got it thanks Jed and Gabe same question for you, what are your thoughts around what kind of support you would need?**

Gabe H: For me it's very much I would need a medical person whom I trusted to let me know if it's a good idea or not from a medical perspective. I think I'm essentially trying to say the same thing that everyone else has been saying, is that sound medical advice concerning the process and that would kind of go both ways. Sound medical advice to say here's how we're going to do it or sound medical advice saying here's how we're going to fight it and I think that's what I would need. That's the support I would feel I would need in the medical realm.

**Wes P: Got it so you're looking for their direction as to whether you should challenge or whether you should make the request, you're kind of putting it in their side of the court I guess you could say.**

Gabe H: In a sense but I don't mean to say that I'm going to wash my hands of the decision but that's the support I would need to make my decision.

**Wes P: Got it makes sense, thanks Gabe and Alex last but not least what are your thoughts? What would be helpful? What could have been helpful when you went through this process a couple months ago?**

Alex F: I wish I would have known because I feel like I would have been able to put some information out there for myself but I just went ahead and did what the office said, just leave it until next month and we'll figure it out then. If I would have known that I could do anything at all I would have done it.

**Wes P: Are you thinking of the challenge process or are you thinking something else that could have helped, what are you thinking about?**

Alex F: Knowing what I would have to do to tell them, to talk to them, I've never had to do it before except for the other one. For me it just felt like I got a door slammed in my face and so I couldn't take that medication according to them. I think the support I would have wanted- I don't know my new doctors very much anyway I've just started them recently and so I would not have known who to say what can I do and I don't have any kind of relationship with them either like Allison said.

**[////]**

**Wes P: Like Allison said, that makes sense thank you Alex. We're almost at the top of the hour. I did want to leave some time for our Janssen team members to jump in and ask any questions so are there any questions from our Janssen team members?**

Gabrielle G: I don't have a question but I did just want to say thank you all so much for joining us this afternoon, as always we so appreciate you sharing your experiences so it's been really great listening.

**Wes P: Thanks Gabrielle, any other questions from the Janssen folks? Great well my dog is chiming in, sorry. He's telling me it's time to wrap it up. In that case let's wrap it up. I wanted to thank you all for spending the time to talk to me and share your thoughts. I know this is a frustrating topic so I appreciate you opening about it. I hope everybody can decompress for the rest of the day and forget about all this frustration but thank you all, I really appreciate it. It's really great hearing from you all. Just a quick note, We do have an email address here for the Janssen PERC at CorEvitas.com. If you have any thoughts, anything pops in your head, any questions feel free to shoot us a message and we appreciate any feedback. Once again it was great to hear from you all. I hope you all have a great rest of the week and a wonderful holiday weekend, take care, and stay healthy and we'll talk to you soon.**

Gabe H: Thank you.

Jed F: Nice working with you all, bye.

Alex F: Thank you so much.

**Wes P: Thanks everyone.**

**[////]**