# Roopa Ramamoorthi, PhD and Marie Abrego

You can watch the video of this podcast at: youtu.be/14h5pclQros

[00:00:00] **Announcer:** Hello and welcome to a "Community Spotlight Edition" of the SRNA "Ask the Expert" podcast series. For this episode, Marie Abrego and Dr. Roopa Ramamoorthi joined Landy Thomas to discuss visual impairment, their collaborative book, *Rare Visions*, published through the Ipsen Foundation, and the power of poetry.

[00:00:25] Marie Abrego, the Welcome Manager and New Mexico Patient Ambassador for the Sumaira Foundation, was diagnosed with NMOSD in 2007. Dr. Roopa Ramamoorthi is a scientist in the field of global health, a published poet, and the director for the Catalyst Program and InVent Fund at UC San Francisco. You can find their full bios in the podcast description.

[00:00:53] SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org. This episode is made possible in part by the generous support of Amgen; Alexion, AstraZeneca Rare Disease; Genentech; and UCB.

[00:01:18] **Landy Thomas:** Hi there. So, this is Landy Thomas, and I'm a representative of the Siegal Rare Neuroimmune Association. I work and manage community resources and today I have two people with me, two amazing guests. One of them is a close friend, her name is Marie Abrego. She is a patient ambassador for the Sumaira Foundation, and she represents New Mexico as well as a Welcome Manager. Just a delight to talk to you. And I also have with me Roopa and she is a wonderful, wonderful poet and a scientist who gathered us together to talk about rare disease and to talk about vision.

[00:01:58] And she made a poetry book collecting our own poems, personal poems that both Marie and I wrote, as well as Leah Campbell, another great member of our community, and a couple other people as well. So, I wanted to bring us together today to just talk about this amazing book that we got to write together and just to take Roopa's brain a bit about why she gathered us together. I think it was a really cool opportunity. So, Roopa, could you just tell us a bit about yourself and tell us a bit about what these books mean to you? I know you wrote this one or helped us write this one and then you also had another one that you helped write.

[00:02:35] **Dr. Roopa Ramamoorthi:** As you said, I'm a scientist and a poet and before all this, I actually worked in global health and at UCSF. We had this rare disease meeting and right in the beginning, I said for the lunchtime we need someone, people with rare diseases to perform their poems or their stories. And the first time I had a workshop, there was this great guy, Michael D, but only one person showed up for the workshop. And then it was Jim Levine, who's the head of the Ibsen Foundation. His vision: why don't you put together a whole collection? And I thought, oh great, I'll have all these poetry workshops but was finding the people, getting them to write the poems. That was the hard part. And this was the book, *Rare Sounds*.

[00:03:27] And the cover by one of the poets is sickle cell strong. So, the flower is red blood corpuscles. And then we had the next one, which was like the rare disease symposium. One of the themes were rare eye diseases. So, Jim Levine and I talked about it to really put together a collection, people with rare eye diseases. When your vision is affected, what other senses heighten, what challenges are there? And for me, like having the workshops, getting to know you all, it really inspires me. Because years ago, I worked with an amazing person who was blind, who did a PhD from computer science from Berkeley. And long before that, in high school, I was the amanuensis, I wrote the exam for a guy in 12th grade who was blind, and I'd read to people who were blind before. And it was not like I was helping them. Their courage really inspired me.

[00:04:35] **Landy Thomas:** That's so awesome to hear. I mean it's very telling to hear that you've been around people that have had rare eye diseases throughout your life. I know that you probably know a bit about our condition. Both Marie and I both have variants of NMOSD, which can impact the brain, the spine, and the optic nerve. And it's hard. It's very difficult to lose sight. It's very difficult to, you know, have the capacity to lose sight at any given point.

[00:05:06] I mean, when I was a kid, I went to bed one night being able to see perfectly. And the next morning I woke up blind in my right eye and that's just how it's been. So, to see somebody that's going to step forward and say, hey, I'm going to help people with these rare eye diseases collect themselves and talk about something that's impacting them in such a beautiful way. It really does mean a lot. So, I do want to just say thank you for that.

[00:05:34] **Dr. Roopa Ramamoorthi:** Thank you so much. It was just amazing to meet you all. Your beautiful work and that I could help you all with the workshops and just to see your courage, your spirit. And I learned like Marie from your poem and your work. For example, OK, you have all these screen readers, but there's nothing for a washing machine or an oven. And I hadn't even thought about that.

[00:06:00] **Landy Thomas:** Yeah, I think that poems like that are powerful. They're able to clear misconceptions and really give perspective on what it's really like to live day to day with a rare eye disease. So honestly, I'm just really touched. So, thank you. Thank you for the opportunity to be part of this. I know Aliyah was super grateful to be part of this as well. She can't be here today, but she sends her best wishes. And you know, just thank you.

[00:06:30] **Dr. Roopa Ramamoorthi:** Like this is something a little different, but I can share. In 2004, I had a stroke. So, I don't have frontal vision loss, but I have lower right quadrant vision loss. So even though it's a teeny bit, I can still maybe just a teeny bit relate to y'all.

[00:06:49] **Landy Thomas:** Yeah. And so honestly, that's great to hear. I mean, you've been able to collect a really wide spectrum of rare eye disease as well. I know there's a certain person in here that has a vision impairment that's just like; she can see a tiny pinprick. A lot of other people have complete blindness. Other people have partial blindness. I feel like this is a very diverse selection of people with rare disease too, whether you meant to do it or not. It feels like we've gotten a lot of different experiences, different variations. It's a great collection. It's really well done.

[00:07:23] **Dr. Roopa Ramamoorthi:** And I have to shout out to Stephanie Riordan from EveryLife Foundation for helping me, putting me in touch with so many of y'all to conduct the poetry workshops and to meet all of y'all amazing, amazing people.

[00:07:38] **Landy Thomas:** Right. I mean, I think the reason why we were even found was because we had submitted work to EveryLife Foundation. I know EveryLife Foundation does a couple like scholarship stuff, a couple interesting things like DC, Capitol Hill. You can have your work displayed there if you win. I know they have that yearly, competition is the wrong word, but a yearly submission for rare disease-oriented work, which includes visual stuff as well as written stuff. And they just opened the category up for poetry last year, I believe.

[00:08:10] **Dr. Roopa Ramamoorthi:** I was a judge for those two years in a row for the poetry.

[00:08:14] **Landy Thomas:** Which was so awesome. I was so pleased to just be able to put, I love writing. I'm fine with writing prose, don't get me wrong, but sometimes poetry is just, you know, a simpler way or a, it's just fun. It's fun to write. So, it was very enjoyable to submit to the contest. So, I would definitely recommend anybody that's viewing this as part of the rare disease community. It doesn't have to just be people with visual impairments. It's going to be anyone with a rare disorder, including any rare neuro disorder. And you can submit it. It's EveryLife foundation. They're a great organization and they really do care about people that have rare neuro disorders and rare diseases. Yeah. So, whenever we're ready, I'm more than happy to read some poems. I'll be reading on behalf of Marie today.

[00:09:03] **Marie Abrego:** Thank you, Ireland.

[00:09:05] **Landy Thomas:** Oh, yeah. No, no worries, Marie. Actually, before I before I read it, I would love to pick your brain. What was really going through your head when you were writing these poems? Like, what were you thinking about? What were you--what comes to mind?

[00:09:19] **Marie Abrego:** When I was writing my poem, I was just thinking, just the things that, you know, make it challenging on a day-to-day thing. Washing machines, they don't really have a way to know where to set it at. Ovens as well, you know. And so, our stoves, microwaves, stuff like that. They don't really have. Everything has to be bump dots or something just so you can know that, you know, that's where you're at. So, like for an oven, I know, I have a certain bump dot to turn on the oven and then I have a certain bump dot to like to raise the oven or whatever and then I have to just kind of remember the click.

[00:10:20] So, microwaves, I normally only put a bump dot like on the start and on the number five. Just because I know like on a telephone, the five has a little something raised. So, I'm like, okay, so I know the numbers where they're at from there. And then the start I know that's the start. But yeah, I was just trying to think while I was writing, like what are things that make it challenging to be blind?

[00:11:10] **Landy Thomas:** It's such a, I mean, it's a really, it's a prompt that hits really heavy for a lot of people in the community. There are so many challenges, and I think that this is such a--it's not niche to the point of not like knowing about it, but it's something that people do overlook.

[00:11:28] Like barriers to independence, barriers to autonomy. It's great to get so many adaptions or, you know, adaptations into your home, like using the raised bumps and using the different types of devices or voice activated commands, all that stuff is awesome. Um, but in the end, it is, you know…

[00:11:47] **Marie Abrego:** I definitely like the voice. Yeah, I definitely liked the voice activated commands way better than like having to do like the bump dots type thing. You know, it's taken me a while to learn how to use my phone as good as I know how to use it now. It's taken me a while to kind of adapt, but I tell everyone, yes, blindness is hard, but it's not the end of the world. And sometimes it might just take a little to adapt but it's absolutely possible and like more than ever.

[00:12:35] I actually think on certain things I'm like, "Oh my gosh, I didn't know I could do that." So, you don't know what you can do till you kind of take the leap and try to do it. And yeah, it might not be perfect the first time or the second time, but you keep at it, and you keep working out what you want to do in life, and you'll be able to do it. So, I tell everyone, whatever you want to do, whatever you want to set your mind to, you could do it as long as you have just that courage in you to keep trying and not letting your disability hold you back.

[00:13:24] **Landy Thomas:** Yeah, you just have to, you have to take the little victories until they're bigger victories.

[00:13:28] I think that's awesome. It's such a, you know, it's a real overcomer mindset and you really need that in this kind of situation. It's so easy to get bogged down and so easy to be, you know, negative and have a really hard time with it. And I've, of course, you know, especially in the first couple of years that someone is dealing with something like this, it's like, it is so hard to get over it. But positivity sometimes has to slip through and believing in yourself is... You have to. You have to do it because your best ally in the world always has to be you. Always has to be you.

[00:14:05] **Marie Abrego:** Absolutely

[00:14:06] **Landy Thomas:** Yeah. So, it's great to hear that. Without further ado, I think I'd love to read your poem out loud.

[00:14:13] **Marie Abrego:** Yes, please do.

[00:14:14] **Landy Thomas:** This is the first one that you wrote? It's by you. It's by Marie Brega. “Many people don’t understand my struggles and frustration with total vision loss. Especially with technology websites not accessible to me, not compatible with voice readers. I've had to learn different ways to adapt. It takes longer to complete a task. Washers, dryers, and air fryers without voice commands, different commands on my computer, phone. May take many clicks instead of one simple click. Get so frustrated from time to time when others don't understand my struggle. Going to the store, especially now, when switched to self-checkout.

[00:14:49] These self-checkout machines don't even have voice interface. I get so upset time to time. We are in 2024. About time this world is accessible to all.” Which is, it's beautiful. I love that hope. If I didn't want to break up this book, I would hang it on my fridge. I think it's really, really well done. I think it's like, it's not overly simple. It really does hit a lot of the core issues that people with total vision loss face. So awesome work.

[00:15:23] **Marie Abrego:** Yeah. And you know, I don't understand why yet the stores have not had the self-checked out lanes have voice commands. Now I've heard some of them talk, but it's like, okay, how are we gonna make it accessible to the blind?

[00:15:57] I haven't seen anything as of yet and the stores continue to use them and actually see even more self-checkout lanes being put in.

[00:16:12] **Landy Thomas:** Yeah, that can be so frustrating. There's so many, there's leaps and bounds that have to be made to make the world accessible. And I'm sorry that it hasn't happened yet. I do, I mean, I like to believe that it will because the world is good, people are good generally. I think there's just so much that hasn't been said yet or people just don't think about it until it's been pointed out. So, I think poems like this are really constructive towards change. Yeah, like hearing about it, if you can get the attention of the right person, the people that make those self-checkouts, et cetera, there's always a possibility that things will change.

[00:16:52] **Dr. Roopa Ramamoorthi:** I'm wondering whether with EveryLife Foundation or something to really lobby for this in Congress or something to really make it a law requirement.

[00:17:05] **Marie Abrego:** Definitely. I think that would be good. I think us people that have vision loss or blind, we just need to continue raising our voice. And as long as we continue raising our voice, at the end of the day, whether they do it now or years from now, we'll come out winning. So, we just need to keep grounded and just keep raising our voice.

[00:17:37] **Landy Thomas:** Absolutely. If you don't mind, I'd love to read your second poem now. If that's ok.

[00:17:44] **Marie Abrego:** Ok. Yeah. I thought I just wrote one, but yeah, you could do it.

[00:17:49] **Landy Thomas:** You wrote two actually. And this one's, this one's great too. If you want me to, I can read it. Otherwise, I won't.

[00:17:55] **Marie Abrego:** Yeh, yeah, no, go ahead. I mean, I probably wrote it a long time ago and I probably don't remember it. So yeah.

[00:18:04] **Dr. Roopa Ramamoorthi:** You wrote both of them in the workshop and this one, I remember you're putting on makeup. If I'm not mistaken.

[00:18:11] **Marie Abrego:** Oh, okay. Yes, do. Sorry.

[00:18:17] **Landy Thomas:** I'll read it. I'll read it. And then it'll jog your memory because it's really good. “Having once been paralyzed. Now having my legs move brings me joy. I love to exercise. The impatience I experience when trying to add speed or resistance on the machine. No voice compatibility for a world that does not include me. I enjoy cooking and baking.

[00:18:40] From tacos to enchiladas to cakes and cookies. To create a dish is an art to me, but the oven does not support me. Touch screen that I cannot see. Since very young, I have always been into glam, from curling my hair to doing my makeup. Go by touch, few strokes for a dark shade, more strokes for a lighter shade. To get it right with no sight. Can touch and know how tight I want to curl. Frustration comes with glamming yourself up with no sight, not knowing how hot the iron is set. When others tell me I look good,

[00:19:09] I really don't know if I look pretty. I hear others complain about trivial things like a little lack of money to buy the fancy things they see. When every day is a struggle that they don't even bother to see. They can just go anywhere they please, but me in a wheelchair without eyes to see needs someone to accompany me.”

[00:19:29] **Marie Abrego:** Yes. I'm so sorry. I forgot totally about that one. I remember the other one, but not that one.

[00:19:37] **Landy Thomas:** That's okay.

[00:19:38] **Marie Abrego:** I'm telling you; I've had a lot going on. So, I'm so glad that you had that one in the book too.

[00:19:47] **Dr. Roopa Ramamoorthi:** Yeah. And they're both amazing. Amazing and give insight for others to really understand.

[00:19:55] **Marie Abrego:** Yes. Yes. I mean, I love, I love glam. And I love cooking. Yeah, it's just, it's being able to do things like this without an eyesight. I mean, was it hard for me at first? Yes, absolutely. But I didn't let losing my eyesight hold me back on things that I love to do. And there were times that I had to slow down and take a little bit longer for me to either doll myself up or even cook a dish. But I'm so glad that I knew that that's what I love to do. And I just had to do what I had to do, so I can get done what I wanted to get done.

[00:20:52] **Landy Thomas:** Yeah, I get that too. I mean, it's weird to like, I don't know, try to do makeup is really kind of a pain. I'm not trying to compare my situation entirely to yours. I do have partial sight, but if I'm trying to do like the side of my face where I can't see or I'm trying to do the side of my face where I can see, but I'm blocking it with my hand because I have to like put eyeliner on or eyeshadow on, I just can't. It's like, it is such a pain.

[00:21:18] For years I had to have my mom do it for me, but that made me not feel very independent. Eventually, I just figured out, eventually I bought an eyeline pen and what I did was I did it over and over and over again until I got the muscle memory for it. But it took a lot of time, and it was hard, and I kept doing it wrong and I just couldn't get it to be at the right angle. you know, because you're not seeing it, you're not seeing how.

[00:21:42] **Marie Abrego:** Yes, definitely.

[00:21:44] **Landy Thomas:** So, I like it. And, you know, I think that in a lot of ways and this is more particular to the femininity side of disease, but it’s hard to feel feminine without being able to glam up and all that stuff. I like wearing makeup. I like curling my hair. But there's a day when, you know, if you're on a day with, you know, low spoons or even a day that you're not having capacity for mobility, that kind of stuff, just, it makes it hard. And that takes away a lot of things.

[00:22:17] For me, I really don't set aside time particularly when I was a kid and I was still feeling really, you know, betrayed by my own body to set aside time to do makeup because it felt like that was the first moment where I could really like sit down with my body again and just take care of it. It felt like an act of self-care for me. Because otherwise I felt really like, you know, kind of disconnected. Because like all of a sudden when you're a kid and you get told, hey, your body's trying to kill you. You just kind of have this, you know, you feel like you're against your body in a way. But makeup was important, you know, make up made me feel connected to myself again, and in a weird way. And that's particular…

[00:22:55] **Marie Abrego:** Yes, yes. Yeah, and not only that, but sometimes like, glamming yourself up, at least for myself, it makes me feel pretty and it brings that spark and that excitement back. And I really like that. I really love glamming myself up and dressing myself up and just all of that. It brings me happiness. And I think having that happiness can bring a person confidence and especially when people compliment you, you know? So yeah, I love, I love to glam a lot.

[00:23:38] **Landy Thomas:** Right. So, I get it. That's a, it's great. I'm glad you talked about it because it's like we're taught and raised kind of in a way where we think that makeup and whatever is stupid and it's like, oh, it just takes time. You know, it's actually really important and it helps you feel good.

[00:24:00] **Dr. Roopa Ramamoorthi:** Yeah, whatever gets self-confidence up, right? That's so important.

[00:24:04] **Landy Thomas:** Right.

[00:24:05] **Marie Abrego:** Yes, definitely.

[00:24:07] **Landy Thomas:** Yeah, so absolutely. I was glad to read a poem about it.

[00:24:12] **Marie Abrego:** Yes, yes. Excuse me again, because I totally forgot I wrote that second one. I've been having...when I wrote that one, actually, I had a lot going on. So, excuse me, I didn't remember that second one.

[00:24:30] **Dr. Roopa Ramamoorthi:** Of course, both of them were so powerful when you were writing it in the poetry workshop with me. And what I also want to call attention to is because of your blindness, you composed it just orally. And we went back and forth. And me being a poet, I couldn't compose things purely orally and correcting it too orally. So, Marie, that was really impressive.

[00:24:55] **Marie Abrego:** Well, thank you, Roopa. I mean, without your help, I don't think I would have been able to do it. So, thank you.

[00:25:03] **Dr. Roopa Ramamoorthi:** But just to recognize that it wasn't like writing, but to compose it orally.

[00:25:08] **Landy Thomas:** Yeah. Yeah.

[00:25:13] **Marie Abrego:** Definitely. It was amazing. So, thank you.

[00:25:19] **Landy Thomas:** Well, as long as it's OK, I would like to read my poems next.

[00:25:24] **Marie Abrego:** Oh, yes, of course.

[00:25:26] **Landy Thomas:** I was so excited to get to do this. I think on my mind when I was writing these poems or being part of this workshop. Like a facet of partial blindness, I was trying to highlight how partial blindness can have impacts. And also, just like how relationships can be impacted by partial blindness, which is, sounds strange, but I hope that the poems can make sense of that. So, I'll just read it. “To see is to believe, but what if I can't see? The vision wanes in ocean waves, cracks apart like an egg in black and gray veins of shadow dark. I don't care for this new mosaic. I prefer the sanctity of the old, full scene. My mother, father, friend, lover's face in complete purview

[00:26:12] unsegmented by the dark of my eye. I crave the old days where I didn't lead my body with my left side, the side where vision thrives like ripe fruit, mine for the taking. I don't care for sobbing in the parking lot at the grocery store, my mother on the phone telling her how I scraped the cars entire right side on the curb because I couldn't tell how close I was to the edge. I crave 3D movies. I crave games of catch. I crave no knocked over glasses of water.

[00:26:39] I don't care for this constant visual reminder that things are changed and that I am sick. I don't care for the fact that I could lose the other eye overnight anytime just like the right. I don't like the threat that my life could get worse. Maybe I'm childish for wishing life wouldn't change, dreaming in static, in frigid, in pause. Even if I don't get better, can't I believe I'll see better days?” Which is...

[00:27:04] **Marie Abrego:** That was really good. That was really good. That was super good.

[00:27:08] **Landy Thomas:** Oh, thank you. I appreciate it. I was just…

[00:27:10] **Marie Abrego:** I mean, you touched on so many things there, you know?

[00:27:15] **Landy Thomas:** Yeah. I mean, the part about me scraping the entire right side of the car is true. I did that. I couldn't see. I'm lucky to be able to drive. I totally admit that. But it's frustrating to, you know…

[00:27:29] Gosh, I feel scared sometimes when I drive when I don't know how close I am to the other road traffic. I don't know how close I am to the curb. I don't know how close I am to the biker that’s on the bike next to me and things like that. You know, you have to be so, so careful when you have a visual impairment and you're trying to do that kind of stuff. It's just like, because you know, I passed my driver's test. I'm good to go to drive. I've been approved for it. Don't get me wrong.

[00:27:56] But there are days that I mistrust myself. I just wish that I had that sense of normalcy that other people do. I am fortunate in a lot of ways. So, it's just, I don't know. I wrote the next poem talking more about being separate from other people, having a feeling that I'm different. I can read that one too, if you guys want.

[00:28:23] **Dr. Roopa Ramamoorthi:** Yes, definitely. Go ahead.

[00:28:25] **Marie Abrego:** Yeah, please do.

[00:28:25] **Landy Thomas:** Yeah. Ok. “It's difficult to be set apart by my vision loss, but I choose to believe for everything bad there has to be something good, and if there isn't, I'll set out to find it or I'll find a way to make it. For every moment I've spent in the optometrist, ophthalmologist, neuro-ophthalmologist, neurologist office, with a flashlight shined in my eye by the doctor himself and a long line of physician’s assistants and doctors in training. I'll be repaid in memories with my girlfriend, playing peek-a-boo by just covering my left eye, and we're both smiling and laughing about it.

[00:28:57] For all the difficulties of learning to drive, the frustrations of having so little sight on my right side, I'll be repaid in storm clouds. Sure, they obscure the sun, but for once the gray is pretty. When I get scared when someone approaches me from the right and I can't see them coming, I'll be repaid by my orange cat sitting on my chest and purring softly whenever I cry. When I'm trying desperately to take photos of myself without my right eye escaping alignment and drifting off. When I so desperately just want to be a normal girl, I'll be repaid by seeing the photos of others just like me, who I find beautiful, even if they too have an eye that floats like mine.”

[00:29:34] **Marie Abrego:** Beautiful, beautiful, beautiful. Yeah, no, you know what? It literally, like how you're saying, like, you wish that you had that sense of normalcy, but maybe it's…I guess that's what makes the rare disease community just so beautiful. We all have something that we could all relate to, you know? And yeah, that was a really great poem.

[00:30:10] **Landy Thomas:** I agree. I think the rare disease community just is the best for finding…like I love being able to go into a room with people that have my condition or a similar condition and to not have to be asked any questions or not have to over explain myself. How much time in my life have I had to spend with a friend trying to explain a condition that they don't have any basic understanding of? And then when I go to like an RNA event or a Sumaira event or what have you, I feel like I'm able to be around people that just get it so instantly. I don't have to talk too much about it. I could just say the title of the disease and they got it. It's freeing in a way to not have to feel different.

[00:31:05] **Dr. Roopa Ramamoorthi:** And hopefully this collection gives others a window into what is happening and what are the challenges and what are the strengths and the ways you'll have dealt with this so that people hope. My hope is that there's a little bit more understanding in the world.

[00:31:24] **Landy Thomas:** Yeah. I think things like this are very integral in order to make changes. I think that people read these types of things, and they see it and they share it and that's how it works. That's the best way to get across perspective and messages.

[00:31:43] **Marie Abrego:** I think this is a great way for us to raise our voice in rare eye diseases and not just rare eye diseases. I mean, a person when you're rare, you start looking into other rare things and you know, it will lead a lot of people to this poetry book, which is great because that helps us raise our voice. I love, of course; being around people that have my disease, but I also love learning and being around people that have other rare diseases. Because the more the world learns about other rare diseases and also vice versa, they learn about my rare disease, I mean, it literally opens up conversation. And that's what we need in the world is for the world to open up conversation. Because the more it's talked about, the more people want to know about it. And I think that's what we need in the world.

[00:33:04] **Landy Thomas:** I agree completely. So yeah. Well, in the end, is there anything else that you guys want to say about this collection or just *Rare Visions* in general? I think that this has been such an amazing opportunity. So, thank you guys for coming together. I was so excited to get back in touch with you both. Y'all are the best and Leah's the best too. I'm so sad that she couldn't make it, but my heart goes out to her. So…

[00:33:30] **Dr. Roopa Ramamoorthi:** You think you want to read one of Leah's poems?

[00:33:32] **Landy Thomas:** Yeah. I mean, I didn't know if Leah…I don't think Leah would be mad at me.

[00:33:36] **Dr. Roopa Ramamoorthi:** The one thing I want to say, because it's so important with something like *Rare Visions*. So, while the cover is an amazing piece of artwork by one of the contributors, there's also the artist statement so that it is accessible in the PDF. So, someone without vision to be able at least to read the writing about the artwork. I think that was very important that it is accessible.

[00:34:05] **Landy Thomas:** Right. Okay. I think it's fair to just do it. Let me just read both of Leah's poems. I think they're just so well done. I'm sad that she couldn't make it, but I think both of them are just, they're so representative of our community. So, I think that we should read them. I have the first one, it's called "A Gray New World," by Leah Campbell.

"The world, once a vibrant tapestry, now veiled in a shroud of muted gray. No brush of sunlight's color or tree leaves so green. Now just a blank canvas where colors once convened. My fingertips once transferred input sharp and true. Now numb, now devoid of texture's hue. Touch, a phantom limb, a memory. Braille's bumpy dot now unreadable to me. No click of computer keys speech my canvas now.

[00:34:26] Bridging the technology divide, my voice became the how. Your tasks, though, I'm sorry, though tasks may take longer, independence, my driving force. My voice, a bridge the digital realm, charting a new. uncharted course. But echoes of sight danced in the chambers of my mind, a guiding light, a compass built from recollection, a world bathed in memory's bright."

[00:35:15] So, Leah is also, I mean, we can provide context for her. She's also having total vision loss, and she's had it…she is the one person I know who was about my age when she got sick and has had it for much longer than me. Leah is a sweetheart and a warrior and works so hard to talk about disability, talk about rare disease. She's a champion of all that.

[00:35:44] And these poems, they read like her, like her voice. She's one of the strongest and most passionate people I think I've ever met. And when she gets into a room, she just is like the center of it somehow. I think that these poems are really representative of that power.

[00:36:07] She wrote one more, which I'll share too. It's "A Symphony of Senses," by Leah Campbell. "Sights tapestry withdrawn, a world in muted hue. Yet sounds like whispers, weave a world anew. Doves coo their peaceful lullaby. Jays screech their territorial claim. Crows caw a ruckus. A Bobwhite quail’s whistled name. Dogs bark a frantic welcome at the door, a symphony my spirit can explore. Wind whispers secret through the rustling trees.

[00:36:35] The world, a tapestry of sounds that appease, no sound inconsequential, each one plays its own unique part. These sounds become strokes, a world painted in the dark. Movement, my solace, a dance with what I know. Muscles pumping, a rhythm, where my spirit can grow. Though sightless eyes see not the path ahead, muscles move with purpose by memory led, Rhythm of a workout. the feel of the wind in my hair, horseback strides of freedom, a joy beyond compare.

[00:37:04] Numbers dance within my mind, a mental picture bright. Equations solved, a hidden dazzling light. A degree earned, testament to will. A world unseen, conquered with memory and skill. Though those sightless now, new adventures I embrace. Experiencing the world differently because of God's great grace."

[00:37:27] Both of those are awesome poems, really well done. I think that Leah has such a, like she's got such a wisdom about it. So much perspective. She's been in it a lot, like in this community, dealing with all this for a lot longer than I have. And in that way, I feel like she's, you know, she's gained a lot of wisdom on it all, perspective on it all. It's perspective that I haven't reached yet. And I feel like, you know, I feel like she's just really a cornerstone of our community.

[00:38:02] Really sweet, really kind despite it all. So, thank you, Leah. I'm sorry that you didn't get to come today, but I'm so, so just touched that you got to be part of this poem collection. I'm so glad I got to write alongside you, that sort of thing. Well, anything either of you want to say or do before we wrap things up.

[00:38:26] **Dr. Roopa Ramamoorthi:** Just thank you for all your powerful contributions and trusting me and coming to the workshops and working. I really appreciate each of you and just the amazing strength, amazing grace.

[00:38:40] **Marie Abrego:** Yeah. I'm very thankful for being part of this collection. Thank you, Roopa, for helping me write my poem. Thank you, Stephanie Meredith for connecting me to Roopa to be part of this collection and just, yes, thank you. I'm so excited that I was able to be part of this collection and thank you, Ireland, for bringing us together so we could talk about it.

[00:39:11] **Landy Thomas:** Absolutely. Ok. This is Landy Thomas with the SRNA, Siegel Rare Neuroimmune Association. And this has been a wonderful, wonderful experience. I'm so grateful to the two people that have joined me today. So, thank you guys. I hope you enjoyed listening. I hope you really got to walk away with something, and you got to see some of our perspectives. And I hope that you enjoy reading this. If you do take the chance to sit down, read the collection, it's really well done. Roopa is a wonderful facilitator and honestly, I'm so just grateful to be part of it. So, thank you guys so much.

[00:39:50] **Announcer:** Thank you to our "Ask the Expert" sponsors, Amgen; Alexion, AstraZeneca Rare Disease; Genentech; and UCB. Amgen is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare neuroimmune, and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Amgen believes science and compassion must work together to transform lives.

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