

Community Roundtable

You can watch the video of this event at: youtu.be/xNdGuPFV3r4

[00:00:05] **Dr. GG deFiebre:** Hi, everyone. Welcome to this Community Roundtable. My name is GG deFiebre and I work with the Siegel Rare Neuroimmune Association. And I am pleased to be joined by Megan and Julie today. So, just to start and give some introductions for those who are listening. But do you mind just telling me your connection to rare neuroimmune disorders or TM specifically? Megan, do you want to start?

[00:00:39] **Megan McCartney:** Sure. Hi, I'm Megan. I was diagnosed with transverse myelitis in July 2018. Found out about, it was called The Transverse Myelitis Association right after I was diagnosed. So, I've been involved since then.

[00:00:55] **Dr. GG deFiebre:** Great. And Julie?

[00:00:58] **Julie Barry:** I have had TM since 2008. So, 15 years and I found the SRNA which was the TMA at that time right away as soon as I got out of the hospital. And the first person I talked to was Debbie Capen and she was great. She told me her story and helped me quite a bit. So, that's where I'm at and I am also a support group leader for Tucson area.

[00:01:29] **Dr. GG deFiebre:** Thank you. And just also some background too I was diagnosed with transfers myelitis in 2009. And also found that at the time the TMA [not] SRNA. So, I'm just going to add in this banner here and that people can see, hopefully. Yes. So, in terms of thinking about how your life has changed since your diagnosis. Can you talk a little bit about how it has changed, what has changed, how it has changed, and how you have found maybe a new normal? And if so, how you got to that point, that new normal? Julie, do you want to start?

[00:02:20] **Julie Barry:** New normal. I would have to say that on a daily basis, I have to find a new normal. My life is changed. Mostly people tell me my personality has changed, which I find interesting. I'm still pretty upbeat, but my husband says I'm not as bubbly, which I find interesting, but every day I work on it, to try and get back to where I was, but I was paralyzed from the waist down, but I do have mobility. So, what changes is that the daily pains, the daily aches, dealing with all of that, that everyone else I hear on here talks about, I have bands, I have bladder and bowel issues. I have all those. So, it's a daily thing for me is all I can really say as far as how my life has changed and whatnot.

[00:03:33] **Dr. GG deFiebre:** Yeah. You say every day you find that new normal, is that something that you get up in the morning and you assess the day or what's that process been of finding that new normal for you?

[00:03:55] **Julie Barry:** The process is I go with the flow on everything. And I never used to do that. I was a planner so that part has definitely changed. I planned everything and always had everything set in stone. Now, not so much. I let everything go with the flow. It's much easier on me and everyone else.

[00:04:24] **Dr. GG deFiebre:** And Megan, do you mind talking a bit about how your life has changed since your diagnosis, this idea of this new normal?

[00:04:34] **Megan McCartney:** So, my transverse myelitis was a little different. I didn't have as much of the motor component. I did have weakness but mine was more sensory and autonomic and those kinds of things. But I think my new normal as I've learned, like to be grateful for what I can do. I feel like my endurance is not where it used to be. So, I have to take more breaks and I have to build that into my day. And like, Julie, I have like sensation issues and pain and things like that. It's not always the same, every day is different. So, like when I get sick it triggers things and that's when I feel worse. So, I might have to take breaks or rest a little bit more than most people. But I feel like it's part of me but doesn't like define me if that makes sense. For a while, I was almost like denying the issues that transverse myelitis brought me and then I came to terms with what I was actually dealing with. So, it's still a process. It's been five years, but it's still a process for me. So, I'm still trying to figure it out.

[00:05:38] **Dr. GG deFiebre:** Definitely. I mean, it took almost 14 years out. I'm starting to lose track of the amount of time, but definitely, there is that -- I don't know, it took five years out, for example. I don't think I had fully come to terms with my diagnosis or fully really accepted that, how it was impacting my life and all that. So, I think it's definitely a transition process for a lot of people. I'm going to put on another. Thank you both for sharing. And maybe you talked a little bit about this where you said it doesn't define you. I think that at the end there. So, on the screen here, it says, if you're comfortable sharing, how do you view your diagnosis in terms of how it fits with your own personal identity?

[00:06:43] And so I want to start quickly just because I feel like this is something about a lot recently. And at first, when I was diagnosed, I didn't want it to be part of my identity at all. I was -- I very much pushed it to the side. I said this isn't me. Everything I identified with before was who I was and I think that really has changed a lot in the past few years, especially getting to know other people with transverse myelitis or other disabilities too has really transitioned my view of who I am, and I identify as disabled, and I don't see that as a bad thing. It's just part of my identity and my experience. But that again has also changed so much over time and has transitioned so much. So, Megan, do you want to start?

[00:07:40] **Megan McCartney:** Yeah. So, again, it's been five years. I'm still coming to terms with everything, but I do feel like it's part of my identity. But again, it's not like the only thing that's part of my identity, if that makes any sense. I struggle with the term disabled at times, because I'm an OT, so I treat a lot of patients and students. I'm in a school setting now. So, I struggled with that just because I didn't really have any issues and then I got transverse myelitis, and so that's still a struggle with me that term and I'm not sure why, because I know it's not a bad thing. I think I'm just still trying to come to terms with it. But it's definitely part of me and it's changed like my perspective on things I feel like I can relate to when I used to see patients at home health and now, I see students in the school setting. So, I feel like there's been positives for the experience that I've gone through as well. Not just -- there's obviously some bad things that come with it, but I do feel like it's part of me, but it's not the only thing that's part of me if that makes sense.

[00:08:39] **Dr. GG deFiebre:** I definitely think as an OT it makes sense because you're using that -- the goal of OT is to help people with, depending on, I guess your focus. But OTs have done a wonderful job for me, for example, in helping me figure out how to do things like get dressed or do these things that my disability has changed or made more difficult for me to do. So, I mean that makes total sense that, those two worlds -- there's an interesting overlap there. But as an OT your perspective, as someone with transverse myelitis, I feel like your pay that it must be very good for your patients to know that you also have that --

[00:09:30] **Megan McCartney:** Yeah, some experience in terms of like different treatments and being in the hospital and stuff like that.

[00:09:35] **Dr. GG deFiebre:** And Julie?

[00:09:41] **Julie Barry:** I don't think it's ever defined to me. I struggle with it at times. I did the -- this is me and a lot of people that have seen the video with that, probably have heard that sometimes I deal with people and my disability slaps me in the face. So, like one time, I was in a parking lot and the lady actually told me I couldn't park there because it was handicapped and I was like, well, okay, do you realize that I am handicapped, which is very hard in our condition, because people don't sometimes see us as handicapped people or people with disabilities. So, sometimes it slaps me in the face and other times I just let it go. It doesn't define me in that way at all.

[00:10:36] **Dr. GG deFiebre:** And so, in terms of - I don't know if you consider yourself as having like more like an invisible disability or one that's --

[00:10:45] **Julie Barry:** Yes.

[00:10:46] **Dr. GG deFiebre:** So for me, it's very obvious. I use a wheelchair and my hand function's not great, so it definitely is more -- but in terms of experience with maybe having more of a quote invisible disability, what has your experience been like with that, if you don't mind sharing?

[00:11:11] **Julie Barry:** Very hard, because people will -- like, for instance, one of the things I struggle with is when I go into a store, I'm very good. I can use the -- I become my mother. So, I use the cart as my walker basically. So, I always have a cart, so it's like that changed. I never used to have a cart if I didn't need it. And people just don't see some of us that are able to walk and stuff. They don't see it. I know when I was first sick, this is a story that's funny. I used to speed around people all the time. I'm going to go off key here, I never realized how fast I walked around people until I was sick, and I had my walker and people were flying by me and I'm like, do they not know I don't have any balance? And my mom looks at me and she goes, gee, this is a good experience for you. You're learning how you used to be. So, it was a big slap in the face, and I go you mean, I used to walk around people like that? And she's like, yes, you scare people that are old who can't stand up and stuff and they're scared of you. And I'm like okay I won't ever do that again and I don't. So, as far as if that answers your question GG, I'm not sure.

[00:12:47] **Dr. GG deFiebre:** Yeah, definitely. Megan, do you have anything to add in terms of your experiences?

[00:12:52] **Dr. GG deFiebre:** Yeah, I think that's like my struggle in terms of I guess saying that I'm disabled or have a disability is just because I feel like most of my issues, I deal with are not visible. So, I guess like, there's almost this fear of like saying that I'm going to get a backlash from other people and that's an issue with our society. So, I think that's where my struggle comes from is because most of the things, I deal with aren't visible. I'm afraid somebody's going to call me out. So, I understand what you're saying, Julie too. When I was first diagnosed, it was a little bit more visible. I had some weakness, and so I had to use a rollator and things like that. But now it's not so much, I seem like I'm functioning fine, but in reality, there's still struggle. So, I definitely relate to the whole invisible disability thing.

[00:13:39] **Dr. GG deFiebre:** And I think also even just beyond the mobility aspect of it too with people not realizing that people can deal with neuropathic pain, for example, and how that can be really debilitating and

really impact someone's day to day life or issues, with bladder and bowel dysfunction or something. Fatigue is a big one. That's why and that's hard to explain to people as well, I'm so tired, I can't function like that's always a challenge too. So, I think it's important to highlight all the different ways that transverse myelitis can have an impact on someone's day-to-day life because obviously seeing someone using a wheelchair or walker is much more apparent, but there's all these things underneath the surface too. So, thank you both for sharing that.

[00:14:42] I'm going to add another question here that says, what advice would you give to patients about how they can advocate for themselves with medical professionals? And I think this is a particularly important question for a rare condition like transverse myelitis where maybe your medical professional doesn't know a lot about TM. So, Megan, do you want to start?

[00:15:09] **Megan McCartney:** Sure, I'm still dealing with this in terms of trying to advocate for myself when I was first diagnosed, I wasn't the best at tattooing it. But just like trying not to downplay your symptoms and just like actually going into the doctor's office and saying like, what your symptoms actually are and trying to like, I forget. So, I get nervous when I go to doctors. So, maybe like writing it down and being like, these are my symptoms, is there anything you could help me with? And then maybe even bringing up certain things. I know when I was first diagnosed, they weren't going to treat me with steroids. So, I had to almost advocate for that. So, just using any resources you can find to try to advocate because a lot of our doctors haven't seen people with transverse myelitis and don't have a lot of experience with it. So, just bringing any like research to their attention can be helpful too.

[00:16:04] **Julie Barry:** I'm glad you advocated for that. That was good for you.

[00:16:12] **Dr. GG deFiebre:** Do you have anything to add, Julie?

[00:16:16] **Julie Barry:** Yeah. I have had to advocate, and I still have to advocate sometimes. My neurologist has only seen one case of NMOSD. And so, I constantly after I come to the seminars and they come to these things and then I go back to him and I'm like, hey, can I test, like, I wanted to test for the aquaporin-4. Is that right? Do I say it right? And he's like, oh, you don't need that. And I'm like, can I get it? And he's like, no you don't need it. So, then I decided, okay, well, then I'll just go to my general doctor and ask her. So, I have learned to advocate for myself a lot and I think it's very important for all of you people, anyone to make sure you advocate for yourself. If you can't, find a friend, find a nurse friend. They're the best, or like you Megan, find someone like you that's an occupational therapist that can advocate for you if you can't, because some people can't.

[00:17:30] **Dr. GG deFiebre:** Definitely. Yeah, it's a challenge, and especially, finding medical providers who are willing to listen and also maybe work with other -- so if you have a neurologist who doesn't know a lot about transverse myelitis, finding someone who's willing to then talk to other providers who actually do know a lot about transverse myelitis that could be one way to make sure that you're getting the best care that you can. It's a partnership or it should be in that, ultimately the care is about you as a person. So, having that open relationship with your medical provider could be challenging, but very important. And then similarly, what advice do you have for people who are newly diagnosed or someone who's either just in the hospital or just got home? Julie?

[00:18:35] **Julie Barry:** The first advice I'd have is when they tell you that you're not going to get much better, don't listen. Definitely do not listen, because there's so much out there, especially with the SRNA that you can get better. It's not all bad. And even, if you are like TG and in a wheelchair, your life is not over. So, definitely stay positive. Staying positive is a big factor.

[00:19:18] **Dr. GG deFiebre:** Megan?

[00:19:20] **Megan McCartney:** I agree with staying positive and just trying to take it day by day, hour by hour, minute by minute. I also feel like for me, like, I never let myself feel the emotions with everything I was going through. So, I feel like it's also important to feel that. If you don't feel that, it can come back later and then cause some issues. So, I feel like it's important to stay positive but also let yourself if you feel like you need to grieve or feel your emotions, especially if you're going through hard times. I also feel like it's important to research, so you can learn more about your disorder, but not research too much. I went down the rabbit hole and scared myself of something. But research, but not to the point where you're like, that's all you're doing.

[00:20:06] **Julie Barry:** What would you give -- what advice would you give, GG?

[00:20:10] **Dr. GG deFiebre:** This is a tough one because I often talk on the phone to people or via email to people who are newly diagnosed. And even it prompted me even to write a blog for SRNA about it just because it is such a tricky time in people's lives. And so, when I've spoken to people before, they typically ask if I share that I was diagnosed with TM. In 2009, they'll say, oh, how are you now? Like are you up and walking? Are you doing okay? And I'm like, I have to say, well, no I'm not up and walking but I am doing a lot better than I was and I have figured out how to live my life. And so, it's hard as someone who I think does have its continued, pretty severe mobility issues to tell someone who's newly diagnosed in the hospital bed and not have that then have them lose hope or something because the beginning we know you don't know what's going to happen.

[00:21:23] People can be really severely impacted at the beginning and recover pretty well, or it could be -- it just depends and so trying to communicate to people that it's still very, very early. And then the fact that it's a marathon not a sprint, which is not something anyone really wants to hear when they're newly diagnosed with something. But it's the reality of the fact that this isn't -- I kept thinking, oh, I'm going to get better in three days, I'll be up and walking around because I had a trip planned, I was like I'm going to go get on the plane that I'm supposed to get on in three days. So, knowing that you're in this for the long haul for a bit. Even if mobility -- people focus, I think on mobility a lot at the beginning because that's what impacts you immediately with the things and how your life has to adjust. But even if mobility doesn't come back the way that you had hoped or expected, there's still so many ways, and through the help of OTs, for example, ways to adapt and adjust and continue on and live your life a full life and using a wheelchair. I mean, I see my wheelchair as a tool for my freedom and my way of getting through the world.

[00:22:53] So, I would say for newly diagnosed to -- again, it's a marathon not a sprint. So, keep that in mind. There's still so much room for things to get better and for things to improve. Make sure that the medical providers are doing what they should, making sure that they're ruling out everything, making sure that they're listening to patients. I mean, I tell people that too if they feel like their physician is not listening to them or not willing to admit what they don't know, that I think can be an issue for people who are newly diagnosed and making sure that they get the treatments that they need and starting stuff like physical therapy. And if open to it, connecting with others with rare neuroimmune disorders or other disabilities. And I know that can take some time. So, that was a long answer. This is something I think about frequently in my conversations with people.

[00:23:56] **Julie Barry:** Everybody's different too when you're talking to people, what they're going through. So, kind of have to go with the flow of what they're feeling.

[00:24:08] **Dr. GG deFiebre:** It's definitely customized too based on the person's experience. There are those universal things that everyone, I think, experiences there. But then there are all these individual things, what

do you do if your house is not accessible, and you need it to be or there's just these other things as well. So, let's see. I have another question here. I'm just adding it to the banner. So, what made you decide to get involved with the SRNA community? Julie, do you want to start?

[00:24:48] **Julie Barry:** Mine is easy. It's an actual name. Her name is Barbara Sattler. I met her when I talked to Debbie Capen and Barbara lives in the same town I do. So, when I met Barbara, we just connected greatly and have been fast friends ever since and she wanted to do a support group and so we started getting more and more people involved. And she was involved with the SRNA already, so she just clicked me right in and I enjoy it. I enjoy all the people I meet, and I have a great time with all you guys.

[00:25:33] **Dr. GG deFiebre:** Thank you. And Megan

[00:25:37] **Megan McCartney:** Yeah. So, I was actually trying to just find more information about transverse myelitis. So, as an OT we learned about - I thought what were relatively rare diseases at the time, but I have never heard of transverse myelitis. Originally, they thought I had multiple sclerosis. So, you knew a little bit about that. But yeah, I was just trying to figure out information on the Internet and it led me to what was the TMA or the SRNA and that's how I found it. And it was nice to know people who had similar diagnosis because I didn't know anybody at that time. So, I was more of me just trying to figure out information. It led me to the website. So, it was like - I think it was almost like two days after I was diagnosed, I found it or something. So, it was pretty soon.

[00:26:20] **Dr. GG deFiebre:** That's good because that's always a challenge to make sure that we're trying to find people early on in that process and it just depends. So, it's wonderful that you got connected sooner.

[00:26:30] **Megan McCartney:** And I was going to say GG, I think you are one of the people I originally talked to, and you were trying to get me to get back in the hospital, get steroids. So, that helped me too. So, thank you.

[00:26:41] **Dr. GG deFiebre:** Good to hear. Again, the goal is people would find us right away. Although we also don't want that information overload Megan that you talked about too where it's like it can be too much sometimes. And so, you do it in little bursts and also providing information that isn't absolutely terrifying too, because there's - I think my family withheld, I think they were handed a piece of paper or like 12 pieces of paper with a whole list of everything. And I think the thing that stood out to them was - it said something like people don't recover until 2-12 weeks or something. I don't even know if that's where that came from or what that information is from. And they were like, we're not going to share this with her right now and they kept it from me, and I wasn't ready yet then either I don't think, and I couldn't use my phone at that time either with the way my hand function was. But trying to balance that, getting the information you need to survive and to make it through this experience in a way that gets you in a good place but not also completely being overwhelmed with a lot of information and some of it can be a little scary and overwhelming.

[00:28:09] **Julie Barry:** They did that with my husband too. They gave him a whole list of papers and he didn't give it to me either.

[00:28:16] **Dr. GG deFiebre:** I know. I don't know what I would have -- I think it was smart that my family did that. I don't know what I would have done if I had read.

[00:28:25] **Megan McCartney:** See, I don't think I got a lot of information. Like I had to research it all on my own. I didn't get much. It was just like, oh, you've like inflammation of your spinal cord. That's about it.

[00:28:35] **Dr. GG deFiebre:** I mean, then that it really varies. People's experience with that too really varies. It's either sometimes you're given too much information over and sometimes they're like, oh, they don't even necessarily explain that it's inflammation in the spinal cord. You get the name of the disorder and you're like, good luck, which is not.

[00:28:58] **Julie Barry:** This is what you have. Go on, go on with your life.

[00:29:01] **Dr. GG deFiebre:** Then you go home, and you look it up and you're like, wait, what? So, there's definitely work there that needs to be done in terms of what medical professionals do with those who are newly diagnosed and how they present this information to people too.

[00:29:20] **Julie Barry:** I think though that, like, Dr. Greenberg and the doctors, I actually think they're helping, because it seems to me it's out there more than it was when I first got it, 15 years ago. It seems like it's becoming more and more known, which is good because doctors really need to know more about it.

[00:29:41] **Megan McCartney:** I almost feel like there's more knowledge in the past five years because I'm a new neurologist, last neurologist moved and he knows, I feel like a lot more in terms of, like, because he was just, like, rambling about all this stuff and I was just like, how do you know this? Because I don't feel like my last neurologist knew as much he had to consult once I was getting steroids and stuff. So, I think maybe even in the past five years and he's younger, so maybe, like, medical schools going over things more.

[00:30:06] **Julie Barry:** Or learning. Maybe it's out there more.

[00:30:10] **Dr. GG deFiebre:** Yeah. I think as also we're learning about the other or immune disorders, like MOG antibody disease and NMO, I mean, there's just so much from when - at the time TMA started in 1994, I mean, there was nothing available and so just thinking about that versus now.

[00:30:34] **Julie Barry:** Even my 15 years, because that was like over 25 years ago that the TMA started. Can you imagine not having any information? That's scary.

[00:30:51] **Dr. GG deFiebre:** And the Internet was obviously in the very early days.

[00:30:57] **Julie Barry:** Those things. So, you could Google it just like boom.

[00:31:00] **Dr. GG deFiebre:** Julie, I don't know if you know Google was -

[00:31:02] **Julie Barry:** Is around? No. I don't think so.

[00:31:04] **Dr. GG deFiebre:** I know. Logging onto AOL and I was seeing what's there. So, we did get a question to the Q&A and just asking if you go back and say a few words about IV and oral steroid treatment for people with TM and can maybe what treatments you did get. I mean, Megan, you're a medical professional, but not a neurologist. But I guess talk a little bit about what treatments you got when you were first diagnosed. Megan, do you want to start?

[00:31:42] **Megan McCartney:** Yeah. So, I got five days of IV steroids. I'm not exactly sure what the dose was, but I think it was the max or whatever they recommended, and they didn't really tell me the side effects going into it, but like, I had trouble sleeping and then I unfortunately didn't get like a taper dose. So, I went from like,

having five. I know I think about it now, I'm like, that's not cool. But I went to like an insane amount of steroids over five days. And then once I was discharged, I didn't have anything. So, I didn't have any oral steroids. So, I almost felt worse when I came home because I think I was like, almost going through a withdrawal of the steroids I was on. But in addition to steroids, I was also on other medications. I was on baclofen. I was on oxybutynin. I'm not sure if I'm saying that right which is like a bladder medication I was on and then I was on some pain medication as well. So, those are the treatments I had first and then I went into like physical therapy and things like that. I'm not sure if the IV steroids worked or not because I don't know. I can't compare it to if I would have gotten it or not, but I definitely wanted to try it just because that was what was recommended.

[00:32:52] **Julie Barry:** I can tell you they work wonders for me, not for everybody. But when I was first diagnosed, I was paralyzed from my waist down and within the first, oh, I want to say six hours I was able to start moving once they started the IV steroids, because I had so much inflammation in my spinal cord that was keeping the nurse from communicating and that's why I couldn't move. So, I wasn't completely paralyzed. So, as soon as those IV steroids started kicking in and I think I was on the fifth day, they must have a set thing that they give you of IV steroids. And then I went to occupational and physical therapy after that. So, definitely helped me.

[00:33:48] **Dr. GG deFiebre:** For the night I was diagnosed, I got IV steroids and I got them for a couple of days. I was diagnosed pretty - I don't know if it's because like, I couldn't move at all. And I don't know if it helps when you're - I don't know, but they immediately -

[00:34:07] **Julie Barry:** It's different, that's for sure.

[00:34:09] **Dr. GG deFiebre:** Yeah. So, I was definitely lucky in that. I got steroids that night. I got IV steroids for five days and then I didn't experience any recovery from it again. Not saying that they didn't help. As Megan said, it's so hard to make these individual. When we look at bigger groups of people, IV steroids, do seem to help and then you typically do a taper with steroids, decrease the dose over time rather than - because the IV steroids are pretty high dose of steroids. So, you slowly reduce the dose over time. And I also did receive plasma exchange as well. I don't remember if it was five or six. I think I did it every other day where I had to get a port put in my neck and it filters your blood. And so again, I don't know if that helped, but I'm glad we did all the things that we could do at the time to treat transverse myelitis.

[00:35:18] I also got - until this test came back, I got antibiotics and anti-antivirals as well just to rule out any of those issues. So, these are the treatments that are commonly done. People sometimes also get IVIG as well. And so, it's something that if this particular person should really speak with their doctor about and come up with a plan that they're both comfortable, comfortable with moving forward. So, thank you for sharing a bit about your treatments there. And then I have this non-transverse myelitis-related question, which is, what's one thing you're looking forward to in your life this year?

[00:36:06] **Julie Barry:** I don't know.

[00:36:12] **Dr. GG deFiebre:** I know. Let's see.

[00:36:14] **Julie Barry:** 36:14

It's a deep question. Go ahead, Megan.

[00:36:16] **Megan McCartney:** One thing for me, I'm looking forward to like traveling I'm hoping to travel this summer. I'm not sure where I haven't really figured it out yet, but that's something I look forward to, is traveling.

[00:36:28] **Julie Barry:** So, I think that's going to be mine too. I have a girlfriend that just moved to the coast. So, she's in Washington State and she's right on the coast there. So, I'm looking forward to going to her new house, so I'd have to say travel too. Definitely one of the things I'm looking forward to

[00:36:47] **Dr. GG deFiebre:** Very nice. This is not exciting at all, but I am very much looking forward to just taking some time to relax and chill out because it's been - I was in school for like almost my entire life and I have had some time now, hopefully this summer just to take a breath there or just -- so good to do that as well. I like traveling too. But that's what I'm looking forward to in the next few weeks and months. So, I'm trying to prioritize and do that more. Any other final thoughts or anything you want to share with the folks watching? I leave it open to both of you.

[00:37:45] **Julie Barry:** I'd have to say just don't ever give up and always try new things. I mean, I'm still trying new things all the time, especially with pain, because I have a lot of pain in my back. So, I'm constantly trying new, different pain medicines or do different things like acupuncture. Just try different things. Don't ever give up on anything.

[00:38:18] **Dr. GG deFiebre:** Megan?

[00:38:22] **Megan McCartney:** I agree. Just for me, I think when I was first diagnosed, I was looking almost too forward in the future. Just taking a day by day trying to just not worry too much about the future and just taking it day by day, I think this has helped me like live in the present more. So, I mean, there's some benefits almost to being diagnosed with something like this too, because it's just like it helps you be grateful for what you do have and be present. So, I know it takes a while to get there. So, don't give up, just keep going and take it day by day.

[00:38:59] **Dr. GG deFiebre:** And that's just feel like there's no end point to taking it day by day. It's a continue for me at least continuing to try to do that every day and all of that. So, if thank you both so much for sharing and being open about sharing about your experiences. I just want to tell for those listening, if you want to be part of conversations with others in the community like this, you can consider attending a support group meeting or being matched with a peer connect leader. So, that's someone that you can chat with one-on-one. If this is a bigger support group meeting setting, doesn't feel right for what you're looking for. So, those are two really good options. And then also there's a lot going on today in terms of the event, but after this, I just head over to the expo area to view a talk on identifying relapses versus a temporary worsening of symptoms. So, thank you again, so much. This was wonderful.

[00:40:10] **Julie Barry:** Thank you for having us.

[00:40:12] **Megan McCartney:** Thank you. I appreciate it.