Panel presentations on diagnosis and treatment of ADEM, AFM, MOGAD, NMOSD, and TM

You can view this presentation at: youtu.be/ju4InqJzOfE

[00:00:00] **Dr. Benjamin Greenberg:** So the agenda today starts off with your stories or representatives of each and every one of your stories. And the idea that we had, and it was not my idea, I take no credit for this brilliant idea, was to invite representatives from the community to come up and tell their story in terms of their diagnostic journey, their early treatment journey and what they've experienced. And we've paired each of them with a different clinician. And we're not going to tell you what the diagnosis was. We're going to talk about the stories without labels, and then we'll apply the labels at the end. But we want a couple of things. We want you to listen for the differences for the commonalities, both in terms of the physical and the emotional aspects of what all of us have gone through, all of you have gone through.

[00:00:57] And we also want this to be interactive. We invite you in person and those of you who are online to ask any questions you have. If you are online and are joining us, if you ask a question, we have wonderful teams in the back who will raise their hand and we will call out. There are individuals, I believe with microphones, so if you do have a question, just raise your hand so we can get a microphone to you so that people online can hear the question you're asking. And so, with that, I think we are going to get started with our stories, and I'm going to invite Chantal Banks to lead us off. And so, Chantal, if you want to come up here, I will give you the podium. And so, what we're going to be doing is introduce yourself, tell us where you're from, and then tell us a little bit about the beginning of your journey. What started everything off for you?

[00:02:02] **Chantal Banks:** Okey-dokey. Let me introduce myself. I'm Chantal Banks. I'm 53 years old and I'm from the state of Maryland. My interests include walking, diamond painting, if any of you may know about that, and spending quality time with my family. I'm honored to be here, participating today in this symposium. I encountered my first symptom in 2019. I remember it like it was yesterday, forgive me if this is too much information, but it is what it is. I was putting on my bra, which I generally snap in the front and slide around to the back. Ladies, you get it. Right? In the middle of my slide, I ran across, maybe, a quarter sized sensitive spot on my back. Nothing there, just felt really bad. Over a week, that spot began to grow and grow and grow and grow. By that time, I thought it was time to see my primary care physician. I get to him, he's looking at me, maybe you have shingles without the rash, and I'm thinking, "No, I don't." But for now, we'll go with that.

[00:03:24] Probably three days after he gave me that possible diagnosis, it shifted to the other side. So now I have pain on both sides. And now it's kind of radiating in the middle. So, it's like a T. So, at that point, I go back to him, maybe 10 days later, and he's like, "Well, this is out of my league now and I think you need to go to the hospital." So, I go to the hospital several times. They send me home with different diagnoses, sciatic nerve, back pain, shingles again maybe without the rash. So, it took me about two months of being very proactive and really running from doctor to doctor to doctor with this unbearable pain. And as I'm doing this, I'm actually like losing the feeling in my legs and I just can't feel certain important parts of my body. And I'm thinking, "I have to find someone who knows what this is." I found a pain management doctor who said, "You don't have shingles, you never did, and you need to get to the ER because your MRI results don't look really good at all." So, I get to the hospital. I'm admitted, I actually end up in John Hopkins, but I went to several hospitals before that. You know, the whole barrage of steroids, the blood work, MRI's, lumber puncture.

[00:04:52] And I think over the next few months, I had several clinicians, the neurologists, PCP, endocrinologist, pulmonologist. I had a lot of people in my life, thank God. After my diagnosis, I was placed on prednisone, which I still take every day, and I get reflexes infusions every eight weeks. I participate in the Kennedy Krieger Physical Therapy Program, which is absolutely amazing. And it has done wonders to keep my mobility and strength up. Today, I experienced severe nerve damage, which has left me numb from my mid torso to my toes, and my balance is a bit off. I have had many trials and tribulations, but with a lot of prayer support from my family and friends, I've made it through those. But they were battles that I could fix. This journey is all mine for me to feel every day. But I have accepted what is, I've let go of what was, and I have faith in what will be even if it's uncertain. Remember, staying positive is half the battle. Thank you for having me.

[00:06:09] **Dr. Benjamin Greenberg:** Thank you. That was great. Before I ask some questions, I'm going to open things up for anyone in the room or online for questions. And as a reminder, just raise your hand so we can get a microphone to you. While people are thinking through your story, I want to take you back to the beginning because it's something we hear often in our clinics about individuals going to their primary care physician or for a child's pediatrician and sometimes urgent care and emergency room. And often the first symptoms don't get recognized as a brain or spinal cord or what have you issue. When you look back, what are your feelings about that experience in terms of those early weeks? And I won't bias you, I'll leave it at that. When you're considering that, are you understanding? Are you frustrated? Are you angry? Where are you in terms of your feelings?

[00:07:09] **Chantal Banks:** I'm pretty understanding. I feel like I'm understanding because I've always had the personality of, "I have to fix this, I can fix the world, so I have to get this done and taken care of." So, I felt like my primary care physician was really doing the best that he could. So, I'm very happy with how that happened with him. It was beyond his things.

[00:07:35] **Dr. Benjamin Greenberg:** And it sounds like it. And one of the things we struggle with in the aftermath once diagnoses are made, and my former chair, Mike's former chair at Hopkins, used to say, Jack Griffin used to say, that the smartest neurologist or smartest physician is always the last physician, whoever has all the time and all the data, they're going to be the smartest. But they have the advantage of all the time and all the data. For a lot of symptoms that people experience, and it sounds like yours was in this category, it isn't a hit over the head in terms of the health care professionals of saying it must be X, Y or Z.

[00:08:14] **Chantal Banks:** Correct.

[00:08:15] **Dr. Benjamin Greenberg:** Although I think some people in the room, themselves or through family, have experienced situations where somebody had a symptom that was hit you over the head obvious and it still gets missed or delayed. I don't know for how many people in the room they feel like there was a delay in the diagnosis or the management of things. But this is a topic that comes up for us quite a bit. As you wound up getting diagnosis and you're in Baltimore, you were at Hopkins, can you talk about that experience of getting the testing and then your initial treatment and whether or not you benefited from that initial treatment. When they first started giving you medicines after all that testing you did, did some things immediately or shortly thereafter get better, or did it take a lot of time?

[00:09:10] **Chantal Banks:** It didn't take much time at all. Once the steroids got in, I was feeling much better within days. I was feeling so good that I did not have to go to rehab because the sensation that I was losing was coming back. It was still bad, but I could still walk and do the physical therapy test that they needed me to do.

[00:09:33] **Dr. Benjamin Greenberg:** And then, I really appreciated your comments at the end, in terms of the past, the present and in the future. I'd like to ask you about the past part of things, because at least in my experience, and I have the privilege of meeting so many patients and families who've gone through situations like this, I have a lot of patients who struggle with the morning or the grief. And that's the best term I've found to apply to this, of this notion of what's been lost. And for a lot of folks, they say I am not, nor will I ever be again the person I was. And there's a lot of sadness associated with that, and independent of any ongoing symptoms. Because you spoke about it so well, would you mind, and I know this is personal, talking about how you got to that place that you articulate of being able to recognize the change and be forward looking?

[00:10:42] **Chantal Banks:** Okay. That was difficult because before I got transverse myelitis, I was healthy running vegan, the whole nine yards. So, it really does feel like a death of a part or a side or a limb of your body. It really does. So, you really do have to take the time, you have to cry at night. You have to cry in the shower, you have to put the kids on the bus and bawl all day. You have to do that. It's like the passing of a human. So, I took the time, I did it, but 10 years ago I experienced my dad's suicide. So, I almost felt like it was the same thing where I had to get down in the dirt and then go, "Okay, Chantal, you cannot stay there." So, I come up. But I do go to counseling through Kennedy Krieger as well. And I talk to a wonderful Dr. Sobelman, and we talk all the time. And I have a grasp on what I have. I understand what it is, I know what I have to do, and it is what it is. I can't change it, and I'm just going to live my life the best I can.

[00:11:54] **Dr. Benjamin Greenberg:** Thank you for sharing that. I'm sorry about the loss of your father.

[00:11:57] **Chantal Banks:** Thank you.

[00:11:57] **Dr. Benjamin Greenberg:** I'm thrilled to hear when people talk about taking advantage of resources, like counselors, therapists, and those types of things. I don't know if Grace or Mike want to comment. I've had some patients who've resisted counselors in the way. I've described it, I don't know what your experience has been, is we all need coaches at that time. So, if I were going to go for the Olympics, I have no idea what sport that would be. But is there debate in the Olympics, can I go argue with people because I might meddle in that. But even the elite athletes, even Mike Phelps had a coach. And it's because we're not objective about ourselves, are very subjective about ourselves. And then some people say, well I have wonderful friends and family and it sounds like you have a wonderful network and a wonderful community. But can you talk about the difference of having a coach, a professional therapist who's invested in your well-being, but isn't going to be as subjective as a loved one, a family member or friend? What's the palpable difference about working with a counselor?

[00:13:11] **Chantal Banks:** The difference is, our families are great, our friends are wonderful, but if you don't have what we have, you just don't get it. You just don't. I mean, they act like they do, and I totally understand, and I think it's imperative that we have coaches or counselors to help us to give us the tools to be able to

navigate this because you can't do it by yourself. I don't care how much love you have, how much money you have. If you're not here with what's going on here, you're just going to be in a sad, dark state.
[00:13:50] **Dr. Benjamin Greenberg:** I'll ask you, and I'll even open this up to everybody here. Has anyone received a piece of advice or a comment of loving support from somebody that totally missed the mark? What you're going to know their hands going up. What's your oh, this is my favorite actually. What was you look so good. Yeah.

[00:14:13] **Chantal Banks:** Yeah. And you just go, thanks because I can't feel anything from my breast but thanks but go with it.

[00:14:25] **Dr. Benjamin Greenberg:** Other comments that people have experienced that were well meaning. Yeah.

[00:14:28] **Audience member:** For me it was, you can do everything. you can function.

[00:14:37] **Dr. Benjamin Greenberg:** You can do everything. you can function. Yeah. There's not a reason to have a feeling of loss. Those are in my top three. My third favorite is, but it could have been worse. Has anyone gotten that one? You should be thankful because you could have fill in the blank, whatever the case may be. And these are very, I think, natural and we can understand where those comments from, they come from a place of love and support and all those things, but they land off the mark in certain ways. Any other questions or comments? I don't mean... Yes, here's we'll just wait for the microphone right behind you. Anyone here old enough to remember the Phil Donahue show. For those of you remember this is our version of the Phil Donahue.

[00:15:27] **Audience member:** The paradox is that I'm allowed to say those things to myself. You're looking good, you're doing well, but no one else can say that to me. I haven't figured that out yet, but that's the reality.

[00:15:43] **Dr. Benjamin Greenberg:** Yeah, it's a great point though. And in fact, not only are you allowed to say it to yourself, but you're also often encouraged to say it to yourself. But there's a big difference if somebody comes up and says, "You need to exercise more." Versus you saying, "I really need to exercise more." There's emotionally a very different response to these things. Other questions or comments. And if you're joining us online, if you put in the message, the question, we will get it. Grace, like anything we haven't covered that you want to comment or question on.

[00:16:23] **Dr. Grace Gombolay:** Yeah. I was just going to touch upon the psychology piece. It's something that's very important and I feel like often gets overlooked because you physically 'look good,' but it's a very important part of our health, our brain health. So actually, in my clinic, I have a psychologist who's with me in the clinic and she checks in with every patient, no matter how you're feeling that day. And it can be a five-minute conversation, it can indicate a 45-minute conversation. But I think it's so important to think about those things because even in our busy lives, you know, you're coming to the doctor, you drive three hours to get there, you have to wait a little bit to see them, hopefully not too long. And then you have this extra person who's coming in to talk to you, but I think it's so important to part of your care.

[00:17:05] **Chantal Banks:** Agreed.

[00:17:06] **Dr. Michael Levy:** Can I ask you a question?

[00:17:09] **Chantal Banks:** Sure.

[00:17:10] **Dr. Michael Levy:** My question is when you were laying in the, in the bed at johns Hopkins and someone came to you and said you have this one in a million diagnosis. Why did you believe them? How did you get to the point where you're like, yes, that I believe that that's what I have. How did how did you accept?

[00:17:30] **Chantal Banks:** Well, based on everything that they were telling me, it coincided with exactly how I was feeling, and I kind of thought, "You guys went to school, I didn't, so I'm going to take your word for it." And then after they left, I did lots of research and it just fell into place. It was perfect, it was spot on, spot on.

[00:17:53] **Dr. Benjamin Greenberg:** And then just I'm going to ask you a question that we're going to ask of all of our speakers because I want folks to keep track. In terms of the diagnostic testing you underwent, I heard you talk about blood testing and MRI's, a spinal tap, was that involved? Based on your recollection of those moments, what did they tell you about which of the tests help them make the diagnosis and which of the tests were used to rule out things? Were there discussions about why they were ordering different test?

[00:18:27] **Chantal Banks:** All I knew was lumber puncture needed to be clear liquid, that's all I knew, and it was. And that the MRIs were ruling out things and confirming things.

[00:18:39] **Dr. Benjamin Greenberg:** And so it was the MRI that helped them make the diagnosis ultimately.

[00:18:44] **Chantal Banks:** Yes.

[00:18:46] **Dr. Benjamin Greenberg:** All right. Any other questions are coming. These are great, thank you so much. You did such a great job. I'm very impressed. Okay, so we have one patient journey, one experience. We now want to compare this to another and I'm going to invite Hannah to join us for our next experience. There she is, you're blocked by the podium. I couldn't see you over there. No, don't apologize. So, Hannah, if you'll walk us through your experience and then I'm going to have Grace take the lead in terms of questions and discussions.

[00:19:30] **Hannah Stadler:** So hello, everybody. My name is Hannah Stadler. I am from San Antonio, Texas, born and raised, and what else am I trying to say? I get nervous when I get up here. So, I'm from San Antonio, born and raised. I just graduated from BYU in Utah last June, so it's been about a year in neuroscience. Really inspired by my experience, I won't tell you what it was, and I recently took the MCAT actually and I'm applying to medical school right now.

[00:20:04] **Dr. Benjamin Greenberg:** Yay.

[00:20:05] **Hannah Stadler:** Yay. I know I tried to tell myself that in the middle of it all. So that's a little bit about me. I guess I also love sports and being active, doing art and music, all that kind of stuff. So, when I was almost 18, I was 17, it was like three days before my 18th birthday, it was the end of my senior year of high school, I was just at home alone, and I decided to go take a shower at night late at night. And I just went in, and I got, sorry if I start crying, you know, it's very emotional. So, I'm going to try not to. But I got a ringing in my ears, and I thought it was very strange and I started getting really lightheaded and dizzy, and I couldn't stand. I felt like I was going to fall in the shower, and so I just sat down to try and catch my breath a little bit. And I guess like all of the movement somehow caused extreme nausea. So, I was throwing up in my shower for like 30 minutes, just like really bad, you guys. The kind of one that you're like, "Oh my gosh, I'm going to die because I think I'm going to choke on my throw up." It was bad. I like figured out that it was a movement that was making me so sick. So, I was like, "Okay, you just sit in one spot, and you don't move until anyone, like someone gets home." So, I was in my shower for like an hour, sorry, in my shower.

[00:21:54] **Dr. Benjamin Greenberg:** Sandy cries at everything.

[00:21:57] **Hannah Stadler:** Kindred spirits over here.

[00:22:00] **Sandy Siegel:** Hannah, nobody makes some judgments if you feel emotional.

[00:22:09] **Hannah Stadler:** Okay, thank you, you are my people. Oh, thank you so much. So yeah, I was there for like an hour. It was really cold obviously. And that's how my family found me, so a little overwhelming for them. And it was probably midnight by the time they got home and found me, and they called the ambulance, and we lived in like a small town outside of San Antonio. So, the ambulance took me to like a local ER, and they are just I didn't see... They knew that something was wrong, but it was kind of more of like, "Are you drunk, are you pregnant?" Or like, "What's going on?" And my mom was just explaining everything like no, like she's I don't know where she's incoherent like she can't... I was super slurred speech, couldn't talk, I just couldn't move. I was so incoherent. And they kept me there for a while, did some tests and they were wheeling me out to get a CAT scan when they came back and were like, "Oh you tested positive for the flu." And so, they sent me home and we're like just take Tamiflu or whatever the medicine is called.

[00:23:22] And so overnight, I mean, things only got worse. I tried to go to the bathroom in the middle of the night and I couldn't walk. I was just like bumping into everything. I mean I could walk technically I guess, but it was super unbalanced. I just was hitting everything. And by the morning time, the right half of my tongue started to feel numb, and my right half of my body was really floppy. And so, my parents knew that something was wrong. So, they took me back to a hospital in San Antonio where they were a super busy day. So, I laid an ER. All day long just in the hallway with my dad while he worked on his computer. And they took me in for a CAT scan and they're like, "Okay, well, you're not going anywhere because you have lesions on your brain." And so, then a few hours went by they took me back to get an MRI. Just saw that it was worsening and so I was checked into the hospital. And they did a spinal tap as well at one point, and yeah, I was checking to the ICU and things just were getting worse from there. I was just couldn't move my right half at all anymore. And is that a good start? Should I stop there and ask a question? Yeah, okay.

[00:24:47] **Dr. Grace Gombolay:** I think it's incredibly brave for you to go through you know reliving that experience and talking about it. So, I really appreciate that. Just to sort of echo what Dr. Greenberg said earlier, what did they tell you about the testing that they were doing and how much explanation did they give you?

[00:25:04] **Hannah Stadler:** They probably gave a lot more to my parents. I don't remember exactly. I mean I just remember them explaining things as they wheeled me back into CT rooms and MRI rooms. And then I remember a memory getting the spinal tap. But after like once I checked into the ICU, it's really blurry. I should have asked my parents for more details.

[00:25:27] **Dr. Grace Gombolay:** That's fine, this is your experience and it's what you went through and that's what we want. And just as a reminder, if anybody has questions or comments from the audience or online it looks like we have a question online.

[00:25:39] **Audience member:** Yes. Hi, we have a question for Chantal, so if it's okay we can go back and forth a little bit and then keep sharing the story. But I kind of wanted to address a question that came in as well from the audience online, this is from Brenda Martin. And from a caregiver standpoint, one of the hardest things to understand is the pain associated with TM. Hannah, I think you can speak to that too, but perhaps getting both of your perspectives, what are the best words to use to offer comfort from a care partner, caregiver perspective? Maybe we can start with Chantal and then Hannah?

[00:26:20] **Chantal Banks:** The only words I used were I love you; I love you; I love you, help me, and that's all that's what she did. She jumped into mom mode and took care of me. That was it, that's all I did.

[00:26:37] **Hannah Stadler:** Yeah, I feel like what helped with me the most which is people being there. One of the hardest aspects of it was, I was in the middle or is the end of my senior year and I felt like, because no one knew what was going on, they kind of cut off contact a little bit. And not because they were like, "Oh, I don't want to talk to you anymore." But they were just afraid, and they didn't know what to say and all that stuff and offending. And from my perspective, it was pretty hurtful. And so, I think the biggest thing is just being there for someone and just reaching out and saying, "Hey, I don't know what you need, what's the best thing that you need at this moment?" And I think that's probably the best way to approach. It is just being there. And if you're not sure how to be there, then ask them what's the best way.

[00:27:35] **Dr. Grace Gombolay:** I think that makes sense. And keep asking questions while we wait for... Oh, there's a hand in the audience.

[00:27:46] **Paul Garrett:** Hi, everybody, I'm Paul Garrett. The reason I'm making this comment because that's my wife asking that question. Okay, so I figured. You know when this happened to me, what happened to her, she lost a lot. She had two people in the house, it was one now. She went back to two, yes, having to organize everything, having to run her own business, having to put the garbage out and do. And I'm not saying that likely she had to take over everything and she came to my life and my rescue. And she introduced me to this group. She's the one that got me involved in this group. So, I pretty much owe everything to her, and I could go on for a while, but I won't. But I tell you without your caregiver, we're very fortunate. That's for sure. Thank you.

[00:28:27] **Dr. Grace Gombolay:** Thank you for that comment. I think it's really important. And I think one thing that this conference highlight is the symposium is that the community that there is here, not only here, but also online and for those who can't join us, how did you find out about this community?

[00:28:40] **Hannah Stadler:** So this is a fun story. I owe it all to my mother. She's amazing. So, I have a complicated health history, aside from everything that happened. I was planning to have a double jaw replacement surgery, like right after I graduated because I just didn't have jaw joints anymore. And when I got sick, they pushed back the surgery, indefinitely. And it's been something I've been waiting on for years. So, I was really disappointed because I was in a lot of pain all the time. So, in a delayed college as well. So, it's just like really frustrating, and in our neurologist didn't have any answers and my surgeons were like, "We're too afraid to do anything with all this brain damage that you just had." And so, she just went searching for someone to help and she found teammate through that search. And she was like, "Oh my gosh. Hannah..." Because it had been like six months since my diagnosis, and I hadn't met anyone. And so, it was pretty lonely, and she was like, "Oh my gosh, I found this amazing organization." All this stuff and we found some doctors in Dallas because I'm from San Antonio. So that's how we found it was looking for someone to give me the clear for my jaw surgery, and then it took off from there.

[00:30:07] **Dr. Grace Gombolay:** Great. That's nice to hear. Let's get back to your story a little bit if you can tell us a little bit more about the diagnostic journey and the treatment and the things you went through right after that.

[00:30:17] **Hannah Stadler:** Yeah, so when I was in ICU, I had all my tests done already and they luckily called or the neurologist on call, he knew what was going on and so he was like, okay steroids and IVIG. So, he gave me a big blast of both of those for a few days I think, and it stopped the progression of everything at least. And then from there, I just kind of did therapy full time therapy. I'm trying to think. I might have taken like a few medications after that, but I can't remember exactly. So that was the main treatment and then a lot of therapy and time and all that stuff.

[00:31:01] **Dr. Grace Gombolay:** And then when you first got the treatment you mentioned that it's got the regression. How much do you remember around that time... Where were you feeling during that time in the treatment?

[00:31:10] **Hannah Stadler:** I know it's kind of hard, it's so hazy. And then I like wasn't able to sleep at all, but I was so incoherent at the same time. So, it's not a fun time. But I'm trying to think. It took me a few days into the ICU to just kind of like realize what was going on and like what it meant for my life. And like Chantal was saying, it's just a huge grieving process because you're not who you were anymore. It was super sudden, just like out of nowhere. And I said that I love sports, and so this one's really hard for me. But I loved running and... Sorry, I mean I'm not sorry. You guys get it.

[00:32:37] I was going into my senior year for track, and I just love the sport so much and I have been working. My goals were to make it to the state meet and I had been working on it so hard for like all of high school, and I was so excited for my last year. And the only meet I ran that year was like right before everything happened. So, it was a terrible meet. I felt so bad and everyone's like, "What's going on?" And I'm like, "I don't know." But obviously something was going on that was bad. But I remember just like having this moment in the ICU with my mom and my sister, and I just was sobbing because I realized that that dream was gone. And at 18, I feel like I rooted my identity in this. And so, it was just, I felt like my identity had been stolen from me. And so, it was just a huge changing point. So, I remember that I was the first time that I like put it all together and I was like, "Oh my gosh." And then of course at the time I didn't know if I was going to recover, and I was planning to go to college and I had cognitive impairments. I couldn't speak, like I could speak, but I couldn't speak in full sentences. Like they were super jumbled, it was hard to talk, and had like vision problems, I had to wear an eye patch at one time. So, it's just like, "Oh my gosh, you know, what is this going to turn into? I have no idea."

[00:34:38] **Dr. Grace Gombolay:** I cannot imagine what that would have been like. So, thank you for talking us through some of that. What I thought was very interesting is how you mentioned your identity right? Like you had this identity and a certain thing like running track was your thing, but now, like when you introduced yourself, I thought was interesting, like you're a Texan, that was important. But you also mentioned that you got your neuroscience degree and that you took the MCAT. So how did that change, and how did that evolve over time after your diagnosis took?

[00:35:03] **Hannah Stadler:** Yeah, the whole focus of all my essays, so it's really good. I'm like, prepared right now. But something that I'm really focusing on was my ability to adapt from it all. And you just, I mean, you either sit there and you are super sad about it, or you just have to move on. So that's just what I had to do, not to say that I didn't, I'm still sad about it a lot. So, it's not perfect, but it just pushed me into... I grew up in a family where service is very important, and so I like just threw myself into service and I fell in love with it. I just like loved the opportunity to connect with people in pain but also help. And I came to camp a year after my diagnosis and I fell in love with it, and I've been coming back as a volunteer counselor. And I try to help the kids and they help me too.

[00:36:16] And through it all as well, I was really interested in the brain all of a sudden. And like why did it heal? Because I met a lot of people at camp who looked very different from me and had the same diagnosis and we went different pathways and I was like, "Why did I not heal in the same way?" And anyway, so inspired me to go into neuroscience and I just fell in love with it, I loved it so much. So, the process to get to medical school has been a journey. I've been so up and down about it. I'm feeling pretty good about it right now, so that's good. But I mean all of it has stemmed from this essentially, and then my path forward from it and all the different experiences that I've added to where I am today.

[00:37:26] **Audience member:** I'm Sergio. Actually, I don't speak so good English, but I have a question. How long it took to recover?

[00:37:39] **Hannah Stadler:** It probably took... Recovery was fast for sure. I was in the ICU for about a week and then I was moved to like just not in critical care in the hospital and I was there for a few days. And then they transferred me to like an inpatient rehab center, where I lived there for two and half weeks, and just did physical therapy, occupational speech therapy three times a day. And I was able to leave my inpatient rehab center, walking with a walker. So, there was a huge improvement because I couldn't walk about a month before that. And so just being able to walk with a walker was huge. It was pretty slow and awkward, but it was improvement, and it was really exciting. And then from there just took maybe three or four months to just kind of regain things back gradually. And like the finer details, handwriting stuff like that took about a year to come back to like what it was before. So, about a month to a year. That's a range over here.

[00:39:09] **Audience member:** Hi, I didn't catch it. How old are you now?

[00:39:11] **Hannah Stadler:** I'm 24.

[00:39:12] **Audience member:** 24, okay. I'm 28, so I just have a similar story because I was 13 when it happened. What was your diagnosis?

[00:39:19] **Hannah Stadler:** I can't say yet. It's a secret.

[00:39:24] **Dr. Benjamin Greenberg:** Remember, we had a whole plan?

[00:39:27] **Hannah Stadler:** You almost got me though.

[00:39:34] **Dr. Carlos Pardo:** So you are going to be a doctor.

[00:39:36] **Dr. Benjamin Greenberg:** I'm sorry. Who are you? You have to introduce yourself. So, you just came and got on stage.

[00:39:42] **Dr. Carlos Pardo:** I am very sorry.

[00:39:44] **Dr. Benjamin Greenberg:** This is the Carlos Pardo, Professor of neurology at the John Hopkins University. And we're so glad you could join us. All right now, you can stand.

[00:39:56] **Dr. Carlos Pardo:** Thank you so much. I'm a little bit right now. So, you experience a very stressful situation and that is the best training for you to be a doctor. Can you teach us what was the most difficult part of that interaction with the people that were taking care of you? And actually, the reason I'm asking the question is because I like everybody to think about that. Because we you are not here coming to learn about us, we are coming here to learn from all of you because we need to understand how to approach the situation when we're dealing with patients like you. So, tell us, teach us in what way we failed, so the people that were taking care of you what things they didn't do well that you felt that you were not very well taken of.

[00:40:56] **Hannah Stadler:** Hmm that's hard to pinpoint. I mean, my family was amazing, all my therapist, my doctors amazing. I think the hardest part about it all is just no one knows what you're going through. And so, like Chantal was saying they can offer all this help and it's amazing and I need it, but it's not quite like connecting with someone that understands. And it was rare, like they said in the hospital, one in a million diagnosis, that all that stuff and no one like pointed us in any direction of like a community. And I don't know if they just didn't know about it or any of that stuff. And so, it took six months to find anyone who had gone through the same thing. So, I feel like as physicians or caretakers, specifically physicians when you have the resources to help these patients is just pointing them to people that they can connect with, pointing them to people who have the same experience. Because in my experience, the care was amazing, and it was top notch and I'm so grateful for it. But it was when I connected with someone who had experienced it, that was so powerful. So, suggesting that to patients or giving them resources, outlets, I think that would be my biggest suggestion.

[00:42:34] **Dr. Carlos Pardo:** Thank you.

[00:42:35] **Dr. Grace Gombolay:** Great. Looks like another question.

[00:42:38] **Audience member:** My name is Barbara and I'm sort of replying to Carlos' question. At one after being diagnosed, I went for a second opinion at Mayo Clinic. And about a year after that, they invited me to come back and see how I was doing. And at the end of that appointment, I said to the doctor, "Is this it? Am I ever going to get any better?" And he looked me in the eye, and he said, "No, you will never get any better." And that was the not true. And that was sort of the worst thing... Most of the doctors were great and you know, caring, but he just, I think that was a horrible thing to say. And of course, not true.

[00:43:17] **Hannah Stadler:** Yeah, I'd like to pay you back off of that because I've had doctors where um, they just, yeah, they don't give you hope to get better and whether they believe it or not isn't important. I think we trust doctors inherently. And so, when they give us advice, we take it to heart, I have personally. And um if you can be someone who's like, well you're going to get better if you keep trying, if you keep working on it, like give them that hope and still that hope to keep going for it, I think that's huge.

[00:43:53] **Dr. Grace Gombolay:** And I think we have a question from the online audience.

[00:43:58] **Audience member:** Yep, we do and also a bunch of comments that we wanted to share because we have quite a large audience. We have over 80 people online now joining and listening to your stories. And just a couple of comments that came in, one from Margaret Connor, Hannah, and Chantal, you're both so brave to share your experiences and to relive those feelings with all of us in the room and online and such an amazing courage to face your own chosen journeys. And one comment also from Shelly. She said, I can relate to Hannah, I still have cognitive spacing challenges and my speech was unclear due to the last time I regurgitated. I awoke with my tongue sideways, thank you Hannah for sharing. So, I think there's a lot of positive comments coming in that we wanted to make sure that that came into this room as well.

[00:44:52] We got a comment from John as well, a question. I'm going to mention it here, but perhaps I leave it over to the panelists to see what to do with it because it's specifically related to TM. And so, the question is for the TM speaker, which we don't know yet, who is who, because we're trying to wait. But it is a question that came in. I would like to ask which medicines you take for pain. I'm on so many, but none work. So, kind of, that's something that came in and I'm sure that we at some point can talk about.

[00:45:25] **Dr. Benjamin Greenberg:** We can, tomorrow morning Dr. Ram Narayan from the Barrow neurological institutes. Sorry, tomorrow 9 AM, an entire session dedicated to that question. So definitely tune in for that.

And if I can, just from the comments that were made, since we don't know diagnoses, and I think it's useful to make a point. In the aftermath after your event, did you have cognitive challenges, just broadly speaking?

[00:46:04] **Hannah Stadler:** Yes.

[00:46:04] **Dr. Benjamin Greenberg:** And so for people in the room just by a show of hands regardless of your diagnosis, how many people here feel as though they were cognitively affected after going through whatever your diagnosis was? To raise it, raise them high. People in this room have, I know some of you, and you all have very different diagnoses. And while you talked about getting imaging of the head and brain having changes some of you in the room with costume changes, I've seen your brain memory and it's normal. And so, I just want to make the point even though we're kind of laughing about, we don't know the diagnosis is that the other there are a lot of symptoms that overlap, irregardless of which part of your nervous system was affected, there isn't always a one-to-one relationship between the two. With that in mind, the one question I have is, when you think about the cognitive impact of this and the physical impact of this, if you had to say which one impacts your day-to-day life more, can you separate the two?

[00:47:19] **Hannah Stadler:** Like now, today, or just? Yeah, the only like, ah, what is the order? Okay, so what I have still is slight weakness on my right side, which doesn't bother me too much. And I feel like I've healed cognitively. Like, I can think at a high level. But I've definitely struggled with anxiety and all that stuff and depression and or whatever, all those. And those are huge today, which therapy is amazing.

[00:48:08] **Dr. Benjamin Greenberg:** If I can ask and I know it's personal. Was that something new for you after the diagnosis?

[00:48:14] **Hannah Stadler:** Yeah, I think growing up, I was more of an anxious kid anyways, but it was never like, disabling at any point, but probably two years after my diagnosis, because I didn't do therapy right after, it took me like five years to find a therapist that I like connected with, and I'm so grateful for. So, two years after I had a panic attack, and I don't know if anyone has had one, but they're the worst. And I went on like a mental down spiral, and it just felt like out of nowhere, like I was blindsided with it, and I was like, "Oh my gosh, like I've already been through too many hard things. I thought I got through it. I'm doing fine." All that stuff. And I went to see like a temporary therapist, and she was like, "Yeah, it's probably from all your health issues that you've had." And I was like, oh, yeah, probably because I never worked through it, and it was a huge like emotional burden that changed my life. And even though in a good way, it was still very difficult, and it was not something that I had worked through. And so now I can better manage my anxiety, but sometimes it can just get pretty bad. And so, my mom knows if she's watching, she knows.

[00:49:45] **Dr. Benjamin Greenberg:** Mothers are always watching.

[00:49:50] **Audience member:** Sure. So, you mentioned that you're interested in going to medical school, which is of course a very challenging experience. Have you considered how you would build an effective support system to get you through the process? I mean I was in graduate school, and I had my first incident, and it took me a couple of years to find people who could even believe that I could finish. So, I know that is probably something that you'll confront as well. So, have you thought about how you would get the people who would get you through the process?

[00:50:25] **Hannah Stadler:** Yeah. My family is probably the number one. They are awesome. My sister's here watching, my support team. So family is huge and we're pretty open with each other, which I'm really grateful for. They've been with it with me through it all. So, they you know what's going on generally. And then I feel like this experience has also really opened me up as a person when I was a lot shyer and more introverted before, and I just blossomed in a way in like connection with other people. And I seek it out a lot, like it's really important to me now, and I'm pretty vulnerable with people as well. So, I guess that's kind of, my plan of attack is just building a team of people to support me. I don't know who those people will be, but I have my family and I have my friends that already have and then this community of course is amazing.

[00:51:34] **Dr. Michael Levy:** Can I ask a question? We have limited resources for research, we can't do everything. But if you could direct the resources to an area of research that you think is most important, like early diagnosis or blood test or treatment while you're in the hospital, or on the recovery side, or long-term consequences, where would you put the research money?

[00:52:02] **Hannah Stadler:** From what I've heard from everyone at camp or just through here, it's the initial diagnosis that I feel like it's super important. And a lot of people just didn't get it for a long time, and a lot of damage couldn't be undone at that point. And it's just yeah, I don't know like setting up more consistent diagnosis or like, I don't know what the word is, but having a set... Sorry, I don't know how to explain what I'm saying.

[00:52:40] **Dr. Michael Levy:** I think I understand. You mean like when a person comes in with X, Y. Z, this diagnosis should be on the list, and this is how you
[crosstalk]

[00:52:48] **Hannah Stadler:** Yeah. That's what I'm thinking. Just getting it out there more and like, spreading the knowledge more and all that stuff.

[00:52:57] **Audience member:** Thank you. I totally agree with you on that. But I do have a question. I know you can't tell us what the results were, but when they looked at you, did they do a MOG antibody test? Was that something that was considered, do you know?

[00:53:24] **Hannah Stadler:** I don't I think it was. I hope I'm not giving anything away. But I don't think I had that tested.

[00:53:31] **Audience member:** Okay. Thank you. I didn't mean to derail the mystery. I feel like that should be done for that whatever had. I'm not a doctor, of course. I feel like that should be done for every symptom like what you experience.

[00:53:51] Oh, I just wanted to know other than things that you've already mentioned, is there any other unexpected ways that this experience has impacted your life today?

[00:54:15] **Hannah Stadler:** I guess I never imagined I'd be here talking about it when I was sobbing in the ICU, just finding this has been so amazing. So just yeah, I don't want to talk about it. Don't do much crying already.

[00:54:47] **Dr. Benjamin Greenberg:** You've done such a wonderful job. My last question is just to confirm that you're applying to UT Southwestern and not Emory or Boston or Baltimore, because you don't want to waste your time with those institutions. Right?

[00:55:06] **Hannah Stadler:** Right.

[00:55:07] **Dr. Benjamin Greenberg:** Okay, good. Thank you very much

[00:55:09] **Hannah Stadler:** Thank you.

[00:55:16] **Dr. Benjamin Greenberg:** We have this recorded, right? We can play that clip of where she's applying. Good. All right, outstanding. You guys all of you doing great job. The questions are wonderful. The conversations are wonderful and my eternal thanks to Chantal and Hannah for not just sharing what you shared, but how you share that this is not easy to do in any way, shape, or form. It's not easy to talk about one on one with the therapist, let alone online with viewers around the world. So, you guys are both amazing. If you guys are doing okay, I'd like to go ahead and have our third presenter come up before we take a break. If everyone can push through, I'd like to invite Emily Martin to come up. And as you're making your way, it's going to be my good friend and colleague uh Dr Levy who will lead the conversation, questions, and discussion afterwards.

[00:56:17] **Emily Martin:** Hi, I'm Emily Martin. And if there wasn't any proof that I have cognitive issues, the fact that I have to do this off my phone because I left the binder, I was going to bring that was going to make me look prepared, it's on my bed at home. So anyway. Did I just turn that off? I did. So, hi everybody, and I'm so grateful to be in this group with these people, with all of you. And I do feel like regardless of what are where we come from our backgrounds, we're all each other's people. I think whether you're on the medical side or the patient's side, we all know we can't do this without each other, no matter what this ends up being. So, I'm 44, I'm really short so I have to do this. I live in Central Illinois, little city called Peoria, which is about two and half hours south of Chicago, two and half hours north of St. Louis. I have three sons. Tyler is 18, Nicholas is 16, and Brandon is 12, and I have two adult stepchildren. As far as like background, I went to college, got a degree in psychology.

[00:57:36] And before I got sick or before my health deteriorated, I worked in social services in domestic violence and advocacy, and then I went into pharmaceutical sales. So, it's super interesting to have become a patient after you've been on the medical, like not medical but the sales and understanding how the pharmaceutical industry works. And my brother was actually pharmaceutical chemist as well. So that is both helpful and it just kind of gave me a different perspective once I could no longer work. So now in addition to, because I was put on disability in 2013, I'm peer connect leader with SRNA. And I also got re-certified in the last year after COVID kind of dissipated to become volunteer for domestic violence and sexual assault advocacy. So, I take on call shifts so that the full-time staff can have a break. And I do probably three shifts a week and go into the ERS when women or men come in with their traumas and with them when they are going through their kits and evidence collection.

[00:58:54] And truly being on a patient and having gone through trauma because that is what a diagnosis is, let's be honest, it's a trauma. It has made me so much better at what I can offer those people without it being about me because of what I've gone through in the last years. So as far as personal. Well, I'm a huge reader. I'll read anything from military history to stuff about, like the Queen dying was a big deal. I love gardening when I can. I used to run as well, and there was a little a lot of falls so that kind of had to go away a little bit. I love watching my boys play football, and in fact if anybody wants to watch my middle son, he's going to be playing varsity and they're streaming it and he's quarterback. So, I'm kind of excited, so I'll be up watching that tonight. I do not enjoy cooking; I do not enjoy organizing. And I don't like dealing with my dysfunctional body. So those are the things that I don't like. When we talk about like past medical history, there was issues that got me diagnosed. But the fact is that my whole life, I never felt well. And the joke in our family is that if something weird is going to happen, it's going to happen to me. And the probably the like as a kid there was situations like, for example, in third grade all of a sudden, my joints started swelling for no reason.

[01:00:24] And my dad actually would make slings for my arms out of world, baby diapers. Remember cloth diapers, anybody? And this was not attention seeking behavior, because there's nothing more embarrassing than going to school with your arm in a sling that was probably on your butt at one point. And they ran tests and juvenile arthritis, nothing came back. And so, the pediatrician said, "Well, it's probably just growing pains." And then in fourth grade, I got this insane headache, I lost vision in my left eye, I lost my ability to speak, was vomiting and couldn't speak like articulate. So, my parents would say, like, "Well, what's your birthday?" And my birthday is July 1st, 1978, and I'd say July 5th, 1776, July 8th, 1718. Like I knew it, but I couldn't say it. And then it takes me a day or two to recover from those. And so, they called those complex migraines. Nobody really knew and my parents are very supportive, but we're kind of a family that's like, you know, if you get better, you're fine, which is positive and negative at times.

[01:01:35] Those complex migraines only happened I think like three times in my youth and adolescents, so they were just so random, you couldn't necessarily consider those like normal. They were so rare, probably the most significant thing that happened when I was 12. I was running and went to the doctor for bronchitis. And my pediatrician noticed that my stomach was hugely distended, and she thought I might be pregnant. And I was seventh grade catholic schoolgirl. And I was like, "Oh my gosh." Which is really scary because they tell you a lot in catholic school about women getting pregnant without doing things that get you pregnant. And so, it was like, "No way this can't be happening." And so that obviously came back negative. And what they found was that I had an enormous football sized tumor on what turned out to be my left ovary. And so, I too was a very good runner and was headed to state. And on Monday they found this mass, and by the next Monday I was in surgery. And in that time period I had my first pelvic exam. I was told we don't know if it's cancer, we don't know what this is because the imaging, I had my first MRI in 1991, not for anything neuro related.

[01:02:49] But in that week timeframe, I learned very young that we don't get to control a lot of things that go on with our body, but what we can control is how we approach these situations when they come to us, even when it just really is unfair, and it really sucks. And so, I don't remember this, my mom said that I actually was asking OB/GYN, who did the surgery, "Can we save my eggs so I could have babies." Because they didn't know if they were going to have to remove both my ovaries. And she's like, you know, I never thought of that and she's like, you were really poised in that moment, and I wanted to sign all my consent forms apparently. Because I felt even back then that having ownership or whatever autonomy I could over my body was really important. And I'm so grateful in retrospect for that terrible experience. And it also introduced me to great doctors and introduced me to very unsupported judgment tells people, because I had to continually go for sonograms and things like that. And there was a lot of judgment about, "Well, are you pregnant, this, that?" No, I have a missing half my reproductive system is missing and I have to have to monitor my other ovary.

[01:04:05] And as I've already told you, I had three children, so spoiler alert. Everything worked out fine in that area. But again, it was a fundamental way how I approached everything that has happened since. As a kid, I also developed ridiculously intense allergies, all fresh fruits and vegetables, all trees, but the birch tree, grasses, pollen, molds, it was just like you couldn't even come near me. I'd still eat those things because I'm stubborn and sometimes not very bright, but it did affect again. It was just now we know; I think those things are immune responses. So, my senior year, I developed mono, my lymph nodes swelled so badly, I couldn't move my neck and it lasted so long, my doctor was like, "Well, it's walking mono." And walking is not what I felt like doing, but like everything, I powered through, I wanted to finish my senior year and I was in dance team and going to college. And so, I just sort of learned to accept, I just don't feel well, and weird things are going to happen to me. So, I got good grades and graduated from college.

[01:05:20] The other aspect of this, when I was probably sixth grade, my uncle was diagnosed with a disease called scleroderma. And he actually died when I was pregnant with my oldest, and he was an amazing example of, if anyone knows about scleroderma. I know you guys all know about it, but it's a really awful autoimmune disease, where you kind of hardened from the outside in. And my uncle had the most amazing approach to life. And it did not matter how much pain he was in, how exhausted he was, he put himself through all kinds of research. And he said, "They're not going to be able to help me or save me, but maybe down the road they will learn something from me." And so that even set a huge example for me growing up that I think set the stage for how I view my illness today. Also in my family, like we don't have cancer, we live forever. In fact, when the queen died, my middle son was like, "Great grandma beat her." Because my grandmother is 96, and we just got her to quit mowing her own lawn like two years ago. But there's a lot of autoimmune disease, Grave's disease, Crohn's disease. My sister had celiac for like 30 years. My oldest son was diagnosed with eosinophilic esophagitis a couple years ago, which was devastating for a kid who loves dairy to find out that he can't have dairy.

[01:06:45] And my middle son has had such severe migraines for so long that I've had him evaluated by a pediatric neurologist, who knows, he plays football and is okay with it. But again, I sort of look at it this way without, I don't want my children to ever let diagnosis keep them from living the lives they want to live. Do they need to be smart? Absolutely. But we take the necessary precautions, but it's not about limiting how we try to look at life, I guess. As far as these the neuro symptoms specifically. I started noticing things like my twenties, my balance was a little off, and again, fatigue was insane. I've been married twice; my children were from my first marriage. And when I got married the first time, my girlfriends from college, they arranged my bachelorette party, and they actually arranged a nap time for me. Like that's not normal for a 22-year-old, where your friends, your entire friend group is like, "Okay, you're going to be home napping and we're going to go out to dinner, and we'll come back and get you." And so that's the level of fatigue that everybody just knew I had and that I learned to just power through that this is just me, I need this kind of rest.

[01:08:00] So, with my oldest son, I got a former Toxemia called HELP syndrome with him towards the very end there, which caused me to swell hugely. And so, after he was born, my hands and my arms were just burning like crazy and they're like, "Well, that's probably carpal tunnel because you were so swollen." And to this day, I don't have very great function in my hands and arms. In fact, I did not slit my wrists. This is from a burn from a pot lid that I didn't feel. And I got them different places, cutting my fingers on things when I'm doing dishes, I don't know until I take my hand out the dishes and I'm bleeding. And so, it just feels like, you know the way I explain it to people are, you know when your foot falls asleep, well, that's what my hands and my arms have felt like for almost 18 years now and it changes in severity. It happens right now. I mean it's burning really bad, but it's not as bad. I can still move them. There are days where it's so significant that I can't tie my shoes, and those are days that I just, I have to take that day as it comes and it may get better um throughout the day, or it may get worse. I just kind of never know. That was in 2004. 2006 when I had my next son, after he was born, I had a huge section of my right thigh that just was numb for like 10 months after he was born.

[01:09:33] And again, I just thought, well, you know they gave me I had another C-section after you know the first emergency one. And well, they just had a nurse that was a trainer nurse and let her give me the shot. So maybe she hit a nerve. And it wasn't until after I was diagnosed that these kinds of things started coming together and now what we know about postpartum relapses and things. So, it's 2006 I went back to work in pharmaceutical sales and by about 2008 I was noticing that there was some cognitive stuff that was happening that was farther than Mommy brain. That's what I called it because I'd be talking about something that I knew like the back of my hand, and it was just gone. And it wasn't just that the information tip of the tongue stuff, like we still get that right? It was this information that I knew it was not there in my brain. And on top of that, I didn't even know how to articulate that it was gone. It was like everything stopped. Or I was in Target one time, and you know, go to Target every week with little kids. And I was in the checkout, and I didn't know all of a sudden what I'm doing there and what I'm supposed to do next, gone. And I couldn't even say, "Wait, what should happen next?" The words weren't there, and I couldn't find them, and I knew that that was not normal. That's not tip of the tongue, that's like something didn't connect in there, and that information is completely unavailable to me as a human being at this point.

[01:11:02] So, I noticed my speech would slur too, but again, was kind of able to play that off. So, by 2009 I was pregnant with my third son, I was six weeks pregnant, and all of a sudden, I was in a physician's office actually, and my left side of my face started to go numb and my arm and my leg and my vision started to go. And I was like, "Oh wow, this is so like that migraine I had as a kid." And I thought, "Well, I'm pregnant, I probably should get to a hospital." And so, I drove myself 45 minutes to the nearest hospital, which is really stupid, but again, it was like, well, I can do this. And as I got to the hospital, one side of my body works like that's fine. And they couldn't do a lot for me because I was pregnant. They did a CT and like, you're not having a stroke and I was like, I didn't think I was having a stroke. And they said Well, we should follow up with another neurologist after this. And I did. And he's like, "Well, I really think this is hormones." And I was like, "With all due respect," I didn't say this, but I thought this now, I would say this. "I've been pregnant three times and no point has my entire left side ever gone away and completely ceased to function because of hormones. But you just go ahead and think that." I never went back to that doctor.

[01:12:23] So again, my vision that whole summer as I was, my pregnancy continued, it just never corrected, and I kept having this headache. And I remember just thinking like, "Gosh, that's so weird, what's going on here?" And then exactly a year later, March 2010 now, I now have this beautiful three-month-old baby and a five-year-old and four-year-old, all boys, because God has a sense of humor. And again, I'm running because I'm going to run the four-mile steamboat that we have in Peoria every year. And my vision starts to go, and I start to get this bad headache and I'm like, gosh, I don't know another migraine. And again, the stubbornness of like, "Well, I'll just wait because I don't want to be a hypochondriac, I don't want to overreact about things." I waited and I waited, and in the meantime my vision had deteriorated so badly that the only way I could function was with frozen peas on my face. And I finally was like... And the thing about Facebook here's something about, you know how the Facebook memories, Facebook memories pops these things up for me when I would say, wow in the middle of a killer migraine.

[01:13:25] And now knowing back that I posted these things about like symptoms that I had maybe randomly mentioned, they really kind of helped me connect the dots a little bit more about this health situation I've had. So, like the pain started here and is radiated through my scalp, it was in my face. And I went to my eye doctor for someone to my primary care and she's like, "Your eye is wonky." And she said Wonky and she's like, that is the medical term. And I love my primary care doctor because she knew she's very she believes that there's a place for pharmaceuticals, for natural remedies, for physical therapy, massage therapy. She is very holistic and sorry; I get nervous when I talk too much. And she's so for her to say it's wonky. She's like, "You need to go see your eye doctor." And so, I did. And he I will never forget this, I've had this eye doctor, you know at this point I'm 31. I had seen him since I was in college. And he looked at my eye and he just backed up in his chair and he said, "You don't have any numbness or tingling, or weird symptoms like that." "Oh, no, I haven't felt my hands and arms and years properly."

[01:14:45] And he kind of backed up and when I left the room and he came back and he looked at it again, he's like, "You have what's called optic neuritis. But this is out of my expertise. And so, you need to see a neurologist immediately." Which again, with all due respect, nobody ever wants to hear that we need to see you guys immediately. And I thought, first brain tumor. And here's my beautiful little boy in his little car seat. And he's like, "I don't think so. I'm just telling you that you need to see someone right away." They wouldn't let me leave without an appointment, which I got the next morning. But at that point, I couldn't even see the e on the eye chart. And I hadn't realized how bad it was. Because you get so used to your own little world and making adjustments for these losses in a way that if you said to somebody, "Well, I'm completely blind in that left eye." They'd be like, "Are you kidding me?" But those of us who don't feel well and have these symptoms kind of, you know, come on gradually. They actually let me drive home with this baby, which I thought was

very odd. I was like, well, you know, I'm blind and you know, I need to see a neurologist, but nobody needs to come pick me up, okay.
[01:15:53] And so, I went home and my next-door neighbor as a doctor and he's wonderful. And I hopped in there and I'm like, "Charlie, what's this optic neuritis stuff?" And he was just like, "Well, we need to just take this one step at a time." And he was wonderful. So had a tremendous support system. And initially, so the next day I saw the neurologist who was a colleague of my friend Charlie. And he said, "You need to get on IV, celiamedo right away. We need to try to save your vision." And he said, "I think it's multiple sclerosis, maybe clinically isolated syndrome." But the bottom line is my optic nerve was so swollen that the imaging that you guys do, it was literally off the chart. It was so bad. My eye doctor later told me, he's like, you've never seen a case of optic neuritis as bad as I was. So, you go harder, or you go home. But that was again the emotional thing, so I'm sitting there with this baby and they're like you know, I said "I'm nursing, can I breastfeed?" And they're like, "Well, we don't know. Call the pediatrician." Pediatrician's like "I don't know what do you mean celiamedo? I don't know."

[01:17:04] Nobody knew and I'm thinking but... And so, it was left up to me to decide to do you... And I said Well you know again what you guys seems like what you're saying is in the absence of knowing this decision is no you cannot continue to breastfeed right now. So, I chose to pump driving home from the hospital, from the doctor's office and home health care is going to meet us there. My ex-husband was a nurse and again my next-door neighbor is a doctor. So, they said they didn't have to admit me. And I'm thinking "How do I feed this baby? Bottles? I don't have that." And so, over the next week or so, or the next month, it was treatment. And as soon as the treatment stopped my vision, I lost it again. And the same thing we did this three times. And finally, and it was mainly because I didn't want to stop, I kept pumping and I don't want to stop. And finally, it was like, "There is a substitute but there is something I can do to feed my baby and there is nothing I can do to slow down what's happening to my body." And so, I had to give that up. And talk about emotion and postpartum and because nursing didn't come easy for me. And I couldn't feed him at first because it was too hard. But at the same time also it was like needles. I don't like needles; I can't do needles.

[01:18:26] And I just thought like these little boys who are never going to know me healthy and my oldest boys, they remember me being on the IV home. And I thought, "If I don't learn to do this, they're going to come a point in their lives where they don't know they think they can't do something, and I don't ever want to say that I ran away from this reality." And so, I forced myself to learn how to give injections, self-inject, which is still like one of the biggest triumphs of my life. I want that in my obituary, that I taught myself how to do that and became a very important skill. So, these diseases stink but they can give us really cool skills right. They may not go on resumes but they're kind of... They're human skills and they're skills of triumph and I think that's really important. We don't sell our sort of self-short on that. And I keep talking to, let's see, I do this too much. So, in the meantime, the multiple sclerosis diagnosis came, which was not my final one, or else I wouldn't be here. So, my diagnosis actually processes went for nine years. And in those nine years, I went through a divorce. So, in 2010 I was diagnosed with MS.

[01:19:42] In 2013, I tried to work, or I had tried to work part time for my church, and I continued to have relapses, what we called relapses. I didn't necessarily always get treatment for these because it's kind of like, it's such a pain, they don't really seem to work that well, one of them was burning in my back my entire low, you know, mid back burned like someone holding a blowtorch on it for like weeks and weeks. And again, in this time period I'm raising these little boys and trying to balance my own body's limitations with what they need from me. So, in 2013 disability happened. In 2015, my divorce was final, and I had been with this person for 18 years and he was a nurse still is. He'd been a neurology nurse actually and under rehab unit. And I cannot describe the emotional and psychological and the whole thing that goes along when you realize that you have to do something you just think you cannot do. And that for me was learning to raise my Children entirely on my own. I left the state. And so now I have these three boys and I am struggling to get upstairs at times, and they would say, well, crawl upstairs with your mom, these three wonderful boys. I cannot say enough about. And we tried to make it fun because there was one time, I was like you know, on the couch and I was struggling and I said, "Tyler," who's my oldest, "Go get your brother, some grapes out of the fridge."

[01:21:12] And I remember he opened up the fridge, he's like, "God, mom, who put the rubber mallet in the refrigerator again?" And I thought it was, I remember like just being like, I just wanted to break down because what eight-year-old or whatever has to say those things. But then I said, you know what, they're watching me, how do I respond? And I laughed and I said, "Well, probably me, let's be honest, it's probably me." But they would try to be helpful, like, especially my oldest, he's like, "Mom, I'm going to make sure you know where your cell phone is." But he wouldn't tell me like I put in the glove compartment so you wouldn't forget where it was, but he didn't remember to tell me where he put it. And so, some of these like cognitive things I did the best I could with them. But there was definitely a point where I remember sitting on the stairs and knowing whatever's going on in my body and whatever is going on in my real world which is raising these three boys. It is probably exacerbating my disease state. And then it's probably did and also knowing that if had I been given the choice, that is what I would have chosen so that I could do what I needed to do for my kids. I also think something else about that.

[01:22:23] I thought too with the whole MS thing, and I think it's wrong true with what's happened since is that if I had to choose between a disability of my spirit as a human being and as a woman, and a disability of my body, I would choose a disability of my body. Because we all know those people out there who are just not wonderful people and they hurt others and they are not great awesome people, and I wish those people well. But I would rather not have a disability of who I am as a person. And so again I had to choose, I would have chosen me, also with my kids and I know there's parents out there and I give them so much props and strength, but my disease has helped me, I think helped my Children learn how to roll with punches better and understand that there are things we just cannot control in life. And that we haven't grieved it because we have, and I say that to people a lot, you're going to grieve and you're going to grieve different things at different times. What I grieved when my boys were tiny is different than what I grieve now. The tolerating issues of fatigue and neuropathy, vision problems. I never did get all my vision back. It's like looking through a lace doily.

[01:23:39] Then the irony is that my middle son was then later diagnosed with amblyopia, and he said the same when I said "Nick, why didn't tell me?" You could see how that he was like, "I got another one mom." And I literally said the same thing to myself at one point. I thought, well, you know, they're going to be okay, they're going to be resilient. But I never just like chase diagnoses. I don't judge people who do that. I just wanted to be a normal person. And I will say that being becoming a single mother taught me that I had to pay attention to my health, whereas I would have blown things off before or minimize them when my eye needed to rest. I forced myself to rest. Now, maybe that meant that we were doing peanut butter and jelly that night, that's okay. Guess what? They're big, they're healthy, they're fine. And I think that that helped me balance, but I still to this day often deal with symptoms that when later on, it's like, "Well, why didn't you say something?" I just want to live my life and I don't want to be unhealthy. My neurologist in Peoria, who when he diagnosed with MS, he was amazing.

[01:24:51] And he said the same thing, I said I was running and he's like, "And you should still keep running." And that made all the difference in the world, as far as how to deal with neuro diseases. So, Dr John Poola, if anybody knows, he is fantastic. So, I actually drove to Chicago to see him for two and half more years until it just became too much. And then when it was 2019, I was six months remarried and I had a new neurologist, and she ran a whole new battery of tests, and she noticed my joints were terribly swollen. And so, she's like, "Well, we're just going to see what happens with this." And my new diagnosis came. So, since that time in

2019. The other thing is I went from having a ton of support with the national MS Society which is great. But they were at one point like us that nobody knew much about MS. I'm from Peoria and that's where Richard Pryor is from. So, we knew a little bit more about MS In Peoria. Also, Susan G. Komen from Peoria. And so, we're not like this medically, you know, back in the woods place. But you can you know, it's still when you have this new rare disease and especially when you kind of look around at other diseases and you're sort of like you know you can share the love.

[01:26:05] Like I get really annoyed at all the pink because I'm like look we are aware of breast cancer. No one's not aware at this point. Let's share the color share the love. And so but there's only so many colors, let's be honest. I did. So when 2019 when this new diagnosis came up at this point like I had done a lot of I've done some speaking with MS And I had done patient advocacy with, MS And I had been writing for an MS Publication and all of a sudden now it was like wait I have all these shirts that MS and whatever and I don't even know how to say this disease. I don't I had to go and like on google like to have them tell me how to say this disease. And I and so I actually found S. RNA. And um and there again it made sense. I looked at these different symptoms. I'm like you know what that really does fit but I must also still fit. So, I not that I doubted my doctors, I knew what they knew what they were talking about. But it was just like how both of these exist at the same time. And it's only this blood test or this one thing that can now differentiate and on top of that you don't even really know what to do for me. Like and possibly the treatment I was getting may have made me worse.

[01:27:15] And I'm not even really sure and I and I wasn't angry by any means. I think it highlights that we don't get a lot of the information we want because we're at the beginning of it and somebody's going to have to be the beginning of it. So, I think it matters how we look at being at the beginning of it and we can be the resentful and angry, and I think those are normal human emotions, and so we should feel those. But also, then just grit our teeth pull ourselves up or however we do it, you know mentally emotionally, and then do what we can for the next generation, for the kids and the people down the road so that they will have a color and they will have advocacy that we May not necessarily benefit from. And I learned that from my uncle Phil. So in by 2019 I have this new diagnosis. I now have a new rheumatologist who says, "We also don't know what's going on with your joints and so like you don't fit in lupus, and you don't fit in rheumatoid arthritis. And so, we're just going to put you on some methotrexate." Where that needle thing came really in handy again. And I just kind of functioned. I ran my last 5K in 2019. And then beginning of 2020 I started to get, I had had actually a respiratory infection right over Christmas.

[01:28:38] And then this was the first one my husband ever saw me go through this relapse, which made a difference because he hadn't seen what had happened in previous years. And I couldn't walk very well, and my whole left side was heavy, and it just kept getting worse and I went through IVC, and I was like I know that this is something is wrong here because I should be bouncing off the walls and I can hardly breathe. And my boys would leave to go to school, and I would sit on the couch and wait till they come home so they could help me to the bathroom. And this is something is wrong here. So, my doctor put me in the hospital on my son's 14th birthday, my middle son. And I had to have a conversation with them, "I'm going to the hospital for two weeks for plasmapheresis and uh everything's going to be okay where everything's going to be fine." Um this was pre COVID, so they did come see me, but I missed, you know, eighth grade night for my middle son for basketball. My parents were there to help, and they've been really supportive. But there's no question that there's things that have robbed me and my kids.

[01:29:46] And a lot of tears, but at the same time, you know what? I'm a very blessed woman, no matter what. Even as in the hospital, not only was my left side weakening this, I don't know how to explain this like paint, it was like someone dumped paint over my head and it was like this thick paint just came over my whole body and I couldn't speak. I could, but it took so much out of me to find the word, and all these doctors and interns and medical students will ask me what, explain it, describe it. And I'm thinking I can hardly breathe right now. My husband actually saw this happen where we're talking in the hospital and I'm eating in my room and I was like, I need help getting into the bed and it was like from head to toe and I lost it, not mentally, but my physical ability. And their solution was given her a bolus which that's kind of a joke like give her a bowl. And I went to sleep, and that part improved a little, but the left side was still bad. And simultaneously there's massive starburst of excruciating burning pain in my back and like how can I have numbness and not feel things on one side and yet still burning. And so, these things can be true both at once.

[01:31:04] So, the plasmapheresis, apparently plasma is supposed to be like bright yellow, mine looks like snot green. It was the nastiest thing and it's kind of cool actually pictures if you want because I like pictures of things. But it was it was gross, and I didn't know if plasma plex therapy would work. On one hand it sucked me in the hospital for 12 days, but I had my own room and they brought me food, and I don't love that whole neck catheter thing, but I went in in a wheelchair and I walked out on my own two ft. But then COVID and I went on my first infusion, so at this point I was on a toxin and methotrexate and steroids and then this thing called COVID happened. And so, if you're going to become immune-compromised, you might as well do it during a global pandemic that kills people. And then have boys that want to go back to school. That was super fun. And I've learned another little thing that we all probably know is that the medications that treat you then sometimes cause problems that require their own medications. And so, it turns out that steroid use for me now makes my face break out in this massive blistering rash, which again, COVID was great masks nobody noticed, but that also meant nobody could see me for this massive blistering rash that I dealt with.

[01:32:23] So, when that happens now, I go on three months of antibiotics because there's some sort of dermatitis that's happened with all of these other things and I've never had issues with steroids like that before. So, throughout COVID it was really hard because I didn't get to finish my physical therapy, and I'm not really self-motivated to move when I don't feel great. But I did get involved with the Mayo clinic and I send them vials of blood whenever they wanted. And uh we just kind of learned to re-function. My oldest son decided to call what I have off brand MS. And so, we do try to like to laugh about this because otherwise it just gets kind of overwhelming and sad at times. Um So at this point I'm on I was on three immunosuppressants, but then I was taken off, but as I've noticed too, as well as new neurologists come through, they have different ways of viewing these diseases and so you might end up being a bit of a Guinea pig in the meantime. Um So I mean life today is pretty good, it’s as good as it can be.

[01:33:34] Um I did forget the binder; I forget a lot of things nearly missed my flight here because I didn't realize I'd switch to terminal again. Um But I just I really try my absolute best to do the things I can do and let go of the things I can't. Um and uh um and yeah, but there's definitely been whole emotional, I've learned to deal with my emotional well-being a lot better in the last year. So, which I think has been huge how I physically feel. Um There are days that I'm leveled by pain and fatigue, like it is just astonishing and then there are days where it's like, you know what I can do this, I can do grocery shopping and laundry, like two things in one day. Um And just so I think a lot of it has to adjust our expectations of what we thought life was going to be, was going to look like um I didn't, the disability thing, for example, didn't bother me as much in 2013 as it did during the pandemic.

[01:34:33] And I don't know if it's because everybody else suddenly wasn't working and all, and everyone's talking online and social media about, oh, you know, not being able to be professional, you're professional and how these changes are, and man, that loss of my career and my idea of what I thought I could earn, uh that really hit me unexpectedly at that time. Um So I think that that's another thing that we need to be patient with ourselves on, not just for the people around us, but for ourselves that that we're going to hit different things as we go through life and it the disease and what we've had to give up in the past might resurface, but it's, you know, we can walk through that and we can just try and accept it the best we can. So, um and I think that that was also again because of that hospitalization that really hit me that I've got to do something about how I manage my stress, and how emotionally it affects me. And I and I was able to kind of learn how to do that. So, I'm talking too long, I know. You're like, let's do it really quick and then you call my name. I know, sorry man.

[01:35:36] **Dr. Benjamin Greenberg:** You're doing a great job.

[01:35:39] **Emily Martin:** So I guess this was the last thing I wrote. So, while I'm essentially powerless over what's going on inside my body, I'm not helpless about how I let that impact my world. The disease lurks just below the surface, like a weird neurological alligator. But I try to use common sense and humor in dealing with it. I appreciate each day for what it is because it's like I think Audrey Hepburn or somebody said, I never have a bad day, I might have a bad hour, I might have 23 bad ones, but I'm not going to have a bad day. And that's kind of what I try to do with my kids. And I look at this situation right now is that I think of myself as in remission now, God willing, that will go until the day I die, which hopefully won't be tomorrow. But for as long as this period of good health is I'm blessed with it, I'm going to do everything I possibly can, and I will not worry about what I can't control down the road. So that's... Sorry, so that was long. Where was the sign?

[01:36:46] **Dr. Michael Levy:** I was going to ask you to kind of expound on a lot of the details but that was so perfect. You know if you come to my clinic, I would just--

[01:36:54] **Emily Martin:** There's probably more details I can give you. Didn't they videotape. I have details.

[01:37:01] **Dr. Michael Levy:** But I have one question.

[01:37:02] **Emily Martin:** Just one?

[01:37:03] **Dr. Michael Levy:** Just one right now. You're a positive person, you're very optimistic and you're also a minimizer whenever something happens, you just minimize it. I have some patients like that who don't even know that they've gone blind in one eye, it happens. But looking back now at some of the things that you've experienced, do you think that you would have done something differently if the doctor had just said, by the time that they said this is just hormones. You already knew that they were wrong, but before that when things were going on that you just dismissed pregnancy or whatever, do you look back on that and say missed opportunity to get a diagnosis even a wrong one?

[01:37:45] **Emily Martin:** That was part of my grief process because and again, it really came up more going through my divorce or afterwards as I'm trying to figure out how to parent these boys of the frustration than grieving the limitations of my illness. And this thought came into my head is like, "Okay, Emily, would you rather have known this in college?" Well, honestly, I liked the fact that I didn't have to know in college. Okay, well, would you have rather known before you had children? Because honestly, I know me and I'm kind of a pansy about things sometimes. You wouldn't know it probably from what I say, but I can be. I don't know if I would have had the courage to have children. I think I would have thought that I would do a bad job at it. And so, I would have completely eliminated probably that option from my life. Not because I think I'm a great mother, but because I think my boys are so fantastic, I think they're going to be tremendous human beings and not from anything I've done. But I think that it happened, I had to accept and part of my process of acceptance, and it goes over years. I think that we want it to happen quicker than it does.

[01:38:52] But my acceptance had to be, it happened when it happened because I could not have handled it... I would not have handled it this way had it happened earlier. You know what I mean? Does that make sense. And I do think though that with, especially my first neurologist when I said, I really have this crazy idea, I want to keep running and he said, "Okay, keep doing it." And on top of that, he then hooked me up with the University of Illinois Kinesiology Department and he said they're doing research down there. And he would ask me, you know, anything different happen this time. And what I learned was, you know, the time they're saying, "Well, you know, if you start feeling this exacerbation of symptoms, then you need to get inside and get cool and rest." Well, I'm stubborn and like I said, not very bright, so I keep pushing until I simply could not handle the pain anymore. And it turned out that guess what, all that pain and the loss of feeling in my legs that would happen when I would run, it first started right away, then it was at a half mile, then it was in a mile, and it was three miles.

[01:39:54] And so, it was like, wait a minute if I'd gone inside and sat down, I wouldn't have known that I can push through. Now, at the same time I don't want to be like, "Oh, that's the cure." It's not because I still had pain. And in the meantime, my joints were like, I mean, insanely swollen and there's again, photos on Facebook of me like ice things all over my joints because I'm still continuing to try to do this thing. But I think that it happened when it had to. And either way it doesn't change anything. Maybe it would have been better back then, but that's not what happened. So, I don't think anything was missed. I think my clinicians did the absolute best that they knew, and they could. And like I said to someone else, we want science to advance, we should want that, we should want a better or different diagnosis because it means you guys are doing what you need to do to ask more questions and say, you know, this weird group of subsets of patients is not responding like all these other ones, why? And so, as a patient, I can't speak for anyone else, but for me, thank you for doing that. Thank you for continuing to ask the questions and look at blood work and say there's something different here and let's keep looking.

[01:41:05] **Dr. Michael Levy:** About questions from the audience.

[01:41:13] **Audience member:** Thanks. I find your story fascinating because there are aspects of it, especially with the early fatigue that I experienced, trying to take care of little kids with debilitating fatigue. I went about maybe 14 years of that, on and off, until some major event happened with me. And it was optic neuritis. But did you ever have a feeling through all of that time that there was a transition to where you almost were in a way relieved or happy that something worse happened because, okay, now they're going to figure it out. This means a transition into something worse.

[01:41:55] **Emily Martin:** I wouldn't say I was happy, but I could totally see how that could have been a response. For me it was like, "Seriously?" I was annoyed. I was more annoyed. I am so annoyed at my body's limitations; I cannot even explain it. I can tell. I also wasn't at the time looking for an answer because I think in some ways I kind of had the sense and I can't explain another way, that there really wasn't going to be a simple one. Because the symptoms I had they were almost reaching in every part of my body. And I had had so many strange things happen. I had had some back pain for a while, and this was like, when I was still drugged up and I got in a car accident and the ER doctor was like, "You have seven kidney stones and your right kidney." I was like, "Oh yeah, my back was kind of sore." And he's like, "Oh my God, you got to go see somebody for that." And so, I think that, like, my just mentality was kind of avoidance, which I'm not proclaiming that that's great, I don't think that that's great. And again, had I not had to go through the single parenting journey of learning how to raise three children with absolutely no one else in the household, so if you're exhausted, you gotta find a way to do it. I think that have helped me realize that I have to be my own, I can't just avoid. I don't have that luxury anymore. Not that that's a luxury.

[01:43:28] So, I didn't go through anger or hoping that something else happened. I was more of somebody who was like let's just stay here, like this is bad enough. At this point, I don't want anything worse. But I'm aware that it could, but it might not. So, today's today, I think we have a responsibility to balance knowing what could happen so that we can alert our physicians and not letting, and I used to struggle with terrible anxiety. So, this is something I think that for Hannah comes with time. You learn to let go as these experiences happen just in life in general, and yet be aware, because we are responsible to be aware of what when something's going wrong or something needs to change. And we need to let our doctors know so there's a delicate balance, I can't say I do it perfectly, but I do think that that has come over time because for me it's been a 13-year journey really for neurology issues, even though my most recent diagnosis is really only like two years old, three, what year are we? Someone does the math. It happened in 2019, it's 2022 now. So, everybody's like shut up so I go to the bathroom, I can be done now, there's no way I can gracefully exit, so thank you very much.

[01:45:03] **Dr. Benjamin Greenberg:** Thank you Emily, and to all of our speakers into the questions. So hopefully so we've gotten through three or five stories and hopefully you're hearing some unique aspects of things and a lot of things that overlap. And that's one of the take homes for today. We're going to have a couple in a bit. So, we're doing fine on time. The next part of the program is to give everyone a chance to connect and to network and you've got several options besides bathroom breaks and things like that. For those of you who are online, there is an online expo area networking feature. For those of you who are here in person in the Carmel room, there are exhibitors in Catalina B is a chance for you to share your story at the "This is my campaign booth." Emily can't go first. And then in the Catalina C room is to learn more about ongoing research. And so, we're going to take about a 20–25-minute break, which usually equates to a little longer than that and we'll meet back here to do our last couple stories before wrapping for the evening. So, we'll see everyone back here in about 20, minutes.

[01:46:21] So again, I think we have had a great 1st, three fifths of the session. I appreciate everybody who shared their stories and everyone who was asking questions and taking part. This isn't something we've done before in this format in this symposium. So, we're very interested when we're all done to get everyone's thoughts and comments on how you felt it went and whether or not it was helpful. Oftentimes in the symposiums, there's a series of talks about the science and the biology and the clinical trials, and we really want to make sure we always keep in context the human aspects and life aspects of everything we're doing. And so, we've heard from three of our community members with totally mystery diagnoses and it will be revealed at the end, and we're going to move on to our fourth. I'm going to invite Jodi to join us. And while she comes up Eoin Flanagan, neurologist at the Mayo Clinic who's leading the discussion couldn't be here in person, but he is available online. And so, Jody when you're done, Eoin will take the first question and then I'll help in terms of folks in the audience and online asking subsequent questions. So, Jodi, I'm going to turn things over to you.

[01:47:37] **Jodi Arminio:** Thank you. I noticed you didn't even try my last name. So, my name is Jodi Arminio. I live just north of Atlanta, Georgia. I'm married and mother to two young men and nana to three grandsons. So, I can relate to Emily, I can't seem to get a girl in the family. In 2010 at the age of 54, I was working full time. My elder son had recently graduated college and my younger son was a senior in high school. While walking down the hallway at work one day, my left leg suddenly went numb and felt like it was going to collapse under me. But it passed within 30 seconds, and I thought I had just been sitting in my seat wrong, I tend to sit with crossed legs, and I didn't think anything more about it until it happened again, it happened again and then it happened again. But every time it would pass within like 30 seconds. But when it started happening more frequently several times a day instead of just once every few days, I finally went and saw an orthopedic. And he did X-rays, and he did an MRI of the pelvic area. And he did nerve conduction test, but he didn't have a conclusive diagnosis and finally wrote it off to a pinched nerve. It went on for the rest of the year and eventually faded away by December or January of 2011.

[01:49:11] Then in September of 2011, I noticed a small black pinhead dot on the left peripheral of my left eye. And I called the ophthalmologist and they said, "Well, you need to come in right away." And I said, "Well I'm in the middle of the workday, can I come at the end of the day?" And they said Well are you having like a window shade effect? And I said no it's just a little black dot. And they said, "Well, if you think you can wait till tomorrow, we can do an appointment tomorrow afternoon." And I said OKAY. So, I went in. By this time had gotten a little bit bigger, a little bit bigger. I went in they said that my ophthalmologist was not there, but I could see the optometrist and he ran me through a bunch of tests and then he said, "Well, you know it's not a retinal issue. I think you need to see a neuro-ophthalmologist and here are three people in the Atlanta area." He didn't say you need to go to the ER; he didn't say you need an appointment right away; he just said you need to see a neuro-ophthalmologist. So, it's Friday afternoon. I went home I noticed that one of them wasn't on my insurance. The second one I called who was very well-known in the area and I was told I could, this was September., they said I could have an appointment in April. So, I said, "I think it needs to be a little sooner than that. Can we move that up? And she said, "Well I'll go ahead and take your information and we'll see and oh gosh my computer just crashed. Can you call back on Monday?" So, I called the third one, and they said they could see me on Tuesday, and I said all right. Well, by the time I got there on Tuesday I couldn't even read the biggie. I was 2500 in my left eye.

[01:51:15] She said, "I want to do an MRI to make sure you don't have a brain tumor because otherwise if I put you on steroids and you have a brain tumor then that's not a good thing." And so, you know I was pretty naive about medical issues at that time because I hadn't really had to deal with anything major. And she said we need to call your insurance for approval. And I said OKAY, and a couple of days went by, and I called the office and I said, "Do you have approval yet?" And they said "No, we haven't heard back from your insurance agency." So, I called the insurance company and they said we never got a request from your doctor. So, I called the doctor back and they said Well we sent it, and I called the insurance back and they said Well we never got it. So finally, it was about three weeks before we finally get the MRI. I didn't have a brain tumor. And they started me on three days of IV SOLU-MEDROL.

[01:52:19] At the place where I was having it done, they dealt with a lot with MS Patients, and I guess MS Patients must respond pretty quickly to IV SOLU-MEDROL. So, the nurses kept coming up to me during the process of this infusion and saying, "Do you have your sight back yet?" And I go no. And a little bit later, "Well how about now?" And I go nope. And day three "We'll surely by now." And I'm like nope. So that was really starting to freak me out, but then I thought well you know there are a lot of people that just see out of one eye. I had a friend growing up who had lost his eye and he did everything, so I figured it was going to be okay with just one eye. She the neuro-ophthalmologist finally just said, "Well you've got optic neuritis. I ran your ANA tests and for autoimmune. But those results are kind of inconclusive but maybe you ought to see a rheumatologist too." So, I went to see a rheumatologist. She put me through a lot of tests. But they were also inconclusive. Two months later in November of 2011, I developed a feeling of sunburn throughout my torso, and I was getting a really bad pain in my left hip.

[01:53:49] I was scheduled to go on a girl’s weekend to Charleston, South Carolina with my mom and my sister to visit my niece. And we went and it got worse, and it got to the point where I was thoroughly constipated, and I was having trouble urinating. And every time mom would go to give me a hug, I'd be like don't touch me. And she was getting really worried. I was getting really worried. Got home, called the doctor. They said, "That doesn't sound like anything, but come on in tomorrow." So that morning I woke up and my feet were numb. By the time I got to the doctor I was numb up to my hips. I could walk but I just couldn't feel anything. And I also had this excruciating pain in my left hip. So, she gave me a shot of Tramadol and said "I don't think this is a rheumatology problem. You need to see a neurologist." So luckily, I have a brother-in-law who at that point was an oncology doctor. And he had a neurologist that had treated him for Carpal tunnel syndrome. And he said, "Dr Hussame is the smartest person I know. I want you to go see him. I'm going to call him. We'll get you in this afternoon." Which he did. This is where I found out that the neuro-ophthalmologist office was not on the ball because he said I'm sending you here for an MRI and then we're going to start you on IV SOLU-MEDROL because I have a feeling your MRI is going to show something that we're going to need

IV SOLU-MEDROL He made everything happen that day. He did the MRI. I did have an active lesion from T1 to TIII. And he had me in the IV chair that afternoon. And after five days of IV SOLU-MEDROL, he put me on oral steroids. Now that first day he said, "I think I know what you have. I'm going to give you this journal article about it, and I don't want you to google it. Just read the journal article, absorb that and we'll talk." He took a blood test and said, "We should have the results within a couple of weeks." So later on, he did call me, and he said, "My suspicions were true." And he started me on another medication. So today, 11 years later, I have surface numbness from the waist down. I have bowel and bladder issues. I have occasional drop foot, fatigue, especially towards the end of the day. Some visual deficits in my left eye but a lot of it did come back, so it took a long time, but it did come back and so I'm now like 20/50 in that left eye. But I still drive, much to my husband's chagrin. And I just try to live my life as fully as I still can.

[01:57:30] **Dr. Benjamin Greenberg:** So I'll invite Dr Flanagan who's online. I'm not sure if we're going to see him like the Great Wizard of Oz on the screen.

[01:57:38] **Dr. Eoin P. Flanagan:** Can you see me or?

[01:57:41] **Dr. Benjamin Greenberg:** I think they can just see me. Oh, there we go. Much better. Hi, Eoin, how are you?

[01:57:48] **Dr. Eoin P. Flanagan:** I'm good, how are you? Sorry I couldn't make it there.

[01:57:57] **Dr. Benjamin Greenberg:** So I'll let you lead off with any questions you have relative to... Were you able to hear everything online Jodi was saying about her experience?

[01:58:06] **Dr. Eoin P. Flanagan:** Yeah, I can hear everything, and a really great story of how patients present and it's really helpful for us to learn because every time we talk to a patient, we hear patients' story of what they've been through. And I think that's really how we learn about these diseases. So that was a perfect illustration. I think one of the themes was delay. You know, there was a big delay to get the diagnosis and lots of times the symptoms were dismissed and maybe I was wondering if she could comment a bit more on the delay and frustrations there and what we can learn from that as physicians to make sure we're taking patients seriously. And on top of things like her last neurologist was.

[01:58:54] **Jodi Arminio:** Okay, so let me understand that again.

[01:58:57] **Dr. Benjamin Greenberg:** It was a little hard to hear. Often there were delays in diagnosis. And so, Dr Flanagan was asking about your perception of your journey and whether or not you feel there were delays or were there points in it where there were more frustrations than others?

[01:59:12] **Jodi Arminio:** Okay. Definitely a delay with the neuro-ophthalmologist. I did find out why she was available on Tuesday and the other one wasn't available till April. And then when I did end up with the smartest neurologist that my brother-in-law knew, he said "I don't want you going back to her, I'll get you in with the other one if you have any other problems." I did have two more attacks after the diagnosis with the right eye this time but got in for IV SOLU-MEDROL right away and both times we went back to 2020 with glasses anyway. So that was a frustration. The fact that even when she did diagnose me with the optic neuritis, she never thought to ask, and I never thought to talk about the episode with the left leg. So that was a little bit my fault, a little bit her fault not asking the right questions and me not connecting the two events. So, but that you know once everything else kind of felt, once the TM came into effect it was like boom, boom, boom, "We know what you've got."

[02:00:45] **Dr. Benjamin Greenberg:** Has anyone else struggled on the access side of things where you refer to clinician X. And it's more than a week to get in, there is a common theme I hear I don't know if this is just a Texas thing and is it ever? Okay. You articulated that the neurologist got things arranged in a timely manner.

[02:01:17] **Jodi Arminio:** He didn't wait for insurance. He just said, you know, and I even said, I do recall saying, "Well, what about insurance?" And he goes, "Insurance is going to cover this. Trust me." Because he knew what I had.

[02:01:39] **Dr. Benjamin Greenberg:** Does anyone want to comment in terms of whether or not they feel like those issues as access issues impacted their experience or outcomes or anything along those lines? This is something we struggle with in our health care system. We have a mic coming to you.

[02:01:55] **Audience member:** Hi, I'm actually from Canada. So, it's a little different there, but definitely there's access issues. Still to this day, they're not 100% sure that my diagnosis is correct, and they continue to say we're calling it this right now. So, I love hearing that people have gotten diagnosis is and treatment because I feel like I haven't really.

[02:02:20] **Dr. Benjamin Greenberg:** That's tough. There's a neurologist at Hopkins Tom Crawford taught me a term for that situation. He called it diagnostic purgatory that until there's a name, and ideally an accurate name ascribed to somebody's experience. It makes it very difficult to get on a path forward. So that's tough. So, one of the Carlos. Yeah.

[02:02:51] **Dr. Carlos Pardo:** So I'm very interested in learning. So, you say that you skip some information for your doctor at the beginning because you have experienced some symptoms before. So, I think that that is a very interesting point of communication from patients to physician, and the physician is obligated always to ask questions about what happened with you before. And the patient is obligated as well as well to say, "Okay, I had this before. What do you think is going on?" Because those are elements very critical for the clinical history.

[02:03:27] **Audience member:** It's tough. I will say on the other side, it's hard to know what's relevant and what isn't on for anybody. And my most feared four words in the clinic and it always happens in the last 30 seconds of the visit. It's usually right before I touch the doorknob of the visit are the four words, oh by the way, and it's whenever I hear, oh, by the way, I know whatever is coming next is going to be the most important piece of information I get like, "Oh, by the way, I went blind in my right eye 10 years ago." Yeah, that's information I probably should have asked admittedly, but it can be hard. I was about to make that comment to a group of doctors at a meeting and I said, "Yeah, there are these four words I hate to hear." And somebody in the back of the room yelled, "I don't have insurance." I was like, "No, that's not the four different four words." But it is hard as we're going through things in terms of what to report and whatnot because just as frequently, I hear from patients bringing up symptoms, I get dismissed. They're like, "Oh, that's nothing, oh that's nothing." So how many times somebody here has hard oh that's nothing. It's kind of reinforcing what do I bring up and it's this and the access issue gets to a topic we used to cover its imposing, we had a whole session dedicated to managing your health care team. Like how do you organize a visit, what you're going to get out of the visit and how do you organize the whole team? And it's a challenge. And it's particularly a challenge when you don't know what's going on when you don't have a diagnosis yet, and that makes it really tough.

[02:05:12] **Jodi Arminio:** I was very blessed, like I said to have a brother-in-law who was a doctor, and he had this connection with Dr. Husami. And then doctor Husami actually was trying to get me on a medication that wasn't approved by my insurance company because I continued to have these visual optic neuritis attacks. So, he transferred me to Dr Ben Thrower at the Shepherd Center. And he was able to get me on the medication. So, I know that a lot of my recovery has come from the fact that I lived in a big city, I had these wonderful hospitals and institutions around me, and I had a brother-in-law in the business.

[02:06:06] **Dr. Benjamin Greenberg:** I'm going to ask Dr Flanagan to comment on this part because obviously the Mayo Clinic is a world class institution with wonderful professionals and I'm not just saying that because you're on the screen, but there's a long history of individuals who don't yet have a firm diagnosis coming to the Mayo Clinic for second opinions, particularly around either diagnosis or management. When you think about your experiences of patients coming to you for a second opinion about diagnosis, what do you think are the most common missed aspects for healthcare professionals? What are the other common cognitive errors or testing errors, and your advice to the world around that?

[02:06:48] **Dr. Eoin P. Flanagan:** I think it's more inexperienced thing or people who have not seen before or not expert needs, maybe general neurologist. And then the key is that people look and try and speak with an expert. Because now virtual care and other options it's important for people to try and get a diagnosis. Because once you have that, then everything speeds up you have a future event treatment comes quicker. So, I think I don't think more inexperienced or not being aware of not being a specialist. So, I think it's important if you're not getting angry trying to get to a specialist as quickly as you can or if your disease is not well managed to really specialist quickly. And one of those that you mentioned for patient in the audience too is that you know the importance of early and treatment we do have a relapse if you know what that is. Because it's still really important because the earlier the better for patients and the be better. So, it's really important on top of your if you do develop symptoms or your ophthalmologist and really try and get treatment as soon as possible.

[02:08:02] **Dr. Benjamin Greenberg:** And so I'll take this opportunity, I'll put you on the spot and we're going to let everybody in the world in on a little secret around access. Okay. So, you're ready, and we're going to share the world on how do you break down the barrier to access to the specialist you want? Okay, so listen to these two questions. And as referrals come into the Mayo Clinic, new patients, so I fax the form to assist in the Mayo Clinic. Do you see those faxes every day as they come in?

[02:08:34] **Dr. Eoin P. Flanagan:** We do. We will see.

[02:08:38] **Dr. Benjamin Greenberg:** Do you see your fax. Do you? Not the Mayo clinic?

[02:08:42] **Dr. Eoin P. Flanagan:** And they give them over and they’re sent to us. So, most of what we're looking for in a referral as if patient does not have access to an expert locally or has not seen an expert in the condition. There are cases where we would like to bring them in or if the issue is an acute issue, we like to try and bring people in as soon as possible. So, I think that's important. At Mayo Clinic, we take self-referral. So, lots of times patients call up and give us the details or physician referrals. And I do think for people if they're struggling to get a diagnosis, it's useful to come to an expert center and there are many around the country, and many of the members of the audience and the panel there are available. So, I think and trying to find a specialist is useful and trying to see if you can get an appointment somewhere and keep trying, because persistence can pay off. And if you're not getting an answer, get your doctor to push more, call us. I think the more you try the more likely you are to get in.

[02:09:48] **Dr. Benjamin Greenberg:** So that was the second part of the question. You jumped ahead. So, if there's a referral and then you get a direct email from a physician. So, if a physician emails you and says "Dr. Flanagan, I have a patient, they've been referred. I really think they need to be expedited." How often do you expedite that appointment?

[02:10:10] **Dr. Eoin P. Flanagan:** Pretty much 100%.

[02:10:11] **Dr. Benjamin Greenberg:** 100% of the time. And he's not just saying that I have referred to him and he does. If I email open and say I need someone the answer from him and Carlos and Mike and Grace are I'll add him this week, I'll add them next week. And so, if you're ever running into an obstacle, the biggest thing that can happen to break down that obstacle is one of your clinicians, any of them. It doesn't have to be the neurologists, it can be your primary care physician, personally message the clinician you're being referred to. I'd say 95% of the time it expedites the visit, it has been my experience. Carlos.

[02:10:49] **Dr. Carlos Pardo:** I have a better option. Go to SRNA. Open the web page and send a consultation. So, in other words, there is somebody in the SRNA that is going to be looking your message and email and that person can direct you to a specialist in neurology, pediatric neurology, rehabilitation that are in different states. And it is important for you to understand that when you are a member of the SRNA, you are contributing greatly to the community. Why? Because even if you are paying your dues every year and you are donating to SRNA, you know what? That money is going to a fund that is going to provide some services for the people that are helping with this type of communication. But the other thing is very important, and this is something that is extremely important to disclose, is the gentleman who is sitting there is responsible for training a lot of neurologists in the area of transverse myelitis. So, when we established the Myelitis Center at Hopkins several years ago, the first priority was to train people on transverse myelitis. And now, there is not only Hopkins that are specialists and a specialized center in Texas, in Massachusetts, in many other areas of the country. So, I think that the SRNA is a good way to establish communication right away. So, thank you Sandy for putting the network together.

[02:12:31] **Dr. Benjamin Greenberg:** Any other questions or comments? Yes, in the back. Just wait for the microphone coming your way. We need some background filler music as the microphone.

[02:12:48] **Audience member:** Hi. When you're talking about delays and getting things expedited and stuff like that, I know it happened to me last November when I first got TM. But initially it was just my left side and I had like a drop foot kind of thing. And my wife was giving me stroke tests and telling me lie down maybe strained a muscle. And so, then we ran over to our local hospital a couple miles away, and they tested me for stroke and said no you don't have that. And they started giving me MRIs. And the neurologist initially went "Oh yeah you got GBS, Guillain-Barré syndrome. And so, they started me on an IVIG. And the next day they're like "Okay, after you're done with the four or five days, "I can't remember what, "of that, then we'll send you off to our rehab hospital." Because by then I couldn't move my legs or anything, it was all paralyzed. And they said, "So then we'll try you out to this other place and work on that."

[02:14:05] And my wife said you know maybe we ought to get a second opinion. And so asked for a second opinion. And the next neurologist came in, and instead of just verbally talking to me about what's going on, he was tapping on my legs and scratching them and poking them and stuff with sharp things and I'm not feeling anything. And he did a few extra tests, and he went "Huh, wait a minute." Up around my crotch area. And then he says, "You know roll over let me and get another test." And he goes "You don't have GBS. You have TM. And so, let's stop the IVIG and let's go with the steroids." or whatever. So, from not being able to move my foot an inch off the bed within a couple of days of doing that I was lifting my foot up three, four inches, there was definitely a change in things. But if you don't ask for a second opinion, sometimes you're certainly not going to get one and they might be going down a path that's not the right path. That was my experience.

[02:15:31] **Dr. Benjamin Greenberg:** Great point.

[02:15:31] **Jodi Arminio:** It's funny because there were people in my family that said, well, maybe you should get a second opinion. Like "I'm positive Dr. Hussam is the smartest guy in the room, and he knows what I have." You talk about accessibility but because he was a friend of my brother-in-law and a doctor for my brother-in-law, he gave me his personal cell phone number and told me you know if I ever had an issue or had a worry to give him a call. After he gave me that journal article and told me not to google it, of course I went home and googled it. I'm up all night on steroids and so I emailed him at three o'clock in the morning and I said something that would probably give it away and his reply was you googled it. And he said you know, just you gotta trust in me, it's going to be okay, that information is old, we're going to get through this, and we did.

[02:16:56] **Dr. Benjamin Greenberg:** Well, thank you, I appreciate it. All right. So, our last presenter Sarah is with us. There we go, Sarah come up to join us. And as she's approaching, the question answering conversation session will be led by Carlos Pardo. Our goal just so you know is I'll be watching the time because we want to leave the last 15 minutes before we go to the reception for you to have the big reveal. Everyone will declare their diagnoses and then just to have some comments from everyone about some of the lessons learned and some of the themes as we're talking about these different diagnoses. So, with that I'm going to turn things over to you. And I can't say why because it would give it away, but I hear you're now TikTok famous. Is that true?

[02:17:50] **Sarah Mendenhall:** I am TikTok famous.

[02:17:51] **Dr. Benjamin Greenberg:** All right. We'll do selfies later.

[02:17:55] **Sarah Mendenhall:** Saved the best for last. So, thanks for having me up here. I hope everyone's doing okay. My name is Sarah. I'm 23. I'm from Dallas, Texas. Yes. Hello, Dr Greenberg. So, I'm going to be talking a little bit about my diagnosis, not the actual diagnosis, but how I got here. So, previous to getting my diagnosis, there was no family history of any severe illnesses besides some cancer that ran in my family on both sides. I grew up healthy. I got several strep infections when I was little. I had some chronic sinus infections. So, when I first got sick, I started to get flu like symptoms. I went to the doctor twice, urgent care. And every time I went, they said, "It's just a virus you're going to get over it. You don't have flu, you don't have the strap, you just have a virus you're going to be fine." So, I trusted that, and I went home, and they put me on antibiotics which wasn't the best move for any viral infection. So, I started getting flu like symptoms, had it for about a week. Then I had a fever that wouldn't break. I had severe chest congestion and had congestion. And that Friday, I did not respond to my SAT tutor and did not respond to any family members when I was home.

[02:19:27] And basically, my stepmom came home and found me in my room not knowing who she was, not knowing who, excuse me, not knowing who she was and not knowing who I was. I didn't know where I was. And this is where my memory gets really fuzzy, and you'll understand why. But I was very combative and if you personally know me you know that I am the least likely person to fight anyone. I will not be physically aggressive with you. But apparently, I wanted to be very aggressive with everyone. So, I went straight to the ER and was admitted immediately just based on you know the symptoms that I was presenting. They ran MRIs and CT scans and saw that I had double brain swelling. So, I had the swelling of my brain and swelling of the lining of my brain. And this is why I do not remember going to the hospital or being in the hospital for about the first month that I was there. There was concern of meningitis. And after seeing several specialists there was concern of West Nile. I saw several infectious disease doctors. Everyone had to be basically in Hazmat. It was like if COVID happened six years earlier that was my room.

[02:21:19] But my family basically said, "We've been around her for about a week. If she's infectious, then we all have it so we're not doing that." I'm very grateful for that. So once the MRI imaging came back, they found that I had double brain swelling and two lesions along my spinal cord in the gray matter. So, they transferred me to the ICU in Children's Dallas. And within 48 hours I became a quadriplegic and was intubated. They ran lots of blood tests. I'm very thankful I don't remember getting so many blood tests. I'm not the biggest fan of needles. But it later came back that I tested positive for the enterovirus which is also known as a common cold. I was intubated and was given intravenous steroids IVIG and plasmapheresis back-to-back. They basically threw the book at me not knowing what I had. And after I became stable, I was very touch and go in the beginning. But after I became stable, they actually came into my room and said, "We're going to start physical therapy." And I'm pretty sure my parents looked at them like they were crazy and I'm pretty sure Dr. Greenberg was a part of that decision, but I was unable to move and was intubated had IVs, everything I had all of the tubes.

[02:23:07] And they were like "We're going to start physical therapy." And I probably was laying there like thinking, "What? Excuse me." But they put me on a tilt table and started trying to get the brain messages to the rest of my body. After they found the two lesions is when I got my diagnosis and was told from Dr Greenberg this is the one memory that I do have from the ICU. There were two things actually, you'll appreciate this because I still do. The first one was him explaining to me my recovery timeline. It was "We don't know what you're going to get back, but we do know for sure that you're going to recover very quickly and then you're going to hit a plateau and then you're going to hit another, spike and recovery." That's one thing I remember. The other thing I remember that I still think about today, I still haven't used this card yet. So, I'm still waiting is him telling me, "You're going to get frustrated and if you need to give the finger to somebody just give it, I'm giving you the green card." So, I was like, okay, so I still have that in my back pocket when I need to. Yes. So, from there, I slowly got some movement back in my hands, and from there into my arms, into my neck, my chest. I had respiratory doctors because I had fluid in my lungs. So, I was getting respiratory therapy as well, as physical therapy in the ICU. But I slowly gained movement back.

[02:25:02] I was in ICU for 41 days and I left and went to a children's rehab center, where I worked on physical therapy, occupational therapy, and speech therapy after finding out my left vocal cord was paralyzed. That was probably the most devastating day. That was a really hard day. As I was a senior in high school, I was 17 when this happened, and I had plans to go audition that is cool for music. I later found out that the movement was actually not permanent and I'm so thankful. And then I finally had my voice back again. I went home after four months, and I continued to work on physical therapy and outpatient. Physical therapy was really hard at times, but it was also probably the most fun I've ever had. The physical therapist I had were amazing and they helped me set goals that I just never thought I would accomplish, but we did it. I walked across my graduation stage with my service dog Oliver. He was still a puppy and decided to eat all of the flowers on the graduation stage.

[02:26:38] So right now, I am obviously walking, and I am able to do full workouts at a spinal cord injury gym. I'm receiving Rituximab infusions every six months. I'm currently a senior in college and plan on graduating in December with a communication degree. I currently have bowel and bladder problems that I still deal with, and temperature sensitivity. I'm also receiving outside mental help from providers working through mental health issues regarding my medical history. I think it's important to note this as it is an important part of my story and I think it's something that many of us can relate to. I currently work in a bakery. So, if you need any sweets in Dallas come meet me. I have a service dog named Oliver who's helped me tremendously with mobility and mental health. Although I'm not the same person that I was before, I have gained so many new experiences and opportunities and I've grown so much through this diagnosis. So, thank you for having me.

[02:27:56] **Dr. Benjamin Greenberg:** Nice job, Sarah. You left one thing out though, the context for the middle finger comment.

[02:28:03] **Sarah Mendenhall:** I don't remember.

[02:28:05] **Dr. Benjamin Greenberg:** You don't remember. We were at your bedside, and I was doing an exam, and I have your permission to say this?

[02:28:10] **Sarah Mendenhall:** Yes.

[02:28:11] **Dr. Benjamin Greenberg:** Great, okay. And I said can you move your fingers, and you weren't moving your fingers. I said, you know, to motivate you when you're ready, the first finger just gives us the middle finger and we'll know recovery is happening. So, context is important. But you can flip off anybody anytime, it's fine. So, I know we have some questions online and there's a couple different versions. I think some were coming in late for Dr Flanagan. Let's hold with those if we have questions for Sarah.

[02:28:44] **Audience member:** So maybe we can circle the room first for Sarah.

[02:28:48] **Dr. Benjamin Greenberg:** Any questions for Sarah? Carlos, do you?

[02:28:53] **Dr. Carlos Pardo:** Sarah, thank you so much for sharing this experience. We are going to introduce the Ben Greenberg finger sign to the neurological exam. I will remember this. I was curious about during that—

[02:29:09] **Dr. Benjamin Greenberg:** I have no problem with that. If I read a chart from Hopkins a few years from now and it says positive for the Greenberg sign, it'll just be the mic drop of.

[02:29:17] **Dr. Carlos Pardo:** So we are going to call this Greenberg positive or Greenberg negative. So, Sarah, when you had the infection, how long were you with the infection? And after how many days did you show up with the problem, the main problem that brought you to the hospital?

[02:29:39] **Sarah Mendenhall:** So I got sick, actually tomorrow's my anniversary of my getting sick or showing symptoms, but I started to show symptoms a week before I went into the hospital. So, I had fever, congestion, flu like symptoms. Just you know, we were sure that I had the flu.

[02:30:03] **Dr. Carlos Pardo:** And this was in October.

[02:30:05] **Sarah Mendenhall:** October, yep.

[02:30:10] **Dr. Benjamin Greenberg:** Other question, a hand up that I was missing, the back corner over there.

[02:30:24] **Audience member:** Hi, thanks for sharing your story. I was just wondering, as far as obviously made great physical recovery, do you still maintain going to physical therapy fairly regularly? And if so, how do you balance that with your school demands and stuff, just asking for personal?

[02:30:42] **Sarah Mendenhall:** So I actually am not currently in what you would call physical therapy, but I'm actually, I found a gym that is specifically for people who have spinal cord injuries. And it is a fantastic place. The trainers usually have backgrounds in spinal cord injuries and so they're very well aware of the dos and don'ts of recovery and everything. It's a fantastic place. So, I do that once a week. And I just have a time that I sat with my trainer, and I just know that during that hour I can't really do school or anything else.

[02:31:26] **Dr. Benjamin Greenberg:** And we have a question over here.

[02:31:35] **Audience member:** My son's been in Seattle Children's for almost 2 years, he has ADEM, transverse myelitis, and optic neuritis, and he's slowly coming back. We know he's aware, but I guess from your perspective, I advocate for him frequently but what are things that I might not be considering that you could offer advice on?

[02:31:59] **Sarah Mendenhall:** That's a hard one. I think as I became more aware, I was never unconscious. I just had so much brain trauma happening that my body just couldn't process what was happening. But as my brain started to heal and as my body started to heal, there was a lot of pain. I had a lot of nerve damage and a lot of neuropathies. And I think listening to body language is so important. I think my mom could tell just with my body language if something was wrong and could slowly kind of try and figure out, "Okay, like her legs are hurting right now, she needs some pain medication for that." So, I think listening to body language is important. If they're slowly starting to come back having a pen and paper right there when they're ready, if they're at that age that they're able to do that, that helps a lot. I remember when I got my white board for the first time I asked if I could take a shower. The answer was no because I was still in ICU. But just having those outlets, even if it's printing out an image of a body and having colors that they could color in, you know where there's pain or where they're feeling okay. You know, stuff like that.

[02:33:41] **Dr. Benjamin Greenberg:** If I can on that, just a follow up, did you ever have an experience in the ICU where you were aware of people talking about you around you and not to you?

[02:33:54] **Sarah Mendenhall:** Yes. I don't want to say dehumanizing because it wasn't that extreme. But you're very aware, the moments that I do remember that you're very aware of when people are talking about you around you, even if you know I can't respond or I can't be involved in the conversation. Even you talking to me about this is your recovery. You know, you knew I couldn't be like great, "Okay, let's do this." Because you know, I was just lying there but you still were talking to the patient, and I think that's important. Just make sure that they're being talked to and being informed. Because they may be aware. Yeah.

[02:34:46] **Audience member:** Did you find—

[02:34:50] **Dr. Benjamin Greenberg:** Just wait. Sorry, not all the way.

[02:34:56] **Audience member:** You want to test; you wouldn't want me to try. Okay. Because you were a minor and Hannah was a minor when you guys got sick, did you find that transition from technically "I don't get to make the decisions" to "now it's on me to make the decisions." How did you find that?

[02:35:19] **Sarah Mendenhall:** I like to say that I had to grow up really quickly. I had to kind of learn that because I turned 18 in the hospital, and so that was kind of like "All right you're the decision maker now." But luckily, I had the support from my family, and we would talk about those decisions. We would discuss treatment plans and what I needed to do. And I wouldn't say all the decisions were on me. My parents still had a very big influence on what was happening and talking to the doctors but all of a sudden it was the doctor is being like "All right, these are your options. What do you want to do?" So just having that support, being able to talk to family, and if you don't have that family, just getting as many opinions as you can to make the right informed decision, I think is important. But I definitely had to grow up a little bit quicker than the average 18-year-old.

[02:36:27] **Dr. Benjamin Greenberg:** No other questions? Nice job Sarah. I appreciate it.

[02:36:32] **Sarah Mendenhall:** Thank you.

[02:36:36] **Dr. Benjamin Greenberg:** We did have a question for Dr. Flanagan, and I think he's still on.
[02:36:41] **Dr. Eoin P. Flanagan:** I'm here.

[02:36:43] **Dr. Benjamin Greenberg:** Roberta, go ahead.

[02:36:45] **Audience member:** So there was a common question that says I was diagnosed in July 2022 with transverse myelitis and was advised to see a neuroimmunologist. There is not any other neuroimmunologist in the area other than the ones at the Mayo Clinic and the Barrow Neurological Institute. Both denied me for my insurance. I have been trying to get into either clinic with the help of my primary care physician but to no avail. Living in the Phoenix area, I was hopeful to get into either clinic. Dr. Flanagan and anyone on the panel have any recommendations? So, over you Dr Flanagan.

[02:37:22] **Dr. Eoin P. Flanagan:** I think they could try and maybe have their doctor reach out to someone at Mayo. I'd be happy to answer, try and see if we can help. I know there can be sometimes barriers with insurance or other issues, but sometimes getting a face-to-face consultation even if the investigations are not covered by insurance can be helpful in trying to get in, like Dr Greenberg mentioned earlier, some communication from your physician potentially to someone at the facility and then we could see if we could work that out.

[02:37:55] **Dr. Benjamin Greenberg:** And I'll just offer to other potential solutions in that situation. I agree with own completely, even if you can't do all the testing, just having a visit can be helpful. So one is, and I think everybody on this panel has done this, if a clinician ever reaches out to us and wants to do a clinician, the clinician consult, we'll just clear time on our schedule, review images, review records, we won't be able to examine a person, we won't be able to talk directly, that's tough. But we can give direct advice to that clinician, and it doesn't go through insurance, and we do that all the time free of charge and are happy to do that. It's common for us. And then the second is we've run into this before in particularly our children's practice, where if somebody's on a certain state Medicaid that isn't in Texas, they get denied. You can petition for a one time out of network consultation with a specialist if you certify there isn't someone with that specialty within your network. So, we actually provide the letter, or if we want somebody to see Mike Levy, I say these glowing things like Mike's the only guy in the world who can do this, you have to let them see Mike.

[02:39:02] And often I'd say 90-plus percent of the time we get the visit covered by insurance. So, you can petition insurance to cover out of network visits with specialists and if you are running into issues with your insurance over and over again, you can ask for a case manager, or some insurance calls an ombudsman to be assigned to your case and that way you get the same person on the phone over and over again. It's not the 1 800 number. You're assigned "Julie" and "Julie" follows your entire history and helps navigate the insurance side of things. So, if you're running into insurance issues, it's a very useful tool to ask for a case manager to be assigned. I don't know if anyone else has other solutions for this or other comments. I know Carlos you do these consultations all the time. Grace on the pediatric side, I know you get this phone call all the time.

[02:39:53] **Dr. Grace Gombolay:** We should talk to other clinicians. One thing I was listening to say which may not be an option for a lot of people might not be financially viable. I know that at our hospital, we do offer self-pay option. I think it might be like $75 but don't quote me on that, which again is not an option for a lot of people but it's not like the however much we charged the insurance company. That's another thought.

[02:40:20] **Audience member:** And we actually have a related question for Dr. Pardo which is what would be the best way to receive a follow up with you? That I'm thinking I must be using the wrong site for messages, do I call and schedule an appointment? I'm 12 hours away. So, do you have any comment?

[02:40:38] **Dr. Benjamin Greenberg:** Wait, just take his number down. His cell phone number is 410... Oh sorry.
[02:40:44] **Dr. Carlos Pardo:** Yeah, it's a very good question, actually. The best way if a patient has been in our hospital is to reach through my chart that is the electronic system. Unfortunately, after the pandemic and this is something that you need to be aware because people believe that we don't want to communicate doing telemedicine is there are the doors for telemedicine were closed in many states. In other words, in Maryland up to January 2022, we were able to do telemedicine with the majority of states in the United States. After January 2022, the doors were closed because legally we are not able to establish contact with patients if we are no licensed in the states where they are. So, if I am in Maryland and you are in Texas, I am not able to consult with you because I am no licensed in Texas. So that's number one. Number two, unfortunately one of the consequences of the pandemics in the hospitals is that they destroyed in many ways the communication system. So, for example, we reduce our personnel in the hospital because there are no people able to come to the offices or be higher to almost 50%. I don't know if that happened in other states. But our offices are depleted from personnel. So, we don't have anybody to answer the phone except and answering machine. And I apologize, if there has been no good communication but please send me a message in my chart. If you were in my chart system at Hopkins and we'll try to communicate with you as soon as possible.

[02:42:28] **Audience member:** Thank you Dr. Pardo. Another question that came in, I was originally diagnosed with idiopathic MRI negative transverse myelitis in July 2021. Every blood test, lumber puncture AMG etcetera was normal. I continued to grow weaker in my limbs until last month I was diagnosed, bear with me with chronic inflammatory demyelinating polyneuropathy CIDP via new AMG. Could the CIDP be related to the original diagnosis of TM or was I struck by lightning twice?

[02:43:07] **Dr. Benjamin Greenberg:** So we heard earlier about uh one of our community members who was originally diagnosed with Guillain Barre syndrome and then a neurologist came in and said uh that's not it, it's transverse myelitis. The difference between Guillain Barre syndrome and chronic inflammatory demyelinating polyneuropathy CIDP and transverse myelitis is which parts of the nervous system it affects. So transverse myelitis is the spinal cord, the other two are the nerves after they've left the spinal cord on the way to the muscles and on the way to the periphery. As you can imagine, if you have two wires, I like to use a stereo and a speaker analogy, if you have a stereo and it's connected through two speaker wires that spliced in the middle to the speaker. If you cut either one, the symptoms look really much the same, you don't hear music. And so, a lot of neurology is trying to figure out which of the two speaker wires got cut. And a lot of it's the physical exam. And so, you heard one story where a better physical exam the neurologist was able to say oh this isn't wire number two, it's wire number one. And in this case, it sounds like there was the discovery that was actually wire number two, the peripheral disease.

[02:44:23] So, without knowing the particulars of the case, if I had to bet, I'd say more likely than not it was CIDP all along in not being caught, versus being struck by lightning twice. But it is important to see somebody who has experience on both sides of that because it makes a difference in terms of how we think about a case. But I'd be willing to bet statistically it was probably the CIDP all along. So, in neurology, so after medical school we do four years of residency and then for a lot of us fellowship after. And the first one to two years are all spent, all of the skills are about trying to figure out which part of the nervous system is broken. It takes about one to two years of listening to patients and doing exams to walk out of a room and say, I think it's wire number one or I think it's wire number two. A lot of this is just nuanced and little details and the way somebody describes a symptom or a way somebody acts on physical exam. And then you spend the next couple years of residency trying to figure out once you know what's broken or where the problem is, how did the problem occur. And so, it can be tricky to separate out these things. I don't know if anyone else wants to comment?

[02:45:43] **Dr. Carlos Pardo:** I think that one of the most frequent causes of misdiagnosis in spinal cord disorders is the confusion with Guillain Barre, chronic idiopathic and demyelinating polyneural pathways. And that will happen in in both directions. Frequently, patients with Guillain Barre are misdiagnosed with TM and vice versa. So, I think that the key of clarifying the problem is what Ben is stating clearly is a very good detailed clinical history, understanding what the temporal profile of the symptoms is and doing a very good clinical examination at the beginning. I frequently see patients that come to our clinic with the diagnosis. MRI negative transverse myelitis. And when I see the diagnosis, I say well this is very unlikely to be transverse myelitis anyway. Because when myelitis means in many ways inflammation is spinal cord and frequently, we see that in MRI. So, if an MRI has been done twice and three times and it's still negative and the patient is worsening, this is not transverse myelitis. The clinician needs to be working in a different diagnosis.

[02:47:02] **Dr. Benjamin Greenberg:** Okay, so as we get to the last quarter hour here, what I wanna do is invite um each of our absolutely spectacular speakers just to announce diagnoses and then we're going to wrap things up. So, I'm going to go in order. Chantal your first. Do you want to comment on your diagnosis back from those years ago?

[02:47:44] Chantal Banks Drum roll please. Transverse myelitis.

[02:47:59] You put your money on transverse myelitis, see the table at the back, they're paying two to one odd on transverse myelitis. Okay so Hannah I think you're next.

[02:48:17] **Hannah Stadler:** Sorry, I'm eating a snack.

[02:48:20] **Dr. Benjamin Greenberg:** I waited. I was watching. In a moment.

[02:48:23] **Hannah Stadler:** Okay, I was diagnosed with acute disseminated encephalomyelitis, ADEM, and it took me a few years to pronounce that correctly.

[02:48:39] **Dr. Benjamin Greenberg:** You nailed it. And then Emily you're next. And if you wanna call it out you can if you wanna come up whichever you want.

[02:48:47] **Emily Martin:** MOG.

[02:48:52] **Dr. Benjamin Greenberg:** MOG. She nailed it. Anti-myelin oligodendrocyte or oligodendrocyte glycoprotein associate disease. So anti-MOG associated disease, or MOGAD. Jodi, you're next. Oh here.

[02:49:15] **Jodi Arminio:** Neuromyelitis optica, NMO.

[02:49:16] **Dr. Benjamin Greenberg:** Neuromyelitis optica. And I didn't ask Emily. So, you were tested for the anti MOG antibody and that was positive. And Jodi, you were tested for the anti… the NMOIGG also sometimes called the AQP4 or aquaporin-4 antibody. And you were tested for that, and you were negative. And Jodi, do you know if they tested for both?

[02:49:38] **Jodi Arminio:** No. There was not a MOG test.

[02:49:41] **Dr. Benjamin Greenberg:** There was no MOG test. That's right. And then we lost Sarah, she left the building. She knew I was going to put her on the spot. Mom, do you want to share her diagnosis back from the ICU. Acute flaccid myelitis or AFM. Okay. So, we have five individuals from our community with very different letters associated with their names. But at least for me listening to all this, it was incredible how much overlap there was in terms of experiences. I'd actually like to ask the four of you are here, was

there anything from one of the other speakers that struck you as very similar to what you experienced or what you had went through?
[02:50:32] **Chantal Banks:** A lot of foggy brain, a lot of it resonated with me. A lot of it resonated with me. The foggy brain just lots of things that everybody said. I was like, oh, I sound like I have that, or I sound like I have that, definitely. It all kinda ran together.

[02:51:03] **Hannah Stadler:** There she is.

[02:51:10] **Sarah Mendenhall:** I had to change my shoes.

[02:51:10] **Hannah Stadler:** I mean, Sara, nice experience. I mean different but the fact that we were home alone found in the same way, it's a lot. And I met someone, I forgot our name. Yes. Well, he had a similar experience where he was home alone and that's how they found him too. So just seems to strike when at the worst times.

[02:51:41] **Jodi Arminio:** Yes, for me it was most of the symptoms. And I really was kind of surprised to hear. Thank you. You know the burning pain, of course the optic neuritis and the numbness. But when people explain the burning pain um you kept talking about shingles and I ran into that too. But I'm like, because I'd already had an experience with shingles and they're like, well it's like shingles, but no rash, I'm like, " No, I just felt more like barbed wire underwear in the hip."

[02:52:25] **Emily Martin:** I like barbed wire underwear. It's a visual. I actually, when I was in the hospital because there's um the challenge of insurance, transverse Myelitis was something that was in this long list of things that they thought it could be just so that I could try to get the treatment I needed. So, I think having doctors who really fight to advocate for us is so important with these, especially the rare diseases, but almost everything, you guys said I was like, "Oh, I had that too, maybe I have that as well." But yeah, I think it's helpful that we're all together.

[02:53:04] **Sarah Mendenhall:** So I think for me, it's just hearing that everybody had weakness. I'm glad I'm not alone and that um, you know, I think sharing common sometimes this stuff is important. It can also be very confusing because I've also been through many, many times where I have been like, "Do I really have this? Is this really what I got." But knowing for sure that there are differences in my diagnosis point to what I have is important. But I think it's important that having shared symptoms also means that you can get support from a community, and I think that's like incredibly important when you have a rare disease because there's not just, you know, millions of us. There's maybe 100 of us or thousands of us. So, it's important to find something that you can relate to and something that you can talk about hearing about the burning and stuff. I remember that was the worst pain of my life and being able to kind of talk about that and be like I understand what you're going through. You know, the burning, does not feel good.

[02:54:23] **Dr. Benjamin Greenberg:** Can we give all five of our speakers as round of applause. Thank you.

[02:54:34] **Audience member:** And maybe before you leave the stage. I think this is a good moment since you're all up there for a question that is directed towards you from someone online, which I'm hoping to hear suggestions regarding diet exercise supplements. So natural remedies that you might have used to assist in healing. As someone who tries to stay off as many prescriptions as possible, I'd love to hear ways to help our bodies heal. So, I thought this was a good question to ask if you have any.

[02:55:13] **Chantal Banks:** She didn't hear me. I just used a lot of turmeric. I thought that would be my miracle drug. I don't know if it worked or not but that's what I took.
[02:55:32] **Emily Martin:** I found an anti-inflammatory diet is helpful. I am terrible about following the anti-inflammatory diet because as I said, I don't enjoy cooking and I'm not great at planning. So, all these things are important to not order pizza. The other thing that once my oldest son got diagnosed with the esophagitis and he had to cut dairy out, that really challenged me to try to maybe cook differently. But I do know that when I follow that anti-inflammatory diet, I do feel better. My brain seems to work a little bit better, my body seems to hurt a little bit less, it's just the consistency. And I do believe that essential oils have a place in the world, and I use them more for like, I think calming. I personally believe that we have a lot of science that I trust, but I'm also aware that there's just things that we can't just know all the answers. And I do feel that the more I move, even though it's really painful, in fact, I'm hearing this like a gym for people who where do you find this in Central Illinois because and I'm not founding it, and my husband's listening and he's an entrepreneur and we're not starting one. But anyway, just the idea of like patient centric movement. And I know that there's uh there's people that are starting to put those videos about just chair yoga and stuff, that's something that when I do it consistently, I find it very helpful. Melatonin for sleep has been helpful. I'm sure there's other stuff, but I don't remember.

[02:57:34] **Jodi Arminio:** I'm the world's worst about not practicing what I preach to our support group. Definitely moving, I try to do a two mile walk in the morning and I do my vitamin D. Keep on top of those levels. Other than that, just multivitamins and I don't really follow a special diet or anything. I should.

[02:58:01] **Sarah Mendenhall:** I got one. So, for me like I mentioned the spinal cord injury gym has been incredibly helpful. But even if that is not accessible to everyone because those aren't just everywhere and anywhere, before I got into this gym, before I found it looking at videos that are on YouTube that are just low impact workouts, beginners' workouts are helpful. Not saying that I did them, but it is out there, and I do think that it is helpful until you can find you know resources. I know that the gym that I go to actually can help sponsor people to fly and be there for several months. They have a fund that helps people who need to come for several months. So, you know just doing your research and finding that is incredibly important.

[02:59:10] **Jodi Arminio:** We do have one support group member that swears by the MS Gym. I don't know. It's online. I don't know exactly what it is or what it costs to subscribe but she swears by it.

[02:59:28] **Audience member:** Thank you very much. Oh, go ahead, please.

[02:59:31] **Emily Martin:** You know I'm going to say. She mentioned fatigue too didn't she in that question? So that's sort of been a learning process. I don't know if that's everybody else, and just because something fatigues me like crazy this week or today, it doesn't mean it will tomorrow. And so, I think just trying to realize what your body can handle is really important. Because I realized I cannot go grocery shopping and put them away. My joints just can't, I can't do it. So, what I try to do is when I go to the store, try to make sure that the things that I need to go in the freezer, if my kids aren't home to help, those going a bag that can just go in the deep freezer. So to help with the level of fatigue that will come when I get home or just knowing when I'm starting to get, I think there's something like an overstimulation, maybe it's like you don't necessarily need a nap, but I am just worn out, that it is okay to just lay down, just try to breathe because it can pass and it's taken me about 13 years to figure out how to do a lot of these things. But trying to figure out buying in bulk is not a great thing for me all the time because it means I've got to now put it in smaller packages. So, for some people that might be helpful, other people might find that a challenge. So, I think it's sort of individual as far you deal with some of those fatigue issues but never underestimate the quality of rest.

[03:01:17] **Audience member:** Yep. Hannah, do you have anything to add?
[03:01:22] **Hannah Stadler:** I really enjoy doing yoga and meditation type practices and breathing. It's been a huge technique for me. I've had a few concussions in the past two years and so some of my therapists said breathing is huge in helping the whole body relax and I think that can help a lot with pain. I found that mental pain seems to be connected to physical pain and it's like a bad cycle. They're just like hug each other on almost. So, trying to stop it with the mentality of things can be helpful in calming everything else down.

[03:02:05] **Audience member:** Thank you. I just wanted; I know you're looking at the time. Dr. Greenberg just one comment of praise from the community. The thing I appreciate about hearing these stories as someone with a new diagnosis is that I see examples of people who still have full lives while living with these complicated diseases, so thank you all so much. And do you want to go, come on, let's give a round of applause and you were about to clap and before you leave the stage, there was a person that was asking if each presenter community presenter could share their diagnosis again because you're lined up perfectly now on the stage you weren't before. So, if you would be able to re-reveal your diagnosis, that would be great.

[03:02:48] **Chantal Banks:** Okay, transverse myelitis.

[03:02:52] **Hannah Stadler:** Acute disseminated encephalomyelitis.

[03:02:56] **Emily Martin:** MOG antibody disease.

[03:03:00] **Jodi Arminio:** NMO, neuromyelitis optica.

[03:03:03] **Sarah Mendenhall:** Acute flaccid myelitis.

[03:03:05] **Audience member:** Thank you. Thank you so much. Dr. Greenberg, am I allowed to ask the final question, or do we not have time?

[03:03:30] **Dr. Benjamin Greenberg:** You always have time, Roberta.

[03:03:31] **Audience member:** Really? Okay. Can you give specific criteria condition to differentiate and confirm a diagnosis if it is TM or NMO, or MOGAD? Like for example a positive aquaporin-4 is indicative of NMO. Is that correct? My diagnosis is TM but I had an aquaporin-4 positive. So, do I have both TM and NMO? How do you make differential diagnosis of these rare autoimmune diseases, AFM, MOGAD, NMO and TM?

[03:04:04] **Dr. Benjamin Greenberg:** It's actually very simple. I email Mike, and he replies and in the subject line it has one and that's the right answer. So, in 30 seconds this is my answer. And this is being recorded so we can play this part back. This is a generalization and there are sometimes specific pieces of history for an individual that may cause me to break what I'm about to state as a generalization. But with that as a background, in general, if you have a syndrome, any syndrome that is consistent with neuromyelitis optica, and you test positive for the anti-aquaporin-4 antibody on a reliable test, and that's a little fun asterisk to put there, your diagnosis is neuromyelitis optica, regardless of if you're onset was transverse myelitis or optic neuritis, or a brain syndrome. If you have any of those syndromes and at some point, test positive, that blood test trumps everything else and your diagnosis is NMO. So that's number one. Number two, if you have a syndrome consistent with ant-MOG associated disorder and you test positive on a reliable test at a high enough level, it's an evolving science, stay tuned, you're going to hear more about this later in the symposium.

[03:05:31] But if you have the right test and a high enough level and the right syndrome, then your diagnosis is most likely anti-MOG associate disorder, there may be some exceptions there. So, the aquaporin-4 rule is very strong, the MOG rule is quite strong. We're still sorting that one out. If you have had inflammation in the spinal cord and nowhere else, not your eyes, not your brain and you're negative for the anti-MOG antibody and negative for the aquaporin-4 antibody and you have no evidence of an underlying autoimmune disorder, that's when we say it's idiopathic transverse myelitis. Notice I threw in that word idiopathic which we've just been dropping off. Transverse myelitis can happen for anybody in this room, whether you have ADEM, whether you have AFM, MOG, NMO, we can all experience spinal cord inflammation which is transverse myelitis. But as a diagnostic category, when we say it's idiopathic transverse myelitis it means you don't have one of those other conditions. You've been tested for those other conditions and don't have it. And in acute flaccid myelitis, the key is where in the spinal cord is the majority of inflammation. If it's in the gray matter honed in on the gray matter and you test negative for these other conditions, that's when we talk about acute flaccid myelitis.

[03:06:48] And then finally the one I haven't talked about, acute disseminated encephalomyelitis is when your brain is inflamed and there may be other things. It may or may not include the optic nerves, it may or may not include the spinal cord, but the brain has to be inflamed, and you test negative for those antibodies, that's when we use the term acute disseminated encephalomyelitis. So, I'm going to do a check if everyone... Carlos? It's close. See, all I do is email Mike and I told you that's the easiest way. So, the reason I check is there are some gray areas. What I just stated was a generalization and this is where the nuance and the details come in and where there's an evolution occurring in the science and the understanding. And I'm going to make one last comment. I'm going to stop speaking and ask everyone to do a closing comment. We have only gotten smarter about this because we did it together as a community.

[03:07:42] Understanding anti-MOG associate disorder, the way we do now, never would have occurred if we weren't following the Hannah's of the world with ADEM, where people with what seemingly had idiopathic transverse myelitis, only to show up years later with optic neuritis or something else. The only way we understand neural myelitis optical the way we do is by separating out people with anti-MOG associated disorder. And we don't just get smarter about how to diagnose these conditions, but we're learning about the treatments. We're learning that certain things I do in clinic day in and day out for somebody with an anti-aquaporin-4 antibody doesn't seem to work in the same way for somebody with an anti-MOG antibody. And so, the community that's been created originally with Sandy and Pauline and the vision of a big tent has paid off for us clinically and scientifically. And what I learned today is from a community perspective, getting those commonalities. It's really scary to be in a rare disease category but when you recognize that there are multiple rare diseases that share so much, it isn't so rare, it isn't so lonely. It actually becomes a much bigger community. But with that I'm going to ask each of our panelists just to give some closing thoughts or closing remarks before we head to the reception.

[03:09:02] **Dr. Michael Levy:** The only thing I would add is that the way I see my clinic is really a learning opportunity. So, when you tell me about your disease, I learned about it as much as I may teach you about it. And it's the common experiences that we try to synthesize and put together and then try to study. So, when we get these wonderful questions about, well, what treatment do I do or what diagnostic tests do I do? We'll be able to answer them by going back to our databases that you've contributed to and be able to answer those questions. So, I just wanted to thank all of you in the room clearly involved and engaged, and for all those other patients who just come to clinic and roll up their sleeves to donate a sample of blood. I just can't express how important that is for our research.

[03:09:57] **Dr. Grace Gombolay:** Yeah, I'm going to piggyback on that. It's one thing I'm very grateful for is for the patients and families who trust me with, you know, I see a lot of children, with your child's care. And so that's such an honor and privilege for me to have. And the other thing is that I'm incredibly grateful for all the patients and families who contribute their time, who contribute extra blood samples, and contribute

their data for research because that's what we're trying to do is try to figure out these diseases and how to improve your lives. So, thank you for that.
[03:10:27] **Dr. Carlos Pardo:** I think that my message is because I'm one of the oldest in the group here. So, in 1999 when we got together, transverse myelitis was in the basket of multiple sclerosis. So almost everybody got labeled MSOTM. 2005 NMO came. And after that actually in neurology, it has been quite amazing development in the past 10 and 15 years. And the reason is number one, many of you have been helping us to understand the conundrum that is my myelitis. Number two, we are learning more and more about the immunology of these disorders. That the reason our colleagues at the Mayo Clinic discovered aquaporin4 and we have neuromyelitis optica, later MOG was rediscovered. Because MOG has been in the picture for many, many decades, but only until recent years has emerged as a leading cause of neurological disorder, only that didn't have the tools to recognize MOG. But if you take a look of 1999 when we got together for the first time and you take a look of 2022, there are more than 10 different diagnoses now in the spectrum of what we call transverse myelitis to the point that we are ready to ditch the term transient myelitis. What that means is basically every diagnosis of myelitis need to be dissected very well by the clinician to characterize if it's NMO, it says MOG, MS, if it's post infectious disorder, if it's an enterovirus D68 associated myelitis.

[03:12:24] And eventually in the next several years we are going to discover more and more those idiopathic cases of myelitis probably are going to be associated with something either an antibody or a virus or a triggering factor or even genetic predisposition. Dr. Levy is working on genetics of transverse myelitis. Yeah, there is a small group of patients with some genetic background. So, in other words, the term transverse myelitis is probably you are going to see this in the next few years, it's going to disappear. It needs to disappear. It needs to disappear because we need to go and more precise diagnosis. We need to say, okay you are NMO, or you are MOG, or you are post infection myelitis or post vital myelitis. And in that way, patients will get benefit in treatment. It's going to be a mistake to put a patient with multiple sclerosis myelitis on medication for multiple sclerosis. And it's a mistake to treat patients with neuromyelitis optica with medication for MS. So, in that way, we are going to get better and better, and the help that you are going to give us is to continue the communication facilitating research. What Dr Levy say is exactly right. We have learned from the donation of blood that you give us to our research or even the registry is that we have a different center in the United States. So that information is actually extremely critical for understanding what the spectrum is of what we call now transverse myelitis, but tomorrow is not going to be called transverse myelitis, it's going to be myelitis and another last name perhaps. So that's basically the message.

[03:14:07] **Dr. Benjamin Greenberg:** And then we'll get comments from Dr. Flanagan online.

[03:14:14] **Dr. Eoin P. Flanagan:** I would just say two things. Firstly, thank you to all the presenters today for telling us their stories. It's really amazing. And hearing from all the patients is what we learned from as was mentioned earlier. And then I would have a message of hope. If we look at neuromyelitis optica spectrum disorder, we now have multiple different approved treatments where we can really treat this disease very aggressively and keep it very quiet. So, I think there's a lot of hope out there for all our patients that we can help keep these things under control and really figure out more what disease you have, treat it effectively, and keep things quiet so people can get on living their lives. So, I think there's a lot of hope out there from all the discoveries that have been made.

[03:15:03] **Dr. Benjamin Greenberg:** Great way to close this out. I would appreciate it. And I'm going to leave everybody with the most important information of the evening. The reception is on the third floor in the in the Malibu Garden. And Dr Levy is covering the bar tab. Yeah let's hear it for Dr. Levy. Thank you very much. So, we appreciate everyone's interactions today. We're looking forward to interacting, talking with you more upstairs on the third floor on the Malibu Garden. Is that correct? Malibu Garden. We will see you upstairs. Thank you.