

Body Dysmorphia

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

[00:00:02] **Announcer 1:** "ABCs of NMOSD" is an education podcast series to share knowledge about neuromyelitis optica spectrum disorder or NMOSD, a rare relapsing autoimmune disorder that preferentially causes inflammation in the optic nerves and spinal cord.

[00:00:22] "ABCs of NMOSD" is hosted by SRNA, the Siegel Rare Neuroimmune Association, and in collaboration with the Sumaira Foundation and Guthy-Jackson Charitable Foundation. 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.

[00:00:55] **Announcer 2:** Hello and welcome to "ABCs of NMOSD." This episode, titled "Body Dysmorphia and NMOSD," was moderated by Landy Thomas. "ABCs of NMOSD" is sponsored in part by Genentech. For this episode, we are pleased to be joined by Heather Sowalla and Meghan Beier.

[00:01:16] Heather Sowalla is an advocate for the NMOSD community. She has been living with NMOSD since around 2004 and has since lost a good deal of her vision, but she is doing well otherwise. Meghan Beier is on faculty at Johns Hopkins and is a health and rehabilitation psychologist specializing in multiple sclerosis at the Rowan Center for Behavioral Medicine. You can view their full bios in the podcast description.

[00:01:46] **Landy Thomas:** Hi, everybody. This is "ABCs of NMOSD." Today, we are talking about post-diagnosis body dysmorphia. I would like each of you to just briefly introduce yourselves to start us off. Who are you? Do you have a disorder? What do you know about the disorders? What do you do? What are your interests? Heather, if you could start us off?

[00:02:10] **Heather Dawn Sowalla:** Sure. My name is Heather Sowalla. I am an NMOSD patient, and I am aquaporin-4 positive. I have been sick since around 2004, so it's been over half of my life now. I've really been from the highs to the lows of the disease, so talking about things like this is really important.

[00:02:41] **Dr. Meghan Beier:** Absolutely.

[00:02:42] **Landy Thomas:** How about you, Meg?

[00:02:42] **Dr. Meghan Beier:** My name is Meghan Beier. I'm a clinical psychologist that specializes in working with people that have chronic illness. More specifically, I was trained to work with individuals that have multiple sclerosis.

[00:02:57] But in my work in multiple sclerosis, I have been part of several neurology clinics that also specialize in more rare neuroimmune disorders. While I started off doing MS, I've had quite a number of patients with all different kinds of rare neuroimmune disorders and have gotten to learn about those a bit more.

[00:03:25] **Landy Thomas:** Perfect. Okay. And then, Heather, do you mind sharing just your diagnosis story? What were your initial symptoms? And how long did it take for you to be diagnosed with NMO?

[00:03:35] **Heather Dawn Sowalla:** Sure. I started off like a lot of other patients, at least some of the older patients. I was misdiagnosed with multiple sclerosis. Around 2004 was when I started to get sick, and I was diagnosed with MS by 2006.

[00:03:54] I went a couple years thinking that it was MS before they decided, 'No, that's not what you have,' because I just kept getting sicker, and I had more relapses. I basically was in diagnosis limbo not knowing what I had.

[00:04:09] We thought it was NMO, but we weren't sure. And I had the aquaporin-4 antibody test, and at the time, I tested negative. Until they tested a few years later, during a flare, an active flare, and my tests were positive. And they stayed positive since then. So, it was a long journey.

[00:04:34] I forget the exact year that I got diagnosed because they all run together. I think it was around 2014 when they decided that I tested positive, and then we knew what it was and knew we had to fight. But it was a long journey, and it was a struggle to get to where I am now. But I'm here, and I'm very grateful because it's not as bad as it could be.

[00:05:04] **Landy Thomas:** And then, Meghan, what is Find Empathy? What drew you to helping people? And how did it come to be that you started really working with those in our community to create these kinds of resources?

[00:05:15] **Dr. Meghan Beier:** Sure. So, Find Empathy is a company that I started really because of the individuals I was working with. For example, several years ago, I was meeting with somebody, and she came into the clinic, and she was like, "Oh my gosh! There's somebody that actually understands what my medical condition is? I don't have to explain for the first four sessions what IVIG is or why I need to be careful when I take steroids?"

[00:05:51] And so, the relief for her to not have to educate me was extremely eye opening for me. And so, what that said to me was that there are lots of people that have a chronic illness, who want to get mental health treatment. And they also don't want to spend a lot of time educating their provider about that, and that sometimes that education can be really exhausting in and of itself.

[00:06:23] And so, I started Find Empathy, which is a podcast, but also continuing education for mental health providers in the community that maybe want to work with somebody that has a chronic medical condition, or maybe somebody comes to their practice and has something like NMO, transverse myelitis, MS, or fill in the blank, and they want to learn more about it so that their patient doesn't have to be the educator. So, that's what we do: we make podcasts and continuing education to provide education on how to work with individuals with different kinds of chronic medical conditions.

[00:06:59] **Landy Thomas:** Every time I hear about Find Empathy it just makes me so happy because that's something that I encountered. Anyone that's wanting to pursue therapy or counseling, it is hard to give the preamble before you can even get into the meat of real issues that you'd like to address in therapy.

[00:07:19] So, thank you again for all the work you're doing with that. I really appreciate it. And thank you so much again for being on today and you too, Heather. It is really important to create resources, to do things for our community, and to make sure that nobody feels alone.

[00:07:37] And me and Heather have been patients for quite some time, which is sad, but also, I feel really bad for people that are just coming into it. I want to make sure that they are welcomed into the community with really open arms, know that they have a place here, know that they are not alone, and that other people have gone through these same types of struggles.

[00:08:00] Today, we're mostly talking about post-diagnosis body dysmorphia. As I describe it, there's just this feeling after having a rare autoimmune disease onset where you just don't feel like yourself. Not only is your body fighting against you, but you may not even be looking like yourself with the need for steroids that bloat you, or you might need new medical devices like a cane, a wheelchair, other adaptive tools, and that sort of thing.

[00:08:29] It makes you feel a little disjointed from yourself, or you have to take on a new self-conception. I've experienced it. Of course, I've experienced it as a child growing up. I was always 60 pounds. Everyone thought I was anemic or something.

[00:08:47] I got my illness, and all of a sudden, I gained 30 pounds in a month, and then 60 pounds. All of a sudden, I was the biggest kid in the class. I went from the smallest to the biggest in the course of two or three months. I also needed use of my wheelchair. I called it the Red Rocket because I was a kid, and it was red.

[00:09:10] And it was things like that where, all of a sudden, I felt not like myself anymore or just different. And in a way, I vaguely identified with myself, and I vaguely could understand when I looked in the mirror that that was me. But I had these moments where I just felt disjointed. Heather, have you ever experienced something like this? Am I crazy?

[00:09:39] **Heather Dawn Sowalla:** You're definitely not crazy. I've been through the same thing. Of course, I was a young adult when I got sick. I was around 18. When I started to get the steroids, I was 19. So, I was in college, and I was supposed to be in the best time of my life. Instead, I was hooked up to IVs, lying in a hospital bed, or I couldn't see.

[00:10:06] It really changed my life. You're right, you gain so much weight. I know I gained over a hundred pounds my first summer with a transverse myelitis flare, between all of the steroids they gave me, lying in a hospital bed, and not really being able to walk around and get all that movement.

[00:10:29] I didn't recognize myself. I hated getting my picture taken. I hated people looking at me. I was like, "Don't look at me." I was so embarrassed between the wheelchair, and then the walker, and then the cane, plus all the weight I gained. It was awful.

[00:10:47] **Landy Thomas:** Yeah. It's exactly the way I felt because I was always told, "Why aren't you running around like other kids your age?" Because if I wasn't in the wheelchair, there was nothing to really identify why I wasn't running around, other than the fact that I had the trademark chipmunk cheeks of steroids.

[00:11:10] It was just like nobody understood. Other people were weird and pressured me to be more able than I was, and just things like that. It just was really a very confusing period. Meghan, I know that it's not necessarily your field, but is there any ways that you've figured out how to advise patients that are trying to cope with the stress of having a rare neuroimmune disorder or maybe these moments of dysphoria?

[00:11:41] **Dr. Meghan Beier:** Yeah. As you both were talking, I hear this from a lot of the individuals that I work with. And some of the things that I think about are, some of this comes from having a new identity, right? So, you are maybe able-bodied, and you have certain identities.

[00:12:04] And then, when you have something that comes on like a rare neuroimmune disorder, all of a sudden, you have this new identity that might be a disability identity, right? Or maybe somebody is looking at you and they're seeing your weight, and that's an identity that's coming forward. People have judgments about that. They don't necessarily know your story.

[00:12:31] One of the things that I go to first is: what's driving the feelings behind it? Some of it is that it might be out of your control, some of it might be others' judgment, and some of it might be, 'I just don't know what to do with this new identity.' Others who have the lived experience and do research in this area of disability identity, I lean heavily on their work.

[00:13:02] And what I've heard from them is, there is a community, a disability community, or there is a community of people who might have your diagnosis. Sometimes, finding that community, and being able to talk to others who've had similar experiences and have figured out how to navigate those looks, what to tell themselves when they're feeling particularly down, or maybe just to figure out ways to be proud of this new identity, that sounds almost antithetical or it's an odd thing to say.

[00:13:42] But where can you find some pride in this identity? Those are some things that I would be looking for. And while I know I often have some strong reactions to that thought, there might be something here where you can collaborate, join with, or connect with others who have similar feelings or have figured out how to navigate that.

[00:14:11] And so, that's where I maybe go to first. Feel free to ask me other questions, though, if I am not talking to exactly what you were looking for.

[00:14:20] **Landy Thomas:** Oh, I think you're pretty spot on. I think, in my own life, I found it helpful to engage in what I call body reclaiming activities. I know it was something that really surged to help. I had it so young. I've been sick with this since I was six years old. And right around maybe 16 or 17, I started to do more of makeup. That was the thing for me.

[00:14:48] I was like, "I'm going to set aside 30 minutes, and I'm going to do makeup. And I'm going to make myself beautiful. Whatever I look like when I'm done doing my makeup, I'm going to say that I'm beautiful." And it was just these moments where I set myself aside and actually took care of my body in a way that made me feel like I was regaining myself.

[00:15:10] But I've really spent years very lost and very sad about the whole thing because it happened so quick. It takes so long, but it happens so quick at the same time. All of a sudden, your life is just completely different than the way that you wanted it to turn out, how other people wanted it to turn out, and my parents that didn't know that this was going to happen.

[00:15:34] But this has been a very difficult thing to surmount, but I think that that really helped -- even like a space mask. And I know there's got to be masculine equivalent to body reclaiming activities, even if that is a little bit different. I know, for me, that makeup was the solution. And even though I have only one eye to work with because the other one's blind, I took an eyeliner pencil stick, and I just sat down, and I learned the muscle memory how to do it while my eyes were shut.

[00:16:07] I was like, I'm going to just learn how to do it. I wasted a whole eyeliner pencil, but I figured out how to do it. And now, I could just close my eyes and do it without even looking. It was stuff like that. Even when it was hard, even when it seemed a little bit insurmountable, like, doing eye makeup with one or no eyes, it was probably pretty hard, but I still went for it anyway.

[00:16:30] And that's my word of advice on how to cope. I know it's a small thing, but I felt like it was really a foundational step for me to start taking care of myself again rather than just going from survival mode into maybe more trying to go through it, thrive a little bit. Heather, is there anything that you've experienced that was helpful on coping with feelings of body dysmorphia?

[00:16:59] **Heather Dawn Sowalla:** Yeah. There were some things that you touched on doing your makeup. I always liked doing my hair, going and getting my hair done, painting my nails, or my sister painting my nails. Just something to make you look like you're vibrant, alive, and you're experiencing life. But then, I don't like the fat shaming and stuff like that, but I was very large, and I hated my body. I hated the way I looked.

[00:17:32] I didn't want to wear tight clothes. I'd rather be in sweatpants and a baggy T-shirt or hoodie. And then one day, I decided, 'Why am I doing that? Why am I hiding my body? I really need to focus on this.' So, I started wearing, I call them the "girlier" clothes and just moved my way up and to the point where I had been getting more exercise. And that really helped induce the endorphins. I was happy.

[00:18:08] And anyway, I started to lose some of the weight. I'm still very chunky, but I've learned to accept that this is the body I have right now, and it's beautiful no matter what I look like. Even if I have five chins, I'm still beautiful -- and really trying to bring that positive energy to myself, and I think that really helped. And even if I end up on more steroids and gain another 50 pounds, I think I still need to learn to love myself in whatever body that I have.

[00:18:50] **Dr. Meghan Beier:** Do you mind if I jump in again real quick? I love what both of you all are saying. I would say a couple of other thoughts came to mind as you both were talking. Sometimes, it's helpful to distinguish whether the feelings that you're having are normal reactions to a really challenging life circumstance, which anybody who was thrust into having one of these diagnoses with symptoms and outcomes that you weren't expecting, would have similar reactions to what you both are describing.

[00:19:25] And then, there's people who might be on the more clinical side, which means, basically, that if this is impacting your life in a way that means you're disengaging from your loved ones, you're not engaging in things that you usually enjoy, it's keeping you in your house and out of the public or out socializing.

[00:19:50] If it's really stopping you from living your life, then that might be a time to seek some outside support. Whether that's with a mental health provider, whether that's with a religious leader, or with even family members who are understanding, but to get some outside support.

[00:20:10] Outside of those two things, some of my own patients have come to me with some ideas. Things like, while recognizing and acknowledging what your body cannot do and what's hard to do, they also simultaneously do some gratitude around what their body can do or what their body is able to provide. Sometimes, that balances out the negative thoughts that show up.

[00:20:38] I've also had people who've gone through anxiety disorder treatments for body dysmorphia. Some of the things that they've done is to provide some exposure to themselves by looking in a mirror and saying something like, "I have two eyes" or "I have a nose. My nose is round." Just describing it in a way that there's no judgment on it but just calling out the features.

[00:21:08] And sometimes, describing the body part in a way that's not judgmental can start to provide exposure for looking at your body and being okay with seeing it as it is, but also, quieting down those really negative thoughts that often pop into our heads because of societal judgments or other things that have brought us there.

[00:21:36] **Landy Thomas:** Yeah. I think a lot of it is internal, but some things are external too. A lot of it is other people's perceptions because you have the standards of beauty, especially for feminine-presenting people. If femininity means a lot of body care, you have to look a certain way, and you have to do your makeup or else you look tired, all those little things, that it's hard to uphold that kind of thing and live with a rare disease.

[00:22:11] I know, as a child, I felt just so ugly all the time, and I just couldn't get it through in my head. I never felt beautiful. I never felt pretty. I didn't think I'd even ever date anybody. I didn't think anybody would want me because you're so ingrained, especially in America as a kid, what pretty looks like and what pretty does not look like. It's very hard to escape those types of standards and say, "Yeah, no, I am pretty." Or, "Yeah, no, maybe somebody will want me someday." And that's really hard. I know, as a kid, I was so just upset at all that.

[00:22:54] We would go on family vacations, and that was the only time that I would be really wanting to leave the house because I was just so stressed out that people that I knew would be at the grocery store or people that I knew would see me. It felt like when we went on vacation, I was going to a place that no one would ever see me again. I would never run into any of these people ever again, so that meant I could be myself, and it's fine that I look different and look weird. While at home, I had this standard that I had to uphold, and I had a very hard time just letting go and actually being a kid.

[00:23:29] It's weird. It's stupid that an eight-year-old was so self-obsessed or terrified of being ugly, but that was just so ingrained in me at the time. I didn't feel like the little princess anymore. I felt like the ogre. But I think it takes a lot of time, especially when you're first starting out, to get to a place where you can stand yourself, like yourself, or maybe even love yourself.

[00:24:03] It's hard, especially when you're first in it. So, I do have to look back at that with a lens of time because it has been 14 years since I was eight years old. But it's just hard to extract myself from it, and it's hard to not just be still sad by it.

[00:24:24] Either way, I am just grateful that we have the opportunity now to perhaps give the next generation of people with these diseases. And I hate that they have these diseases. I don't want any more people to have these but at least give them some head start or fallback for living with rare diseases and trying at the same time to survive the mental health challenges that are inherent to this whole ordeal.

[00:24:57] Just speaking of that, people that are newly diagnosed, Meghan, is there any words of advice you'd like to give to someone who's newly diagnosed and is experiencing a mental health challenge common to just being diagnosed?

[00:25:04] **Dr. Meghan Beier:** Yeah. I think exactly what you're saying is something that I would say too -- is that find representation. Find others who have walked this path. I shouldn't say walk this path-- who've traversed this path. Because if you were an eight-year-old and couldn't see anybody else in the world that had your similar experience, 'How could I ever date somebody? How could I work? How could I volunteer? How could I be a friend?'

[00:25:48] And if you couldn't picture that because you didn't have anybody in your world who represented that, then it's very hard to feel like you can have a life. When you are doing podcasts like this where somebody can listen to it and say, "Oh, hey. This person did it this way." Or, "Hey, it's challenging to do it, but they've navigated it in this way."

[00:26:26] I think that's some place I would start first -- is find somebody on social media, find a podcast, find somebody who's been there so that you can start to create a picture in your mind of what it looks like to live

with this and also live with it successfully with all of the ups and downs. Because there will be downs, and maybe there are some ways to find the ups.

[00:26:43] The second part is, I would say, really think about what coping strategies might be most helpful for you. So, there's a colleague of mine that when somebody's newly diagnosed, and I wish every hospital or clinic did this, they do four sessions with somebody. They say, "Here are some of the strategies that we recommend when you're newly diagnosed to deal with the uncertainty of this disease or to deal with some of the thoughts that come up," or, "How do you communicate this to people who don't get it, don't understand, and might say things that are really insensitive."

[00:27:18] So, they give them some skills to figure out how to navigate some of those very common experiences. And then they say, "Come back if you need us." So, it might be that when you're newly diagnosed, maybe you do want to meet with a mental health provider, even if you're not having mental health symptoms at the time, just to say, "Okay. What's the baseline? What do I need in order to navigate a really uncertain diagnosis?"

[00:27:49] And it might only be a few sessions, but maybe it gives you enough of a head start to be able to do that. Or maybe you pick up a self-help book. I really like Acceptance and Commitment Therapy or Dialectical Behavior Therapy skills.

[00:28:05] So, there are workbooks out there for those two types of therapy. I think both of them are really great for people living with chronic illness. And if you read some of those books, they probably would give you some coping skills that you could start off with. So, I would say those are some of the starting places that I would go to first.

[00:28:23] **Landy Thomas:** That's awesome. I appreciate it. Heather, as someone who has been through the emotions of NMO for quite a long time, any words of advice you would have for newly diagnosed patients?

[00:28:36] **Heather Dawn Sowalla:** I really liked what Meghan was talking about -- going and finding someone on the social media, someone that has walked your path, rolled your path, or hobbled your path because I always said that I hobbled with my cane. Some of the support groups that are on Facebook are a great place to connect with people.

[00:29:04] But I think it was really going to one of the patient days, and the first ones that I was offered was through the Guthy-Jackson Foundation. Being able to connect with other people that have the same disease, see how they're doing, and then I could stay connected. And a year from now, I can see how they're doing.

[00:29:29] And being able to see that if they can do it, I know I can do it too because we're fighting it together. We're fighting the same war. Every case might be different, but we all struggle. We can also lean on them when we're having the bad days.

[00:29:50] So, if I'm feeling down about being stuck in the wheelchair or having to use my cane on a bad day, I know that I can go to them, and they're going to understand a lot better than some of the kids that I went to school with. Because they may have seen me every day, but they weren't fighting what I was fighting, so they didn't totally understand it.

[00:30:18] And I know, especially when I was in college, a lot of my friends were going out. They were partying or on different sports teams, and I couldn't really do that. I spent a lot of time in the library because I couldn't get out and do some of the other stuff that they were doing. So, it's like, 'What am I going to do? I'm going to go to the library.'

[00:30:39] It was just finding the Guthy-Jacksons on that first patient day, really connected me. There were people that were my age. So, they were the same age as me, going through the same motions. Some of them were in college, so we really understood each other, and that made a big difference.

[00:31:00] But then, I also found that spending time with my sister, for example, and doing, like, a girl's day out, on days when I felt good, where I could go and buy a new shirt or just do something to get out of the house really made a difference. I know COVID pushed us all back so much, where we couldn't get out and socialize, and it takes a hit on you, even the patient days.

[00:31:31] So, for those first two years through COVID, they didn't have them. So, you could really feel that you were disconnected, and it really hit a lot of patients. I know it really hit me, and I missed them. So, having that allowed me to really get myself back, I think I would say, because I felt lost.

[00:32:05] **Landy Thomas:** No. I think that is something that's really true for all of us. Now more than ever, we are better connected. I think me and Heather have been in it for a while. Back then, there was next to nothing. There was Guthy, and there was the Devic's Family Group on Facebook, and that was pretty much it. Those were the only ways that we were able to really get connected.

[00:32:31] But luckily, with the rise of so many new organizations or so many new ways to connect, I think that we're in a better spot now more than ever. And even though it really sucks that newly diagnosed patients are diagnosed with these types of things, I do have a lot of hope that they're going to have better outcomes.

[00:32:56] Physically, yes, because of new medications. And mentally, yes, because there are so many more resources, so many more people, and so many more ways to really see each other. And that's great. I'm very, very happy, that those are y'all's words of advice. Is there anything else either of you would like the chance to say before we wrap things up?

[00:33:18] **Dr. Meghan Beier:** I would say, I have worked with an organization. There's tons of great organizations like you said. I do also think that patient advocacy organizations are a great place to go. Because you not only get connected to other people who might be living with similar symptoms or diagnoses, but you also can get support that maybe you didn't expect to get.

[00:33:45] One that I really love outside of SRNA is Can Do MS. While it is MS, there is an education arm that's now coming up and getting more attention for rare neuroimmune disorders. There's even a coaching series that will be going on next year, led by mental health providers as well as other kinds of medical professionals who know these diagnoses.

[00:34:11] So, you not only get the community feel, but you also get to interact with somebody who maybe has some expertise in your diagnosis. Having that combination can be really awesome because if you just go in for a clinic visit, you might only get some of your questions answered. But if you can be part of a coaching series, then what you didn't ask the first time, you can ask the next time if something else comes up.

[00:34:37] So, I would advocate to just look at these different organizations that are around and providing education and find one that really may be having the resources that you could benefit from the most.

[00:34:53] **Landy Thomas:** Awesome. And then, Heather, did you have something to say?

[00:34:56] **Heather Dawn Sowalla:** Yeah. I was just going to say from the patient aspect, that it's okay if you need help. Don't be afraid to reach out and ask for it if you need it, whether that's help of another patient,

family, friend, clergy, a doctor, or your mental health provider. Don't be afraid to ask for that help if you need it -- there's nothing wrong with it.

[00:35:22] Even if you need medication to help you through it, there's no shame in it. So, ask for it if you need it. Don't be ashamed. A lot of us patients have been through it, are on medication, or do something to help us. Just don't be ashamed, and you're worthy. That's one of the biggest things: you are worthy.

[00:35:50] **Landy Thomas:** And just as a note, we at SRNA, have gotten to partner with Can Do MS, and they are a great organization. And please, anybody that's listening, please look out for future series. We want to continue working with them. They are really great. That's pretty much it.

[00:36:08] Thank you guys both for being on the podcast today. We are so just ecstatic about it all. Thank you so much for helping us create these resources. Thank you for helping us to help patients.

[00:36:21] **Heather Dawn Sowalla:** You're welcome. Thanks for having me.

[00:36:23] **Dr. Meghan Beier:** Yeah, thanks for having me.

[00:36:28] **Announcer 2:** Thank you to our "ABCs of NMOSD" sponsor, Genentech. 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.

[00:36:47] The company, a member of the Roche Group, has headquarters in South San Francisco, California. For additional information about the company, please visit www.gene.com.