I am the past CEO. I just stepped down in this month in July, but PWSA USA is a national organization for families. It's been around about 50 years. In 2025, it will be 50 years old. And our organization is here to serve families who've been diagnosed with, their children have been diagnosed with Prader-Willi syndrome. And we have three pillars. We have advocacy and awareness, family support, and then research. And we are here from the time that the child is diagnosed in the NICU through their lifespan. And we've always been very strong in family support. In the last couple of years, we've really expanded our advocacy and awareness pillar. In fact, last year we actually went to DC and we took over 50 of our families, advocates to the Hill and had over 75 meetings with our representatives. And even had an opportunity to meet one evening with the FDA, the head of CDER, which is the area where any drugs for PWS would be approved. So that was an exciting meeting. And actually from that meeting came an opportunity for PWSA to host what's called an externally led PFDD, patient focused drug development meeting. And we just had our national convention, which is every two years. We had that in June in Orlando, Florida. And we had one day, a half a day that was dedicated to an FDA meeting where families could come and talk about their experience of living with Prader-Willi syndrome and really reach out to the FDA and tell them what we need as far as treatment approvals. We have many, many resources. So our website is pwsausa.org. And when you go to the website, there are several tabs. One of them is a resource tab. And under that, we offer all kinds of information from medical information, we call it medical issues A to Z. And so anything that you're wondering about Prader-Willi syndrome is under the medical A to Z. We have a new diagnosis form. So if you're newly diagnosed, you could fill out the form and we send you a package of hope, which is again, just information about Prader-Willi syndrome. We have a newsletter, it's called The Pulse. We email that out every two weeks. We have a huge resource library. We have a school success because once your child is in the school years, school age years, there are different things that families need to understand. They need to understand the IEP process and how to work and collaborate with schools so that we have a whole section on school success. And then we offer webinars just from our conferences, we've hosted several just learning webinars on sleep issues in PWS. So there's a lot of resources there, but our website is a great place to go to check out just everything that's going on and get up to speed on all things PWS. When my son was diagnosed, he's 13 now, we were at Children's Hospital here in Omaha and it took us quite a while to get a diagnosis. For the first three to four weeks, they really couldn't figure out what was going on with him. They knew that typical characteristics of Prader-Willi syndrome are floppy babies. So when you hold them up, they just have no muscle tone. He was unable to move his arms, legs, head, anything. So once we received the diagnosis, then obviously we started trying to educate ourselves and reach out and believe it or not, I mean, that was 2010. And there really weren't Facebook groups at that point. There was a Yahoo email listserv type thing, which it doesn't seem like it was that long ago, but we've come a long way in the last 13 years. So once I discovered PWA USA, I started reaching out to them. And then in 2000, I believe it was 18, I became a member of the Board of Directors. And I was on the Board of Directors for a year and their current CEO left and they asked me to be an interim CEO. And I did that starting April of 2020. And then about six months later, they said, hey, would you be interested in taking this on full time? And my previous career was, my last job was 20 years in banking. So I didn't really have a lot of nonprofit experience, but I knew I could bring my business experience to the organization. So I said, sure, I'd love to try it. So it was a great experience for me. And I'm really, really happy that I was able to serve in that capacity for three years and serve the community that way. We made great strides, both financially and expanding our programs and also putting a new emphasis on research. So I'm really proud of all the things that I did while I was there. And then the team that was built, we have a great team there. But again, I was never really looking for it. Another job that was 50 plus hours a week. And I was spending, we have 15 team members, but we're all working very hard in long hours. And I made the decision after our conference, which was wildly successful. This year we had over 1,010, a lot of pharmaceutical

companies and new families. And I thought, this is a great time. The organization is doing really well. So it's a good time to kind of step down and let somebody else take over and get a little more balance in my life. Again, with my son being 13, he's going into seventh grade. And I just wanted to spend these last few years not working so many hours and trying to have a better balance. So that's sort of my journey into the PWSA world. And I guess I should add in 2019, I believe it was, I also organized and founded the PWSA Nebraska chapter. And so we had our very first meeting I believe it was February of 2019. And we had over 30 families from across Nebraska. We had one family from outside or one or two families from outside of Nebraska as well. And our goal there was to really have a place locally that people could go and share stories and help each other. Once they took the job at PWSA, we started, we weren't able to focus as much on the Nebraska chapter plus COVID hit. And so it's still there, we still have it, it's active. We have a Facebook page, PWSA Nebraska. So we're still here to support any new families. Many of us have been involved in the different hospitals in NICUs like at Methodist and Children's and University of Nebraska. So a lot of people know how to reach us if they have a family that is diagnosed, but it's still a really rare genetic disorder. And a lot of people still really don't know a lot about it. So there is that resources for both of the organizations for the national and the local, the Nebraska chapter. It's really about the community that we're building and getting to know other families that have children and adults now with Prader-Roulli syndrome and being able to just share life with them and figure out, if I have this issue, have you been through that? What resources do you have? So that's been great. I think on a national level, it's really just trying to get the word out to families to let them know we're here to help and support them and just be another set of ears and helping families. It is a different disorder. It's a little hard to understand. So many families, it's hard to even explain to their immediate family, let alone their, once their children hit school age, the teachers and everybody in the community. So I think the most rewarding part has just been able to help families and then get the feedback that, gosh, this helped or that helped, or having you come to an IEP meeting made all the difference in the world. So I think those things, just the messages from families. National organization, if they go to pwsausa.org, again there, that is our main website. And there are a couple of options. Like I said, there is the newly diagnosed, there's a little button you can click. You can join the newsletter and receive that newsletter. You can also just send an email to info at pwsausa.org. And ask a question. And one of the family support coordinators or somebody from our advocacy group or our parent mentor will reach back out and communicate with families. A lot of times there are family members that once you get the diagnosis, some people dive right in and they get involved. And some people take a year or five years. There isn't really a good or bad time to get involved. Obviously, the sooner you get involved and educated, the more you know, and the more help you can get. And I think probably not unlike many people, it was hard for me to ask for help. But once I realized that these resources are there and people have been there before me and can really help my child live his best life, I think there's such a comfort in community. And so I would encourage people to reach out and either again to the national organization or locally. When you get to our Facebook page, there are a number of us that will answer questions as well. And yeah, just don't be afraid to ask for help

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