

Community Roundtable

You can watch the video of this event at: youtu.be/8lirMOtU1mQ

[00:00:05] **Skye Corken:** Hi, everybody. Welcome to our Community Roundtable for AFM Together. I can't believe it's already our last Community Roundtable of our Awareness Months. That's so crazy. But I'm really excited. We have a great conversation lined up to wrap up our Awareness Month. Today I'm with Rachel and Sarah, who I'm going to let introduce themselves in just a second. But to get us started, first, I am Skye Corken. I am the Communication and Engagement Coordinator with SRNA, and I'm really, really excited.

[00:00:41] Just a couple of things, you can go ahead and put your questions in the chat section, but you may notice there's also a Q&A section. So today we're going to have an opportunity for you the audience to ask questions for Rachel and Sarah as we go through. So, feel free to put any questions in there and we'll try and answer them as we go. So first, we'll do some quick introductions. Rachel, do you want to go ahead and go first and just say how you've been involved with SRNA and why we asked you to do this today?

[00:01:18] **Rachel Scott:** Sure. My name's Rachel Scott and my son Braden is my link to this community. He was diagnosed with AFM in 2016. And so, we've had a long journey learning about AFM and learning about what resources SRNA has. So that's my connection here. We've gotten to go to two of the SRNA camps and we just got back from the most recent one a few weeks ago. So, we've gotten to meet a lot of great families that way. And I'm also involved with the AFMA, which is the Acute Flaccid Myelitis Association. And I've gotten to do a lot of things to help advocate for that community. Sarah?

[00:02:04] **Skye Corken:** Thank you, Rachel. Sarah, go ahead.

[00:02:07] **Sarah Mendenhall:** Hi. So, my name is Sarah Mendenhall. I was actually also - well, I was diagnosed in 2016 and I'm a college graduate. I just graduated this past May and I basically stumbled across SRNA, and they've just helped me find a community with support groups and doing the conference in October that I got to speak at, which was amazing, being able to share my story. So that's who I am.

[00:02:56] **Skye Corken:** Well, welcome, both of you. I've said this already I think twice as we've gotten started here in a few minutes, but I am excited for today's conversation just to get the different perspectives. But, Sarah, you being someone who is diagnosed, and then, Rachel, you with being a parent and a caretaker, so I think it's going to be a really valuable conversation today with two unique perspectives. So, with that, we're going to go ahead and get started. I was telling Rachel and Sarah this on the back end, but for the audience, one of the main themes that we've been trying to cover during these community roundtables is discussing new normals and what that means, because we know there's a lot of people who struggle with that.

[00:03:40] So I'm going to go ahead and put up our first question, and either one of you can go first, whoever wants to tackle it. But how has your life changed since your diagnosis or, Rachel, in your case since your son's diagnosis? And you can talk about that from your perspective as a mom. And then also building on

that, have you found a new normal? Do you identify with that term? And if so, what does that currently look like? So, whoever wants to go ahead first.

[00:04:18] **Sarah Mendenhall:** So, I feel like, any time somebody gets any diagnosis, whether it's severe like AFM or it's something more minor, we always have to change our life around a little bit, whether that be through diet or whatever the case may be, medications, treatment, with AFM it's pretty significant. I was a quadriplegic and was in the ICU for 41 days, life support the whole thing. And I don't have memory from that time. It wasn't until I really got out of the ICU that my memory started to, I call it stuck. I remember being in the hospital and having everything explained to me about what was going on and what my life was going to look like. And Dr. Greenberg telling me, "We don't know what you're going to get back, we don't know how you're going to recover," there's just not a lot of information there.

[00:05:37] And so right off the bat, it was immediately like, this is going to impact my life very much long term. And I'm incredibly lucky that I have progressed as much as I have. Most of the time it's not the case. And I feel incredibly blessed and humbled by how much I have recovered. But I mean, in regard to having a new normal, I feel like my new normal is like ever changing. It changes every day. I have my routines, I take my medications and I do go to a spinal cord injury gym, that is incredible. I'm back in physical therapy. So those things are scheduled, but when it comes to, you know - I'm dating and it's like, there's certain things that I can't do on a date, like I can't go on a hike. If somebody suggested I went on a hike, I was like, "I can't do that." So, the term new normal, for me, it's like ever changing. Every day is a new challenge, new thing that you have to overcome and deal with.

[00:07:01] **Skye Corken:** Thank you for sharing. I appreciate you bringing up the ever-changing theme within that because it is something that I've heard a lot within support groups. And yeah, it's funny the juxtaposition for that. But thank you for sharing, Sarah. And we'll come back to you a little bit to just on you graduating and your experience speaking at RNDS. I'd love to dig deeper and pick your brain about how that went for you as well but, Rachel, do you want to go ahead?

[00:07:38] **Rachel Scott:** Yeah. And I want to first say something that gave us a lot of peace in the beginning when Braden was in rehab. Sarah was in the same rehab, and I remember talking to her and she was telling us that she didn't remember anything from the ICU. So, it was really reassuring and helpful for us as parents to know that the trauma that we experienced watching our child go through like a very, very traumatic scary thing he had no recollection of. So, I think that from a parent's perspective, we have a different version of the same fears and worries that the person with the diagnosis has. So, it's helpful to listen to someone who's lived through it and say like, good news, I don't remember that particular trauma.

[00:08:21] But I think for us when we think about like the word new normal, it's something that people are really, I think, resistant to obviously in the beginning because we all assume that our lives are going to continue along one straight path. Everybody thinks that our lives will continue with the same normal way we expect them to. No one expects a diagnosis or a disaster or any traumatic incident. So, with something unknown, like AFM, we see stories of all the different types of recoveries that people have. So, I think people cling to the fact that maybe they won't have to have a new normal, maybe things will go back. So, I think it's a slow kind of, like walking into the ocean, like a slow waiting into figuring out like, what's the new normal going to be and that it's not necessarily a scary thing. Like, nobody's life goes the way that they think they're going to go regardless of if it's AFM or something else. So, everybody eventually has a new normal. Things like AFM just happened very suddenly and so we have to adapt a lot quicker.

[00:09:28] And I also think about, like, Braden was five when he was diagnosed, and he was not going to be five forever. Like, if he didn't have AFM, he still would not be five. Like I wasn't going to get to keep five-year-

old Braden, he was going to turn into a different person regardless. So, the person he's turning into is just a person with AFM. So that's different. But I didn't know what 12-year-old Braden was going to be like. Anyways, he was going to be a surprise no matter what. So, I mean, for us how life has changed since our diagnosis, he's the second kiddo in our family and we have five kids. So, we're busy and we adapt to figuring out what he needs to be included and things like - I mean, I can't speak highly enough about the camp that we went to last week because my kids were all able to participate in the same activities together and obviously, we're home together a lot in our house, but they all scatter and do their own stuff. So, it was just a really amazing opportunity to get to do things together.

[00:10:25] So there's lots of ways, whether it's like going to Disney World where it's very accessible and they are super accommodating, which is obviously expensive. But like, there's lots of ways that Braden can still be included and get to have the same experiences. It's just different. So, it requires more planning and it's challenging, but we're able to do the best we can. And I think, what does it look like having a new normal? It just means our future is a little less sure. I'm not sure what college will look like for him, what career he's going to have. When you have a kid who's like typically developing, it's anything. So, it's just a narrow window of what might be a great fit for him. But we have a lot of hope just watching other people go through this journey and a lot of peace knowing that, like, it's definitely different than what we thought, but it's not terrible, it's not negative, like it's just adapting and figuring out how we're going to do this. So, I guess that's our new normal. I don't love that word though because I feel like everything is a new normal. Like, nobody gets normal, right?

[00:11:37] **Skye Corken:** Right. And that's okay. Like, I think that's the point of bringing up that like, why we put it in quotes, because people have different experiences and they either resonate with that or they don't. So, thank you so much for sharing.

[00:11:50] **Rachel Scott:** I just always think about like nobody is like, I bet my kid is going to have a terrible thing happen to them later, like we all just assume we're going to get normal stuff, but that is generally not the case for anyone. It's just different.

[00:12:03] **Skye Corken:** Well, thank you for sharing. And I do want to expand just a little bit on what you said, because I had the opportunity to meet your beautiful family at camp. And I think your family is just an awesome example of both parental support for a child that is diagnosed and also sibling support, like seeing all the Braden siblings and you guys were such a unit and I'd love to just maybe hear, and obviously, your kids aren't here to speak for themselves. But as a mom and watching over these years, can you just talk about the sibling perspective from what you've seen and how they've handled that and just how they support and lift each other up, I guess? Does that make sense?

[00:12:59] **Rachel Scott:** Yeah. I mean, one of my sweetest little memories is when Braden was first diagnosed, my daughter was nine months old, and we were in rehab on her first birthday. So that was like traumatic for me. It's like her first birthday party was in the hospital, but Braden at that point couldn't swallow. So, we had to suction his mouth with a little suction machine. And as like a one-year-old, she would do that for him. Like she would turn on the machine and go suction his mouth and turn it off. And that was a normal thing she did. So, I love watching, I mean, it's funny because like my oldest is 14, he's best friends with Braden, like, doesn't think anything differently about him and that I think affects the way that other people treat him. Like the fact that Finlay treats Braden just like everybody else means allows other people to come in alongside and not act like it's strange that he's in a wheelchair or doing anything differently.

[00:13:52] And I'd love to say that because of our experience with Braden, my kids are like super kind to people with any disability or like really accepting, but like sometimes they're still like punk kids and say things that are inappropriate about other people. And I'm like, you can't do that. You should be better because of Braden.

But like, I think that's another good lesson I've learned is that like, I can't hold people to a higher standard about how to treat Braden then I hold my own kids who treat other people, like they still act like children and there's still like work to do and helping them learn how to interact with the world of people who have different abilities, whether it's like physical or intellectual or anything. Like, it's still our job to help create little like well-rounded people that are sensitive to everybody's differences.

[00:14:39] But I mean, I love watching them take care of Braden and ride on the wheelchair with Braden. And we try to be sensitive about not like forcing them into roles where they're his caretaker and let them just be like kids together because we want them to get to like play games together and fight together and do all the things that children are supposed to do, have little weird sibling games that they make up and everything.

[00:15:06] **Skye Corken:** No, I love that. Thank you so much. I just had to comment on that because it really was great to see and to watch. And you can tell that your - that like lesson of teaching them to not so much be his caretakers but like his siblings still, you can tell that that really translates. So, just wanted to make a quick note about that.

[00:15:33] **Rachel Scott:** Sometimes Braden will hit one of them or hurt somebody and I'm like, "You're strong enough to hurt your siblings. That's great, you punch them." He can hear me from the other room and is now yelling.

[00:15:47] **Skye Corken:** Well, thank you for sharing a little bit more about that. I do want to stick and keep continuing on the support network theme. And, Sarah, I'll have you pipe in first, if you don't mind. I want to ask for each of you what your current support network or support system, however you want to phrase it, looks like. We've asked this in the past and have just also asked like, is it something that you think in your own personal life needs improvement or what are the sources of support that you're getting at this point in time? And maybe that's changed over time since, Sarah, you were first diagnosed, but I'd love for you to tackle that one first if you don't mind.

[00:16:36] **Sarah Mendenhall:** So, my support network, it's changed a lot since I was diagnosed. Obviously in the hospital, my support network was the doctors taking care of me and my family. Once I was out of the hospital and into the rehab hospital, I would have friends come and visit, but it was a very - at that point in time, it was hard to talk about everything that had just happened because I don't think I understood what had just happened completely and I couldn't really translate that to my friends and be like, "This is like life changing." I think they all thought everything that had happened equated to a broken foot that was going to heal in a month. And that just wasn't the case.

[00:17:28] And so once I left the hospital, there was a time period where I just didn't know who to lean on and I didn't know who to talk to about everything that had just happened, and all of the fears and the worries that come with AFM because our future is very unknown for anyone, but especially when you're diagnosed with something so rare, you don't know. And it was really in those first couple months where I really leaned on my mom who had stayed with me in the hospital every day and asking her questions about, what happened? Like, what did I go through and like what procedures were done, what medications was I on? And it's not so much that anymore because I know what I went through and what happened and where I'm at now and how I got here and everything.

[00:18:34] And now it's like I get this opportunity to really branch out and make friends who aren't necessarily diagnosed with AFM but TM or MS, and our struggles are very similar, and I can talk to them about it. And I've gotten a lot of that from SRNA and speaking at the conference in October. I met a lot of great people that I'm excited to continue having a relationship with. The support groups here at SRNA are great. It's a great

way to talk to one another and really just have a community that understands what you're going through and isn't going to judge you for being angry one day, because you're going to get angry and that's just going to happen, you're going to be really frustrated that you're in this situation in the first place.

[00:19:37] But besides that, I've also been able to really start looking at communities that - I'm trying to think of the word, like places that allow people with disabilities to like to be a part of something. I was really - my family wanted to go skiing and I loved to ski before I got sick, before I was diagnosed and I always thought I was like, I'm never going to be able to do that again. Like, that's just not something I can do anymore. And it was this, like, really cool opportunity where my mom was like, no, like, let's look for something. And it was amazing that we found all of these adaptive skiing programs, like across the country. In Colorado, New Mexico, there's like a bunch of them, but we ended up going skiing in Durango, Colorado, and the community there doesn't know about AFM very much, pretty rare, but just being able to see other people with disabilities, amputees, people with intellectual disabilities, people who just like have MS or AFM or whatever the case is being able to like ski with these people and getting to like share my story, like that in itself, it was a support system for me.

[00:21:16] And even the instructors, I still am good friends with one of the instructors now and I'm already planning my next trip. I went twice this past year and it's just been great. So, my support system has really changed from the very beginning to now. It's opened up a really cool opportunity to find just a bunch of amazing people.

[00:21:49] **Skye Corken:** Thank you, Sarah. And it's interesting because I feel like I'm coming across community members more and more that are getting involved with adaptive sports or adaptive recreational activities, just what it can do for their mental health and just that feeling of inclusion of like, "No, I can still do this," it's just great to see and I think programs like that are so vital. So, I'm glad that you found something like that and we're able to find like a surprising community connection through that way. So that's great. Rachel, do you want to touch on this a little bit?

[00:22:33] **Rachel Scott:** Sure. So, I guess from a parent's perspective, my job is more to support Braden and then this third line of defense, I guess, are the people supporting like our family. So, we've been really fortunate to have family friends that think of Braden when they invite us to do something like we're going to a birthday party tomorrow for one of my little kids, but the mom texted me and was like, "Is Braden going to come? Because I'll call and make sure they have stuff he can do if we're going to a ninja place, if Braden's going to come." So, I'm grateful that we've found families that are - because we are a lot, like, besides having five kids, that's a lot, but it's also a lot to plan ahead and make sure that Braden can be included. So, we're grateful that we still have friends who are willing to spend time with us and go that extra mile to build a ramp so they can get into his house or - I mean, we've just been really fortunate with friendships.

[00:23:27] And similarly, even though most of our close friends don't have a kiddo with disabilities, it's been nice finding people who just know that their future is going to look a little different because of what kind of kids they have. So it's important to have - regardless of the diagnosis, I've been really fortunate to find just friends that we can talk about like, oh, I have to do this appointment or we have to do it a sleep study or whatever it is, like, who just like know the medical language and can just commiserate about the extra weird things that you often have to do as a caretaker. So even if it's not another AFM parent, it's really, really crucial to just find someone who gets it and can support you just emotionally in that way.

[00:24:18] The same thing, we went skiing this past winter also and that was super magical to find - I mean, everything that's like that, every adaptive thing we've ever done, we just like cry because it's so amazing to be like, people are like taking extra time to do something that like to help people. Like if there's a LEGO set

with a little LEGO set that we need to buy, that has a little skier and a sit ski, I was like, LEGO can have all my money, like, just take it. It's all, I don't care anymore. So, I think all of those adaptive experiences that we've had that are people who are willing to take like the extra time and energy to support families like ours, it's just like the most magical thing and, I mean, it's just magic. That's all I can think of.

[00:25:01] **Sarah Mendenhall:** I just want to say something really quick. I just watched the Barbie movie yesterday and there was a girl in a wheelchair that was in a scene for a pretty long time, and I just started sobbing in the movie theater. And the guy that I'm seeing, he was like, "Are you okay?" And I was like, "You don't understand. This is amazing."

[00:25:24] **Rachel Scott:** It's just special. It's important. Like, we know representation in media is important, but like, I knew that before but now I really know it.

[00:25:32] **Skye Corken:** Well, thank you, both. Sarah, I want to actually go back to something that you had said. I want to talk about RNDS because that was - you said that was so special and that was such a cool experience. Was that your first time, I guess, sharing your story in a more formal setting like that or what was that like?

[00:25:58] **Sarah Mendenhall:** So, I had never like really stood up in front of a bunch of people and said, this is my story, this is what happened, here I am now, this is what I'm doing now. I've done news interviews and I've done interviews with the CDC, but those were all different, those were over the phone or having a camera on your face, and it's awkward and it's weird and they edit it then. But this was like a really cool opportunity where it was like, I get to just like say what I want to say, like as I am in front of all these people and just like let it be raw. I cried. It was emotional because I know that everybody who spoke really touched on talking about mental health. And that was like the first time that was like, oh, wow, like these people also struggle, like, this is like a big thing. And that in itself was emotional, just hearing people bring up the fact that like their mental health suffered a lot. And I was like, I'm in the same boat, like this makes me feel really a part of something.

[00:27:18] But being able to just like stand up and share my story as it is, raw, and nothing was taken out and I got to just say like, this sucks but here I am and this is what I'm excited to do, it was really special. And then, like I was talking about earlier, I met a bunch of great people and we talked and shared stories and laughed and we joked about all of the things that people have like said to us or all of those stereotypes that we face every day if we're in our wheelchair. Or I park in a handicap spot, and I get out of my car and walk into the store, I get all of these looks like, why has she parked there? And it's like, "Well, I have a disability, you know?" And so, it's just like so nice to be able to talk about that and to have people get it. And I don't think I expected to get that out of it, but it turned out to be the most special part, just meeting the community and being able to - I was in LA which was fun, and my best friend ended up surprising me and flying out. So, the whole experience in itself was just, there's so much that was unexpected that I got out of it that I loved.

[00:28:57] **Skye Corken:** That was my first RNDS. I mean, I've been with SRNA about a year and a half now, but that was my first RNDS and I felt like - you did cry, and I also got emotional. And the community story sharing aspect of RNDS, like, that whole session I thought was so powerful and I know a lot of people really loved that session. People were like, that was my favorite session of RNDS. And I'm like, I don't blame you. Great. Well, thank you, Sarah. I just wanted to touch on that because it was such a cool moment to have you on stage and share your story and we love you for that. I'm going to go ahead and move on to the next question. But at this point, I did also want to tell the audience that if you have any questions for Rachel and Sarah at this point, you can go ahead and put them in the chat or the Q&A, and if any come up, we'll try and get to those before we have to wrap up.

[00:30:02] But I'm going to move on, and we haven't touched on this too much just yet, but I really like asking this question because it really varies and it's so personal to the person and I'd love to just obviously get your guys' perspective. But, Sarah, I'll probably have you start on this one again too, if you don't mind, Rachel. But if you're comfortable sharing, how do you view your diagnosis in terms of how it fits in with your own personal identity? And this can come in with that label of a person with a disability and how you connect with that. Do you? I think it's something that is really great to ask our community members because, like I said, it's such an individual experience.

[00:30:57] **Sarah Mendenhall:** I think my own personal identity has completely shifted since being diagnosed. And it was because of my diagnosis that my personal identity like really did shift. I was 17 when it happened, I was a senior in high school. I had all of these big plans and aspirations and what I wanted to do, I wanted to sing. I originally wanted to go to college for music and that was quickly very much taken away from me. And I was for a long time incredibly frustrated about it. But I think with AFM, it's taught me so much patience and not everything is going to work out for you and that's for anybody. Things change all the time, and it was because I didn't get to pursue that original dream and goal, I actually found something better that I love to do, which is this, like, I love talking to people and sharing my story and helping other people.

[00:32:12] So I went and pursued a communications degree, and I loved it and I'm excited to wherever this takes me, I'm still trying to figure it out. But the one thing that like is so important is viewing everything is like, just a journey. It just sounds so cliché. It's like, oh, come on. But I think it's important that - my disability is a part of me, I didn't ask for it, but I got it and I'm not going to reject that part of me because it has shaped who I am. Like, right now in this moment, like I wouldn't be here without my disability. And I think saying that I have a disability is important, because for me, if somebody saw me on the street, most likely they wouldn't recognize that I have a disability. And that's where the invisible disabilities like come into play is, like, there needs to be an advocate for people like me who don't necessarily look like they have a disability but still struggle all the time.

[00:33:32] Like, there are times where I do have to get in my wheelchair. And I went to a football game at my college and was sitting in the disability section in my wheelchair because I can't walk from where I was living to the stadium and we scored a touchdown and I hopped up from my wheelchair because I was like excited and like, people were like, what, like, you're faking it? And I'm like, that's not what's happening. And so, I think, like, just having - my disability has just completely changed my personal identity and like, who I am, what I stand for, what I want to do, who I want to be. So that's where I stand with that question.

[00:34:24] **Skye Corken:** No, I think that was beautifully said. Thank you for opening up about that. I know sometimes people are still at different stages with personal identities and a rare neuroimmune diagnosis. So, I appreciate you opening up about that. Beautifully said. Rachel, do you want to touch on this? I know this is - I mean, you could talk about, I guess, I know Braden's not here to talk for himself, but maybe how he thinks --

[00:34:56] **Rachel Scott:** He will come in.

[00:34:58] **Skye Corken:** Or even just your personal identity as a caretaker and how that's evolved and things like that?

[00:35:04] **Rachel Scott:** I mean, so as a caretaker, I try to draw a line and have, I don't want to take his identity and make it mine. Like, he is the person with the disability, he's the person with the diagnosis, and like painting myself too much as an AFM mom or something like that, like, that's fine, but I don't want that to become my identity partially because I have like five other kids also - or no, I have four other kids. I have

four other kids and I'm their parent, too. Being a sibling of a child with a disability is hard enough, so I don't want to also make it feel like I exist solely for Braden.

[00:35:42] And for Braden, speaking on his behalf, at least as his parents, we try to - and I think he does take pride in his disability and take pride in like what he's gone through and not see it as something negative. Like, I don't want him to hear the words AFM and think bad. Like, that's part of who he is and it's part of what makes him his own special person. And it was traumatic, and I obviously wish I could protect him from any pain and suffering, but it's also like contributing, just like Sarah said, you've found your kind of a different path for yourself that you wouldn't have had otherwise. And we want our kids to have good things. We want our kids to be happy and we don't want them to struggle. So, it's tough to find a balance of helping him find pride and be grateful for who he is, but also like, obviously I don't want him to ever have any hardship. So, it's a fine line to walk of like celebrating who he is, but also being like, also I wish I could take away everything hard, which is the same for any of my kids.

[00:36:43] And for myself, I think similar to Sarah, like I love doing this, I love helping parents who are at different points in their journey, make progress towards, I guess, making peace with what is the trauma that's happened. I love getting to advocate for parents and do this kind of thing. So, I don't know what I want to do when I'm a grown up either, but you've lots of times, Sarah, I don't know either. But it's been wonderful I think in just helping me relate - as I was talking about earlier with community support. It's just relating to any parent who is going through anything. Like, we have a couple little like coffee groups that a few friends and I have set up that we get together just to like talk about how we can support each other and like navigate stuff and help each other make decisions, and with kids who don't have anything to do with AFM. But I really enjoy that, I enjoy getting to like just help people.

[00:37:48] **Skye Corken:** Great. Thank you so much, both of you. This is our last question for me, and I don't know if we have any questions that have come in on the Q&A, but that's okay. This last one is actually for you, Rachel. So, in terms of navigating new normals, new routines, and you had said that it is ever evolving and there's not really such a thing as normal as you said. But do you have any advice for parents caring for a child with a rare neuroimmune disorder on that front? Do you want to go ahead and speak to that?

[00:38:30] **Rachel Scott:** Yeah. I mean, because every kid with AFM is unique and at every month to month they're changing, there's not like one piece of one-size-fits-all advice. But I think finding other parents, like the AFM community is amazing at crowdsourcing ideas and being like, has anyone dealt with this? Has anyone dealt with this? Like, what should I do about this? What kind of specialists would I see for this? Finding the AFM parents or if it's a different diagnosis, finding those parents to help just get ideas, helps give you a sense of peace that like you're going down the right path, even though we don't know what the path for it is. I think it's really important to find people just to bounce ideas off of.

[00:39:13] Braden was diagnosed in July of 2016 when he was five and then he was in hospital in rehab for like eight months. So, he came home in February of 2017. So, I carried this five-year-old out of my house to the ER because he couldn't walk and then he came home eight months later, in an ambulance, on a ventilator. So, it was strange, like that's obviously a very difference. Like, in the meantime, we had to change a room of the house to be his bedroom so that he could have a hospital bed in there and get used to what it was going to be like. We had 24x7 nursing for a very long time. We still have a little bit of nursing hours. But that is like such a shift in what the household dynamics are, to go from like, it's just my little family here to like there's this stranger in my house now, so like, shouldn't yell at my kids or whatever it is. Not that I yell, I never yell. [00:40:12] But it's still like, every aspect of our life was touched in some way, like there wasn't a corner of our life that wasn't disrupted by it. So, it was a huge adjustment at first and everything is - as it's become less new, as it's become just what it is, it doesn't feel as strange. Although sometimes, like, if someone walks into

my house, now I'm like, oh, yeah, I forget that. Like, this still isn't like "normal." Like, we have weird medical things all over the place. But once you've adapted to it, it feels less weird and you can make those little pivots of like, okay, we don't need this anymore, we're going to cut back on therapy or we're going to do some more therapy. So, I think it's just like it's an ever-evolving balance and I think it's really important for us.

[00:40:55] This has been hard for me because I think in the beginning you just want your kid to do like therapy, therapy, therapy, therapy, like all the therapy, all of the time. Like, we're just going to get as much as we can, which is why we were in the hospital for eight months because we were like refused to be discharged from rehab. But you have to listen to your child and take cues from them of, "I want to scale back on the therapy, I don't want to do this anymore." Like, we talked to Braden a lot about, do you want the nurse to go to school with you or do you want like a paraprofessional to help you? And trying to be respectful of what he wants because it's his life that he's living. And sometimes we have to be like, "No, we need to do this," but I try to listen to him and help him guide us with what he thinks is best for his routine or his therapy or whatever. Obviously, he's still a child, but we have to take our cues from him as best we can and try to let him have that childhood.

[00:41:53] **Skye Corken:** No, that's awesome advice. Thank you, Rachel. Well, we're coming down to the last few minutes, but before I close things out, did either one of you have any final thoughts for anybody watching? Sarah, if you had any final thoughts for people your age who might be watching this conversation? Just any final thoughts?

[00:42:15] **Sarah Mendenhall:** Yeah, I'll say a few things. Just this happened, it's coming up on seven years I think, since my diagnosis, and I am just now getting to a point, like this past year, where I've really been able to fully accept where I'm at. And I want to make it clear to people who either are older and they've been diagnosed or even like young kids, like, it's going to take time to mentally get to a place where you're like, okay, I can breathe, like, I'm in this spot now and it's at this point where I'm like, okay, like, I can do something with this if I want. I think there's a big pressure when you get diagnosed with something, people expect you to become like, this, like, really important advocate or speak out on things and do this. And I mean, I like to do that. It's like, I'm fine with that, but I think there's something important to be like, you don't have to do that. Like, you can just be and get through processing whatever just happens because it is like a wild journey that not a lot of people have answers to, so.

[00:43:42] **Skye Corken:** Thank you. I wish I had like the Zoom clapping reactions on here because I wanted to give you one, but that's okay. Rachel, did you have any final thoughts before we part today?

[00:43:55] **Rachel Scott:** I actually love what Sarah just said. So, coming in as the parent, like I do try to be mindful of like, I don't want Braden to feel like he has to be forced to be some inspiring figure or some like poster child or like he doesn't exist to be the object of people's inspiration or like something they used to make themselves feel good, like, "I prayed for this child today." So, I try to make sure that as much as we can, he doesn't feel like, in addition to the burden that a disability is, a burden of having to be a certain person for other people. Like, he gets to be his own person. He doesn't have to like inspire people. That's not his job. So, I love that you said that, Sarah. And he was five when it happened. So, like the way his brain is going to process it, he's not even to the age that you were when you were diagnosed. So, he's got a lot of journey in figuring out what this means to him. That's his thing that we have to support him in.

[00:44:57] **Skye Corken:** All right. Well, thank you both so much for being here for our last Community Roundtable. Like I said at the start, I can't believe it's our last one. But I appreciate both of you for opening up and sharing your personal experiences. I know sometimes that can be difficult, but just sharing in this way, it really just makes such a difference, and it really can make an impact on somebody who's watching. So, thank you both, again.