

What's my Diagnosis?

Community Members Share their Diagnostic Journey

You can view this presentation at: youtu.be/U4awgJE6lxo

[00:00:05] **Dr. GG deFiebre:** All right. Hi, everyone. Can you hear me ok? Yes. I hear myself on it. My name is GG, and as Dr. Greenberg said, this panel, we're really gonna talk about people's, the folks we have up here, their diagnostic journey, symptoms they had, what happened during that diagnostic process. But we're going to keep the diagnosis a secret. So, just in your head, you can maybe start seeing where you see some similarities or differences to each of your experiences. But just to start, do you mind, just if we go down, say your name and where you're from, and then we can get started with the questions? So, I'll start with Ashley and Jeff. Yeah?

[00:00:47] **Jeff Harrington:** This is Ashley Harrington. I'm Jeff Harrington, her father.

[00:00:52] **Lyd Lacey:** I'm Lyd Lacey. I'm from Denver, Colorado.

[00:00:55] **Angela Jackson:** Angela Jackson, Houston, Texas.

[00:00:59] **Andreas Melitsanopoulos:** Andreas Melitsanopoulos, from Connecticut.

[00:01:01] **Andrew Jopson:** Andrew Jopson, and I'm from Baltimore.

[00:01:04] **Dr. GG deFiebre:** Awesome. And are we good with the microphones? Do you want them closer?

[00:01:11] **Andreas Melitsanopoulos:** I've never needed a microphone.

[00:01:14] **Dr. GG deFiebre:** I know. [laughing 00:01:17] Yeah, so the mic, are for people here as well, but we also have live streaming, so to make sure that they can hear what's going on. All right. So, to start, I would like us just to kind of set the scene. What year was it that your onset of symptoms happened? How old were you, and what did everyday life kind of look like before the symptom onset? We'll just kind of go down the line.

[00:01:44] **Jeff Harrington:** For Ashley, it was 2007, June 29, a Saturday. She travelled for the first time alone. She had just finished her freshman year at Saint Mary's College in Notre Dame, Indiana, was working her summer job as a neighborhood pool manager, and doing swimming lessons. She was a competitive

swimmer in high school. So, her boyfriend was taking summer classes at the University of Virginia. So, she had planned, with the 4th of July falling on a Wednesday that year, to fly out and spend some time with him. First time again traveling alone, ever flying alone. Felt great. Got on the plane, flew out, and things started to change from there. You want me to keep going, GG?

[00:02:41] **Dr. GG deFiebre:** No. That's perfect. Yep.

[00:02:42] **Jeff Harrington:** We gotta jump.

[00:02:43] **Dr. GG deFiebre:** Yep. So, yeah. So, Lyd, if you wanna help.

[00:02:45] **Lyd Lacey:** Yeah. So, for me, it was, -- can you guys hear me? Okay. So for me, it was 2014, so 10 years ago now in August. I was six years old at the time. And before my diagnosis, I was always, you know, very happy, very energetic, running around a lot. I had a lot of energy. You know, just average 6-year-old stuff.

[00:03:09] **Dr. GG deFiebre:** Got it. Angela? Okay. Angela? You have the microphone on?

[00:03:15] **Angela Jackson:** Well, I remember my date. It was February 27, 2019. I woke up with a numb thigh, and I kind of blew it off. I kind of hide it a little bit. Then I got ready for work, and I put on my Dallas Mavericks stuff, because Dallas was having a game that night, and I had been invited to attend. But I had a rude awakening. At work around three o'clock, my left leg was totally numb, and I was dragging it across the floor. I didn't want anybody to know or take me anywhere. I was like, I got my left leg up. My right leg is still operating, so I went to my primary care doctor. She gave me some steroids, told me if I didn't get any better to go to ER. And she also did the best thing ever. She referred me to a neurologist. But later on that night, my sister and husband had to take me to ER because my right leg had become paralyzed as well. So, I went to ER and received a diagnosis that I'm not gonna share with you. [laughing 00:04:47] But to make a long story short, I got to the right doctor, the neurologist. He diagnosed me and admitted me into the hospital.

[00:05:02] **Dr. GG deFiebre:** Got it. Okay. Thank you. Andreas?

[00:05:07] **Andreas Melitsanopoulos:** Hi, everybody. I guess leading up to my diagnosis, it was late 2021, early 2022, during COVID. So life was anything but normal then. Working remotely, trying to stay active, playing soccer or tennis. I come from a collegiate athlete background and just tried to have some normalcy outside of that. It was Christmas Eve of 2021 where I was unfortunately working a little bit, and I noticed some just blurry vision in one of my eyes and a sort of numbness, coldness in my feet that I had never really felt before. So, and it was difficult time just in general with COVID and going to hospitals. Was in an emergency room, which I was just kind of told I was a little stressed and anxious at the time. And over the course of that December to January, my vision worsened, and I went from going for a couple miles of a run earlier in December to needing a walker, and being hospitalized from there.

[00:06:25] **Dr. GG deFiebre:** Got it. Andrew?

[00:06:28] **Andrew Jopson:** So, my journey with this began in May of 2022, I was 32 years old. I was a PhD student at Johns Hopkins University. I was writing my proposal for my dissertation, and was supposed to go to a class seminar to, I was preparing, you know, to present at least some of my ideas to my peers and some faculty in my department. And I think the night before I was having dinner, I was on a date and this person was actually making me food. And I started getting really nauseous and I was worried that I was actually like, oh, I don't really like what you're making or cooking for me. And I was able to get home and the next morning I got some blood work that sort of initiated a lot of events that I guess we'll kind of get to next.

[00:07:25] **Dr. GG deFiebre:** Got it. Yes. So, I would say a theme here is that everyone was kind of just living life normally or as normal as you can during a pandemic too. But in general, you know, just existing when these symptoms started. So, do you mind just going out into a little bit more detail about the first symptoms that you each experienced, and how did you feel when this was happening? And did you go to see a doctor or did you seek care somewhere and how did these symptoms kind of develop over the course of time?

[00:07:59] **Jeff Harrington:** So for Ashley, she arrives in Charlottesville, Virginia, and just starts to feel kind of funny. Realized that as she was speaking, wasn't necessarily slurring words, but words weren't coming out right. Just felt kind of odd. Went out to dinner and just really didn't have an appetite. Went to bed. At about four o'clock in the morning, our phone rings. And she's talking with a very labored voice. Arms are tingling. Hands are tingling. Feet are tingling. And, we're like, ok, you just travelled. You're, maybe you're dehydrated. Who knows? But you need to have your boyfriend take you into the ER. And she's talking with my wife on her cell phone, and she's saying I have to find my Notre Dame t-shirt, I'm gonna wear that. And she couldn't see it, even though she was able to get on the phone and she was walking around getting ready. So, they go into the ER. And, again, I go back to bed. I'm thinking, she's gonna be fine. They go in and, coincidentally, as she's entering, a resident neurologist is going through the ER. He sees her coming in, and it appears that she's favoring one side. He immediately thinks she's having a stroke. So, immediately did an MRI, and what they saw in that MRI led to an immediate conclusion. We get a call that they're, you know, looking further into this.

[00:09:40] My wife and I are gonna paint the hallway. 9:00 in the morning, we're driving to Lowe's to pick up some paint, get a phone call back from University of Virginia Medical Center, your daughter's nonresponsive. So, we zip home. I grab my go bag, and get to the airport, get the next flight that'll get me from Fort Wayne, Indiana to Charlottesville, Virginia. Shockingly, no nonstop flight [laughing 00:10:09] Couldn't believe it. So, I get on the plane, and I'm in Atlanta for like three hours talking to family. I get a hold of my sister, and I'm explaining what the physician had told me. And she gets on the internet and is literally researching 2007. And I get there. Ashley's just moaning when I get to the ER. Boyfriend been with her all day. And talking again with the physicians of what's going on and what they're suspecting. And, again, nothing really happening with Ashley. She's -- they're hitting her nail beds and that. She's not reacting to anything, just moaning. But then my sister calls back and says, I got a phone number you need to call. And it's that guy's kitchen phone, I later find out. Yes.

[00:11:16] So, this is a Saturday night and I call him, and he gives me a number for the physician sitting to his left. And I'm like, ok. So, I'm exhausted. I've been traveling all day. I get up on Sunday, and I call, what I assume is his office number, to Dr. Greenberg on a Sunday, and I'm just praying that Monday morning is not hectic for him and I'm going to hear back from him. He calls me Sunday night, and I explain to him what's going on. And, unlike people that we have met with Ashley's condition, we almost have an immediate diagnosis. We met at the first symposium I went to with her brother in Seattle back in '08. We met a couple. The husband had the condition. Her wife was a physician. They lived in Miami. The initial conclusion there was that he had an aggressive brain cancer. And to make your final arrangements, he's not going to leave. We visit with them when we go down to Florida. He's still with us. Thank God. Actually doing well. So, what we encountered from what we've experienced with most people with a rare neuroimmune attack was very much different, in that, you know, we almost immediately knew what we were confronting, and then it was a matter of how we're going to confront this.

[00:12:55] **Dr. GG deFiebre:** Got it. And Lyd?

[00:12:57] **Lyd Lacey:** So, for me it was a little different. I was six years old, and I remember I was at the pool with my mom and my brother and, you know, just playing, having fun. Some of my friends were there too. And then as we're leaving, I started to have a cough, which was normal because I had asthma. So, you

know, didn't think much of it, and then that turned into a mild cold and a fever, which turned into a severe cold and a fever that lasted for about a week. And then I got better from the fever and everyone was like, ok, we're fine. Surprise, we weren't. And as it turns out, I started to have weakness in my left arm. And, I kept saying, like, hey, mom, like, you know, I'm having this weird thing. But, of course, me being the six-year-old that I was, I also was starting school soon, and I did not want to go to school. So, my mom was like, oh, you know, you're probably fine. You're probably just exaggerating things because you don't want to go to school, which valid. [laughing] But as it turns out, we ended up going to my general doctor who did some blood work. Everything came back normal, but there were enough things that were adding up. You know, I was trying to eat like, corn on the cob, and I couldn't hold it. I was trying to play piano, couldn't play piano. All of these different things. And so finally, we went to an orthopedic person and everything was normal there, but he was concerned. So, we went to one neurologist, at one hospital and they didn't find anything, but they were still concerned. So, then they sent me to a different neurologist at a different hospital. Hi. And then after that, I got a lot of tests, some MRIs, CTs, that kind of thing. And then I was eventually hospitalized, and that's where I received my diagnosis.

[00:14:59] **Dr. GG deFiebre:** Got it. Angela?

[00:15:04] **Angela Jackson:** Well for me, first of all, I was 62 years old and living my best life. My girls were grown. My husband and I were having a good time, enjoying each other's company. And, the symptoms that I had was tingling toes, numb at the ball of my feet, my legs were just tight. It felt like I was carrying logs. You know, I just and I had no control. That's the worst thing is that I had no control. My left leg would jump, and I'd have to push it back down. And while I was hospitalized, I got plasmapheresis, 20 bags for 10 days, one every other day. So, I had some issues with the plasma. I had allergic reaction, so that meant my hospital stay was extended. And outside of that, I was just thankful that they were trying to help me walk again, even though it was not while I was hospitalized, but they did help me by, with the exercises and pulling me up and, you know, helping me. But my mindset, you guys, was to beat it, but I cried every day. I just want to... every day for, I know, a month. I couldn't answer the phone. I couldn't talk to people because I felt I had lost so much at that time.

[00:16:56] **Dr. GG deFiebre:** Andreas?

[00:17:03] **Andreas Melitsanopoulos:** Yeah. I guess I fortunately was able to see a lot of different doctors, albeit with different answers in a short period of time. From my emergency room visit thinking, that I was stressed with pink eye to seeing my local eye doctor, who noticed issues with my vision, to an ophthalmologist and then to eventually a neurologist where I underwent multiple MRIs and a spinal tap. I was given an initial diagnosis on February 1, but like any serious life-changing diagnosis, I was seeking a second opinion, which I was fortunately able to get at NewYork-Presbyterian Columbia Neurology in New York. My sister-in-law is a surgeon there who was able to get me seen quickly, and we kind of had to start from scratch again, despite having all the other test results. So, again, multiple blood tests, CT scans, new MRIs, two more spinal taps, and a couple of weeks in the hospital, relearning to walk and under various IV treatments, I eventually found my correct diagnosis.

[00:18:22] **Andrew Jopson:** So, before I was hospitalized, a little bit of context. I had been losing a lot of weight for about six months, beforehand, so I was about 30 pounds less than this. And I was on the West Coast for a wedding, and my mom said, I really am worried. I went to go get some blood work. I went to University Health Services and got some blood work in early April. The doctor who was there called me immediately after the results came in and said, there's a lot wrong here. I'm going to send you to endocrinology. So, I met

with an endocrinologist the following week at Hopkins, and she was like, you have Graves' disease. So, we're just going to get you on that, a medication to resolve that. I went on that, but I continued to get really, I was just really sleepy and tired. The regular blood work from that, found that I had just really low white blood cell count. And so, she took me off of that medication immediately, within three weeks. And so, she just said, I'm really worried about your low white blood cell count. So, this was end of April.

[00:19:26] A couple of weeks later, I again was on that date, and I got really nauseous and sick. I wasn't feeling good. I was able to lift home. And, the next day, I had regularly scheduled blood work for the thyroid condition from my endocrinologist, and I went in, got that blood work. I was supposed to go to class and present. I couldn't. I didn't feel great. And the endocrinologist called me, and as you can tell, I don't like calls from doctors at all. [laughing 00:19:55] She called and she said, I need you, she's like, do you have a fever? And I did. And she's like, I need you to go to the ER. I'm going to call them that they're going to look for you, when you come in. I said, why? She said, because you have, like, you have low, you have leukopenia. You have lymphopenia. You have neutropenia. Like, I'm really concerned.

[00:20:15] And so, I did have a high fever. My roommate drove me to the ER. I sat in the ER for a few hours, and I was admitted with actually, like, a neutropenic fever. And for about a week at Hopkins, I was treated with, they weren't sure, I was actually seen over by an infectious disease doctor. They were giving me IV antibiotics for about a week. And then after a week in, and I don't really remember this, I do remember getting up and throwing up a lot. So, I was throwing up. I was able to get up out of bed. My friends, my other peers in my program were there. We were supposed to be grading final exams. They were grading my exams that I was supposed to be grading for the class I was TA'ing. And they told the doctor there or the nurse, they said, you know, he hasn't actually gone to the bathroom at all today. And they said, you know, I was kind of out of it. And they tried to get me up, and I couldn't get up out of bed. And then they did a bladder scan and realized, wow, he's full. And so, then they put a Foley catheter in me and then ordered an MRI. And slowly over the next, like, 48 hours, it took about 24 hours, I think, for me to get an MRI, I wasn't able to walk, a lot of retention, developed intractable hiccups, and started getting double vision.

[00:21:48] **Dr. GG deFiebre:** Got it. And so, each of you had talked a little bit about what the diagnostic tests you got were, but do you mind just going into a little depth about what test you received and kind of what that process was like within this journey of yours?

[00:22:06] **Jeff Harrington:** For Ashley, again, it was pretty quick. It was an MRI that was pretty conclusive. And luckily, as the saying goes, you know, her mother is saying I never should've let her travel alone. I'm saying, thank God, she's at the University of Virginia Medical Center. They know their stuff. And, so, really, it was again, just, you know, looking at the MRI and the neurologist, although rare, realizing what was going on and, our ability to confer with the folks at Johns Hopkins.

[00:22:39] **Dr. GG deFiebre:** Got it.

[00:22:40] **Lyd Lacey:** Yeah. So, I had, ok, let me see if I can remember all these. An MRI, CT scan. I'm looking to see if everyone is nodding. A spinal tap. I know that. Was there a PET scan? No? [Background, "Not that I remember." 00:23:02] Ok, cool. Yeah. But so, I know the big thing though was that on the initial MRI, no one found anything, but then later they went back and they were like, oh, that's what that is. So, it was very subtle, but then later looking back with what we know now, we were able to see it. There was, you know, at the time it was very much like a game of like just whack a mole. And, you know, have you travelled to these countries in the past however many months? Do you have cancer? Like, all these different things. So, a lot

of different tests. And I was six at the time, so I didn't really know what was going on. I just knew that I didn't like needles, which was kind of an issue, but we got through it.

[00:24:01] **Angela Jackson:** Let's see. I had quite a few MRIs. Starting with the ER, I had MRIs with contrast, without contrast. I had x-rays of my spine, my hip area. They drew a lot of blood. I had a spinal tap when I got admitted to the hospital, and then I went through more MRIs and CT scans. And I think that's about it. Just constant testing every day to try to identify what was happening. None of the nurses knew about my disorder. And, it was kind of difficult trying to explain to them something that I just found out and just wasn't much aware of. All I could tell them was what I've been told. But outside of that, I can't remember all of the testing that I had, but most of them were MRIs and scans of my back.

[00:25:21] **Andreas Melitsanopoulos:** Yeah. And in my journey, I kind of had to, we kind of had to throw everything at the wall and see what stuck. So, my initial MRIs of my brain, thoracic, cervical, and lumbar spine, and spinal tap led me to an initial diagnosis. But once I was at Columbia Neurology, we redid everything again. So, all of those MRIs, two more spinal taps, an EMG, which I wouldn't recommend to a friend, not that that wasn't fun. A lot of visual field tests for my vision, and then just the general strength and sort of touch and feel neurology test that you would do every morning and night, which is very eye-opening. I didn't know exactly where my limbs were in space and couldn't feel vibrations or a pinprick. So, it was helpful as I was getting treatment to see some things coming back, but, obviously, scary during the process to kind of feel myself losing my body in that way. So, happy to have been tested with everything and to eventually get an answer, but it was very extensive.

[00:26:39] **Andrew Jopson:** Yeah. Most, similar. I had an MRI and also had a spinal tap. I remember they asked, -- they wanted -- I think a physician assistant did their first spinal tap. They trained him on me, and I remember that. They asked me, and I was like sure, whatever. Everything's bad already. So, whoever that is, I was your first spinal tap. But I guess that helped with the diagnosis. And I also had blood work that was done internally and then also sent off to kind of help with the diagnosis.

[00:27:12] **Dr. GG deFiebre:** Got it. So, I'm seeing some themes of MRIs, blood work, lumbar punctures, spinal tap, and then just testing in general. So, during that your acute inflammatory attack, what treatments did you receive for at that point in time when you were first diagnosed?

[00:27:35] **Jeff Harrington:** For Ashley, at Virginia, so, obviously, had flown out there, so we're going to be camping out, did IVIG immunoglobulin to really try to overwhelm her immune system and try to get it to shut down. What it was doing, to give her relief. Of course, was on steroids immediately. Probably as soon as they got her off the MRI, had her on steroids. And then we were planning on going home, but kept getting infections, cancelling air ambulance flights. I was there for three weeks. Mary, my wife, her mother, they ended up being there for four weeks before we were able to bring her back to Indiana.

[00:28:26] **Dr. GG deFiebre:** Lyd, do you remember what treatments you got?

[00:28:28] **Lyd Lacey:** Yeah. So, I got nothing. Sometimes I took Ibuprofen. And that's about it.

[00:28:34] **Dr. GG deFiebre:** Got it.

[00:28:38] **Angela Jackson:** Well, I got steroids in ICU. I was in ICU for about five or six days, and it was a constant drip of steroids. And then when I got moved to an acute room, they started me on plasmapheresis. And I spoke about that earlier that I had 20 bags of plasma for every treatment, and it was every other day. And that's about it.

[00:29:16] **Andreas Melitsanopoulos:** Yeah. When I, in that month span of sort of my body deteriorating, getting test results, and getting an initial diagnosis, I was sent home with a bottle of prednisone to take about, I think, 15 or 20 pills a day until we could work on an infusion therapy with insurance. I then went to Columbia Neurology within a week to get the second opinion. And we didn't do anything originally, so we could figure out, ok, what is actually happening. After a couple of days, the treatment plan was five days of high dose IV steroids and IVIG.

[00:29:58] **Andrew Jopson:** Yeah. For me, pretty much once they had a good idea of what they thought was going on, and so I was given IV methylpred, yes.

[00:30:07] **Dr. GG deFiebre:** Got it. So, --

[00:30:07] **Andrew Jopson:** -- actually.

[00:30:07] **Dr. GG deFiebre:** Yeah. Again, seeing some themes here. So, again, everyone here has a different diagnosis, but we have somewhat similar diagnostic journeys in terms of the onset, what was happening before, what physicians were seen, and then the treatments and what was happening at that point in time. So, yes, so anything else you want to add kind of about your diagnostic journey or experience, in those kind of beginning stages?

[00:30:34] **Jeff Harrington:** It sucked.

[00:30:36] **Dr. GG deFiebre:** Understandable, yes.

[00:30:40] **Lyd Lacey:** Yes. Yes.

[00:30:43] **Jeff Harrington:** No, for Ashley it was the hardest thing. She came home, was in subacute care. We went to what was then Rehabilitation Institute of Chicago, her and her mom spent four months there. They tried plasmapheresis, really kind of outside the window, but grabbing at anything. It wasn't so onset at the end of June. We were unable to communicate with Ashley until December when she started lifting an arm to yes/no questions. She's screaming at night. We don't know if she's in pain, if it's just the psychological. It was hell.

[00:31:29] **Dr. GG deFiebre:** Yeah. Go ahead. Yes, anyone.

[00:31:31] **Andrew Jopson:** I think one thing that was really for me during all this process, you're getting tested, my body's being touched, and, you know, people are coming in, different specialists. I was still, you know, they were still bringing in rheumatology, endocrinology was still trying to see me, infectious disease, neurology. And I didn't always know who was there. And I would say I felt really, really lost. Right? There's all of these testing going on. But in terms of each specialist had a different opinion about kind of what they thought was going on. And so, I had a hard time figuring out, well, who do I trust? How do I understand what is happening in my body?

[00:32:06] **Andrew Jopson:** And I'll say one really important moment that I remember, because I started just getting really frustrated, it was like, I've been in there for two weeks. I trusted everything that was going on, but it hadn't really resonated with me what was actually happening. And, a second-year resident could tell how confused I was, and I really appreciated when she pulled up the screen. She's like, do you actually know, did anyone even show you your MRI scan of what is going on? And nobody had. And it made a really big difference, when she pulled up the screen and said, see all of this, you know, like inflammation? That is why you're not able to move. And that was really, you know, 10, 12 days in. And that made a really big difference

for me in terms of understanding where I was, what was happening. So, I really am appreciative of that resident who made the time to do that.

[00:33:01] **Angela Jackson:** I'd like to add that I did start physical therapy inpatient, and then I was moved to a rehabilitation hospital where I was there for three weeks in rehab and getting tests in the morning. And then I had a full regimen all day for therapy. So, I went in in a wheelchair and came out with a walker.

[00:33:35] **Lyd Lacey:** I think one thing for me is that it was very isolating because at the time, you know, I was six years old. I did not understand what was going on. And I think also too, because of hospital policies and the condition of what was going on with me and potential of is this a transmittable infectious disease? I wasn't really allowed to see a lot of people. So while I was in the hospital, I saw very close family members, and that was it. Guys, Children's Hospital has hospital dogs, and I really wanted to see them, and I didn't get to.

[00:34:20] But I think you know, just also too from a social perspective of I, as a six-year-old, if I didn't understand what was going on with me, like, how am I supposed to be able to explain this to my friends? Because I did end up missing a lot of school. How do I tell them yes, I'm at the hospital right now. I'm sick with this thing, and it's really weird, and we don't really know what's going on. Yeah, it was just very isolating is the word that comes to mind.

[00:34:53] **Jeff Harrington:** I just want to throw out the the changes for Ashley. So, as I'm speaking for her. Ashley's all here. She didn't lose really anything, but almost everything was compromised for Ashley. She can speak, but it's very, very difficult. But we do communicate. She didn't lose her memory. In fact, we rely on Ashley to remind her old folks what's going on, where we have to be and when. [laughing 00:35:24] Great family support, friend support. She still hangs with high school and college classmates. Great family support. So, we are, you know, onward and upward. And some people comment on Ashley's smile every once in a while. She does light up her room everywhere that she goes. It's really kind of amazing, you know, [clapping 00:35:49] this aura that she carries.

[00:36:02] **Dr. Benjamin Greenberg:** That was great, but I just have to say I feel a little cheated. I thought we were going to hear the diagnosis at the end. Right? Am I, I mean, do we need to take a vote, or...? I mean, is it ok if everyone shouts out their diagnosis or we're going to wait till the lunch break, and...?

[00:36:21] **Audience:** [inaudible]

[00:36:22] **Dr. Benjamin Greenberg:** Yes, ok. [audience laughing/inaudible/background audience] Yes. All right. Let's see. I'll go in order here. At where Jeff, do you want to shout out for Ashley? I don't know where everyone went up. ADEM. So, for all of you who guessed ADEM, you got it correct. Now, where's Andrew? No? Okay. Do you want to shout?

[00:36:50] **Andreas Melitsanopoulos:** I have NMOSSD [inaudible].

[00:36:52] **Dr. Benjamin Greenberg:** Double seronegative neuromyelitis optica spectrum disorder. Lyd, what did our dear friends in Colorado finally come to an answer for?

[00:37:02] **Lyd Lacey:** AFM.

[00:37:04] **Dr. Benjamin Greenberg:** AFM. Andreas. Oh, wait. Where were we? Okay. Sorry. I don't know where everything went.

[00:37:10] **Andreas Melitsanopoulos:** Anti MOG.

[00:37:11] **Dr. Benjamin Greenberg:** MOG, anti-MOG associated disorder. Okay. Angela. Where's Angela?

[00:37:16] **Angela Jackson:** Transverse myelitis.

[00:37:18] **Dr. Benjamin Greenberg:** Transverse myelitis. Am I leaving anybody off? All right. So, we had transverse myelitis, neuromyelitis optica, anti MOG associated disorder, acute flaccid myelitis. So, I appreciate everybody sharing their stories and going through things and, appreciate GG moderating. Hopefully, what you got out of that is even though people wind up in what are seemingly very distinct, very different diagnoses, possibly with different treatments, there's a lot of overlap between these conditions. And one of the tremendous gifts that Sandy and Pauline and the board did, even before I even knew about the Transverse Myelitis Association, was to expand the tent. So, even though the organization started as a home for individuals who had transverse myelitis, there was a quick recognition that there were a lot of people with a diagnostic code or category or title, that may not have those terms in it, but there was so much similarity, that was important to include everybody.

[00:38:24] And that was a critical decision point for the organization. Because the big tent allowed for not just a lot of families and caregivers to come together, but on the clinical and science side, as we got to meet more and more community members, recognize that there are a lot of conditions that share a lot of similarities and we have accelerated the rate of discovery and understanding by that big tent approach. So much so that we struggled for a decade on renaming the Transverse Myelitis Association. Long discussions, with horrific names of an organization. The NMO, MOG, Transverse Myelitis, ADEM, Optic Neuritis, AFM Organization doesn't roll off the tongue. And it was exceedingly appropriate to rename the organization in honor of Sandy and Pauline who did so much. And so that's how we got to the Siegel Rare Neuroimmune Association.