Parenting is Hard

Part 6

You can watch the video of this podcast at: youtu.be/Ixzhe0MXZTQ

[00:00:02] **Krissy Dilger:** Welcome to the SRNA "Ask the Expert" podcast series, "Research Edition." I'm Krissy Dilger with the Siegel Rare Neuroimmune Association. This is the sixth episode of "Parenting Is Hard," a miniseries exploring an often overlooked but deeply important topic, the experience of parents raising a child with a rare neuroimmune disorder and how this impacts their other children.

[00:00:28] 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 condition. Through this series, she'll share her findings and offer guidance for families facing these unique challenges.

[00:00:54] 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. 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.

[00:01:18] This episode was made possible in part by the generous support of Amgen; Alexion, AstraZeneca Rare Disease; Genentech; and UCB. Please note at the end of this mini-series, we will host a Q and 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.

[00:01:48] Thank you Barbara once again for joining me and discussing the research you have done into how parents approach parenting a child who has a diagnosis of a rare neuroimmune disorder, as well as that child's sibling. So, we are now going to discuss theme four, and the theme is support from siblings, makes parents' lives easier. So, can you please just introduce that theme for us? What are some of the surrounding factors that made siblings support important to parents?

[00:02:31] **Barbara Babcock:** Well, this this theme was something that I noticed was very prevalent in the data. And it was in the context of discussing with the parents: what kind of support do you draw on why and, why that support, what support do you have available to you?

[00:02:54] And out of the six families taking part, five said we do not have practical, ongoing support from extended family. And oftentimes that was due to, they didn't have extended family living nearby or extended family weren't in a position to help consistently. So, the families were pretty much doing it on their own.

[00:03:20] And it's really tough to be doing it on your own because you don't know what you don't know. And it was the most prevalent form of support across all the different types of support parents drew on, the sibling

was the most prevalent and I thought that was really interesting. So, the parents were saying because they didn't have that practical ongoing support from family nearby, they were saying we have to manage it ourselves.

[00:03:50] And so that can magnify the impact, caring responsibilities that the parents have and the impact on their availability for the siblings. And whether explicit or implicit, it probably drawing on that sibling support, it could alleviate some of the constraints they experience, some of the concerns they have, some of the workload that they feel that they have if they know that the sibling is there helping them out. And they talked a variety of ways in which their siblings helped.

[00:04:28] **Krissy Dilger:** Great. Thank you. So, how do siblings' characteristics play into the dynamic of the family or how they participate in helping the household function?

[00:04:44] **Barbara Babcock:** It could be a number of ways. Like four families refer to the characteristics of they get on with it. They cope really well. They're really helpful, they're flexible. They're independent and the parents really appreciated those qualities in their children. So, one family member talked about the elder child, they could just drop them off at clubs. The kid loves having a go with stuff and the parent was really grateful.

[00:05:14] Because it's like, well that's easy because if I need to attend to the child with the rare neuroimmune disorder, then okay, this one they can go to a club and they love it and they enjoy it. That makes my life a bit easier and I'm really thankful for that. And as a parent, of course you would be, of course you would feel that way.

[00:05:35] And then some say where it's quite a young child, maybe about four or five, where the parent found them really flexible and helpful. The mothers like would turn around and they would already have socks for the child with the rare neuroimmune disorder because it was really important that they looked after the condition of the feet so nothing would happen.

[00:05:57] So change into fresh socks after being out and about. And here their younger sibling was getting them for their elder sibling who has the rare neuroimmune disorder. And there is something there. Children are watching and learning, and so there's like, right, okay, this is what I could be doing. This is how I could help.

[00:06:22] There is something around siblings helping is across the research literature. When you look at the role of the sibling in the family, oftentimes they do help. It's not uncommon for that to happen.

[00:06:39] **Krissy Dilger:** That's awesome. Yeah. I am interested to learn more and during our discussion about, about that dynamic. So, to that end in your research, did you find that siblings would volunteer to help?

[00:06:57] **Barbara Babcock:** Yes. And I was really surprised at this. Five of the families refer to how the siblings helped regardless of age and regardless of gender. From a 4-year-old young girl to a 16-year-old male, they voluntarily help the parents.

[00:07:17] And I see this in my own family. For example, a nephew when he was two years old, when his father, my brother, opened the dishwasher, he toddles up, starts to get a plate out and handed it to the father, mimicking what the parents were doing, and voluntarily going to help. And there is, there are a number of reasons why young people do this.

[00:07:43] It could be helping with caregiving activities, which is what's common with four families. It could help with daily routines and chores in the house. Three families spoke about that. It could be asking or looking after the parents' wellbeing. Two families spoke of that. Or maybe it's the young person, the sibling,

looking after their own needs, whether it's hygiene, brushing their teeth, changing their clothes, helping out with meals in whatever shape or form.

[00:08:23] But it's you know, they would do quite a lot. So, some of the examples that I have here is the eldest child, a 16-year-old male was saying actually I'll take her out to the shops, or I'll take her to the park. I'll give you and dad some time. You've been like, ships passing of the night.

[00:08:44] You haven't had much time together. So, he's, so the eldest child, who is, the mother thought, well, they were on the cusp of possibly doing that anyway, given their age, saying, oh, I see there's a lot of, like there's a lot of effort for the parents in looking after my sister, so I'm gonna help out.

[00:09:03] And this helps them to look after themselves. And in some ways, I think children automatically do that because research shows that parental mental health, parental wellbeing will have a direct impact on child's mental health and children wellbeing. So, in some ways, children want to look after the parents to make sure they're in a good enough place to look after them.

[00:09:30] So it's, I'm not surprised that we came across this, and it's, you see how young people like four years old, they'll look, they'll see what the parents are doing, and they'll get on with what they need to be doing. So, one parent talked about a 4-year-old sibling saying she's really independent.

[00:09:52] She probably sees that we have to do all these extra tasks, which with her sister that we don't do with her. So, she goes to brush her teeth. She knows the routine. And then even go downstairs afterwards to get mugs for the hot milk before bed. And there is something for young children. This could be a form of play, "I'm playing house. I'm helping mommy and daddy. And in some ways, this isn't a bad thing because the children are learning about chores in the house."

[00:10:29] It takes people to work together to get a meal on the table, to do laundry, to tidy up. And this is a way of them getting involved. But there is also a, another side of this where parents would talk about providing an opportunity for the sibling to talk about, well how's it going for you? Trying to give them opportunities to talk about how they're feeling. And they could create these opportunities where the children, the siblings don't talk.

[00:11:09] They're not sharing how they're feeling, and that too is commonly found in the research literature where you have a child who has additional needs due to a physical illness and possibly disability. Where they don't want to worry. The parents have enough. I don't wanna be adding to their burden or adding to their stress. So, so children will withhold that as well, just even despite parents giving them the opportunity to talk and to share.

[00:11:43] **Krissy Dilger:** Yeah. That's really interesting. And I, I am particularly interested in that portion of your research because it can be difficult to share your feelings when you already know you're, as a child your parents are dealing with stress and other emotions and you potentially don't, you think you're helping by not burdening them.

[00:12:09] So, so I guess going off of that, can you talk more about how parents can try and open that, that chasm I guess, or open that box so that their children, the siblings, do feel the room to communicate how they're feeling. And what are the potential negative consequences of withholding feelings from parents?

[00:12:42] **Barbara Babcock:** Well, there, we have to consider the young, the siblings' chronological age and their development age. So, a child could be 12 chronologically, but developmentally they might act more like 10 or 11. Or 13 or 14. So it can go either way. So, there's being mindful of the child's development age.

What are they showing? We also have to consider a 10-year-old, a 12, a 13-year-old. It can be really difficult to articulate how they're feeling.

[00:13:22] It also links to how emotionally literate the family is. So, do the parents recognize how they're feeling in themselves? Can they name and acknowledge their own feelings? I'm feeling frustrated. I'm feeling anger. I'm feeling sad. I'm feeling happy. I'm feeling joyful. I'm feeling hopeful. So, if the emotional literacy isn't very high in the family, it can be harder for a parent to support a young person to articulate their emotional feelings.

[00:13:58] And it's also not just emotional literacy. Literacy, it's the relationship with emotions. So oftentimes we could think of quote, I say quote negative emotions such as anger, sadness, frustration. Well, we should not feel that way. And I often tell people all the emotions are valid.

[00:14:23] It's what makes us human. It's about how we respond to it. Also, emotion has the word “motion” in it, and motion is about movement. So how do we let these emotions flow through us? How do we let them flow through the family? Recognize and acknowledge them? So, when you have younger children five, 10, even 13, they might not have the language.

[00:14:54] So as a parent, you may have to say, I noticed how when you know your sister, maybe the one with the rare neuroimmune disorder did this, and I asked you to do this, you went [and showed a facial expression], and you seemed a bit frustrated there or angry. Which one was it? I'm really curious what were you feeling angry about?

[00:15:20] Is it, are you feeling like you're always having to help and no one's helping you and you want some help? So it might be that you need to provide some suggestions to younger people also influencing it in addition to emotional literacy in the family, in the child's development stage and chronological age, reflecting back what you noticed, what you saw. Making sure you're letting the child know you're not in trouble. You're not in trouble.

[00:15:54] This is, I just want to get to understand you a bit better. How are you feeling about things? And for some families, this, they may do this already, other families maybe not so much and they're having to do it now because emotions are more heightened in the family due to this physical illness coming through.

[00:16:16] I was saying before about voluntary help can be a demonstration of concern, emotional care, a form of play, imitating parents for younger siblings, it could be a way to reestablish one's role in the family because when you have a, an illness come into the family, maybe accompanied by disability, the different roles people play.

[00:16:41] It could just be thrown up in the air and it's like, okay, so if I help out, then this could be my role in the family. I help my mommy, I help my daddy, or I help my sibling. So, it, and it could also be used as a bid for connection with the parent. This is how I now need to get my parents' attention is by helping out.

[00:17:07] Now I didn't find that in my study, but I also didn't interview the siblings. If I had interviewed the siblings, maybe that would have been the case, but I don't know. But in others, other research where they look at sibling report and there is a study by Aktar Etal in 2012, which was conducted at Stoke Mandeville here in the United Kingdom.

[00:17:35] And there were several young people with transverse myelitis who took part in that. And that study did find that voluntary help was a bid for connection in some of the young people but on the other hand, a form of helping, if it's age appropriate, caregiving tasks and illness knowledge.

[00:17:59] So the young person knows about the illness sufficient for their age and development stage, and they do get in some--involved in some tasks that, again, are appropriate for their age and development stage. That can help to lower sibling anxiety. It could develop adaptive coping skills. It could help with the sibling's wellbeing, and it could enhance the sibling relationship between the young people and for the families were showing that in how they describe the relationships.

[00:18:37] **Krissy Dilger:** Great. Thank you so much for sharing that. I think it's what you said specifically about how it can help the relationship between siblings. It's really important because that's another factor that I think as parents you might worry about, but to know that's a reinforcing factor when the siblings help out.

[00:19:05] That's really positive. Really positive thing. So, did parents express that they received emotional support from their children? Who are the siblings of the child who's diagnosed or just support in the sense of taking care of responsibilities?

[00:19:28] **Barbara Babcock:** There was a couple of families mentioned where the sibling would go to the parent and be like, "Are you okay? Can I give you a hug?" So, I did come across that and I think I'll get it. We'll be talking about this in a bit. That can be entirely okay because I mentioned in one of our previous podcasts, one of the earlier ones, how we have this intensive form of parenting, particularly around mothering, that you have to be the expert in all your children and do everything right, know their needs intimately, and you take care of all their needs.

[00:20:16] And this intensive form of parenting has, it like puts the child, it views the child as in a vulnerable position they can't help. Helping is a one-way activity, parent to child, but children do help. Like that personal example I provided of a family member, children want to help oftentimes, which we saw with the voluntary helping.

[00:20:45] So it's about how we can support them to help in the way that they want to help, that's appropriate for their age. And of course, they're going to help emotionally because the parent does that for the child. The child is learning it from somewhere and it's appropriate because they're learning how to show empathy.

[00:21:10] And of course, we want to raise our children to be empathetic human beings capable of receiving love and giving love. Now, sometimes it could be the child is worried for the parent. "Is my parent in a good enough place? Can they look after me?" That could be a subliminal thing going on, but it could be that they genuinely care for the parent.

[00:21:34] So as a parent to have your child recognized and say, "Well, thank you for recognizing that. Let me give you a hug." And there is something mutual in that, the child's saying, "I want to give you a hug. I care about you." And the parent then is like, "Well, thank you for that. Let me give you a hug too."

[00:21:55] **Krissy Dilger:** Yeah, that's great. That's I, I don't think you have to automatically categorize a parent showing their emotion and leaning on their child who's a sibling a little bit as an inherently negative thing. I think there can be positive outcomes when done, as you mentioned, in an age appropriate and controlled way.

[00:22:25] And we've touched a lot now about voluntary support from siblings. Helping out with responsibilities. Establishing their role in the family. How did parents set expectations for siblings and what sorts of responsibilities or activities were expected of siblings?

[00:22:51] **Barbara Babcock:** Some parents did explicitly expect the sibling to help out and four families shared how they did this, whether it was to look after themselves or with caregiving activities, or household chores,

or being the companion of the sibling who has the rare neuroimmune disorder and maybe a disability as well. So it could be, like household chores. Not a problem in one family, asking the sibling, okay, be a companion to your sibling who now has this disability.

[00:23:33] And there was a bit of a no, actually no, I don't want to do that role. I don't wanna have to be their companion. And so sometimes you, you will see children be, oh, I don't wanna have to do that. Some of it, it could be that they make their own lunch. It could be that they walk themselves to school.

[00:23:54] It could be fetching things for the parent. And sometimes you might have a child who has a higher level of disability, say a tracheostomy. And so, if something's happening and the child with the tracheostomy is struggling, you've got to sort that out as the parent. And so of course you will be asking the sibling, can you get X, Y, Z for me?

[00:24:22] That does happen. Sometimes in those moments of emergency, the family does have to come together very quickly to sort out something like an emergency where the young person's life is if it's not sorted out, then that's not great. The family will come together very quickly to sort that out and parents, again, they were really grateful for it.

[00:24:50] **Krissy Dilger:** That's great. And I think something that comes to mind when we're having these discussions of these, the siblings taking responsibilities and sometimes helping out with caregiving duties here and there. It can be tricky as a parent to find the balance between setting expectations for your child and crossing the line into parentification, which is a word that I don't know if everyone fully knows what it means. So, to start off, can you explain what "Parentification is and how it relates to your research?

[00:25:34] **Barbara Babcock:** So, parentification is when a child adopts a parental role, either voluntarily or by parental invitation or expectation, which could be implicit or explicit, and the child becomes part of the parental subsystem. And that role of helping becomes part of the child's identity.

[00:26:06] So now it wasn't my job as part of this research to make that assessment, is this child is parentified, this child isn't parentified. I wasn't doing that, but because the sibling helping the parent, it was so prevalent across the families, across the data that I collected.

[00:26:30] It was a consideration in my discussion chapter about parentification in families where one sibling has additional needs, and this could be in the case, say you might have one child who is neurodivergent and has additional needs.

[00:26:48] One parent said as part of this research that when you have a one child with additional needs, you know they have the greater need, so you have to prioritize them. And then sometimes you may recruit the sibling to help out, like I would just say, in times of emergency, or to help out with chores in the house, which is a normal part of growing up.

[00:27:11] You want your children to be functional adult, but you can have this thing where children end up, it becomes part of the role. They're invited into the parent subsystem. You can see that where there's conflict between the parents. So, I'll just really quickly, if you have two parents and then a child with a rare neuroimmune disorder and the sibling, if the parents here aren't getting along, they're fighting.

[00:27:46] A parent could say, okay, well you help me, they're useless, but you and I, we could sort this out. You help me look after this child. And so, they become part of the parental subsystem and that parent could

become alienated. And so, then that child, the sibling can have a more of like, okay, well I help daddy or mommy or whoever with my sibling who requires additional support.

[00:28:21] And if that's part of their identity, then that could have knock on implications for that young person and later in life. So, do their needs, get a look in is the parent attending to that sibling's needs, or is a sibling have to actually look after not just their sibling, but their own needs as well.

[00:28:44] And so that could be a, an unhelpful form of parentification because the sibling's needs are being subsumed with the other child who has the additional needs, so their needs don't get a look in. And that's a maladaptive form of parentification. And it's not uncommon in families who have a disabled child.

[00:29:09] It's not uncommon where there's marital conflict. And it's not uncommon in single parent families. There'll be a number of our families where there is just one parent, they're having to do it all. They are going to recruit the older siblings to help out with the younger siblings. And you see that in in single parent families where you might not have additional needs, such as a rare neuroimmune disorder or disability, for example.

[00:29:43] So it's very much about assigning these appropriate age and development stage caregiving tasks and household chores. And that when it's age appropriate, development stage appropriate, then that could be an adaptive form, a really useful form of parentification that could just be learning about how you work together as a family and help one another out.

[00:30:12] It could support developing maturity in caring and social skills. So, it, it is a tricky balance and there is something I want parents to, as they listen to this podcast and this one in particular, to show a lot of compassion for themselves. It's not like you're given a handbook on. "Oh, watch out for parentification and adultification." You don't always get that handbook or anything.

[00:30:43] So you know, if you find, oh gosh, maybe I do rely on them more. So, like another form where parentification can happen is where the parent is confiding in the children with adult theme topics like, "Your father did this and it really annoyed me," or "Your mother did this," or "The other parent did this and it really frustrated me, da, da, da, da."

[00:31:14] If they're consistently venting about the other parent to the young person, that can foster Parentification in a less useful way because the young, the child might think, oh, I have to emotionally support my parent, but I can't get emotional support from them. So, there is something around how we're attuned to this and how we deal with it if we think it's happening.

[00:31:40] But also how can we foster it in a useful way with, again, the chronological age appropriate and development stage appropriate caregiving task, household chores. An 8-year-old they can make, they can learn to make their bed potentially a 6-year-old may be able to pick up their laundry and put it in the basket and tidy up their toys.

[00:32:09] So the, so link to that, and this is what we talked about a little bit before, in two things, siblings may withhold information to protect their parents and family from additional stress. And so, an indication of that it might have been happening, I can't say for sure, in the families I spoke with, a lot of the parents were saying, “I don't know what they're really thinking and feeling.”

[00:32:37] But keep in mind, children may not be able to articulate how they're thinking and feeling. The parent might have to make some suggestions but hold them lightly. Is it this, it this is it something else? And it's

about creating those opportunities to talk and having that one-on-one sibling time where the young person can talk about their worries, which we spoke about how parents did that in a previous podcast.

[00:33:07] But it might be that the research has found, sibling might not wanna talk about it, they might not wanna talk about their feelings at all because they're having to deal with this situation day in, day out, and they just might not have the energy to do that. So, it does make, it can make it difficult for the parents to then attend to siblings needs.

[00:33:27] And so you could get into a bit of a vicious cycle. The sibling doesn't wanna talk because they're fed up. They don't want additional stress. The parent doesn't know how they're thinking or feeling. They create opportunities for their child to talk. Sibling doesn't wanna talk. And the parents might think, oh, they're doing okay.

[00:33:45] Okay, we'll give them some additional, they can help out with this. They can help out with that. And then the siblings might show that they're coping well, but on the inside, they could be, oh, well, no one looks after me. They might not even be able to articulate that. And so that can further compound the sibling feeling, obligated, isolated, no one can care for them. So, it's if they're in mutual caregiving roles and there isn't a sufficient open communication, then that could add to the stress in the family system.

[00:34:21] **Krissy Dilger:** Yeah.

[00:34:22] **Barbara Babcock:** I, also, there was another point around parentification in our society it's a real western concept around, well, children should have a childhood, and I was talking about that intensive parenting approach where the parent does everything it's one way parent help child and there is something to that. But there are other cultures where you might see a 5-year-old or a six, 7-year-old carrying around a 2-year-old. Playing with them, looking after them, helping out.

[00:35:01] These are very different cultures, so different cultures will have different ways of approaching this. And it's not right or wrong. It's about what is appropriate for the family, what is appropriate for the children, and how does everyone in the family get their needs met or a decent amount. Most of the time, knowing that is a tricky balance that probably will never be perfect and what balance look like will change from day to day.

[00:35:37] **Krissy Dilger:** Great. Thank you. I think that's a lot of a lot of good information and a lot of healthy ways to look at these tough topics because it can be overwhelming, I think for parents and the need to be always perfect can come into play.

[00:35:57] And I know we'll discuss that a little bit in the next podcast when we talk about theme five, but I appreciate you explaining that theme of parentification versus establishing healthy responsibilities and expectations because that is something I think a lot of parents with.

[00:36:24] **Barbara Babcock:** Yeah. Yeah. And yes, it is challenge in a family where you can have one or more children with additional needs. Very much so.

[00:36:33] **Krissy Dilger:** Yeah. So, what advice would you give parents who want to foster a healthy, supportive sibling relationship in this context.

[00:36:48] **Barbara Babcock:** There is, I come back to open communication in the family. How do parents role model it with the other parent, whether they're together in a committed relationship or not. So how do the parents' role model, because they're the first role model, so how they relate to the other parent, but also

how does the parent relate to their siblings and how do the children see that? That's another way, but it's also knowing your kids as best you can. You won't be perfect, but their likes, their dislikes if they want to help if they're voluntarily helping.

[00:37:32] I appreciate though sometimes when kids voluntarily help, it a task that you could do in 10 minutes if they get involved, it's gonna be 40 minutes or an hour, and you might not have that. So how, can you let a young person help for some of the time, at least because they know, oh, when I voluntarily would go to help take the dishes out of the dishwasher or do this, it's valued.

[00:38:01] It's welcomed. What message are we sending the children around voluntarily helping but also receiving help as well. How do you role model receiving help? In western society, it can be very much individualistic culture. You have to be very self-reliant and that is prized and don't need help, and it becomes very imbalanced because then.

[00:38:29] We're expected helping people is good, but if everyone's helping and no one wants to receive help, we get into a bit of a bind. So, it's really important. We role model with our children how we receive help in addition to how we give help. And there is something around siblings.

[00:38:52] What do the siblings want to help with? Maybe it's just playing games with their sibling, like any sibling would do regardless of whether one or the other has additional needs. Maybe they can go fetch something, help out with that. Again, it's what is appropriate to their developmental stage and into their actual age.

[00:39:20] **Krissy Dilger:** Awesome. Well, thank you so much. I believe that's the end of the questions I have for you. I did want to open the floor in case you have any final thoughts on this theme before we wrap up.

[00:39:32] **Barbara Babcock:** Let me see if there is anything else. No, I think, no, I think that's everything. Well, I think, that's everything around this theme for now. It, it is a big topic and it's prevalent across the literature, the chronic illness research, whether it's parent report or sibling report support from the siblings is a factor that has been looked into. And so, it is a popular topic. Yes, I would say.

[00:40:12] **Krissy Dilger:** Yes. And very important I think as well. And I'm glad to have the chance to have a conversation around it because I do think talking about these dynamics are that, talking about it is important because if you are suffering in silence, so to speak you might not realize that it's more common than you think to be worried about, or am I, am I putting too many expectations on my child who is a sibling of someone with a rare diagnosis or is, they're volunteering to help a positive thing or am I burdening them? So, these conversations are super important, and I appreciate you showing us the research that you did into it.

[00:41:04] **Barbara Babcock:** Yeah, I think one of the comments I wanted to make earlier about relationship to help, emotional literacy in the family, the parents the relationship with the emotions is what was the relationship, the parents' relationship like with the siblings? Prior to the rare neuroimmune disorder coming into the family, that will also impact how things are.

[00:41:29] So if it was, say, a fraught relationship, it, the parent may have to put in even more effort after this, doing relational repair. If there were ruptures in that relationship, they might have to put up even more effort into that relational repair with the sibling.

[00:41:52] But interestingly, a number of the families said, I don't know, come back in 10 years and ask me then because then the children might be 20 or twenties or thirties and be in a much--be in a position where they could really talk about, well, this is how it impacted me back then. Now I can articulate how I feel. But

there is something the sibling from the age of 10, 15, 20, 30, up until they're 50, their perception of their experience having been a sibling of someone who had additional needs that could--their perception of it could evolve over time as they grow and have new experiences in life.

[00:42:42] So it may not be a static thing. It could change. So, yeah. And just one other thing that came up. Not so much in my research, but it was in other research papers where in some families, parents may say, right, we're gonna prioritize a child with a disability. They'll get all the attention all the time, all the effort. That is my goal now is to focus on this child and then it might be up to the other parent to focus on the other children. Their needs parents will make different choices about how they approach that together, or they might not approach it together.

[00:43:27] It might be that one prioritizes, and the other says, "well, oh, I better focus on the others." They might actually agree, "No, let's do it this way because that's easier." So, they have different approaches. In some, young siblings can say, "Oh, well, yeah, they always get the attention. They get preferential treatment. They don't get in trouble as much. We get in trouble." So, you can see some of that. I didn't see as much of that. There seemed to be a lot of what I refer to in a previous podcast around parent mutuality where the parents were actively communicating and working together to decide, "Right, how are we going to approach this?"

[00:44:11] "You work with that kid that day. I'll take that kid. Then we'll swap over for the bedtime routine." And so, there wasn't a lot of open parental conflict. I'm sure there might've been some, conflict is inevitable. But it wasn't so much as one of the papers that I drew on in this research.

[00:44:36] **Krissy Dilger:** Gotcha. Well, thank you so much for sharing and for joining me once again on a very enlightening and interesting episode of this series. I wanted to remind everyone who's listening that if you would like to submit questions for our Q and A episode, you can do so at srna.ngo/submit, and that link will be in the podcast description. Thank you again, Barbara, and I look forward to our next conversation.

[00:45:11] **Barbara Babcock:** Thank you.

[00:45:17] **Krissy Dilger:** 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.

[00:45:51] 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.

[00:46:18] 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.

[00:46:46] 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.

