

Disability and Rare Neuroimmune Disorders | Part 1

You can watch the video of this podcast at: youtu.be/6cv7gkuGMuE

[00:00:00] **Dr. GG deFiebre:** Hello and welcome to the SRNA "Ask the Expert" podcast series. This podcast is titled "Disability and Rare Neuroimmune Disorders." My name is GG deFiebre and I moderated this podcast with Dr. Cyrena Gawuga. SRNA is a non-profit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our web site at wearesrna.org. Our 2023 "Ask the Expert" podcast series is sponsored in part by Horizon Therapeutics, Alexion, AstraZeneca Rare Disease, and Genentech.

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[00:00:52] Alexion, AstraZeneca Rare Disease, is a global biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development, and commercialization of life-transforming therapeutic products. Their goal is to deliver medical breakthroughs where none currently exist, and they are committed to ensuring that patient perspective and community engagement is always at the forefront of their work.

[00:01:14] Founded more than 40 years ago, Genentech is a leading biotechnology company that discovers, develops, manufactures, and commercializes medicines to treat patients with serious and life-threatening medical conditions. The company, a member of the Roche Group has headquarters in South San Francisco, California. For additional information about the company, please visit gene.com.

[00:01:37] For this podcast, I was joined by Dr. Cyrena Gawuga. Dr. Cyrena Gawuga is Director of Research at the Preparedness and Treatment Equity Coalition. As Director of Research, Cyrena facilitates the design and implementation of the coalition's health and equities research grant programs that further the coalition's mission to increase the use of data metrics to reduce health inequity in the health care system. Before joining the Preparedness and Treatment Equity Coalition, Cyrena completed a PhD in Molecular Pharmacology and Physiology at Brown University focused on the influence of adverse childhood experiences on inflammation and health outcomes in adulthood.

[00:02:13] Subsequently, she earned an MSW in Macro Social Work at Boston University. She also was Research Associate on a PCORI funded, community based, participatory research program at Boston University School of Social Work. Cyrena has also participated in patient advocacy and outreach for many years, serving as advisory board member for a number of organizations including Patients Like Me and the Lupus Foundation of America. She is part of the inaugural class in the AcademyHealth/The OpED Project Public Voices Fellowship and was recently appointed to the AcademyHealth Diagnostic Equity Advising Group.

[00:02:46] Thank you so much for joining me today to talk about disability and rare neuroimmune disorders. I just wanted to start at disability 101. We're talking about what is a disability and how are medical conditions like rare neuroimmune disorders related to disability?

[00:03:11] **Dr. Cyrena Gawuga:** So, that's a really - I think it seems like a simple question. It's actually quite challenging. So, a disability, if you think about it like the typical standpoint or like the medical model of disability, it's a condition or health status that impairs the ability to function in the world. So, whether that's individual settings, like maybe it impairs your ability to function at work, function in your life, maybe interact with your children, whatever it may be, it's some condition that impairs your ability basically. So, how does that interact with medical conditions like rare immune disorders? Well, I think a lot of people know that there's a really wide range of conditions that can occur in the context of the rare immune disorders that can be visual loss, pain, particularly neuropathic pain, weakness. So, leg weakness, limb weakness, cognitive issues can happen. Mental health and mental illness can also be things that happen in the course of rare immune disorders.

[00:04:38] So, I think that what's interesting about rare immune disorder is because there's quite a number of them and each of them have different effects on the body, but they really create a broad array of potential disabilities. And so, each one of us has our own unique combination of disabilities and some people really come out of rare immune disorders without any perceived disabilities at all. So, I think that's how disability is related to chronic illness. Of course, as we may discuss later, part of it is a perception of whether or not you consider an effect of your rare immune disorder and a disability or not.

[00:05:31] **Dr. GG deFiebre:** Thank you. And as you said, someone might have a medical condition, but it doesn't necessarily mean they have a disability, but there's often that overlap there of medical conditions and disabilities that can occur. And we hear people talk about visible versus invisible disabilities or maybe having both of these types of disabilities. What are these and what are some examples of those for people with rare neuroimmune disorders?

[00:06:01] **Dr. Cyrena Gawuga:** So, visible disabilities are basically disabilities that in a lot of ways other people can see. I mean, that's how you think about that. So, if you have very obvious limb weakness where you might need a cane or you may even need a wheelchair, that's something that other people can see. If you have vision loss to the point of needing a cane or seeing eye doc or something like that, that's a disability that somebody can see. So, it's really things that can be seen, perceived not just by yourself but other people as well.

[00:06:44] And invisible disabilities on the other hand, are things that are hidden to the world. So, you may have vision loss that it still allows you to function to the level that other people may not notice they have vision loss, perhaps you have limb weakness that you work with. And so, you may make changes to your gait that are not obvious to other people that may be an invisible disability. Pain is something that is not perceived by other people. It's only perceived by ourselves internally. And that can be a very significant disability because it really affects very broadly the way that you interact with the world and your ability to get things done - to get the things that you want done or the things that need to be done.

[00:07:19] People may have migraines that are a significant disability that's invisible. It's really anything that can't be seen. And I think a lot of times with rare immune disorders, you can have both. So, in my situation, for example, I have neuropathic pain that can't be seen by anyone, but it really impacts the way that I interact with the world. I have balance issues that can't be seen by anyone that affects how I interact with the world. I also have limb weakness and a foot drop to the point that I use a cane, that's something that's visible to people. If I'm having a good day, I don't use the cane because I can move to the point that other people don't notice, then it becomes invisible.

[00:08:28] So, sometimes I think that these conditions can move from visible to invisible, visible to invisible. I mean, if you're looking at like optic neuritis or MOG disorder, you can see sometimes and perhaps when you're having an inflammatory phase, you may not be able to see so well. So, you're moving in between invisible and visible disabilities and so they can fluctuate and that can make it difficult for people to understand how to deal with their rare neuroimmune disorder. But that's where we can think of invisible things that people can't see and visible things that people can see.

[00:09:22] **Dr. GG deFiebre:** Thank you. That was a great explanation. So, you mentioned earlier about the medical model of disability, what are the different models of disability that we talk about? There's the medical model, the social model and how do they impact how we view disability in the world?

[00:09:42] **Dr. Cyrena Gawuga:** So, as succinctly as possible, the medical model is what I mentioned before, a condition or an illness or some sort of injury that makes it difficult to interact with the world or it impairs your perceived inability to interact with the world. So, basically, what it does is it in some way pushes the injury or the health condition ahead of you and makes that a significant part of how you function. And that's how the medical community interacts with us. It's like here is your failing. This is how it inhibits you; how can we maybe eliminate it, fix it, or cure it? And so, really the medical model focuses on the illness, the condition, the health status that impairs the person.

[00:10:49] On the other hand, again, as succinctly as possible, the social model of disability is in some ways the inverse of that. So, rather than saying you have a failing that needs to be accommodated or fixed, it says that the world is the problem, society is the problem. So, it's not that you have a condition or an illness or a health status that needs to be fixed or cured, but that society is structured in a way that makes it difficult or impossible for you to interact with the world with that health condition or status. So, rather than you being the problem, society is the problem basically.

[00:11:33] And so, it really - I think most people have the medical model in mind when they think of disability. And I think that even most people with rare neuroimmune disorders probably also have that model in mind because that's just the world that we live in, we internalize it. And so, it's difficult to see it from the other way, the social model that says that you are not the problem, society is the problem. And so, transportation difficulties, accommodation at work, being able to move through the world with a reduced vision and how society is not structured for that. And instead of you saying I have a problem, I am the problem, you can say, well, why is it difficult for me to navigate the world? Why are there not adaptations in the world that make it easier to function?

[00:12:48] I can think of, for example, when I went to Japan quite a few years ago and I was at a crosswalk and I'm sure a lot of people are familiar with crosswalks in the US, like you basically had to run across the street. I was at a crosswalk, and it actually was like 120 seconds, which is way longer than here. And there was a loud beeping sound and that was to tell people that it was safe to cross. And so, it's the thing that helps not only people who have hearing issues, but it also helps people who don't because now they're aware, oh, it's time to cross and this is how long it's safe to cross.

[00:13:38] And so, the thing is too, that as an extension of the social model of disability is that adaptations and changes that are made to the world that make it easier for disabled people to live their lives, actually make the world better for people who are not disabled as well. So, those are the two ways of looking at disability, the two different models. And I think it's very - I think like many other types of marginalization and oppression, we've internalized the medical model and some of it is like breaking out and seeing how we can think about it differently.

[00:14:22] **Dr. GG deFiebre:** And your point about how when we use the social model and then change the environment so that it isn't disabling to people anymore, it does help everyone like thinking about curb cuts, for example, on sidewalks where that helps people with mobility disabilities with a wheelchair or walkers, but it also helps people with strollers or have a cart or just those things that - and then the environment becomes less disabling to those folks as well.

[00:14:55] **Dr. Cyrena Gawuga:** Yeah, absolutely.

[00:14:56] **Dr. GG deFiebre:** And so, when thinking about the medical model of disability, in my experience is someone who has worked with medical professionals. I am not a medical professional, but it seems that the medical model of disability is what is maybe taught in medical schools or in medical training. So, do you mind just talking about some of the issues that come with the medical model of disability?

[00:15:26] **Dr. Cyrena Gawuga:** Sure, I think that to a large extent disability is not really explicitly taught at all in medical school. So, that's one of the major problems is that people are in very many ways seen by their disorders rather than seen as people who are experiencing disorders. I think that the idea of accommodation is really pathologize. And so, instead of accommodation for, say a particular worker being thought of as a benefit to the company at large because if we provide accommodations for this particular worker, they could be more productive. Of course, that's a capitalist idea, but they'll be more productive, and they'll produce more - that they'll produce more value for the company instead as seen as a cost and it's seen as a burden, and it's seen - and one of the biggest problems for me as well is it's seen as a potential legal liability.

[00:16:38] So, the ADA is not seen as a positive by a lot of companies. It's seen as a negative. It's seen as like, "Oh, this disabled person could cause us legal problems. So, let's do as little as possible." And in a lot of ways too, asking for accommodations in the context of the medical model forces the person to disclose their disability, which of course, again reinforces this medical model and now this person is their disability, not a person who is dealing with this particular medical condition or other type of health condition.

[00:17:27] And I think the other problem too, with the medical model and as we just mentioned before about health care professionals is that they don't know any other model of disability. So, the idea that they have is how do we - the ultimate thing of course, is curing, how do we treat this? How do we make this go away? How do we become more comfortable dealing with this particular person? And it's not to say that seeking treatment or seeking a cure is inherently bad, it's more the reason why it's being done. And I think it's a lot of times to try to make the person to fit back in. I mean, again, like I said, we've all internalized this to a large extent. But I think that that's ultimately the problem is not recognizing the fact that this disability is now a part of the person, but thinking of it as something outside of the person that needs to be treated, cured, eliminated.

[00:18:45] **Dr. GG deFiebre:** Yes, definitely. And how have views of disability changed over time?

[00:18:52] **Dr. Cyrena Gawuga:** Oh, wow. So, it's very interesting. I was just listening to a podcast about mental illness treatment, like in the 1800s and it was brutal and just appalling because people who now would receive some effective treatment on the whole were just tossed away into asylums and that was the end of - they would die in asylums. That's the end of their life. So, if you were 19 and you were experiencing voices and visions, they'd just toss you away. That was the thought process for centuries that throughout, perhaps the beginning of human civilization as it were that people with disabilities were broken, people with disabilities were tossed aside. I mean, sometimes they would - if there was a baby who was born with a disability, they would just leave them to die. I think that's what the Spartans did. You would just leave them on a cliff to die.

[00:20:03] So, if you had some disability you were transgressing against the natural order. A fair number of the people who were killed as witches had disabilities of some sort. And rather than that being seen as just another presentation of humankind, it was something that again had to be eliminated except the way that they eliminated, it was killing people. So, I think it's very recent, I mean, extremely recent within the past 50 years or so that disability has not been seen as - and it this abject failure or horror that needs to be hidden. We have a long way to go. But that's where it's been for centuries, thousands of years in general, people with disabilities were broken in some way and if they could not be fixed, they had to be tossed away.

[00:21:17] **Dr. GG deFiebre:** And I don't think people realize, I know the Americans with Disabilities Act obviously doesn't solve all of our problems at all. But it did a lot in terms of helping give access to people, to things that they weren't able to access before. But in terms of how recent that was, it was 1990, I think sometimes people forget how recent even that landmark legislation was.

[00:21:50] **Dr. Cyrena Gawuga:** Yeah, absolutely. And even at the time it was still controversial that, oh, gosh, now we're going to have to accommodate all of these, like broken people. How are we going to do that? But, yeah, it's really recent that people with disabilities have been seen as part of society.

[00:22:16] **Dr. GG deFiebre:** And so, is disability a negative word? What about euphemisms, like, differently abled or handicapable is another one I have heard?

[00:22:27] **Dr. Cyrena Gawuga:** I've heard those too. I think they're terrible. I think they are euphemisms that are generated and created by non-disabled people. It makes them feel - I think it makes them feel better. I think it makes them, again, feel as if these are people rather than this idea of again, like we said, disabled people being tossed away. But now if we call them handicapable, there are people now that can do things. Differently abled, it's ridiculous. What does that mean? I don't know what that means. It's like, well, this is normal abled and you're different and it still again separates people from the rest of society. You are different rather than just existing.

[00:23:21] And I think a lot of people think of disabled as a negative word because most of us are floating around in the medical model of disability. So, if you have a disability, something's wrong with you, something is bad, and we need to find a way to mitigate that. I don't think of disabled as a negative word. I think it's just a descriptor. I think it's a descriptor. I think it's something that is increasingly reclaimed much like other previously negative descriptors have been reclaimed by marginalized groups and it just is what it is. I don't think that we need to obscure it. Like I just don't find any benefit in using words that are euphemisms that obscure the reality of the situations that we're in.

[00:24:19] It doesn't mean they're bad situations. Perhaps someone thinks of it as bad. That is their right. But it's merely a descriptor and if we go to the extent of it being an identity, I think that's a different question. But I don't think we need a euphemism. I just don't - I don't like euphemisms. I think we should say things the way that they are. If you're disabled, it just is what it is. It doesn't mean you're - I think euphemisms make other people feel better.

[00:24:54] **Dr. GG deFiebre:** Yeah, I would agree. I think there's been a push within the disability community to actually say the word and not dance around it and pretending that - because I think for people who are not disabled, it makes them uncomfortable because they perceive it as this negative thing. And so, when you separate that value judgment of this is a negative bad thing from the word, it doesn't become this scary word that you're not allowed to say. So, just saying it, I think there's been this push to just say it and not use

these euphemisms to describe something that's, as you said just a descriptor and people's identity too and part of their identity.

[00:25:45] **Dr. Cyrena Gawuga:** I just have one funny anecdote about this, I was at a talk, and I had my cane and sometimes the cane gets in the way when there's a lot of people. I was making a joke with my wife. I'm like, oh, okay we're going to go back to our cripple spot. I have a handicap - I have a handicap sticker. And I was like, okay we're going to go back to the cripple spot and this woman overheard me and she's like, "oh, no, you're not a cripple, you're not disabled." And I was like, okay I mean, not everyone agrees with the word crippled. It's like a lot of other words. But like, yes, I use that as a joke, but the reality is that I am disabled. I have a cane, I have limb weakness, but I don't need you to tell me what I am and what I'm not. And I think, again, that's not necessarily a word that everyone accepts, but I think I can use it sometimes, but I don't want other people commenting on it. So, I think disabled is the same way. It just is what it is.

[00:26:59] **Dr. GG deFiebre:** Yeah, definitely. And so, in talking about language, there's conversations around person first versus identity first language. Do you mind talking about what each of those mean? And then is one preferred over the other?

[00:27:15] **Dr. Cyrena Gawuga:** Yeah. So, I mean, if we say, really generally person first would be like people with disabilities, identity first would be disabled people. And is one preferred over the other? I think it depends on the person. I think it depends on how they view their disability. And I'm not one to say to someone, no, that's inappropriate. You shouldn't use language like that. I prefer identity first. I don't see anything wrong with being thought of as a disabled person. But if someone else feels as if this disability perhaps, they may say, oh my disability doesn't define me or my disability is just something I'm living with. And so, I don't want that to be how I refer to myself and they choose person with a disability. I will accept that.

[00:28:28] I think that more generally disabled. So, let's say identity first. So, disabled people create more of a kinship that is necessary to advocate for ourselves within society. I think that one of the difficulties with disability rights and disability justices, we have so many other identities, we have so many like health conditions, illnesses, injuries that lead to disability. And so, it creates a tent if you will, under which many different people can collect and start to recognize that we have very similar issues. And this is who we are. We are disabled people. I think like we are people with disabilities, it like shunts these disabilities to the side and makes it difficult to band together to advocate for each other.

[00:29:48] **Dr. GG deFiebre:** I typically I respect whatever the person I'm referring to wants. That's generally a good rule I would say overall in terms of language, but sometimes I use them interchangeably, I think I lean more towards identity first language. So, I say disabled people more but sometimes in sentences, it just sounds better to say people with it. So, I find myself saying that just depending on the like structure of the sentence and how that works.

[00:30:15] **Dr. Cyrena Gawuga:** I know, I totally agree. I mean, there are some contexts in which people with disabilities just flows better or if you're like - I've seen that a lot more in like, disability justice research and things like that sometimes that's just what works. So, yeah, I agree.

[00:30:39] **Dr. GG deFiebre:** And so, we haven't really talked explicitly about this, but do you mind just mentioning out what ableism is? What that means? And maybe how it might impact someone's life and day to day life?

[00:30:54] **Dr. Cyrena Gawuga:** Sure. I think throughout our conversation already, we've had threads of describing what ableism is, but most generally ableism is like institutional or structural discrimination or even on an individual level, discrimination against disabled people. So, if you say, let's say institutional discrimination

against disabled people, it may be having a company that makes it really difficult to have accommodations or makes it really difficult even to get hired. We're thinking about structural, like we talked before about curb cuts. If let's say a city says, oh, it's way too expensive to put in curb cuts because there's such a limited number of people who will use them and they're really only disabled people and how often do they go for walks or need to get around as much, that can be conceived of as ableism.

[00:32:03] I think there's a lot of people who encounter ableism in the educational settings again when they look for accommodations in the classroom and professors make it difficult. And the fact that a lot of schools really put it upon the disabled student to actively seek accommodations, that's like a structural and institutional ableism. They shouldn't have to do that. It should be comparable to other marginalized identities and that they don't have to necessarily advocate for themselves and so it's really the barriers that disabled people face to fully interact and thrive in society.

[00:33:01] **Dr. GG deFiebre:** Yes, thank you. That was a good explanation of something that's pretty complex. So, I appreciate that. And so, we've talked a little bit about this too where disability can be part of who a person is, their identity. So, how does disability interact or affect other identities that someone might have?

[00:33:22] **Dr. Cyrena Gawuga:** I think that probably for me, the way that disability interacts or affects other identities, the most is that disability is not really recognized as an identity by many groups. So, if you are someone who identifies as disabled alongside other identities, you may encounter situations in which people say, well, that's not why are you talking about this all the time. This is not a struggle that's important. This is not an issue that maybe needs to be dealt right now. That's an individual thing you need to take care of that in another setting.

[00:34:06] I think another way that - of course, I'm right now going to talk on more like an activist level. But another way that disability can interact or affect other identities is that there isn't space made for disabled people in other activist movements. So, people can be shunted to the side or seen as not as - seen as not as effective as advocates because they have disabilities, whether they be invisible or visible. They may not be seen as effective in those identities.

[00:34:56] I think that on a more group or individual level, one of the issues can be how does one's social group, how does one's family think about disability? What's their concept of disability? How do they react to the disability or disabilities that you have? How do they react to you identifying as a disabled person? You may come from a culture again, like we described, there are cultures still in which disability is a really bad thing.

[00:35:36] And so, if you're someone who is presenting and saying I am a disabled person as well as being XYZ, they may think, no, this is terrible. We can't tell anybody else about this. You can't do that. You can't tell people you're disabled. I mean, I'm sure lots of people have encountered that you can't tell people that especially if it's an invisible disability. That's going to be bad for you and it'll be bad for us. So, yes, of course, disability, whether it's a small part or a large part of who they are can really be a barrier because a lot of people don't see it as an identity on par, say with race or gender or nationality, sexuality, et cetera. People with disabilities are still marginalized within all of those groups.

[00:36:33] And so, it is minimized as an intersectional identity to the detriment of other groups. Because there's, what is it 20% of the US population has some form of disability? That's a lot of people with very unique experiences that are left out and their voices are minimized. And so, that's a significant problem that we have in relationship to identities and just about everybody but the disability and like, of course, we all have different identities and there's a lot of people with other identities that struggle to integrate that with their other experiences.

[00:37:29] **Dr. GG deFiebre:** Yeah, I don't think the 20% of the population having a disability or being disabled is - I think that's often people don't realize that, that it's that many people, so for sure. And then in talking with people, it can be difficult for people to be proud of their disability identity. How has your experience with this identity changed over time? I know it's - for me has changed over time since my diagnosis.

[00:38:04] **Dr. Cyrena Gawuga:** Yeah, sure. I would say that, I've gone through multiple phases of like acquiring illnesses if you will. And in the beginning, it was definitely something like I need to - I can't tell people about this. I need to hide this. I only need to tell as many people as necessary. And as I progressed, like that started off like one of probably the most - one of the most stigmatized mental illnesses with depression. And then I developed lupus, which is where you start getting into a disease that has both invisible and disability - invisible and visible manifestations. So, you start getting to a point where you have to start telling people and it was still something that was - I only have to tell as many people as I need to tell because I want to keep this as quiet as possible.

[00:39:08] And I think actually it wasn't until I was diagnosed with TM, transverse myelitis, for the first time. And all of a sudden this was all really real, it wasn't something that, "Oh, I could wear a hat, or I could just stay home for a couple days while I wasn't feeling great." "Oh, I've lost hair, let me try to hide it." I used to get like, really big hives. I would just stay home, which of course, was detrimental to my medical career, but I digressed, it wasn't till I had transverse myelitis and I was in the hospital for three weeks that all of a sudden it became a reality to me that this is a lifelong situation.

[00:40:01] I first went to the ER, and I'm paralyzed in half my body. I'm like, "Oh, I'm going to go home. I'm just getting ready." I was seriously ready to go home. And so, when I was in the hospital and then they were like carting me off to the rehab hospital I thought this is real. And so, that's when I started going on Twitter and connecting with other people who are disabled. And that changed it. I think that - also again, having a disability that was externalized. Now that was a visible disability. I had a cane and I had got out of the hospital and like a week later, I had a committee meeting for my dissertation for my PhD. And I'm standing there, like you stand up in front of a room of people, you have to present your results.

[00:41:04] And so, I just got out of the hospital a week ago. So, God, my results were like two months ago and I had a cane and I'm standing there with this shiny cane. And I had to say, "Can I sit down because I can't stand for an hour and do this." And that was real. It's like you feel all of a sudden, everybody knows I have a disability and I started realizing that this was just going to be how I was living now and it's okay I didn't do anything wrong. This is something that happened. I have to thrive with it. And there's nothing wrong with this.

[00:42:01] And of course, that's developed over time. And I had the opportunity to give a talk at a conference at Stanford. This was like during my PhD, and it was really just to talk about my experience and like it got a positive response and I thought, "Okay, this will work." And as I've moved forward, I've become stronger and stronger in that identity and feeling more comfortable talking about it. I think in part because I realized I have talked about it and it's on the Internet. So, now people know anyway. But yeah, I feel like this is - I have no problem saying that I am a disabled person because that is where I have come. And I will say it took many years to get here.

[00:43:01] But people shouldn't feel like they are under pressure if that's not where they are. I think how many would I say - oh my gosh, like if you add everything up it's like 20 years. So, don't feel under pressure to stand up and say I'm a disabled person and I'm going to fight. It's ok like I didn't feel like this when I first had my instant, my first hospitalization, I didn't, but I do now. So, I think that it is difficult. I think that it takes time to come to terms with your new reality and it's totally real. You have a new reality. It doesn't make it inherently bad.

[00:43:54] **Dr. GG deFiebre:** It's the way you describe the way that you started becoming more okay with your disability identity finding other people with disabilities was very similar to how I experienced that transition as well where if you had told me in the hospital that I was disabled, I would have been like, "No, you're wrong. I'm going to overcome this. I'm going to be - I'm going to overcome this. I'm not disabled." Like I would have just - I would have rejected it. And I did for many years until I saw other disabled people and connected with them. And that really changed my perspective and as you said, took years.

[00:44:36] So, this isn't to say that - and it's as you said, an adjustment, a transition process that's really challenging because the world is not, we're faced with inaccessibility and people's perceptions of disability and how that impacts how we move through the world. So, it's not necessarily an easy new reality at first. And so, I don't - again if you're in - this is a new thing for you, it totally makes sense to not feel that identity. But I have been noticing too. I don't know if it's social media or what, but I've seen people earlier on in their diagnosis or journey identify with disability and I don't know if it's from seeing other disabled people in more space. I don't know, but I have personally noticed that as an anecdote. I don't know if that's the case obviously more widely.

[00:45:35] **Dr. Cyrena Gawuga:** Yeah, I've seen that too. I think that especially younger generations more comfortable adopting, naming their identities, adopting labels to me in a - some people will say labels in a positive way, but labels are good. Labels help us understand who we are, and I think definitely younger generations are more comfortable adopting labels and more comfortable in a lot of ways with themselves. So, I think that's another thing in addition to social media and people connecting more effectively.

[00:46:18] **Dr. GG deFiebre:** Definitely. And then some people have felt nervous attending a support group or what they perceive as taking up space depending on their recovery. So, maybe they had more recovery, maybe they don't have any more lasting impacts from their diagnosis. And then on the contrast too, some people who have maybe more of a disability from their diagnosis have felt nervous about connecting with others in the community because of this. So, just any thoughts on how - I guess, I don't know exactly what my question is here but just any thoughts on why that might be or how to approach these situations, these community building, things like support groups when this might be the case.

[00:47:11] **Dr. Cyrena Gawuga:** Of course. So, perhaps I can start with an anecdote. That's not a rare immune disorder anecdote, but that's actually a mental health anecdote. So, I was participating in a support group, and this was actually during writing my dissertation, but it was like a mental illness support group. And there were people around me who had really difficult lives, they were experiencing domestic abuse, they were experiencing drug use, all of these conditions that I wasn't living with. I was basically there because I felt really depressed during grad school. So, I went to the doctors leading the group and I said, "I don't know how I feel about being here" and he said, "Well, we'll talk about it during the group." So, we talked about it during the support group. And I reiterated what I told him, I said, "I really don't feel like I belong here because I'm having this ostensibly bourgeois problem. I'm feeling really just like severely depressed. But I'm in grad school writing a dissertation, this is very different" and he said to me, "It does not matter why you are here; it is important that you are here, and you have value in being here."

[00:48:42] And I realized after that I did have value in being there because I connected with people over different types of issues. And you realize that despite what may have brought you there, you have a lot of commonality even with people who you may not have thought you would be able to connect with. And I think with rare immune disorders, it's the same thing. There's a broad range of disability that can occur with all of these disorders. And especially if you're on the end where you feel like, "Oh, I'm lucky I didn't come out with really" - everyone says to you at least, "Oh, I'm lucky, you're lucky you didn't come out with like too much

disability. You can feel like you're not valid. Like you came out not that bad and maybe I shouldn't like - you said you're taking up space, maybe this is space more for people who really struggle and that's not true."

[00:49:52] And on the other hand, too, the people who may have experienced more disability, you also have something to contribute, and you have something to contribute even to the people who perhaps "got away" without much disability because there is still struggle on that continuum. And perhaps you may not, for example, be in a wheelchair, but you may still be struggling with getting accommodations at work. And if this person who had their primary disability is mobility and they're in a wheelchair, they still may be able to contribute to you information about how to fight for yourself, how to advocate for yourself. And so, I think that, wherever you are along the continuum, you have value to a group. And so, if you feel as if you might be taking up space, just go to the group and see how it feels. You don't have to be part of the support group. It's not a requirement, but it's helpful for a lot of people. And if you want to try it, you should try it because there's a continuum of injury, but there's also a commonality of experience, and that I think people with rare neuroimmune disorders have.

[00:51:28] When I went to the RNDS conference last year, I met all these people with the hip disorders. I've never met anyone with this disorder, but we still had a lot to share about our experiences, whether it's people giving you dirty looks for using disability space or trying to build an effective medical care team, you have stuff to share. And so, you should just go and give it a try and see if you can get comfortable in this space. And if you can, you can find a lot of resources, and if again, if you're not comfortable with the support group, that's okay, there's other ways of engaging and learning from others.

[00:52:24] **Dr. GG deFiebre:** Very well said. I just want to be respectful of your time. I don't know if you have time for one more question and then final thoughts?

[00:52:32] **Dr. Cyrena Gawuga:** Oh yeah, I've got time, don't worry.

[00:52:34] **Dr. GG deFiebre:** Okay. Perfect. So, some people have described instances when their family or friends have not liked them calling themselves disabled thinking that they are giving up or being negative by saying, I've even had family members say like, "Oh no, don't say that about yourself." Even me describing myself as a quadriplegic, they're like, "No, don't." I'm like, no, that's subscription term. It's factually accurate. But how do you suggest or is someone handling these conversations or going about these conversations?

[00:53:10] **Dr. Cyrena Gawuga:** I think probably one of the most important things is first check in with yourself and see how comfortable you are engaging in that conversation like that. Because if you're not comfortable with engaging in conversation with that, you can try to find it out whether it might be changing the topic or frankly leaving if that's something that is there for you. But if you engage with - like you check in with yourself and say, okay I can engage in this conversation, it can be helpful to understand why they're saying that. Is it because they feel that they failed you? Is it because they're afraid of the concept of disability that they think that you won't be able to do more in your life? You might be able to have that conversation with them. Some people don't want to have a conversation, they just want you to stop and that's probably the most difficult situation to be in and that may require multiple conversations or multiple engagements to get them to the point where they can realize that you're not giving up and you're not being negative, that disabled is literally a description of your situation and there's nothing wrong with that.

[00:54:36] There are some things about ourselves that we will never change. Like I've had a bunch of MRI s and there is a scar on my spinal cord, and it will never go away. I can't do anything about it, which means

that I have transmission issues, when it's really cold, when it's really hot, my leg basically drags along behind me. That's I'm disabled. That doesn't mean I've given up, I still walk. I can walk like two miles now; I'm really excited about that. It doesn't mean I've given up. It doesn't mean I don't try, but it also means that I've recognized that this is the situation in which I'm in and it's not a negative thing to describe it as it is. Like you said quadriplegic, that's just what it is. There are some things that you're not going to change. I'm not going to get enough PT to make my leg magical again. So, I think that maybe being able to say this is the state that I'm in now and I'm okay with that and I hope you can be okay with that too, maybe that's a start.

[00:56:02] Obviously, depends on people's family situations, social situations. But I don't think being disabled means giving up, you can still - disabled people participate in the Boston marathon, they never gave up, they just learned to work with what they had, and it's the same idea, you can be disabled and work with what you have. And maybe that's a place to start.

[00:56:37] **Dr. GG deFiebre:** Thank you. And we've talked about a lot today, but we have a lot more if you like to talk about. So, I hope we can continue this conversation. But I just wanted to know if you had any final thoughts.

[00:56:52] **Dr. Cyrena Gawuga:** Yeah. Sure. I think that my final thought is really, if you're a person with a rare immune disorder and you want to identify as a disabled person, it can be a good thing. It can be a powerful thing and empowering thing. It can be something that makes you feel like, "Okay, I can go out and advocate for myself." These are the things that need to be done and I can do them. I think that it can improve your interaction with medical professionals as well. I don't necessarily declare myself as a disabled person to every doctor that I have but at the same time, I think that it makes it easier for me to speak up for myself and to say this is something that's not going to change. So, I know that you want me to keep doing PT for this, but this is a waste of my time.

[00:58:00] And I think it can also help in interactions with friends and family because it can make you feel comfortable talking about your experience with rare neuroimmune disorder. I think that especially people who may have more invisible disabilities may not feel as if they have the - like they feel comfortable speaking about it or like we've used the word before, maybe they're taking up space and speaking about it. But if you can identify as a disabled person, that may make it easier for you to say I'm a disabled person and this is why and then describe it because I found that I explain it to more people now that I'm more open with it.

[00:58:54] Increasingly, it takes a long time. Of course, I'm sure there's a lot of people with rare neuroimmune disorders who are younger and may need adaptive technologies whether they be something like a cane or a wheelchair, all the way through. And if you're young, I can tell you if you're younger and you're using a cane, it is a very weird experience because people have so many questions and initially you just say, "Oh, I had an injury" and I've gotten to the point at least now I can say I had a spinal cord injury. Maybe I'm working to the place that even perhaps with strangers, I can describe what happens. But right now, I just say spinal cord injury and that's fine.

[00:59:47] So, I think that identified as a disabled person can be empowering, it can help in recovery as well because you can understand there's a range that it doesn't mean you're giving up, but that there's a range of places you may end up. And so, I really think that it is valuable for people with rare neuroimmune disorders to start thinking about what it means to them to have a rare neuroimmune disorder and perhaps if they have the resources and the time and the space in their lives to start looking into thoughts about disability and that may help them understand what disability means to them.

[01:00:43] **Dr. GG deFiebre:** That's great. Thank you so much. This was wonderful and I am very excited for our future conversations on this topic.

[01:00:52] **Dr. Cyrena Gawuga:** Yeah, I am too. I mean, I am learning along the way as well. Learning is an ongoing project and I think that as disability becomes more and more of a discussion within medicine, within health services and science and all of the different realms of study, it will like the real blossoming of understanding what it means to be disabled and how disabled people live in the world. So, that's a space for rare neuroimmune disorders to really start thinking and perhaps even contributing.

[01:01:41] **Dr. GG deFiebre:** Yes, thank you.