

# Raising Funds for Rare

You can watch the video of this discussion at: [youtu.be/KccE36uyhYY](https://youtu.be/KccE36uyhYY)

[00:00:04] **Lydia Dubose:** Thanks for coming to the “Raising Funds for Rare” session. I'm Lydia Dubose, Community and Volunteer Engagement Manager for SRNA. And I've asked Cheryl and Sarah to come and share a little bit about their experiences. But this is really a time for us all to share experiences, share questions, share ideas together.

[00:00:31] So the intention for this session is to learn tips and tricks for participating in fundraisers, participating in our charity walks that we call Walk-Run-N-Rolls, and in that way to support and raise awareness, raise funds for rare neuroimmune diseases. So, hopefully you'll come out of this feeling informed about how to get started and get involved, and we're excited to have you here.

[00:01:08] There's a few different ways that you can raise funds for rare. There's a one-to-one, peer-to-peer fundraisers that you can set up on the SRNA website. And then there's these larger walk events that you can participate in. I can describe a little bit later how you can get involved in a peer-to-peer fundraiser if there's not a walk in your area, or if a walk is not something that you feel prepared to do, but we'll start with our Walk-Run-N-Roll experiences with Cheryl and Sarah.

[00:01:45] So, Cheryl and Sarah, would you please both introduce yourselves, share a little bit about your background with rare neuroimmune disorders, how had you found SRNA, and just a little bit about you? Cheryl, would you like to go first?

[00:02:00] **Cheryl MacInnis:** Sure. Hi, everyone. My name is Cheryl MacInnis. I had a spinal cord stroke at C2, C4 at age 52. But unfortunately, I was initially diagnosed with transverse myelitis and not until I found the SRNA and went to many symposiums and met Dr. Pardo, did I see him in 2017 and he reevaluated all of my initial MRIs, et cetera, and he re-diagnosed me and corrected it to a spinal cord stroke. And unfortunately, at that time in 2010, it left me paralyzed from the neck down. But thank goodness with PT, I was able to walk out of the hospital six weeks later using a cane and a rollator. So, I've got many deficits unfortunately, a lot of nerve pain, et cetera, as I'm sure all of you can relate to, but I feel blessed that at least I was able to walk out of there and did not end up in a wheelchair.

[00:03:10] And since joining SRNA in 2011, I've gone to, I think, six or seven symposiums. I've participated in seven walks, which have been a terrific way to meet other members, the doctors as well, because many doctors have also participated, and just be involved in a light community, so you could have some people to share all of your concerns. So, it's been a terrific way over the years for us to be involved and help raise some money. Thank you.

[00:03:51] **Lydia Dubose:** Sarah?

[00:03:52] **Sarah Pritzker:** Hi, I'm Sarah. I don't really know how I found SRNA -- oh, I found TMA. So, before it was SRNA, it was TMA, and I found TMA and they had just like a few things and I would read online and I think part of their social media, and then I went to a gala and realized like, "Wow, there's a lot of people who are part of this and I want to be part of it." And then, in 2021, I hosted a Walk-Run-N-Roll. And then again in 2023, I hosted a second Walk-Run-N-Roll.

[00:04:29] Oh, and I was diagnosed with TM in 2006 and I was an incomplete quadriplegic, and then I was inpatient at just like a regular children's hospital, and then an inpatient at a rehab hospital with three hours a day of PT. I did a week at Kennedy Krieger for PT bootcamp. Since then, last year I also went to Family Camp, and I attend Zooms and the support groups.

[00:05:07] And so, SRNA has really been a very welcoming home of other people who just get it. And it's nice to have conversations with people who understand you on a different level. And then hosting the walk was really important to spread awareness and share awareness, because it is invisible, and we need more people to understand.

[00:05:33] **Lydia Dubose:** Yeah. It's awesome that you've both been involved in walks in some different ways, as a host, as an attendee, and you've already spoken a little bit to why you've participated in walks or what the value you found in participating in Walk-Run-N-Rolls. But can you share a little bit more about what are some of the highlights of Walk-Run-N-Rolls for you? What are some of the whys behind why people might want to be a part of that event and anything else that you'd like to share?

[00:06:07] **Sarah Pritzker:** I know for myself, I think for me it was almost a healing process of I had really struggled with even coming to terms with having TM, I know what that meant and what my life looked like after my diagnosis. And hosting my first walk was for me a very healing way of saying, "This is part of me now." Oh, I brought my shirt today, if anyone wanted to see it, in support of it. Here's my Walk-Run-N-Roll shirt.

[00:06:36] **Lydia Dubose:** That's awesome.

[00:06:39] **Sarah Pritzker:** But I think we need some orange in our life. So, for me, it was also just really nice to have a reason to share my story. And then it's also just really cool to see the sea of orange. And these people support me because they know me personally. They support me because they understand. They support because they have a family member, or there's somebody who just wants to learn. And I think that that is really important because the people who know about TM or other similar diagnoses in my life know about it because of a very personal reason.

[00:07:19] But it's one of those things that unless it happens to you or someone that you know, you don't know anything about it. And there's been a lot of people who have said, "Wow, I wish I knew more. I want to know more about that." And if I'm not wearing my brace or not holding my crutches, people would never know. So, I think it's important to make the invisible visible. I don't know. I wish there was a better way to word that but make it possible.

[00:07:45] **Lydia Dubose:** I love it. That's awesome. How about you, Cheryl?

[00:07:50] **Cheryl MacInnis:** It's funny, because I would meet people at the symposiums and then I would start to connect with people online. So, I would see where the events were, because it was so nice to connect with them personally as opposed to just making comments online or whatever. So that's why my husband and I have gone to seven. Four of them have been within driving distance, a couple of hours. But we've been crazy enough to go to Ohio--we live in Rhode Island--to go to Illinois. I became friends with Liz Beutel online.

And when she was hosting one, he had business to do in Illinois. So, we did a detour to go to that walk. We've gone to Ohio for the walk. Where else have we gone? We've been to Baltimore for a walk when all the John Hopkins doctors participated as well.

[0:08:51] So it's just been almost a healing process, because when you're talking to people online about your similar situation and then when you physically get to meet them and have that connection, and many I'm still -- you're still friends with them, now 13 years later, and you can still connect on other personal things as well. So, it's just really nice to get that sense of community and also have -- I'm very thankful that my family also supports me by going to the walks with me or just participating by contributing towards the research. So, it's been terrific in that respect, too.

[00:09:38] **Lydia Dubose:** That's awesome. So, thinking about being a part of an event, like a Walk-Run-N-Roll, or thinking about trying to raise money or to spread awareness can be really intimidating for folks who have never done it before, and so how much can you relate to that feeling and what advice would you have for others who want to be a part of these kinds of activities?

[00:10:00] **Cheryl MacInnis:** Me, a lot, because I feel like -- because I'm sure because Sarah has dealt with the illness almost as long as well or longer, you keep asking them every year, "I'm doing a walk again, can you please contribute?" And thank goodness, they've been forthcoming with that. I'll just say if one comes in your area, just do it. Even if you end up going alone, everybody's very welcoming. Bring one family member or a friend, and don't have people put pressure on it. Sometimes they feel if they don't contribute X dollars, then they shouldn't contribute at all. Every little bit helps, even if it's a dollar or five dollars, whatever. Every bit goes towards, because we were all surprised.

[00:10:53] At least the walks I've done, I think almost every walk has raised over \$10,000. And we don't have a big group of participants, but everybody's amazed that, whether they're family friends or if you're working, many companies have also been very forthcoming and contributing. So, I would say just go for it and do it and don't panic, it's not a 26 mile. In some cases, it's only a quarter of a mile, but it's more of a social event than it is doing like a walk, but it's well worth it.

[00:11:34] **Sarah Pritzker:** I don't even think mine was quarter of a mile. You guys walked very far.

[00:11:39] **Cheryl MacInnis:** One of them was almost two, and they took the picture before I finished because everybody that had TM or related illness had wheelchairs. I was the only one walking. So, they were cheering me on as I walked up the hill.

[00:12:01] **Sarah Pritzker:** I think it's definitely overwhelming if you're like, "I'm going to do this," and if you are doing it, I would say, give yourself time and give yourself obtainable goals, because I think my first year, I gave myself unobtainable goals, and Lydia was like, "It's your first one ever. You've never even hosted people in your house for dinner, like, chill, bring it in." And then the next year it was just build on it. And I think I totally agree with what you said, Cheryl, even if you go by yourself, just go, because there were four or five people that came to the walk that I didn't know, they didn't know anyone, and every single person there, you automatically know you have one thing you can talk about, what brought you here. And that in itself is -- you already have a bond; you already have a connection.

[00:12:58] And then it's also a great way to find community people. I went and found a bagel shop, and when I told them what it was for, they were like, "I've never heard of this before, but I love this." And when I went to pick up the bagels the day before, and I got there an hour early, they're like, "We're out of bagels today. We're donating them to a good cause, you missed it." And I was like, "Oh my gosh, thank you." But you still have an

hour to sell things and they're like, "No, we want to really support the people in our community." So, it also just kind of, it helps you find the good in people, but I think go slow and remember that every little bit counts.

[00:13:37] **Lydia Dubose:** That's great advice. And we only have a couple of minutes left. I know this is a really short period of time we have together. A big thing for us is thinking about the future with -- we're looking back at the last 30 years of SRNA, we're looking forward to the next 30 years of SRNA. So, what are your hopes or what is your vision for Walk-Run-N-Rolls in the future, or for similar events like that in the future?

[00:14:07] **Sarah Pritzker:** That it becomes like those walks where they block the streets off because hundreds of people are coming, and people know what it is, and it's just known.

[00:14:21] **Cheryl MacInnis:** I would add to that, Sarah. I think it would be wonderful if there was one in every state, because I think it's been pretty sporadic. I don't think there's more than maybe a half a dozen or so that have gone on, but it's almost the same states are doing it. So, if the word continues to spread more that maybe there is at least one in every state, I think that would be fabulous to work towards some goal. Maybe there's only two or three or half a dozen extra every year and it multiplies from there to spread the awareness that way.

[00:15:02] **Lydia Dubose:** That's awesome. It's a beautiful vision. I love what y'all said. Awesome. Well, I wanted to make sure to mention also, I know we focused mostly on Walk-Run-N-Rolls, but also other ways that people can get involved in raising funds. You don't have to be a part of an event in your local community to be a part of raising funds and raising awareness.

[00:15:28] We had several people last year who just set up their own fundraiser through our website and they had different projects or different things that they did to raise awareness. There was somebody who was the spouse of somebody diagnosed, who had some races, like triathlons that he was doing. So, he was raising awareness doing that. There was somebody else who -- she was in the UK, and she did this plane walk. You were on an airplane, and it was a physical challenge and raised awareness in her community that way. And then there's somebody else who is marking a significant milestone of living for 10 years with transverse myelitis. And so, they marked that as a time to raise awareness and did her own challenge. She does rowing and so she did this rowing challenge for her 10 years and raised awareness that way.

[00:16:30] So, there are lots of ways to get involved. If you can be a part of a Walk-Run-N-Roll, that is always amazing. But our community is always very creative and imaginative, and there's always new ways to raise awareness, new ways to be involved. So, I encourage folks to consider that as well. But that brings us to the end of our time. Cheryl and Sarah, is there anything else that y'all would like to share?

[00:17:03] **Cheryl MacInnis:** I'd just say to everyone, we're all in it together. Everybody understands what you're going through, even if it's not the exact same diagnosis, but we're all there to listen. And if you have an opportunity to go to an event, whether it be the walk or symposium, whatever, go and meet other people and just make that connection.

[00:17:27] **Sarah Pritzker:** I think use the resources that SRNA has, because there are so many.

[00:17:34] **Lydia Dubose:** It's been wonderful. Well, thank you, Cheryl and Sarah, and thanks for joining the "Raising Funds for Rare" session.