

A conversation on disability and rare neuroimmune disorders

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[00:00:05] **Dr. GG deFiebre:** Thank you all so much. Let me just pull up some questions. So, I'm excited today to talk about disability and rare neuroimmune disorders. So, I'll just give a brief overview of the conversations we've had so far about disability and rare neuroimmune disorder. So last year at the RNDS, we had a panel on adapting to and embracing disability where people described their personal experiences with their rare neuroimmune disorder and how it relates to them with disability. And so, we discussed ideas about calling a disabled person inspiring and the ways we've adapted and how our experience with medical professionals has impacted the way we relate to the identity of being disabled.

[00:00:54] And then earlier this year, we had some great conversations with Cyrena who's going to be joining in a second about disability and rare neuroimmune disorders. We have some podcasts available on our website that have more information about that. And just to introduce myself as well, I'm GG DeFiebre. I'm the director of research and programs at SRNA and was diagnosed with transverse myelitis in 2009. And use a wheelchair to get around and have definitely adapted to and my experience with disability has changed over time. So yeah, we got Cyrena here.

[00:01:38] **Dr. Cyrena Gawuga:** Hi.

[00:01:39] **Dr. GG deFiebre:** Hello.

[00:01:40] **Dr. Cyrena Gawuga:** Hi. So, it says it prefers Chrome, but I'm using Safari, so got to break the rules here.

[00:01:49] **Dr. GG deFiebre:** No problem. So, I know we're waiting for one other person to join the panel, but I will let Aidan in once he's able to join. So, I just kind of - Cyrena, I gave a brief introduction, the conversations we've had at the symposium and then through our podcasts. So, I'm going to ask each of you to just introduce yourself, share your diagnosis and how you are connected to SRNA. So, I'm going to start with Maria. Oh, Maria might be frozen. So, in that case, I'm going to start with Leah if you don't mind going.

[00:02:30] **Leah Campbell:** Okay. So, thanks to the SRNA and you GG for asking me to be here. My name is Leah Campbell. I am the disability accessibility liaison with the patient advocacy council at the Guthy-Jackson

Charitable Foundation, a rare disease and disability advocate. And I have aquaporin-4 positive NMOSD. I was diagnosed May 31st, 2006, after 17 years and one week exactly. And my connection to the SRNA is as a peer connect leader and a co-group leader for Oklahoma.

[00:03:17] **Dr. GG deFiebre:** Wonderful. Thank you so much, Leah for introducing yourself. Cyrena, do you mind introducing yourself next?

[00:03:22] **Dr. Cyrena Gawuga:** Yeah, sure. So, my name is Cyrena Gawuga. I am connected to SRNA as a peer connect leader. I spoke at last year's in-person RNDS, and I did a couple podcasts with GG about disability and rare neuroimmune disorders. In my daily life, I am director of research for a nonprofit foundation and my diagnosis is transverse myelitis. I've had a couple episodes and next year will be 10 years since my first episode.

[00:04:09] **Dr. GG deFiebre:** And so, I know Maria, I think will be back as well. She just dropped off, so I don't know if there's some connectivity issues as we're all used to with computers now at this point. And I see Aidan joining. So let me add Aidan really quick. Let's just give Aidan one second to join. Hi, Aidan. Aidan, can you hear us, okay? Maybe not. I will put in the chat here. So, I guess once Aidan is able to connect and hear us, we'll ask Aidan to introduce himself. So, for now, I guess Cyrena do you mind just talking about when you were newly diagnosed or before diagnosis? Did you consider yourself disabled? Do you identify as a disabled person now or a person with a disability? You're muted, Cyrena.

[00:05:35] **Dr. Cyrena Gawuga:** Wow. It's been three years and I still do that. So, before my diagnosis I actually did consider myself disabled, in the more expansive sense because I had a couple of chronic illnesses. One of which is lupus, which led to my TM. I still consider myself disabled. I do have a residual mobility issue and I use a cane to help myself around. So, which is the outward manifestation of my TM related disability. I do have other disabilities associated with it which again aren't as obvious like neuropathy, but they do affect my daily life. And so yeah, I consider those disabilities as well.

[00:06:33] **Dr. GG deFiebre:** And then Leah, what about you? When you think about when you were newly diagnosed or before diagnosis, did you consider yourself disabled? Or do you today identify as a disabled person?

[00:06:51] **Leah Campbell:** I will say before my symptoms began in 1989, no, I did not consider myself a disabled person. I was a healthy active child and had no other problems. Now the time in that 17 years, yes, I did consider myself disabled because about 14-16 months after my symptoms began, I was totally blind. So, I did consider it there. And then in 2001, I had the paralysis and TM attack. So, I also considered that a disability and invisibly, I lost the sensation of touch. So definitely consider myself a person with a disability for sure now.

[00:07:42] **Dr. GG deFiebre:** Thank you. And then Maria, I think you froze there for a little bit. So, I'll just going to ask you both questions we've talked about so far, which is if you could just introduce yourself, share your diagnosis and how you're connected with SRNA. And then also talking about your experiences with a disability when you were newly diagnosed before diagnosis or/and now.

[00:08:08] **Maria Cerio:** Absolutely, and apologies for the connection issues. So, my name is Maria, and I am a young adult community member of the Siegel Rare Neuroimmune Association, and I was diagnosed with transverse myelitis back in 2001. At the age of three, I was originally paralyzed from the neck down. So, at the C 2 level.

[00:08:36] **Dr. GG deFiebre:** Oh, looks like we may have lost Maria there for a second as well. That's okay. Aidan, are you able to hear us now?

[00:08:49] **Aidan Morse:** I can, yeah. Can you hear me?

[00:08:53] **Dr. GG deFiebre:** Yes, we can. So, I guess until Maria gets back, if you don't mind just introducing yourself, sharing your diagnosis and how you're connected to SRNA.

[00:09:08] **Aidan Morse:** Sure. So, my name is Aidan Morse. I connected with SRNA, I'm the young adult volunteer, peer support group leader. That's a mouthful. But basically, I volunteered to get a young adult support group off the ground. I was diagnosed with transverse myelitis in 2010. I was a freshman in high school, originally paralyzed from the waist down. At this point, I have some mobility issues. I have foot drop on one side and some bladder bowel, sexual dysfunction, and some sensory issues too. So did I get everything on the intra?

[00:10:00] **Dr. GG deFiebre:** Yeah. That's perfect. And then just thinking about when you were newly diagnosed or before your diagnosis, did you consider yourself disabled? Do you just identify as a disabled person today?

[00:10:11] **Aidan Morse:** It took me a long time to identify as being disabled. I did a lot of just shoving that part of my identity down and trying to pass as able bodied. So, if I wear long pants, you can't see my mobility aid. So, it was easy for me to try to pass for a long time and just not embrace that part of my identity. So, before my diagnosis, no I didn't, diagnosis disabled. The last few years I've been trying to wear that on my sleeve a little bit more.

[00:10:48] **Dr. GG deFiebre:** And Maria I see you're back now. So, I just wanted to - I don't know exactly where it cut off on your end but didn't know if you wanted to add anything about your experience of disability over time from newly diagnosed to before diagnosis to now.

[00:11:04] **Maria Cerio:** Yes, definitely. And thanks everyone for your patience, take two at this. So, on my end [audio cut] at mention that I was paralyzed from the neck down originally. So, my arms and legs were impacted. I have since regained the ability to walk although there's still a lot of challenges associated with that. And even with my mobility aids, I do still have a very unique gait. I use a wheelchair on an as needed basis as well as forearm crutches. And I go way back with the SRNA and for me personally, I do really strongly identify proudly as an individual with a disability. And I think a large part of that is because my years as an individual with a rare disease and disability very much outnumber my years as an able-bodied person since I was diagnosed so young and that's really what I know these days.

[00:12:12] And I don't think I really started using that word though until I got to college because I grew up in a small town. So, everyone knew my story. They had heard it from friends or family. I very rarely had to explain myself, but once I arrived on my college campus, everyone was new, and I definitely got a lot of questions and things like that. So that was my easy one-word explanation and when someone would ask, what's wrong, and all that and I was able to find a really strong community in college. And now I'm postgrad, three years out of college. So, I'm faced again with trying to find community, I think college, there's very naturally, so many different pockets. And there was a large, rare disease and disability presence on campus, part of which I helped create to foster community. So now I proudly connect with that identity since it's really all I know.

[00:13:20] **Dr. GG deFiebre:** Thank you. And so how have your relationships been affected related to your disability? So, this can be friends, family, significant others, the random person on the street. And how do you describe your disability or access needs in different situations? Leah, do you mind starting?

[00:13:43] **Leah Campbell:** You definitely find out who your true friends are going through the disability and those that weren't really true friends weren't around after getting paralyzed. For me, family and things adapted. They learned to let me set the bar on where we go from here, what I can handle. A significant other for me, I was married at the time, but he couldn't deal with it, didn't want to, whatever. He was abusive before that, but he did not stick around, and we ended up getting divorced. So, you sometimes see the negative in people. But my true friends, my family are there to support me and help me with my independence and doing what I can.

[00:14:49] **Dr. GG deFiebre:** Definitely. Cyrena, what about you? You're muted, Cyrena.

[00:14:58] **Dr. Cyrena Gawuga:** One day I'll figure this out. So, when I was first diagnosed with TM, I was actually in grad school and this was back when - and it makes me feel old now, but this was back when there basically was no strong disability identity in society at large, but especially in the higher education setting. And so, it was challenging. Let's put it this way. Again, much like Leah said, you find out who values you as a person when your life becomes - the challenges go beyond just, oh, my research is really hard today too. I'm going to be in the hospital for four weeks plus.

[00:15:58] In terms of my personal relationships, I've always kept a small network of very close friends and they were all people who stepped up when I needed assistance. And I know that's not something that everyone has opportunity to experience in their lives. But I think, because I've always been someone who tries to keep my network small and people that I really almost feel that are my family, I think my chosen family really showed up. I am married. And I think in some ways it made our relationship stronger in the sense that I was forced to recognize that I was disabled, and I was disabled -- I have lupus and I basically spent my whole life trying to pretend I didn't have it.

[00:17:05] And this was the first time it was -- yes, this is a very serious manifestation of your illness and perhaps you need to slow down, and this is something she's been telling you for the longest time. And so, I think that I was finally able to stop and say, okay, I need you and to have someone who was there to hold me up. But I think probably the most difficult space and I think many people can relate to this was more the working world where it's really this whole capitalist idea, you're either productive or you're not productive and if you're not productive, get out of the way. So that has been the toughest area of relationships for me has been the work world, which is important, unfortunately.

[00:18:04] **Dr. GG deFiebre:** Yeah, definitely. What about you, Aidan?

[00:18:08] **Aidan Morse:** Yes. Thank you, Leah and Cyrena for sharing a lot of that. Definitely resonates with me. For me when I was first diagnosed, I was still living with my parents, so I had a good support system but then with my family and, some friends early on. And I guess I was never super open about my disability mostly I think because just opened up the door for reliving a lot of medical trauma that I experienced early on in the hospital and in rehab. And it really wasn't until the last - I entered a relationship about 5.5 years ago and I've really had to reckon with a lot of the aftereffects of my disability and that, still with my girlfriend after 5.5 years and through being in that more serious relationship, I've had to deal a lot more with the mental health effects of being disabled.

[00:19:26] And have had to - I thought of it as I guess coming clean about a lot of my symptoms, it felt like something that I had to hide for a long time and what Cyrena says I really had to let someone else hold that which is super difficult especially because telling people about my disability meant I had to be very vulnerable, which can be hard especially as someone that's socialized as a man. So, I think opening up more about my disability and sharing that part of my identity has been really healing for me. It's allowed me to revisit some

of those early experiences and reprocess them to be less dramatic. And also, I don't think I'd show up for my friends and family and loved ones the same way if I wasn't disabled. So, I think it opens up the door for a lot of relationships in that way.

[00:20:30] **Dr. GG deFiebre:** Thank you. And Maria, what about you?

[00:20:35] **Maria Cerio:** So, for me, there's definitely no separating transverse myelitis and my disability from relationships. Even if I'm walking with no mobility devices or I am using braces, which I haven't in a while, but something that's not visual. If it's under your clothing, there's still no hiding how I walk and then in addition to that, there's all of the unseen lasting impacts of transverse myelitis. So, it's definitely my built-in character test and I very quickly figure out if someone is going to accept me and if it's a person, I'd want to surround myself with, I'm really grateful to my family who's been very supportive and similarly, it's all they know. I'm the middle child. So, we all grew up going to doctor's appointments and PT and OT and all that together.

[00:21:37] And then in more my adult years, I found that it only does myself a favor and protects myself if I'm meeting someone new to do my elevator pitch of my disability that my gait might look different that we might need to take an Uber somewhere instead of drive or something like that. That's how I protect myself before going in new cases so that I'm not met with questions or in consideration for things of that nature. I am in a relationship with my boyfriend who's very supportive, but dating with a disability is very unique and there's a lot of missteps along the way, especially in the era of online dating apps and things like that where in pictures, it may be not clear at all that you have mobility challenges or health needs.

[00:22:34] So there's been a lot of crafting messages with my family about how am I going to explain this to an employer, to this person I'm going on a date with? But I've learned it's in my best interest to be open about it. And yeah, sometimes it means getting closer to people sooner than you'd like. But that's how you find out who the real ones are.

[00:23:04] **Dr. GG deFiebre:** Thank you, all. And I feel like you've all talked about adapting or ways you've adapted a little bit here and there. But I just wanted to ask, specifically what are some of the ways you've adapted and what has made adapting to or living with a disability difficult? I'll start with Cyrena.

[00:22:28] **Dr. Cyrena Gawuga:** Yeah, sure. I think probably the most obvious adaptation that I've made is that I walked with a cane. I don't always need it, but I have a significant foot drop because my injury was at CAT 1 and despite, on and off for a number of years, the foot drop has stuck with me. And so, I do also have a somewhat unusual gait, but it's not obvious if I use a cane. And because of the foot drop and I live in New England, so we have very uneven sidewalks and so I will trip every other block, but if I have the cane, it's not so obvious. And I've found that people often don't notice the cane initially. And so that's the adaptation that I've made is not so much to hide my disability from people because it is a part of my being. But it increases my mobility, it makes my life easier. It keeps me from face planting.

[00:24:38] The other adaptation that I've made that was really challenging in the beginning is learning to accept Gabapentin as a part of my life. I have severe neuropathy from chest level down and I can't live my life without it. I'm at the maximum dose possible, unfortunately, but I can't think of how my life would be without it. And it's not ideal and it's not something that is the best choice for everyone, but that's what I need to function. And I didn't want to do it initially because I thought I don't need another medication. But I'm glad I did because my life is definitely much easier to get through bumping into things and it would be without it.

[00:25:37] **Dr. GG deFiebre:** Definitely, yeah. What about you, Aidan?

[00:25:39] **Leah Campbell:** For me, my adaptation changed once I got paralyzed at two months and three days after college. So, before that, just being blind pretty much and dealing with fatigue, it was a screen reader. It was being able to use a keyboard, being able to use Braille labeling and conserving energy, I might use a wheelchair if I was going to an amusement park and having to stand in lines and that way, I could do more things. Post paralysis, I still have to conserve the energy and things, but adapting means planning things out. It's not like, oh let's go take a road trip. No, I got to plan out everything from lift assistance to wheelchair, everything on the airlines and wheelchair accessible transportation. So definitely requires a lot more planning.

[00:26:39] **Dr. GG deFiebre:** Definitely, yeah. What's your experience been like Aidan?

[00:26:45] **Aidan Morse:** I guess committing to using my AFO all the time for my foot drop. I used to try to get around a little bit without it and I would walk slow, or my limp would be worse or would just get tired. So, I feel like my biggest adaptation is just admitting that I need more help and being more compassionate to myself. So that admitting I need more help includes the mobility aid, includes taking my medication when I'm supposed to and taking the medication I'm actually prescribed and not like, oh, do I really need this when? Yeah, pretty much everything I take I really do need.

[00:27:34] And then also as far as compassion goes just when my symptoms get worse because they ebb and flow, especially with the bladder function, if I'm having a bad day just making time to go to the bathroom as often as I have to instead of beating myself for - instead of beating myself up for not being able to hold it longer than 30 or 40 minutes. So, for me, that was the big two is admitting to myself and other people that I need help and also when my symptoms flare up or just in general, letting myself down easier.

[00:28:14] **Dr. GG deFiebre:** Thank you. And Maria, what has your experience been like?

[00:28:21] **Maria Cerio:** So, for me, I think the most helpful are some of the obvious, like a handicap parking pass, things like that. And although obvious I went literally 17 years; I think before I got my own pass. And it's interesting to think about what adaptations you need when you become an adult. So, when you're younger and you're a kid with a disability, maybe your friends and family are dropping you off at the door and it didn't even dawn on anyone that maybe we would need a special parking pass. And then when I became independent and was taking myself places that was finally something that I explored and I know there's a double-edged sword but in claiming that identity as someone with a disability, it has opened the door to so many adaptations. So, I find that being a part of that community and using that word sometimes allows me access to ask for things like handicap parking or assistance when boarding a plane and accommodations in the academic spaces or workplaces.

[00:29:31] And it was hard to ask for those accommodations without describing myself as someone with a disability. So, there's definitely pros and cons to that. But I echo what everyone here has said, definitely conserving my energy and whether that be parking somewhere close or driving somewhere instead of walking and really picking and choosing what I commit to, to make sure that I do have energy at the end of the day for those mandatory tasks. I need to make myself dinner, I need to shower and sometimes if I over commit, I don't have energy for those activities of daily living. So really trying to get creative about how to make other areas of my life more accessible, whether it be asking for help or putting some of those more official accommodations in place, so to speak.

[00:30:32] **Dr. GG deFiebre:** Thank you all for sharing. And I'm just going to ask one more question since we are actually past our time. But I just want to get all of your takes on this if you have the time. What advice

would you have for a newly disabled person about claiming that identity or that process of doing that? Maria, I'd like to start with you because I think you were diagnosed at the youngest age, and so maybe your perspective on that as someone who's diagnosed so young.

[00:31:05] **Maria Cerio:** So, I definitely felt liberated once I started identifying with that identity. I went to public school my whole life and there were three people with physical disabilities, and our school is so small, so we all knew each other. And that felt so isolating so to be in larger spaces or even a part of something like today's event has felt very empowering and I know those words are sometimes cheesy or fall into the same category of inspiring, which has mixed feelings around it. But I have found different ways to express myself such as writing for the SRNA blog or different things like that to really explain also what that means to me because everyone who identifies as having a disability, it is so different, even if you share the same diagnosis, it could manifest itself very differently.

[00:32:12] And so even within the disability community, sometimes I find it hard to find someone that I relate with to a tee but instead of focusing on how it's all different, I guess focusing on the similarities. And when you think about it, the outside world sees us all the same as people with disabilities. So, within those shared spaces, I guess I try and focus on the similarities rather than the differences. For instance, at college there was a community but it's not like it was a community of people with TM or rare neuroimmune diseases. So, I'm still finding ways to relate, and it feels less isolating the sooner I accepted that identity.

[00:33:03] **Dr. GG deFiebre:** Yeah, for sure. I've experienced that too with other wheelchair users. It doesn't really matter the diagnosis, but as a wheelchair user myself, there's some similarities there. And then Leah, do you mind talking about what advice you would have for a newly disabled person about claiming that identity?

[00:33:23] **Leah Campbell:** Of course, having it as a child like when you're younger. The acceptance, I didn't have the independent stripped for me that adults do but my advice would be just the sooner you can accept it and learn how to deal with it and adapt from it, the sooner you can get to a new normal.

[00:33:48] **Dr. GG deFiebre:** Thank you. And then Aidan, what about you?

[00:33:55] **Aidan Morse:** Yeah, I think acceptance is really, really good advice. That's something I was thinking as well and same with finding a community, whether that's in person or virtually through this or support group. I also think for me just finding a therapist who is more well versed in disability, chronic illness, related work was really helpful and also just opening up to other people, I think about what your needs are. And I guess for me that's been helpful. I think also just consuming more media that is written by people with disabilities or features people with disabilities. I feel a lot by reading some memoirs about others, by authors with neurological conditions or listening to podcasts about disabilities. I think for me that's all good advice focusing on acceptance, finding community and take care of your mental health, I guess.

[00:35:13] **Dr. GG deFiebre:** Thank you. What about you, Cyrena?

[00:35:20] **Dr. Cyrena Gawuga:** I think that probably the first thing that I would say is that don't be afraid to take up space. However, you define that for yourself, I think that a lot of times whether you call yourself a person with a disability or you call yourself a disabled person, people feel compelled to hide their experiences, to hide who they are. I mean, we've been talking about ways we hide our mobility devices, and things like that. I would say also don't be afraid to affirmatively ask for help and sometimes asking for help can come from a position of power.

[00:36:03] I went to a conference once and it was a conference for patient advocates. And I was telling one of them like, oh my gosh, it's so hard to get around the airport. I'm so tired. So, basically almost missed plane sometimes. And she said, why haven't you ever asked for transport? And it's like, I didn't know that was something that I could do. I thought that was something for other people. And she said, no but it's there for us, ask for it.

[00:36:34] Same thing with a parking pass. It never occurred to me to ask for a parking pass until I told my doctor one day, in February, it's sheets of ice here in Rhode Island. I have trouble walking around and she said, I'm going to give you a pass. I'm like, I didn't realize it was for people like me. And I think that as much as you can affirmatively say this is something for me even if it doesn't feel like this should be for you, if it's a tool that helps you live your life, take it. I also really agree with the idea of getting therapy to whatever extent it is accessible for you, whether you can have an individual psychotherapist or you have to do group therapy or even just building an informal community in which you can share your life experiences.

[00:37:30] I had a therapist before my diagnosis because I have other mental and physical chronic illnesses, but it was of immeasurable value because I think we all do go through a significant amount of medical trauma with these diagnoses. I know I definitely did, and no one had ever told me that it could happen again. And having a therapist to process that with was of - I mean, definitely if you can find someone who has experience in working with chronic illnesses and I mean, I don't think we're going to find someone who's very specific in that place, but someone who just knows what it's like for a person to move through the world in a different way and how that affects their lives. And so, I know that mental health care is unfortunately not well distributed or easily accessible, but however you can deal with your mental health.

[00:38:41] I think that in our treatment settings, it's really under-discussed how much mental health impacts our daily lives as disabled people, but also how rare neuroimmune disorders can create mental health issues. And again, like I said, we don't talk about them enough and they're so important to our survival and recovery with these illnesses. So, I guess being able to take up space as a, again, this is a terminology thing, person with disabilities or disabled person to affirmatively ask for help and to try to take care again, like Aidan said, of your mental health to whatever degree that you can, I think is really important. I want to draw attention here too. There's a comment here from Corey Wolf about rarecounseling.com. I don't know if people could see this, but that sounds like a great idea, something that if you have access to or time to look at it, please do so. Thank you for the referral, Corey.

[00:40:00] **Dr. GG deFiebre:** Thank you Corey. And thank you Leah, Maria, Cyrena, and Aidan. I really appreciate you taking the time. If everyone can or some of you can head to the stage now, we will start streaming that next video. So, thank you all so much for taking the time. We really appreciate it at SRNA. So, thank you.

[00:40:19] **Maria Cerio:** Thanks everyone.

[00:40:21] **Leah Campbell:** Thank you, GG.

[00:40:21] **Dr. Cyrena Gawuga:** Thank you. Goodbye.

[00:40:22] **Aidan Morse:** Thank you for having us. Bye all.