



Voices
OF OUR REGION
THE DISABILITY CONNECTION

Interviewee: **Tammy Harper**

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Interviewers: **Athena Aardweg & Tony Buba**

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Track 1
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Tammy: I am Tammy Harper. I grew up in the city of Pittsburgh, Pennsylvania. I lived out in Washington County which is a very farm rural area for some time. Then moved back in the city again as I graduated high school. Then met my husband, got married. Then four years later, had my first daughter, Samantha, who's now going to be 15 the 29th of this month. The day in the hospital when she was born the doctor said, 'There's something wrong with your daughter's skin. We do not know what, but there's something wrong.' And it wasn't the typical, as I know now, when a baby's born they put the baby on your stomach and oh hurrah. It was kind of like they took the baby away right away into, I guess, the separate room. And I wasn't...I wasn't really sure being that she was my first that what was normal and what wasn't, like I said. Then soon after they got some specialists to come in the room and then they said, 'Well, she has a skin disorder. We think it's a Lamaller Ichthyosis. We're not sure. We're going to get a specialist from Children's Hospital Pittsburgh, in the dermatology department.' So, of course, another day of waiting and he still wasn't sure. So they said when she was about three or four months of age they would do a skin biopsy and then they can determine better which type of ichthyosis she had. And, well, they did that and they said it was Lamaller. Then they suggested that my husband and I not to have any more children because it's recessive genetic, which means that we both were carriers of this and it could be pretty horrific, although her case was not. Then we realized by the time she was 12 months, 15 months, 18 months she wasn't walking and I kept bringing it up to my pediatrician. And he said, 'Oh, it's okay. Some kids, you know, it takes a little while.' I wasn't comfortable with that so I did call a specialist at Children's Hospital and the orthopedic area of the hospital and a doctor saw her, and at the time he just said she had flat feet. And I just was not comfortable with that at all. So then I talked to some people, family members, and they gave me a different doctor's name. So we went to see him and I told him our frustration what we thought and what was happening. So he was wonderful. He took a lot of time with us and Samantha and he had her walk, try to walk, all over his office. And then he did decide that yes, she had spastic dysplasia. It's a form of cerebral palsy. And with that said within a few months time I got a phone call from my pediatrician and asked me to meet with a mom that had another girl with a form ichthyosis. And we did. We talked on the phone for some time. And then she encouraged me to go down to the National Institute of Health so they could study Samantha and her skin disorder. She was about 2-1/2, 3 years old. She was still pretty young at this time. And so we went down and they took another skin biopsy down there. And they had said that with that they weren't really sure. And he took her skin biopsy and did some gene workup on it was confirmed she had ichthyosis shorin larsen's

syndrome and she was, at that time, the third in the country confirmed. And what that meant, it gave me answers. But, you know, knowing...doing that really helped me with her. She's done really well. She's had a few surgeries. I have a plethora of ointments and creams and glycolic acids, and shampoos we use on her, and scrubs on her skin daily. And I have 21 hours of nursing services for her that...to help, even at this age, to care for her skin. Because it's hard for her to do with her CP to take care of herself. Knowing what I went through with her and the fighting I had to do, in a sense. And there were fighting. There was fighting involved with the insurance companies to get things covered. With all that knowledge, now that I have divorced, remarried, two more children. Lydia and Weston. Lydia is six and she actually was diagnosed at the age...Well, we finally had a confirmation last fall of metabolic genetic recessive disorder. Completely different. So, I married a different man and carried...I carried that gene and he carries that gene. But I did my own research as far as how to take care of her because she would wake up. Oh gosh, starting about the age 18 months, maybe a little older. Let's see, she walked at 15 months and then a little after that the behavior really started where she'd tantrum through the night. She'd wake up screaming and these massive tantrums throughout the day. They would last 45 minutes to almost two hours sometimes, nonstop. And then she couldn't speak, so she couldn't tell us what she wanted. She didn't know how to tell us what she wanted even though we tried. So, and then I took her to the doctor's and, of course, a lot of people just said, 'You know, you have an older daughter with a disability. You think there's something wrong with her. She's fine.' And I thought, 'Oh, no no no no. There's something wrong with this child. I knew it.' It was a long road even with her through the Children's Developmental Unit in Children's Hospital. Thank goodness for the doctor there that sent us out, on our way with a lot of different testing with an EEG, a neurology. They found she was having seizures. And, you know, we never knew it. Went to Dr. Faber at the Children's Institute who sent us on the road of recovery, in a sense, as far as at least finding out what was going on with her internally. Why...How...Why was this affecting her? So we found out she's...you know, she can't have dairy, gluten, and soy, which soy is the worst thing for her. And it was affecting her behavior. So complex and hard to understand and, you know, like I said, because I learned so much with my older daughter I was able to persevere through this with her. Which was actually so much harder to deal with, the behavior aspect, the mental health arena, is for me, is so much harder to deal with than the physical or cognitive. It affects everyone. She had a skin biopsy as well. To send it to the Netherlands to test for certain disorders over there. And they ruled out a couple different very, very rare ones. It turned out she has what's called orotic aciduria syndrome. With her it presents itself as autism but not all cases. It's behavior...It affects the behavior with the food. How they ingest the food. The metabolics of it. How we metabolize everything and how it acts as a drug in her, you know, her body and sends these neurons to her brain that would make her act a little like she's on drugs. And I got this one book that really helped me understand more to it than what I'm thinking I'm doing. Am I doing the right thing? I don't know. Let's test it. How do we test it? Then I realized she has an extensive amount of allergies and sensitivities to many foods. But, with removing them, and she's on a plethora of supplements, and vitamins and minerals

to replace what she's not getting. She is doing so phenomenally well. Unbelievable. She's actually in the gifted program at school. She's in kindergarten. She's reading sometimes at a fifth grade level. So next year they're putting her in the scholars program all the way. And I'm just grateful, like I said, from knowing what I went through with my older daughter I was able to keep, you know, going to these specialists. Not being told to go. Not being told to go to the geneticist. I thought, they're giving me all these different diagnoses. I went through this with Samantha. And they kept telling all these different diagnoses. And it finally ended up with her, like I said, one...one diagnosis. Now my son, Weston who's four. He's had a lot of behavior issues. And not autism. We took it as, you know, the other girls are getting all this attention with all these professionals coming in and here's he, just off by himself, and I have to deal with them as well as the children. So, I had him evaluated a few times. And finally...And they kept just saying, 'Well, he's just, you know, what's going on in the home? I had him with me one day with Lydia at Dr. Faber's office, and he was just going ballistic in his office in front of doctor. He was just throwing toys and up and down the wall. And I said, 'Dr. Faber, I am so sorry.' He says, 'Tammy, I need to get to see him. We have to do testing on him, too. He is a sibling. And if this is genetic there is a chance he can have a component.' So, we went through again, all the blood work and the urinalysis. The poor kid being picked and prodded, and all the blood being taken from him at a young age. And he, too...But he diagnosed him with ADHD, Attention Deficit Hyper Disorder, combined type, which meant, along with that, which again Lydia had, too, oppositional defiant disorder. But not severe. And I say not severe because at a young age, with him, I know he had a lot of sensitivities to food. But when Dr. Faber did do all the testing he found out, he, too, had to be removed from gluten and soy. The gluten was doing it. I met a woman where she has a heart for moms that have kids with special needs and especially those with autism. And we met, oh gosh, I guess a year ago at McDonalds. And we exchanged numbers and she...we're starting this program, Special Families, Special Friends, so, we're trying to get volunteers involved in helping families that have special needs children or someone they care for that can't do stuff for themselves, but with volunteers going in and helping. So, it's a long process, but we're starting that, so. That's where I get my joy. My heart goes out to the parents. Obviously... let me quote if I say this I'll calm down and go back to statistics, get my mind going. I've been to conferences, church conferences, huge ones, based on disabilities. And I've learned through going to that one 75% of families that have a child with a disability or a serious medical condition end up in divorce. Okay. Eighty percent of that with an autistic child. You put so much into the child, into the situation, there's going to be lacking with the husband and wife aspect. When the two need to both come together and get that happy medium to say okay, I understand you're going to do that. Or I understand you're going to do that, but let's keep time for ourselves because that's the most important thing. So, I mean, that's just part of it, plus there's always other issues involved. But I think...So I really didn't feel I had a lot of support there because, number one, with my first husband and family, denial. Denial and blame. The blame issue. They wanted to blame the doctors, they wanted to blame every, instead of, me, I don't want to blame I just want to get the help and get...get it right as much as I possibly could and get some answers. Then denial, partially, and in the

beginning, and just kind of like, I don't deal with all that because it's too much to think about. It's too much stress. I've got enough stress here at work and da da da, which is true. Honestly my support is probably my faith. So through my church I got a lot of those answers. When I first went to my church and felt like that was my home in a sense my faith, and I realized, but Sam was little. She was three. She was in a big walker. And I took her down to the big mini-children's ministry and when I went in there, and she wasn't like the typical kid. She had to be looked out for more so she had to be, really brought along side when they would take the classes and go from this area of the church to the other, because they're moving around. I went down one day she was left behind. She was by herself, three years old, bewildered. I was heartbroken. I was upset. And I went and talked with my pastors. And I went and talked with the woman who runs the children's ministry. And over a period of years, because of that, we went from nothing to a...it was started the Angels Helping Angels ministry which is now called the One to One program. It's a...an aid for all the kids that have special needs and diagnosis in the classrooms, to a special, when they built a wing on a floor for the new children's ministry, I pushed for a special needs room. So we have it's own room for sensory issues for children with autism and a place...for a resource room for the parents to go or the teachers to go to get stuff they need for the kids to help modify the curriculum. Just this past year was the first year with a separate room for kids, maybe that don't quite fit into the big church setting for kids. That it's a little more crazy or too much overload sensory. So they have a special...a teacher with a special ed background that teaches these kids and it's...so it's its own class. But most kids are included in all the classrooms with their peers with an aid, if they, you know. It's all volunteers. They're trained. And I was the, you know, first coordinator to run the program and I trained the people taking over.

Interviewers: What would the last bit of advice you would give to somebody?

Tammy: Don't give up. Never give up. Persevere. See you guys can get me crying and I get so emotional. My pediatrician, said that, they and their whole medical career of schooling they were only taught maybe 10 seconds they talked about this. Ten seconds of it and that's it. So he said that basically we were going to teach the doctors. And so with that said, that empowered me as a parent to really pour myself into understanding what she had and understanding the terminology that these doctors use. When you research some of this stuff it goes back to the '40s and the '50s. And it's all in these medical journals and these huge words you have to research what every word means, read it 20 times for it to sink in, and then so you can share and explain to other professionals and doctors that your seeing and they look at you, 'I'm a doctor, but what does she have?' You know. You know. So I would actually have to be their teacher, their instructor. And he empowered me to go forward with that. Gave me the, like, oh okay, even though you're a doctor I'm going to know more. So, I'm going go...I'm going to teach you. The history of all of this. Just grateful that there are...there is a lot of help out there. However, you know, as a mom who will continually go through this standing out, I see where things could be better. And what I would like to see is some type of task force of parents, with much experience, to go in maybe certain areas of the

disability community or the medical aspect or the mental health community to maybe come up with, where are the greatest problems and let's make a team. Let's bring some parents in to be part of that team to really start implementing what might help.