

# Disability and Rare Neuroimmune Disorders | Part 2

## Accessibility and Disability Pride

You can watch the video of this podcast at: [youtu.be/zb00bRLkq9E](https://youtu.be/zb00bRLkq9E)

[00:00:00] **Dr. GG deFiebre:** Hello and welcome to the SRNA "Ask the Expert" podcast series. 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](http://wearesrna.org). Our 2023 "Ask the Expert" podcast series is sponsored in part by Horizon Therapeutics, Alexion, AstraZeneca Rare Disease, and Genentech.

[00:00:23] Horizon is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare, autoimmune, and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Horizon believes science and compassion must work together to transform lives.

[00:00:48] 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.

[00:01:10] 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](http://gene.com).

[00:01:31] 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.

[00:02:09] 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.

[00:02:43] Thank you Cyrena for joining me today to talk a little bit more about disability. Today, we're going to talk about accessibility and some other topics related to disability in the world. So, to start, I just wanted to ask you, what is accessibility?

[00:03:07] **Dr. Cyrena Gawuga:** Well, I mean, I think everyone has their own personal definition for it. But the way that I think of accessibility is whether it's the built environment, the social environment, the structures in place that make it possible for all of us to do what we need to do to the best of our abilities. So, often when we think about accessibility, we really think about the built environment. Are there ramps, are there curb cuts? Is there an elevator? How do I get on the commuter rail if I'm a wheelchair user? But accessibility is about more than that. It's about, are there accommodations in the workplace? Are there accommodations in the educational system? Are there ways for people who identify as folks with disabilities to be part of the world instead of isolated from it?

[00:04:17] **Dr. GG deFiebre:** And so, you talked about how accessibility we think about things like ramps and curb cuts and stuff. But I have heard this discussion happen and I think it's interesting and frames accessibility in a little bit of a different way. But just talking about how everyone, even someone who's maybe non-disabled has access needs. So, the idea that if someone lives on the 20th floor of a building, they need to access that apartment, for example, they need an elevator that access need is there regardless of having a disability or not. And so, I mean, that's just one example, but I wasn't sure if you've had conversations or thoughts about access needs for everyone and how it's just framing. I guess that impacts how we think about that.

[00:05:17] **Dr. Cyrena Gawuga:** I think it follows - again whenever we talk about accessibility, we immediately go to disability, but it's really again about making life functional, making life doable for everyone. It reminds me, for example, so when I was an undergrad, we used to have to register for classes, it's late summer, it's like August, early September in New England. And we go into this building that's been on campus since like the 1700s or something. It's got these narrow stairwells, everything's all hot and crowded and there's no air conditioning.

[00:05:46] And so as registration deadline gets closer, you've got potentially, 100 plus people snaking through the hallways of this building, and everyone has to do their registration on paper and not everybody knows all the different codes for the classes. So, you could be in line in this really hot stuffy environment, climbing up these narrow stairs for hours on end and we did it. People also fainted; perfectly healthy young adults who had no identifiable health conditions passed out because it was 90 degrees in a building from like 1780 something. So, when they moved to a computerized registration system, and when the registration office moved to a building with an elevator, things were so much easier, not just for disabled students, but for everybody. And if you think about making the environment easier for people to use, it will inherently be easier for disabled people to use. And I think often when we are talking about how can we make something more accessible if we look to disabled people as a small population or a marginalized population, it's like we're doing this for them and we're not going to get anything out of it.

[00:07:38] Well, just about every modification you can think of that helps disabled people, helps abled people as well. And as we always say, all people are really temporarily abled. So, you have to think about it and how does this make life easier, more functional? I mean, we can look again to Zoom like we're doing this over Zoom. Like this is totally easy that disabled people have been asking for years. We have the technology. Can we get remote work? No, it can't be done. Yes, it can because we did it on that. And it was something that helped parents with small children, it helped people who had skills that didn't necessarily fit, I don't know the geography that they lived in. Let's say you're an expert in social media engineering, but you can't move to California, well, it made it possible. Is that something that helped people with disabilities? Absolutely. Did

it help other people? Yes. So, access is about more than just like, can I move around my environment, and can my life be improved by making changes to the world in which we live?

[00:09:08] **Dr. GG deFiebre:** That was a great explanation. I think, as you said when people focus just on this is just for the - I mean, 20% of the population has a disability, it's not necessarily just ability but all of all types of disabilities. But people think, "Oh, this is only just helping 20% of the population." And when you think beyond that, there's so much that these different - the way that the built environment is created that helps everyone. And as you said too everyone. If you get old enough as you age, or things happen, and everyone eventually has a disability at a certain point basically.

[00:10:01] **Dr. Cyrena Gawuga:** Just one other thing about that. I was just reading an article not - but like a couple days ago about how younger generations have really high rates of closed caption use on one watching television. And it made me think I have normal hearing, but I've been using closed captions on my television for probably almost 20 years. I like it. I can follow what's going on. I can look down, I can look up and I know what happens, and I think a lot of people are the same way and for whatever different reason they may use it. It's something that makes television accessible for people with hearing impairment or who are part of the deaf community. But millions more people are using it for a lot of other reasons. And it's still an accessibility issue. I might be like, I like plants. So, I'm often potting plants. I'm watching television, I might look down and be completely lost but because there's captions, I can catch up because they always linger a little bit.

[00:11:20] And so there's a lot of things that are - and I think probably other people may think, oh, I do this all the time too and might not necessarily think about how the battle happen to get that to be a normal part of going on your television just turning on captions. It used to be so much more of a struggle to even find it. And before that, for it even to become implemented as a normal part of TV function. So, there's a lot of things in our lives that were for some other reason that we have purpose for ourselves and that are still considered accessibility. It's not just for disabled people.

[00:12:17] **Dr. GG deFiebre:** I'm definitely also a captions person. I don't know why it just helps me. I don't even - it just helps me process the information better or something. So, although there's still issues with things like theaters and stuff not having it. At home, it's very easy but definitely still some access issues in that the broader, that watching movies in like a theater, for example. So, in terms of thinking about accommodations and where someone might need accommodations, like with family, maybe who don't necessarily just know what accommodations or what access needs someone might have with friends at work or school. How should someone go about asking for these accommodations or access needs?

[00:13:18] **Dr. Cyrena Gawuga:** Now, I want to preface and say I cannot speak to every type of accommodation need or accessibility need that someone may have. But I think probably the first thing is being able to recognize that you need an accommodation, or you have an accessibility need. I was thinking about how - there's this need to be strong for people especially when they are newly disabled. And maybe not even recognizing that this is - what they're struggling with is something that can be accommodated, that can be fixed. So that's the first thing and that, of course, goes to some extent back to where we were talking about what does it mean to be disabled? And are you speaking of being comfortable with the idea of needing assistance of some accommodation? Now, settings are all very different.

[00:14:31] I think that there's a degree of confronting ableism, stigma, fear in any setting that you may need accommodations or have accessibility issues. Hopefully one of the closer relationships to you, so family and friends would be somewhat easier. Hopefully, people would be able to see that you're having trouble. Of course, if you have an invisible disability, that may be more difficult. But I think that in those situations, if

there is a good relationship, just asking, just explaining the situation, and asking is a good start. I read a lot of advice columns and people have very complex relationships. So, I'm predicating all of this, of course, and you have a good relationship with your friends or good relationship with your family and that they want to love and support you and just asking.

[00:14:56] So say, for example, your sister wants to have her wedding in a place that is inaccessible to you in some way, whether it be there's no elevator or maybe it's like - for me, I've lupus, I can't sit in the sun all day. So maybe it's something that's like in Phoenix in the summer, you may have their many different issues but just saying perhaps we can talk about ways to make this easier for me to be part of this. Perhaps we can find a compromise even, but at the end of the day, it's about what you need. So, you don't want to compromise your accessibility needs or the accommodations that you need to fully participate. But it's a negotiation because I think there are a lot of people who may not want to recognize that their friend or their family member is disabled and that things will have to change for them to continue to be included as part of the family unit, as part of the friend unit.

[00:17:08] But I think just having a frank and civil and caring discussion about the things that need to be changed for you to continue to be part of social life is the place to start. As for more institutional settings like work in school - I want to want to say everyone that's such a blanket statement. So, if you have the Americans with Disabilities Act, which dictates that a - as I say, reasonable accommodations for increasing improving accessibility must be made for disabled people. The problem is with Americans with Disabilities Act is that it requires you to advocate for yourself. It's more of a stick than a carrot and you have to try very, very hard before it really kicks in. And so, you may run up against issues where they want to accommodate only to the degree necessary by what they think they can get away with legally.

[00:18:39] And reasonable is such a soft and floppy word because that's how employers got away for many, many years for saying we can't do remote work even though you would be able to do. You're sitting in front of a desk at work, you can sit in front of a desk at home, but we can't do that because that's not a reasonable accommodation. So, it's a soft word. So it's something that in an institutional setting will require you to have a better knowledge of your rights, both the rights under the Americans with Disabilities Act, any rights that you have in the state in which you live or, if you live in a different country, the country in which you live, and say, the school, whether it's a public school, private school, the laws that govern what it is they have to provide you as well and go into those situations armed with that knowledge so that you can push back because it's a lot easier to roll over someone who doesn't know what they're entitled to.

[00:19:58] And it happens to people all the time and if you can go in - if you don't want it to start off confrontational, but at the same time, you have to be prepared for one because you have to be your best advocate. They can easily push you off and say this is too much work for us. We'll find someone else to do this job. They can't legally say that. But they always can find another reason to get rid of you. And in the school setting, they can say, well, we just don't have the funding for this, maybe this is not the right place for your student. And even though public schools have to educate everyone, they often find ways not to do so for people who have accessibility needs. So I would say friends and families, start from a position of kindness and perhaps having to educate them about what you need.

[00:21:00] And I think with the institutional settings, with work and with school, come in prepared to advocate for yourself and know what you need, and what they are supposed to provide for you because the ADA is not a carrot. It is a stick and it's an expensive stick because you have to wield it. So, you have to file a lawsuit under the ADA for it to start kicking in. So, unfortunately, it is a litigious environment when you're trying to pursue those things. So, you want to make sure as much as possible you can head off any of that by knowing exactly what it is you need and how to get it as expeditiously as possible without acquiring a lawyer because

it sucks that that's how the ADA is generally set up. So, if you can go in and advocate for yourself and often when you are able to say what it is you need and what they are obligated to provide you, it can facilitate things in a way that not having that information doesn't.

[00:22:23] **Dr. GG deFiebre:** And in schools, there are offices for students with disabilities. So, it's important to meet with them and come up with a plan. And there's definitely a lot of resources I think available online with - obviously you get into legal stuff with employment and education and things in terms of accommodations, but there are definitely resources out there that we can't obviously cover everything. So, you also talked about obviously, for example, during the pandemic that we saw that all these accommodations that disabled people have been asking for years were able to be made for the general public. So, thinking about hiring people with disabilities or disabled people, what do you think some of the benefits are of hiring a disabled person?

[00:23:26] **Dr. Cyrena Gawuga:** I think one of the biggest benefits of hiring a disabled person is frankly just hiring someone who has the skills that you need to do the job. A lot of the employment that is available today is increasingly sedentary. It's increasingly cognitive, it's work that it's not heavy labor, so a lot of jobs out there are - I mean, uses them, but they're fully accessible to people who have skills and need to be able to use them. So first and foremost, it's really just having someone who can do the job. And if someone who has a disability is the person who has the skills that you need that's the advantage of hiring them, they've got the skills you need. But we're going to talk more about like someone who is a disabled person, let's say identifies as such. I think without wandering into the minefield of adversity is a strength thing and all that stuff. There's a reality in that. As a disabled person, you have to be more persistent and you have to be a stronger advocate, you have to be willing to go at a problem over and over again because we have a world that is not accessible that we have a world that's ablest.

[00:25:00] So to get the things done that able bodied people can do, you have to work harder. Perseverance is a skill that I think just about any employer would want from an employee. I think there is a degree, especially when you're looking at health care, social services, nonprofit settings of empathy and compassion that is often gained from the experience of being a disabled person in this world. Not all marginalized identities are the same. And of course, there's a lot of difficulties within the disability rights, disability justice group in terms of intersectionality. But as a whole, I think there is a certain degree of empathy of compassion for people who are struggling that you may find more in disabled people. Then you wouldn't find - well, I'm not going to say you wouldn't, that you may find more disabled people by virtue of the experience that they've had.

[00:26:13] And so I think that's another advantage and frankly too, the advantage is having people interact with all different types of disabilities and recognizing that these people are capable because so much in our society that there's this isolation, this walling off disability. And therefore, it's conceived of as a weakness and that these are people who aren't capable and now you have someone in your environment who openly identifies as a disabled person and they're able to keep up and they're able to do the job of to keep up because we know lots of people who are able-bodied. But you have someone now in your environment and perhaps you've never known anyone who was openly disabled and working full time in the type of field that you're working in. And now here's an example, it's the same type of argument that we have for other types of diversity but the fact of the matter is, it's true.

[00:27:32] Encountering someone who has an experience that is not like your own can open you to the fact that one, there are experiences that are not your own, but two that people can thrive in the same type of environment that you're in even if they have a different life experience. So, I think it opens up the workplace for a group of people who face challenges every day and just living that can transfer that same drive and energy and skill set to any range of workplaces along with what they're already capable of doing. I mean, there's no reason for someone who's - I'm working on an op-ed right now about disability and science education

and there was a study that shows like there's a higher percentage of people if this is esoteric, but a higher percentage of scientists at PhD level with disabilities that are unemployed than people who are able bodied. There's no reason for that really. I mean, skills are transferable.

[00:29:03] Maybe you can't stand at a bench anymore, but that doesn't mean that you don't have other skills that you can move to but because we are in such an ableist world, there's blocks in people's brains and so we need to move those blocks away and say what are skills that someone has irrespective of their body habitus or their mental health status, neurodivergence, anything under that whole umbrella of disability, what skills do they have? And are they able to do this job with reasonable accommodations? That says yes. Then this is a good hire for you and broad in the way that you think about things, but we're still fighting through this.

[00:30:01] **Dr. GG deFiebre:** Definitely. And so, you talked a little bit about this, but do you have any other thoughts on why you think employment rates of people with disabilities are so much lower than non-disabled people?

[00:30:14] **Dr. Cyrena Gawuga:** I think some of - I mean, we put aside people who cannot work to whatever extent it may be because of their disability. But people who can with reasonable, that work 88 defined reasonable accommodations can do a job and do it well, I really think that a lot of the issues are related to the facts of ableism, whether it's a lack of vision of being a disabled person in your workplace and/or fearing that someone with a chronic illness will always be absent. And now that that's the first thing in your head that whether or not they are capable of this work. I think that until recently - and it actually still to some extent now that there's a whole return to office move, not acknowledging the different ways in which people different ways, in different settings in which work can be done, the inflexibility of a lot of employers in understanding that the work that is done a lot of this positive work that this disabled people can engage in quite easily, can be done out of an office setting. I think that some of it too is just the - I mean, frankly, people being told that they can't work because they have a disability.

[00:32:21] And again, that cycles around to ableism in a lack of role models. And it's a self-fulfilling prophecy, if you're told that you can't work, you don't work. And then if you don't work, you don't have a work history. If you don't have a work history, you can't get a job and we're not going to cure ableism overnight. But I think that's a big part of it and this lack of imagination and how can we find a place for this person. I'm not saying that everyone gets to do whatever job they want to do because there are some jobs that maybe just aren't students to people. Like, I'm not going to bypass in here and that's okay. But, like I'm not saying that, like we should give people to do anything they want. Like, no, but a lot of the work that is done in this country today can easily be accommodated.

[00:33:27] And I think it's ableism and a lack of flexibility in thinking about how these jobs can be done differently that really keeps employment rates so low because I know a lot of people who are unemployed or underemployed and it's not because jobs aren't out there because they certainly aren't out there. And a lot of them are open forever and it's like this job can be done by someone with a disability, you're just not seeing those people. And I think sometimes too we found ourselves out and think, oh, they're not going to want to interview me, or they might be really excited until I show up and I have a mobility device and then the interview goes downhill from there. I mean, I'm sure people have had those kinds of experiences and when their motivation goes down, they're deflated because of this ableism that they're friends, so we can just say it's ableism. Obviously, there's all of those reasons are underneath that heading overwhelmingly.

[00:34:46] **Dr. GG deFiebre:** Definitely, yeah. And I remember going to job interviews and never knowing like when to disclose that I use a wheelchair, like do I tell - I have to make sure that the office that I was going to was accessible. So, like you have - it's just was a stressful thing and trying to figure out like when to have

that conversation with the potential employer and then just knowing that - I don't know the fear that they'll look at you differently too, just basically. And then also - I mean, in terms of like systemically, we also just don't have the way benefits in terms of someone having, if someone becomes disabled and getting Social Security disability income for example, there are so many barriers to working because there's limits to the amount that you can earn. People have to be really strategic about how much they work. It just there isn't - you either have to be in a job that's making enough money to cover all your expenses or there's aren't great societal supports there.

[00:36:01] **Dr. Cyrena Gawuga:** So, we don't have the structural support to allow people to move in and out of - I mean, especially in talking about chronic illnesses, including, like, rare neuroimmune disorders. A lot of people ebb and flow, you have flare, sometimes you feel better this week and maybe not next week, or maybe this year and not next year and we don't really have structures in place. You're right, the systems do not accommodate just the natural flow of illness, of disease, of disability that will let you be successful and to the degree that you want to be however you define it without running into so many barriers.

[00:36:54] **Dr. GG deFiebre:** And then you talked a little bit about education, about how you - in the context, I guess of the employment of people, the study you saw of people not having lower employment rates as disabled, I guess, I think you said HD or - there's issues obviously as well as with employment, there's issues with education inequality in schools in terms of students with disabilities or disabled students not having the same access to education as their non-disabled peers. So just your thoughts in terms of how education inequality in school might contribute to inequality in other areas of life and how inclusion in classrooms might benefit everyone.

[00:37:51] **Dr. Cyrena Gawuga:** Yeah. I think, when you're talking about this and you're thinking about this outside of the employment idea, and you tie education to employment. But school, especially the primary secondary level, a lot of it too is about learning to be a social being a part of society and building social networks, meeting friends, joining sports teams, extracurriculars, all of those things are part of the educational experience and overwhelmingly, those are not accessible to students with disabilities in many school settings. So, they're isolated, they're kept away from those skill building opportunities, those opportunities that allow them to be part of a friend network, part of a social network, part of a community, to build an identity that's more than being a disabled kid. And I think that's probably something that's really overlooked is inequality and access to opportunities outside the classroom.

[00:39:12] I think there are probably a lot of people who would say some of their fondest memories of being in school but are not about being in like at a desk, taking a test. There's so much more to school and even if you talk about college and beyond, there's so much more to school than the actual classroom experience. And so, by making it difficult or challenging for people to have accommodations necessary to fully participate in their entire school experience, to keep people from developing socially. The surgeon general has said quite strongly that loneliness is a health hazard. It's one of the most dangerous things happening in public health today. And that's still for a lot of disabled kids and disabled students in general, part of their experience is loneliness and going to class and going home is hard, your friend and people make friends through these extracurricular activities. And if you don't have that opportunity, you don't have access to the friend network in the same way. And that's inherently can lead to loneliness, especially if you're an introverted person like myself. So, there's a lot more to inequality in schools than the classroom experience.

[00:40:55] And I think that there are probably many parents who would say that that's something that is more difficult to remediate because there - I mean, what are the rules for that? There's no like individualized education, program for the soccer team, but there's a way that even if the kid cannot fully participate in the activity that they can still be part of it. And again, this is a matter of the inflexibility of seeing how things can

be done differently. How can we structure our systems to be more inclusive? Equity is not about making everybody do exactly the same thing. It's about making sure that people can thrive in society with resources that allow them to reach the potential that they would like to reach. That's how I think about it. But I think there's a lot of inequality and the biggest thing to me, especially thinking like K through 12 and even an undergraduate is not having access to all of those other educational opportunities outside the classroom can leave you on the outside of society. And that's really bad for our health.

[00:42:34] **Dr. GG deFiebre:** All of this stuff is tied to health. So, moving on from employment and education and those are two also huge topics that I think we could have a five-part series on each of - there's a massive potential discussion there. But thinking about health care settings and how experiences, we talked a bit in the last podcast about the medical model of disability. But in terms of how experiences might differ in health care settings if you have a disability and potential lack of accommodations there.

[00:43:18] **Dr. Cyrena Gawuga:** So, if I think about the health care environment there's so much in the health care environment that is not welcoming to disabled people. I am thinking, for example, last time I went to the rheumatologist to get an exam, hop up on the table, I'm like, what? The table is not adjustable. And this is an office where lots of people have like inflammation and joint problems and all of these things that in your head, you say like obviously you should have an adjustable table in this place. So, when you want to examine people, they can move themselves with - because most people want to be able to move their own bodies to the degree possible for them to be able to do this with the level of assistance that they want. And I can throw myself up there but someone else can't. And I think that there's a lot of things in - again, first thing I think that access to building the built environment. But, I mean, it's a reality, there's a lot of things in the built environment in health care settings that are made to accommodate the needs of the provider, not the patient.

[00:44:47] So whether it's tables that are not adjustable or scales that don't accommodate wheelchair users or beds that are not wide enough for people who are of larger size, that can go on and on and on. I mean, like even, like if you're in the hospital and you have one of those nice little remotes, and they tell you press this and this and this, but all the buttons are smooth. If you have a visual impairment, you don't know, unless someone literally shows you and no one has the time for that. So, there are these smooth buttons, and you don't know what you're pressing. That's the thing that if you had more disabled people in health care, they might be actually able to point out. But I think also the other thing that can happen with a lot of people, especially people who maybe don't feel as confident advocating for themselves or maybe don't feel like they have the degree of health education or literacy that either they don't know that they don't have or don't feel confident with is that providers can think you don't know anything. I think, there's enough studies that show that people rate the intelligence of bafflingly people who are wheelchair users as the lower intelligence. I still don't understand it but lower intelligence.

[00:46:25] And so if you're presenting yourself to a provider who has been educated in an abler system, you may very well be engaging with someone who has perceived you to be of lower intelligence or lower knowledge or understanding of your condition. And you're starting from a position behind where you should be, even if you might know more than them about your particular condition. So again, ableism rears its head. But in between the built environment, which is really constructed more for providers, not for patients and people assuming as a disabled person, you don't have the capability to learn and understand your condition. Those are just two of the things that you can run into in health care setting.

[00:47:17] Of course, there's many more if you need a caregiver and people don't understand, say your family relationships, not everybody has a mom or a dad or spouse, some people have other types of familial relationships that aren't necessarily by blood or marriage. If you need someone to be there at an appointment



with you and they don't understand who this person is, that's another issue you might face if you're a person with a disability. So, if you have more people with disabilities who manage to make it through the gauntlet of education and actually practice, you might see some of these issues start to be addressed more readily than for those of us who are knocking from the outside.

[00:48:12] **Dr. GG deFiebre:** Definitely. I mean, I see in my own experience when I go to see a medical provider how the medical model definitely also impacts how they approach conversations with me or just a lack of awareness of the difference between a medical condition and a disability, like there's overlap there obviously, but they're not necessarily. And as you said, there's a ton of barriers that exist for people trying to access care with a disability. It's just the built environment, provider biases, insurance issues, not having enough time for the appointment, just so many things and again that it could be its own podcast with...

[00:49:10] **Dr. Cyrena Gawuga:** Transportation.

[00:49:14] **Dr. GG deFiebre:** ...transportation, all of that stuff. So, there's definitely a lot there. So, it's currently a shift to different topic a little bit. But July is Disability Pride Month. If you had any thoughts on why you think people with disability pride should celebrate this and how could people get a - what should maybe non-disabled people do this month for a disability pride?

[00:50:00] **Dr. Cyrena Gawuga:** I think that disability pride - I'm so glad you brought this up. I think disability pride is really important because it's somewhat different from other marginalized groups in that although 20% of the US population has at least one identifiable disability. They're not all the same and there's no unifying disability experience or range of experiences that I can sit next to this person and say yes, you can. Beyond that, we both identify disabled people, if all my disabilities are invisible and yours are all visible, we may not hear very many experiences. So, I think the idea of disability pride, first and foremost is important because it helps create some sense of community of a shared identity as disabled people living in an ableist society.

[00:51:15] So, however, we confront, engage or fight ableism, it's going to be different based on our disabilities. But it's the same in the sense that it is ableism that is holding us back. I think that disability pride is also important because it gives us the opportunity to think about what it means to be disabled. It's a huge question and I have my opinion, someone else has their own opinion. We can introduce people to the idea of the social model versus the medical model of disability. And why it's important to understand that those are two of the models of disability, but those are two of the most impactful ones. And to introduce the abled world to the idea that disability is part of the human condition is not a failing or it's not a failure, it is a way of existing in the world. And the problem for many disabled people is not necessarily their disability, it's the lack of accommodation.

[00:52:43] And I think it's really because we're so spread out and - I mean, but there are a lot of groups are spread out, but I mean, there's like a lot of universal, like when you think about interest groups, whatever. So, for example, my university that I went to put out a thing on LinkedIn yesterday, they're doing alumni affinity groups and it was the first time that I had seen them mention something for people with disabilities and neurodivergence. And I was like shocked, I can't believe that you guys are actually doing this. This is amazing because for me, that is always - the ableism has been a bigger barrier to getting through the professional world and that's who I want to talk to. I want to know how other people deal with them. Like, how do you find up? Which means if you walk in with a cane, how do people respond to that? How did people - you talked about being a wheelchair user and trying to figure out, how did you, at what state - like there's some practical things that with something like disability pride opens up the space for discussion about like, how do you disclose, when do you disclose, how do you feel comfortable disclosing?

[00:54:26] And these are questions that you can only ask people who've had similar experiences and I think the disability pride movement is just about embracing this as our experience and not hiding from it. But understanding how - it doesn't make you a better person. It makes you a different person who contributes to society in a different way and making it a better place for everybody to live in. I'm not wandering in the inspiration point. Disabled people are not better people. I've known some terrible people, but it makes you interact with society in a different way that makes it better for everyone. And I think in terms of non-disabled people, it's - let me illustrate this with an anecdote as we often do. I wear compression socks and I have to learn to wearing very loud, very lovely fashionable compression socks because if I have to wear them most days, I might as well be fine.

[00:55:47] So I found myself at July 4th party where I was the only person wearing socks because it was extremely hot, but I knew that I was going to do a lot better wearing socks. I consider that's just one of my... It's like my pain. It's something that helps me get through the world a lot easier. And this kid asked me, "Why are you wearing socks?" Which at first, I was like, "Because I'm wearing shoes," then I realized no one else is wearing socks. So, this is strange for him. And I told him, and I didn't make anything of it. I said, "I have a medical condition that requires me to wear socks and it helps me feel healthier." And then he asked again and - I don't know, I was like, did I not answer your question right? So, I tried to maybe explain it a little bit simpler, and his mom is like, "No, don't ask that question." And I'm like, "No, it's fine for him to ask the question."

[00:56:55] And I think that's often something that happens with abled people, like they either ask questions that are way too invasive or don't want to and are afraid to ask. And then there's a happy medium in there. Don't be afraid to ask but just be civilized. I'm not going to give you all the details. But I think that like a society that keeps people from childhood, teaches them not to ask, keeps them from learning. It keeps people from learning. And I think a big part of what abled people who gain from disability pride is learning that disability is a part of the human condition. It is not a medical diagnosis. It is not something that requires you to be a wall in society. And it also means that for you to learn, you have to be comfortable asking like a civil human, do not ask questions that you would not answer. And I think that, obviously people are really open as with social media. But I think most people understand to some extent how to ask a question respectfully. And I don't have a problem with answering questions.

[00:58:19] For example, I might go somewhere with a cane one day. And then two weeks later, the same person sees me with that one and they'll say, oh, what happened? I'm honest, I would say sometimes I need a cane, sometimes I don't, that's my disability. That's the life, that's what I live with. I don't think that - that's not offensive to me. Abled people sometimes feel uncomfortable with it, but I'm frankly proud that I managed to get through my life every day and get things done and accept that a cane is part of my life. And since it's a part of my life, it might as well be fun. That there's a disability pride flag, it's got all these colors on there. I think it's brilliant. We're all different and we all have different experiences and able people you're eventually going to have some disability. I would say, if you're lucky, you're going to end up with a disability of some kind because you'll live long enough to have one.

[00:59:33] And so just listen to the voices that you're hearing. Don't tell people they're not disabled, by the way, I've heard that. No, that's definitely for me to define, not for you. Just listen to people's voices much like we have all of these other wonderful pride months, we have all kinds of history months for all these different races and ethnicities, and women's history month. Just listen to people's voices. I'm not saying only during this month, but I think definitely having a space in which disabled people can just live and openly truthful life as a disabled person and be honest about their experience is really critical. And if this is an entree for people particularly who are newly disabled to recognize that they have not failed, then July is a great place, great time to start. And if your accommodation is you need air conditioning, this is a great month to advocate for that. I mean, because it's a reality. For some people that's their accommodation and just taking this time to

learn more about yourself and being proud to stand up as a person, whether you identify as a disabled person, a person with a disability and just being to whatever extent you want to be a resource for the non-disabled people around you to understand that it is just another way of being.

[01:01:30] **Dr. GG deFiebre:** Yeah, exactly. And as I said, the Internet has so many - there's no reason to be asking people these very intrusive questions.

[01:01:41] **Dr. Cyrena Gawuga:** Absolutely not.

[01:01:43] **Dr. GG deFiebre:** So, you can think before you do that but there's so much to learn like you can - and there's so many disabilities, as you said, also, I have mobility disability, I don't know about every other type of disability. Having that lived experience is very different than just learning about it more academically or social. And so, it's great that we - I think disability pride it also challenges people like, wait, you're proud of your disability? What? A lot of -

[01:02:20] **Dr. Cyrena Gawuga:** You're supposed to hide it or just like, excuse it and no I'm quite pleased with what - I mean, I'm not pleased with the circumstances, but I'm proud of what I've managed to do and that's an ongoing process. I think that's the other thing for people to not feel like they need to borrow from the LGBTQ movement to be out and proud. It's an ongoing everyday process. I'm not proud every day. I'm really not, today, not feeling very proud but still, it's at least to put the thought in your head that you by virtue of living in the ablest world that we live in right now should be proud of your survival. That's how I see it.

[01:03:27] **Dr. GG deFiebre:** Definitely. And I think also having pride doesn't mean that there aren't these barriers that still exist as we've talked about ableism a lot. So, it's not to erase that or to say - I think I've seen a lot of enduring Disability Pride Month calls to action for non-disabled people to be aware of how ableism impacts people's lives and society and all of that. So, as you said, I mean, it can be really hard having a disability with the way that the world is and having a lot of like, internalized ableism as well. But I just wanted to talk about it since we're in Disability Pride Month to talk about that. Any final thoughts? I feel like you just touched the surface of so many things.

[01:04:30] **Dr. Cyrena Gawuga:** I think I would say that speaking, it's a little bit more specifically to people with rare neuroimmune disorders. A good start is understanding your particular illness. So, SRNA, for people, go to the website, there's a lot of resources that you can use just for yourself to understand. But as we were talking about family, friends, work, school, also for when you're looking for accommodations perhaps again to the degree you're comfortable, but it can at least help you understand how to explain what's going on with you and why now you need XYZ for you to be able to remain in the workplace or what the school needs to do to support you, or whatever it might be, understanding your illness and the way that it manifests as disability can help you advocate for yourself.

[01:05:42] And self-understanding and self-knowledge is always great for pride. And I can only speak from personal experience, but if you think about all of the things that could have happened to you and that you're still getting out there and fighting the good fight, you should be pretty proud of yourself because these are not minor things that can happen to you and a lot of them just come, there's no warning and for you to still be going through life and chugging along is something to be proud of. And there's the peer connects, there's people who have experience and are great, if you want to talk about issues like this, are great people to talk to. I'm always happy to talk to people about this and I can go on and on and on and on.

[01:06:43] I think when you're starting to navigate your worlds, whether it's you're newly diagnosed or you're starting to experience different symptoms, you've had recurrence, whatever it might be you're again going

to be dealing with what is a disability? What is my disability? Like I've heard of occurrence. How do I explain this to people who thought this is a one and done thing? So, I think SRNA is a really great resource, peer connect leaders, support groups for finding people who have a somewhat more accessible experience for you to discuss this with because it's a challenging role and because they're rare, a lot of us... Who else is in your life that you can talk to about this? Well, we can help you find somebody.

[01:07:50] **Dr. GG deFiebre:** Thank you and hopefully we can continue having these conversations and there's just again so much to cover. So, thank you for taking the time again to do this.

[01:08:02] **Dr. Cyrena Gawuga:** You're absolutely welcome. I'm very happy to do this.