Parenting is Hard

Part 1

You can watch the video of this podcast at: youtu.be/uncptc08NLk

[00:00:02] **Krissy Dilger:** Welcome to the SRNA "Ask the Expert" podcast series, "Research Edition." I'm Krissy Dilger, and I'm excited to introduce a new miniseries exploring an often overlooked, but deeply important topic, the experiences of parents raising a child with a rare neuroimmune disorder and how this impacts their other children.

[00:00:24] Joining us for this special series is Barbara Babcock, a family therapist with the UK's National Health Service. Barbara has conducted insightful research into how parents navigate the needs of their non-diagnosed children alongside those of a child with a rare neuroimmune disorder.

[00:00:43] Through this series, she'll share her findings and offer guidance for families facing these unique challenges. Barbara holds a Master of Science in Family Therapy from King's College London and a Master of Arts in Coaching Psychology. You can find her full bio in the podcast description.

[00:01:02] 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. This episode is moderated by Rebecca Whitney and made possible in part by the generous support of Amgen; Alexion, AstraZeneca Rare Disease; Genentech; and UCB.

[00:01:27] **Rebecca Whitney:** Welcome to the podcast, Barbara, and thank you so much for joining me today for our new podcast series featuring experts in parenting children with the rare neuroimmune disorders. And I would like to start by asking you to introduce yourself. Tell us a little bit about your background and how you came to do this work.

[00:01:55] **Barbara Babcock:** First of all, I'd like to say thank you for having me here. I'm really excited. It's a real opportunity. My name is Barbara Babcock. If you listen to my accent, it's American. However, it's shifted over the years since I've been in the UK for 20 plus years now. But I'm originally from Pennsylvania, the Northeast part of the state.

[00:02:21] I came into this work initially in 2008 when I had an episode of TM myself as an adult. And I, of course, looked for support and came across the Transverse Myelitis Society here in the UK. And I attended the support group meetings to find out what is this thing that I have and how long will it last. In the scheme of things, I had a good recovery. You wouldn't know that anything is wrong with me. What I have are some leftover ongoing residual symptoms that are invisible.

[00:02:59] And I attended the meetings, and I was asked, did I want to be on the committee, the management committee for the charity? So, I said, “Yes.” I was a trustee for three years. And then in 2013, I was elected its chair, and I served as a chair of the Transverse Myelitis Society from 2013 to 2016.

[00:03:21] And while doing that I was really noticing there isn't much done for families, particularly families who have a child with one of these rare neuroimmune disorders. And I thought, "My God, something is really lacking, and we need to do something about this." And I knew they had the Quality of Life Camp that the SRNA did in the US. I thought doing something like that here would be good. And I was keen to have UK Healthcare Professionals because our healthcare system is different.

[00:03:56] **Rebecca Whitney:** So different. Yes.

[00:03:57] **Barbara Babcock:** Very different with the National Health Service called our NHS. I wanted the families to be able to start to network with this community as well because it's useful to know that they can know, "Oh, well, if I want to get a second opinion or I want a referral, I can name the neurologist I want to be referred to for my child."

[00:04:19] I wanted them to get to know the medical professionals, the healthcare professionals in this country. I did a feasibility study in 2013, including speaking to some parents in the UK, and that continued into 2014. Did put a budget together, and I found a charity to run the event through something called The Calvert Trust here in the United Kingdom where they provide a whole suite of outdoor activities that anybody can do. They adapt everything. No matter if you have a tracheostomy, whether you're on a ventilator, whatever, they adapted.

[00:05:00] And so I worked with them and ran our family weekend from 2015 to 2019 for families from the UK, and sometimes further afield from Europe, would come and attend this weekend. And it was about individual well-being for every family member, but also for the family collective well-being. That by doing these challenging outdoor activities and adapting it, they could take that ethos back into their home life.

[00:05:34] **Rebecca Whitney:** Love that. I love that you thought of the programming for the families, and it is so important. And like you mentioned, our SRNA Quality of Life Family Camp impacts not just the child diagnosed, not just the parents, but the siblings too.

[00:05:51] **Barbara Babcock:** Yes. And that was a key thing as well. We even provided a forum within the weekend for the siblings, and for the children with the condition, just the children. Because we had a Q&A between the adults and the medical professionals, but not between the children, including the siblings. And so, it was a forum for them to talk about questions they had, to ask each other questions, which would happen, and for siblings to talk about their own concerns.

[00:06:20] So, it's really poignant to watch that take place, and it just gave us a better flavor how can we support these families. But I also very interested in research. So, when I did a master's in what is known as coaching psychology or psychological coaching, and when I did that research, I focused it on adults living with rare neuroimmune disorders and the person they consider their primary caregiver.

[00:06:52] What happened with that is I ended up working with mothers and daughters. It wasn't planned. So, I coached mother and daughter pairs. On the whole, there was one person who it was just – I just coached the mother, and it was looking at the themes that came out of that research. Then this time around when I did the family therapy master’s, I thought, "Well, this time I want to focus on the children. I want to focus on the families where they have a child." The work at the Family Weekend inspired me to train as a family therapist.

[00:07:30] And how the topic came about, I might be answering this question -- you might have this question. I'll probably be answering it now, is when I approach research and when I approach the family weekend, a key value for me is around co-production. How can we do with families rather than do to families?
[00:07:55] So, it's very much about collaborative working. So, in a Facebook group for parents, I asked a

question, "What do you want me to focus on? What is your biggest concern regarding the impact on family dynamics, given I'll be studying family therapy?" And 16 parents participated, mothers mainly. And 11 of the 16, which represents 69%, said I'm concerned about the impact on the siblings.

[00:08:29] **Rebecca Whitney:** That's really interesting. Really interesting.

[00:08:32] **Barbara Babcock:** And so, I thought, right. There is something around with research. It's about involving the people from the beginning. What concerns you? And then involving them in the research then. And then at the end once everything's been written up, sharing it saying, "Right. Here are the outcomes." "What do you want to do with these? What would be meaningful for you?" So, it's like bringing it full circle.

[00:09:04] **Rebecca Whitney:** And when you were at your Family Weekend, was there anything in particular, any situation or circumstance, that really drove your focus on those siblings? Any situations that stood out to you or emotions that maybe you felt come across from the families?

[00:09:31] **Barbara Babcock:** Good question. There's a range of things that came out for families. I noticed the emotion the parents felt regarding the situation to the family. The dreams that they have for their family, all of a suddenly are shattered. And dreams for a child, they're shattered and is wondering what will happen and that uncertainty because you don't know.

[00:10:07] I noticed how the kids fairly quickly jelled and started to play together. And after a couple of years of running the camp, it was like I made sure to design that introductory activity, introducing everyone, a way that enabled people to make connections on different levels. So, getting all the siblings together in this age group so that they could start to meet one another.

[00:10:35] At that time, the impact on the family was probably more figural for me than just the impact on the siblings. I'm trying to think of was there a specific moment where it was just the siblings. What I do remember is in the Q&A for the young children talking to the medical and healthcare professionals, the type of questions the siblings would ask. And I won't repeat them because in some cases this was a confidential thing.

[00:11:15] And they would -- some would talk about their worries about their own life. "I have a query. How am I going to deal with X? What am I going to do about Y?" And then they were just queries running their own life. And what we would do is open the floor to: “Has anyone else in this room have that same issue?”

[00:11:36] Several kids would raise their hand, and we'd be like, "What did you do?" And then they would share the information. "I tried this, and I found this really helpful." And someone else said, "I did this, and I did that." And the young people they would find that, "Oh, that's really useful. Thank you." So, it was noticing how the concerns that they had and how they brought that up in the group.

[00:12:03] **Rebecca Whitney:** It's very interesting the power of the different communities that we can parcel out of this rare neuroimmune disorder community and families and then the sibling peer group and making sure that they also can recognize that they're not alone and that these disorders are indeed a family diagnosis. It changes the family. I sincerely appreciate that you recognize that a family's dreams can be shattered. Going back to your research, if you can share with us the title and what you identified. You have some themes that really stood out in your research. If you could just walk us through those different themes, we'll start there.

[00:13:03] **Barbara Babcock:** The title is a bit of a mouthful, but in some ways, it has to be that to get across the flavor of it. It's, "Being Fair as a Parent is Hard. How Parents Attend to the Needs of Siblings of a Child with a Rare Neuroimmune Disorder Who Requires Significant Parental Support and Time."

[00:13:27] **Rebecca Whitney:** It is a long one, but I think you've encompassed the situation quite well with that title.

[00:13:36] **Barbara Babcock:** Because inherent in the title is, what's the official jargon, so to speak, is parental differential treatment. When one child receives a lot more time and attention due to their circumstances as compared to the other children. And there is something around what are parents' experience of this. How do they feel? What do they notice? What are their strategies for dealing with it? And the themes do focus largely on that as to what came out.

[00:14:15] So with the themes there are five themes, and within each theme, there are sub-themes. And this is what happens. In this research, it was a qualitative research project, which means I wasn't testing a hypothesis. I was working with families. I was being mindful of my bias. I was being explicit about my biases in writing in the research. I was bringing me into the research.

[00:14:52] And for anyone who does research, medical professionals who might be listening to this, I used what's known as Reflective Thematic Analysis to analyze the data, which came from the interviews I had with the parents. So, the themes were -- there's a theme around, "Beliefs Around Being Fair as a Parent Have to Change." So, parents have ideas around this is how I want to be as a parent. This is what I consider important.

[00:15:23] And a key theme that came out was around fairness and what being fair as a parent means. So, in the research, I identified five themes. They do have sub-themes, but we'll get into the sub-themes in the future, and we'll stick to the high-level themes for now. The first one was "Beliefs Around Being Fair as a Parent Have to Change."

[00:15:49] So parents, it's not uncommon that they have ideas, "This is how I want to be as a parent. This is what I consider important. These are my values. These are how I want my children to grow up." Which is very understandable. And what we found is when an illness comes into a family, how you parent your children oftentimes may have to change. You may have to adapt it a bit. And so, there was something around how parents perceived what fairness meant and how they had to adapt that. The second theme is called, "I Can Only Split Myself So Many Ways."

[00:16:36] **Rebecca Whitney:** I love the title of that. [laughs] I feel that title.

[00:16:43] **Barbara Babcock:** And with that title like with some of these themes, I use the language that the parents used. So, you say I feel that. That's what the parents were feeling, and that was coming out. And so, I really wanted to honor the parents' experiences because that is what this dissertation was about is what are the parents' experiences?

[00:17:06] And so to really get that through to people, I often use their language. So, I can only split myself so many ways. And it's about the constraints the parents live with that constrains their choices in how they can be fair as parents. The third theme is, "We Work Hard to Find a Balance in Attending to the Siblings' Needs." Again, it's the fair thing to do.

[00:17:40] **Rebecca Whitney:** And balance I feel is a keyword in that theme.

[00:17:44] **Barbara Babcock:** Yes. And it's like what balance is possible? What balance is appropriate? And that will differ from what it was like before the onset of the illness, before it came into the family. And it'll be different from other families who don't have a child with chronic illness or a disability.

[00:18:07] **Rebecca Whitney:** Absolutely.

[00:18:10] **Barbara Babcock:** The fourth theme is, "Support from Siblings Makes Parents' Lives Easier." And again, it can lessen their need of striving to be fair. And so, we'll get into that as to what goes into that theme around the support from siblings and what does it mean for parents. And this last theme, it was the language that I used, and I took a play on a common expression in the English language, "For Parents, All Roads Lead to Guilt." A take on the saying, "All Roads Lead to Rome," which evolved to mean that whatever you do, there is guilt.

[00:19:05] **Rebecca Whitney:** It's going to be there regardless if you find that fairness or that balance. It almost for me personally, sometimes feels like a no-win situation.

[00:19:22] **Barbara Babcock:** Exactly. And I have some--what feels to me--some really powerful stuff to share around that theme when we get into it in a further podcast. Really, really important that I want parents to listen to and take it away because I think there are ways to lessen that guilt.

[00:19:43] **Rebecca Whitney:** I know I am looking forward to that. [laughs]

[00:19:48] **Barbara Babcock:** Yes. And so, you notice in the themes, what connects them like these golden threads is about fairness. It is about parental differential treatment and what it means to be a good parent.

[00:20:06] **Rebecca Whitney:** Yes. And overall, I think that is. That absolutely is the overreaching. The theme of it all is what does it mean, and am I a good parent? Am I good enough? And being a good parent for one child may look different than being a good parent for another child. So, I'm really interested and looking forward to diving deeper into these themes that you found with you, and I really truly appreciate the fact that you've looked at the relationship and the experiences of the siblings and the parent-sibling relationship. It's one that's so overlooked and one that I feel we don't talk about enough.

[00:21:02] **Barbara Babcock:** And I found that in the research because as part of this project, I had to do what's known as a literature review. I had to review the existing literature, A, to see, has the topic been researched already? And if so, what did they find? And how is it similar or not to what I want to look at?

[00:21:23] And I looked in the databases a researcher would typically look at and things like PubMed is just one of them. But I looked probably about five or six different databases across three different points in time in June 2022, September 2022, January 2023. And the amount of research I found on the parents' experience of parenting the siblings was minimal. I found three papers focused -- well, two papers focused directly on parenting siblings.

[00:22:10] All the appropriate keywords I used crossing neurology, neuroinflammatory. I have a list of them. I used all the neuroimmune demyelinating conditions including those in the keyword searches. Very little. I found two papers that included rare neuroimmune disorders. One, that was conducted here in the UK, but it talked about -- but it was from the sibling perspective not from the parent perspective. And then someone's doctoral research on brain injury, and that included ADEM among the different brain injuries. So, I included that. But again, that was from the sibling perspective.

[00:22:53] But I included them because they were focusing on our community of rare neuroimmune disorders. But with parenting siblings, I found two papers that focused directly on it and a third paper that focused on it in one section of a doctoral dissertation. They talked about the parents' experience of siblings, parenting siblings, but it was a bit more indirect. And I included that paper because it focused on pediatric multiple sclerosis, which falls into rare neuroimmune disorders.

[00:23:30] So, in all of that we're talking about five or six relevant papers of which two were directly relevant on the parenting of the siblings. And that's between 2002 and 2022. Minimal research. And even within the family therapy looking within that research, again, very few studies. And so, it's usually cases or this is if you're working with a family with illness, these are things you need to think about. But even in those books you might get seven to 16 pages where it talks about parenting siblings. It's in the wider context of the family, so you just get the small amount.

[00:24:15] So, there just isn't the research that has been done. There has been a lot of research on focusing on the family within chronic illness and a lot of research on the sibling perspective. Some of it will be quantitative research, but I was primarily looking at what qualitative research has been done.

[00:24:30] **Rebecca Whitney:** Thank you. Thank you for explaining that. I know sometimes for us parents as we're looking at these different studies, it's without having necessarily a scientific or research background. It can be difficult to understand what is available and how to view them differently.

[00:24:59] And my hope is that with this podcast, with your research too, that we'll be able to take what you've learned, what you've researched, what you've identified, and help families with that and make changes, whether it's in their own thoughts on how they are parenting. Perhaps even giving them a boost of confidence in that. Maybe they're not doing as bad as they think they might be.

[00:25:29] **Barbara Babcock:** I think it isn't a natural thing we do. We focus on what we're not doing well. The question I was asking the families in the interview, and I'm like, "Tell me, you made it this far. What are your strengths as a family that enabled that? What are you good at? What do you enjoy?" I think it's really important parents think about, "Well, gosh, what are our strengths as a family? What am I good at? What is my partner, if you have a partner, what are they good at?" Even if you're separated or divorced and you're co-parenting, "What are we good at with our kids? What are my kids good at? How do they contribute to family life?"

[00:26:27] **Rebecca Whitney:** I think this is going to be really interesting, and I'm really looking forward to diving into each of these themes. So, I thank you so much, Barbara, and I really look forward to our next podcasts where we'll dive a little deeper into those sub-themes of each one that you've identified. Thank you so much, Barbara.

[00:26:48] **Barbara Babcock:** You're welcome.

[00:26:48] **Krissy Dilger:** At the end of this miniseries, we will host a Q&A episode, where Barbara will answer questions from the community. To submit your question, please visit srna.ngo/submit . You can also find this link in the podcast description.

[00:27:14] Thank you to our "Ask the Expert" sponsors, Amgen; Alexion, AstraZeneca Rare Disease; Genentech; and UCB. Amgen is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare autoimmune and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Amgen believes science and compassion must work together to transform lives.

[00:27:47] Alexion, AstraZeneca Rare Disease is a global biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development, and commercialization of life transforming therapeutic products. Their goal is to deliver medical breakthroughs where none currently exist, and they are committed to ensuring that patient perspective and community engagement are always at the forefront of their work.

[00:28:14] 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. 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.

[00:28:42] UCB innovates and delivers solutions that make real improvements for people living with severe diseases. They partner with and listen to patients, caregivers, and stakeholders across the healthcare system to identify promising innovations that create valuable health solutions.