

Siblings and Severe Childhood Epilepsy
The Impact of Seizures on the Family's Mental Health
CURE Epilepsy Webinar
(Transcript)

- Dr. Laura Lubbers: [00:04](#) Welcome, everyone, to today's webinar. I'm Laura Lubbers and I'm the chief scientific officer of CURE Epilepsy and I want to thank you for joining us today. This past Saturday, we celebrated siblings as a part of National Siblings Day. Today's webinar will explore the impact of epilepsy on siblings, brothers, and sisters of children diagnosed with severe childhood epilepsy. This is a topic that is close to my heart too, as I am a sibling of somebody who had epilepsy.
- Dr. Laura Lubbers: [00:32](#) Often siblings are asked to participate in caregiving, which can bring great joy and satisfaction, but can also lead to significant stress that may remain unspoken and unaddressed. This webinar seeks to address these issues. This webinar is funded with support from Zogenix and is a part of CURE Epilepsy's 2021 Leaders in Research webinar series, where we highlight some of the critical research that's being done on epilepsy.
- Dr. Laura Lubbers: [00:57](#) As an additional resource, today's webinar as well as all of our webinars are recorded for later viewing on the CURE Epilepsy website. You can also download transcripts of all of our webinars for reading. For over 20 years, CURE Epilepsy has raised more than \$70 million to fund epilepsy research that supports our mission, which is to find a cure for epilepsy by promoting and funding patient focused research. CURE Epilepsy provides grants that support novel research projects that advance the search for cures and more effective treatments.
- Dr. Laura Lubbers: [01:31](#) In 2020, we launched our CURE Epilepsy Catalyst Award to help accelerate the basic research we've traditionally funded into the next stage of development and prepare potential new treatments for clinical trials. As I introduced earlier, children who have a sibling with a severe childhood epilepsy may experience very strong emotions such as guilt, anger, sadness, fear, anxiety, and depression.
- Dr. Laura Lubbers: [01:56](#) The Siblings Voices Study, which has included siblings in a variety of age ranges, was created to help families understand more about the impact of having a brother or sister with severe epilepsy. This webinar will discuss some of the key research findings, including some strategies to help improve the mental wellbeing and social development of siblings and resources that are available for families.
- Dr. Laura Lubbers: [02:20](#) Today's webinar is presented by Dr. Kelly Knupp, who is an associate professor of pediatrics and neurology at the University

of Colorado. Dr. Knupp practices medicine at Children's Hospital Colorado in Aurora, Colorado, and is the associate research director of the Neuroscience Institute and director of the Dravet program. Her interests are epileptic encephalopathies including Dravet syndrome and infantile spasms. CURE Epilepsy is so lucky to have Dr. Knupp as a member of our scientific advisory council as well.

Dr. Laura Lubbers: [02:53](#) Before Dr. Knupp begins I'd like to encourage everyone to ask questions. You may submit your questions anytime during the presentation by typing them into the Q&A tab located on your Zoom panel and click send. We'll do our very best to get through as many questions as we can. We do want this webinar to be as interactive and informative as possible. However, to respect everyone's privacy, we ask that you make your questions general. So with, I'd like to turn it over to Dr. Knupp.

Dr. Kelly Knupp: [03:24](#) Thank you, Laura. That was a very kind introduction and I'm really very honored to talk about this topic. As pediatric neurologists, we are first and foremost pediatricians, which means that we really like to care for the entire family and that includes siblings as well. So today, as Laura mentioned, I'm going to talk about siblings and the impact of seizures on the family's mental health. See if I can get my slides to advance here. There we go.

Dr. Kelly Knupp: [03:56](#) And just in all fairness, I do have disclosures of research funding and consulting funding. I don't think that it impacts anything that I'm going to discuss today, but just wanted to make sure that information was out there. So I'm first going to talk about some factors to consider when we think about siblings in a family with epilepsy and then talk about some of the facts of what we actually know, and then hopefully give some concrete ideas about what to do based on some of that literature.

Dr. Kelly Knupp: [04:26](#) So first off, factors to think about. So we know that the care of a child with a developmental epileptic encephalopathy changes the family in so many ways. I mean, the most obvious way is seizures. Seizures in themselves are unpredictable and disruptive. And anything disruptive to the daily schedule can create a problem for the family. Many times these children require lots of medical appointments and therapy appointments, and so that can also be intrusive in the daily schedule of the family, including siblings who may have other things that they need to do or want to do.

Dr. Kelly Knupp: [05:03](#) Because of the burden of seizures, many families may find themselves avoiding seizure triggers. These seizure triggers can

be different for every child, but sometimes trying to avoid them can be very disruptive to the family functioning. So things like making sure that everybody is getting good sleep, sometimes that means that you can't actually sleep in a hotel room because sleep is so important and you wouldn't want to do anything to disrupt it.

Dr. Kelly Knupp: [05:30](#) Some children can't be outside in heat because that may trigger seizures. And so that means on a warm afternoon the family really has difficulty going outside to do outdoor things. The ability to tolerate events can be impacted by a child with epilepsy. Sometimes it's just too much activity, too much stimulation, and that in itself can lead to either behavior problems or seizures.

Dr. Kelly Knupp: [05:55](#) Some children with developmental and epileptic encephalopathies can have behavior concerns, and that can also limit the choices that the family makes. It can make it very difficult to go to things like a movie or a baseball game, or sit on the sidelines of a soccer game. So again, disrupting some of the normal, typical activities that we would expect a family to do.

Dr. Kelly Knupp: [06:16](#) Activities of daily living may be altered. The child with epilepsy may require assistance with feeding, may have a G-tube, may not be able to eat food in a restaurant, there may be co-sleeping so that families can monitor for seizures at night. And so all of these things can be somewhat disruptive to the family. And then of course there's the financial impact.

Dr. Kelly Knupp: [06:39](#) The cost of having a child with any chronic illness can be expensive to the family and particularly when faced with having to support a child throughout the lifespan, this can change the financial impact of the family. In addition, one family member may actually need to give up employment to stay home and take care of the child with a developmental and epileptic encephalopathy, which can also create an additional financial impact on the family.

Dr. Kelly Knupp: [07:07](#) And these have been well-described about the cost of having a child with epilepsy. And so all of these things impact daily function and daily decision-making and make them different from choices that other families may make and are important to keep in mind. And when we talk about parents, we also need to think about the impact of having a child with epilepsy on parents.

Dr. Kelly Knupp: [07:31](#) And there's a wealth of literature about higher rates of depression, higher rates of anxiety, higher divorce rates, higher

rates of stress, family malfunction, pressures on time and finances, as we've already mentioned, poor sleep. When children are having seizures at night, it means one of the parents are usually up monitoring those seizures which having poor sleep then leads to difficulty functioning the next day.

Dr. Kelly Knupp: [07:56](#) Many parents report feelings of burnout, the need to monitor their child navigating the healthcare system and having to act as a child's advocate for healthcare and education. So all of these things impact parents and anything that impacts a parent impacts a child and therefore impacts siblings of somebody with epilepsy. And I know this all sounds really negative. There definitely are positive feelings that people describe, feelings of personal growth, feelings of being proud to gain skills and expertise and the satisfaction of being able to manage some of these struggles independently.

Dr. Kelly Knupp: [08:33](#) And then also families describe their feeling of belonging to a specific community and feeling that bond of other families around them who may be going through some of the same challenges. But let's face it, no parent has the hopes and dreams that their child will have epilepsy. So these are all challenges that parents and siblings are going through that they probably wouldn't have chosen otherwise.

Dr. Kelly Knupp: [08:59](#) And then last, I think the other thing that we need to keep in mind when we talk about siblings, is that there may be genetic underpinnings of the epilepsy. So many epilepsies are genetic in origin and they may actually impact a sibling as well, even if they don't have seizures themselves. And there has been some really nice literature that's come from families living with juvenile myoclonic epilepsy where siblings compared to healthy controls were found to have slower psychomotor speed, decreased verbal fluency and exhibited traits associated with executive dysfunction.

Dr. Kelly Knupp: [09:37](#) In addition, there was another study that demonstrated deficits in prospective memory compared to healthy controls. So even though the sibling doesn't have epilepsy, there may be some genetic reasons related to the child with epilepsy that leads to some dysfunction in that sibling, and that is important to keep in mind as well. So with all of that as our framework and things to think about that may be impacting a sibling, what do we actually know about siblings?

Dr. Kelly Knupp: [10:04](#) Well, we do know that there's reasons to be concerned. This is a study that was done recently that looked at quality of life in siblings of children with chronic diseases, so it actually looked at

several types of chronic diseases, including diabetes, epilepsy, oncology, so a whole host of types of chronic diseases and compared these siblings to healthy control group and found that they in fact had lower scores when it came to psychosocial health scores, physical health scores, and total health scores.

Dr. Kelly Knupp: [10:39](#) So being the sibling of a child with a chronic disease has an impact on that sibling. This difference was also present in parental reported measures but these were measures that were actually taken directly from the children and I think that's even more meaningful because this is how the children think of themselves. So we know that there are reasons to be concerned.

Dr. Kelly Knupp: [11:01](#) When we look more specifically at children with epilepsy, this particular study did interviews and questionnaires of siblings and it's really important to look at who was actually asked the questions because we do sometimes get different answers from siblings than we do parents. This particular study looked directly at siblings and they actually divided the siblings up into siblings with frequent seizures, siblings with rare seizures and then healthy controls.

Dr. Kelly Knupp: [11:27](#) So they had three groups that they were looking at. They did find that all of the siblings had normal IQs and I think very reassuring that there was no difference in self-esteem. So I think that was a really positive thing that was identified in the study. And there was no difference in behavior between these three groups, although there was a trend for increased aggressive behavior in siblings who had frequent seizures. Whether that was acting out or trying to cope, I don't think that we can draw any conclusions from that.

Dr. Kelly Knupp: [11:58](#) But I think one of the things that was really important about this particular study is that the siblings did have concerns. So despite the fact that the siblings were doing well, the siblings actually had a fair amount of concerns. And these are not surprising, but I think it's important for us to know what these concerns were. And so I apologize for the clarity of the slide. This is actually a pretty old manuscript and so finding a more clear copy, I was not able to do. I think this was from a time before we would copy things into slides.

Dr. Kelly Knupp: [12:35](#) But the things that I really want to highlight on this slide is when we look at questions three and four, these were questions that asked, do you worry about your brother and sister getting hurt during seizures and do you worry that seizures might cause death? And these siblings were worried about both of these

things at really high levels, both in the group that had frequent and infrequent seizures.

Dr. Kelly Knupp: [12:59](#) And particularly for worrying about whether their sibling might get hurt during seizures, 90% of the siblings had that concern regardless of whether the seizures were frequent or infrequent. I also think it's notable that this study was performed in 1996 and so this was a time before SUDEP was something that was really discussed as openly as it is now. And I hope that everybody is discussing SUDEP more openly.

Dr. Kelly Knupp: [13:27](#) But we still see a fair amount of these siblings who 55% of these siblings who are concerned that seizures might cause death. And so that's really striking to me. And I think that's a very natural thing for children and parents and all of us to be concerned about but it was very notable to me that this came out in this study. I think one of the other things I'd like to point out is one of the questions that was asked is do you worry that people will make fun of you because of your sibling's seizures?

Dr. Kelly Knupp: [13:59](#) And we do see that some children responded yes to that, 45% of children responded yes to that. And when we look at question eight which is, I worry that people will make fun of my brother and sister because of his seizures, we also see that 35% of people... I'm sorry, 60% of children were concerned about that. So the siblings are a little bit more concerned about their sibling with epilepsy than they are themselves, but they are concerned about some of the stigma related to this.

Dr. Kelly Knupp: [14:35](#) This is another study that asked questions directly of siblings. These were actually more defined measures looking at depression, anxiety scales, and quality of life. This was done in 2008. And then there was a child behavior checklist that looked at parental report of child behavior. And again, we see that there were no siblings with concerns for depression, the scores were actually better than expected in the general population.

Dr. Kelly Knupp: [15:02](#) There was some concern about anxiety, but those siblings themselves had a chronic condition. The parents though did identify some increased scores about internalizing behaviors. And those internalizing behaviors are things like feeling sad and lonely. So while this is somewhat reassuring, I think there is some reason to be concerned here. And again, a little bit different than the recent data, these siblings had good quality of life whereas the slide I showed you before, which is a little more recent showed that there was some decrease in quality of life in siblings with chronic diseases.

- Dr. Kelly Knupp: [15:41](#) This particular study looked at structured interviews of parents. So I think it's important to keep in mind that they're asking parents and not siblings. And I think one of the highlights here is that these parents do think that their children had feelings of sadness and fear and also some feelings of worry. And so I think that is notable and I think that I've already presented data that supports that siblings actually do have feelings of worry.
- Dr. Kelly Knupp: [16:10](#) They also, these parents, this group of parents did identify that siblings probably were concerned that the sibling with epilepsy receives more attention because of epilepsy. And so parents had some idea that that is a concern for their children also. This is a study that did some very nice interviews with siblings and found some of these same themes of being lonely, scared, worried about death.
- Dr. Kelly Knupp: [16:41](#) Again, this is in 2009, so this is a time period where SUDEP was probably a little bit more openly spoken about but again, we see this worry. I think one of the things that was really striking from this study is that the siblings were able to very well describe that they feel relief when they're told what to do. And so this is the first time that the literature really started to suggest that siblings want to know what to do and want to know how to help.
- Dr. Kelly Knupp: [17:10](#) These siblings also had lots of positive feelings about their sibling with epilepsy, saying things like they wouldn't change him for anything, they loved them enormously it makes me laugh. So they really have some very positive feelings about their siblings as well. And many of the siblings felt a responsibility for their sibling with epilepsy. So some really positive things that came out of these interviews.
- Dr. Kelly Knupp: [17:34](#) Again, when we look at parental questionnaires, and this is something that was done very recently in 2018, these parents reported that their siblings are protective of the sibling with epilepsy, they're proud of their sibling with epilepsy, they do recognize that there's feelings of worry and that it may make them sad or angry and that they perceive that their child thinks that seizures might hurt.
- Dr. Kelly Knupp: [18:01](#) It was somewhat interesting to me and I put this in here that a very small percentage of people thought that their sibling wanted to keep epilepsy a secret. Now, keep in mind these are parental perceptions. But I think that's an important thing for us to keep in mind as we're talking to siblings, that we may need to meet them where they're at. We did see in this group that

siblings who witnessed seizures were more likely to be having trouble in school.

- Dr. Kelly Knupp: [18:32](#) Keep in mind that not all siblings with epilepsy have seizures that can be witnessed. They may be well controlled, they may be seizures in the night, so not all siblings may seize frequent seizures but they definitely seemed to have some correlate with difficulty in school. And the other thing that is probably not a surprise is that parents themselves who had anxiety were more likely to report siblings with worry.
- Dr. Kelly Knupp: [18:54](#) And I think it's hard to know for sure what to make of that, but I think it's really important to keep in mind either as a provider, as a parent, that if you have anxiety that we probably need to keep that in mind in this whole picture whether it's a genetic predisposition for anxiety, or if it's just that you perceive because of your own anxiety that your children may have worry. But that's an important thing to keep in mind as we talk about this.
- Dr. Kelly Knupp: [19:22](#) Another researcher looked at caring roles of siblings. They actually did interviews with both families and children and identified three themes of different caring roles that siblings have. And I think it's very, very common for siblings to have caring roles. And I really like how they divided this up. And so they started off with a theme of an alert assistant. And so these are children who identify or anticipate needs and then support those needs.
- Dr. Kelly Knupp: [19:51](#) And so they described this as the sibling would recognize that their sibling was having a seizure and they will call for their parents for help or alert their parents that something happened. I think that this happens fairly commonly in siblings with epilepsy. And then there are some siblings who take on a bigger role where they function as a substitute parent.
- Dr. Kelly Knupp: [20:14](#) And so they'll take on the parenting role when parents are not around, for example, giving medication or able to prepare a keto meal when parents aren't available or babysitters are around, and I hear this fairly commonly in my office of things like this happening. And then I hear their last group was parenting assistants. And these are children who are taking on the parenting role even when the parents are present.
- Dr. Kelly Knupp: [20:38](#) And so they're able to help provide first aid alongside the parents, maybe will call for 911 when a seizure is happening, so taking on a more active role. And I think that these roles are really great but I think it's really important to keep in mind

whether this is the role that the sibling wants. Because we want to make sure that we're not pushing siblings to do something that they're not prepared to do or that they would prefer not to do.

Dr. Kelly Knupp: [21:04](#) They did see that these roles increase with age, seem to happen more often in girls than boys, and were present more often in single parent families. And I think this is a nice framework to talk to parents about what is the sibling doing and is that really okay, and is it causing disruption for the sibling? And then if you had the opportunity to talk to the sibling is this a role that they really want to do or is this a role that scares them or causes distress for them?

Dr. Kelly Knupp: [21:35](#) And so now I'd like to move into Lori Bailey's work which is the Sibling Voices project that she has been working on. And this was really one of the first surveys to look at both sibling and parental responses about how siblings feel when they live with complex epilepsies. And there's so much rich data here and I think gives us a much better picture of what's going on in large part, because we are looking at both the siblings and the parents and able to compare those together.

Dr. Kelly Knupp: [22:05](#) A lot of the prior work as I presented was largely parent reported or solely sibling reported, and we didn't really have comparisons. And one of the things that we see in the Sibling Voices work is that across all ages, siblings reported worry and stress with seizure, and they were at much higher rates than parents' reported sibling concern. So while this was recognized in the early work that siblings do have worry and stress, it turns out there's some discrepancy between what siblings are feeling and what the parent thinks that they're feeling. And I think that's a really important thing to take note.

Dr. Kelly Knupp: [22:42](#) And I think one of the other things that really came out in the Sibling Voices that hadn't been reported before is that siblings are also worried about their parents. They're worried about parental stress and they're worried about their parents being unhappy. And this actually increases with the age of the sibling and 77% of adult siblings reported that they had concerned about their parents. It's not surprising that this increases with age of the sibling.

Dr. Kelly Knupp: [23:08](#) Anybody who knows children throughout the lifespan recognizes that children when they're very young are mostly concerned about themselves and as they mature and grow older, they start to appreciate the world around them and recognize that those around them may have difficulties as well.

So I think part of this is developmental that we see this increase with age, but I think it is quite striking that this is a major concern for these siblings and something that we should acknowledge.

Dr. Kelly Knupp: [23:37](#) And so I had mentioned in the other slide that the siblings reported concerns and symptoms at a greater rate than their parents perceive them. And that really is what I would like to demonstrate here. And so we have some different symptoms here being easily startled or having bad dreams. And we've divided this up by age, but we can see in every single one of these symptoms that in the majority of the age ranges, these siblings are reporting these symptoms at a far greater rate than their parents are perceiving.

Dr. Kelly Knupp: [24:09](#) Particularly with bad dreams, we can see that this is happening at a far greater rate than parents are perceiving this. And this may be that the siblings are hesitant to talk to their parents about this. You can sort of construct a way to explain this, that if you're already concerned about your parents' stress and being unhappy, the last thing you want to do is tell them about something that may worry them. And so you're not going to tell them that, that you're having bad dreams at night, and they may not recognize that you have bad dreams because you may not have woken up enough and sought help for it.

Dr. Kelly Knupp: [24:39](#) So we can sort of construct something to make sense of that, but I think it's just really important to recognize that there is this discrepancy between the siblings report and the parental report. And we see this in other symptoms as well, such as feeling unhappy, not enjoying things and feeling tired, that again, all of these are being reported across the age span at a far greater rate in the siblings than the parents recognized.

Dr. Kelly Knupp: [25:07](#) And so I think that is a key take home point for our parents is to be aware of this and make sure that you're checking in and tuning in to see what's going on with those siblings and encouraging them to talk to you about it. The Sibling Voices project also looked at coping strategies, which do vary by age. And I think there's also discrepancy here between what the siblings thought that they would like to do and what parents thought would be helpful for them.

Dr. Kelly Knupp: [25:35](#) And so I think this is also really important, and I think it's also important to keep in mind that each sibling is a unique individual and may need their own thing and not to necessarily follow the numbers here but I think this gives us a little bit of a guide. Many of the siblings reported that they would like to

have special outings with their parents and have those as unique outings.

- Dr. Kelly Knupp: [25:56](#) And that's something that the parents thought would be helpful as well although the parents thought that would be far more helpful than the children did. And I think particularly in this teenage group has really stood out because these siblings would also like to spend more time with their friends. And so I think it's really important for parents to recognize if your child says they want to spend time with their friends, you may need to let them do that. That may be a better coping strategy for them than spending time with their parents.
- Dr. Kelly Knupp: [26:24](#) I think one of the other things that really stands out here is this need for more information about epilepsy, and we see this even at the younger ages and then even more so in the adult siblings. These adult siblings also want to spend more time with other siblings who have siblings with epilepsy and they also wanted to learn ways to help with stress, worry and sadness.
- Dr. Kelly Knupp: [26:50](#) We didn't see that in these younger ages in the teenagers, they really don't want to learn ways to help with their stress, worry and sadness, and this may have to do with where they are developmentally. But I think that's important to keep in mind that it may be somewhat difficult to encourage these siblings to seek help outside the family. Not that that doesn't have value, I think it has great value, but it may take a little bit more work and effort to think about an approach that way.
- Dr. Kelly Knupp: [27:20](#) So action items for families. I think the most important thing is to talk about it, talk about the epilepsy. Keep in mind that some children may actually need a job when a seizure occurs and sometimes that may be something as simple as standing at the door and waiting for EMS, or they may need a bigger job. But I think the most important thing is to talk about it and making sure that you're continuing to have that ongoing conversation.
- Dr. Kelly Knupp: [27:45](#) And also as a parent, making sure that you're providing education when asked, but I would put the caveat on this to make sure that you're answering the right question. And in my mind and the way I described this to families in my practice when this comes up is it's kind of the same approach you would have when your children ask you about sex. When a five-year-old asks you where babies come from, they probably aren't asking about all the details of where babies come from, they probably want to know what hospital did my sibling come from.

- Dr. Kelly Knupp: [28:16](#) And so you need to make sure you're answering the right question and that you meet the kids where they're at, and that may require some clarifying questions on your part. One of the things that I've learned from families in my practice and from siblings is that sometimes it can be really helpful to consider things like basic life support classes that really empowers kids to know what to do in an emergency and sometimes can be really helpful when that's coming from somebody else.
- Dr. Kelly Knupp: [28:46](#) You want to check in with your child and see if they want some protected alone time with you, and it may be important to schedule that and make that happen and make that happen on a reliable basis. And first and foremost, I think acknowledge the sibling's feelings. These are real feelings and they need to be validated and they may not be so different than your feelings, and knowing that may be really helpful.
- Dr. Kelly Knupp: [29:09](#) These siblings may often feel very alone, that's what we saw in the data. So knowing that they're not alone and that they're feeling the same thing that everybody else in the family is feeling can really go a long way to validate their feelings. And absolutely don't hesitate to get help if you need it. If you feel like your child is having overwhelming feelings of loneliness, sadness, worry, and you don't feel that you're coped to handle it, that's the time to get help. And there's lots of help out there.
- Dr. Kelly Knupp: [29:38](#) And I think particularly for adolescents, we're really learning that this is something that we really need to be attuned to and make sure that we're giving them that support. I don't know how many providers might be on the call, but I think there's some action items for providers. And I think first and foremost, it's ask, talking about it, asking how those siblings are doing, asking how those relationships are going and asking the parents if they have some strategies to deal with some of the concerns that may be coming up, and acknowledging that this can be difficult for siblings.
- Dr. Kelly Knupp: [30:11](#) As a neurologist, all of these siblings should be going to see their pediatrician, but their pediatrician may not know to ask about some of these things. So we may be in a very unique situation to be aware of the impact on siblings and to actually raise that awareness with parents so that they're paying attention to it. I think it's really important to know your local resources. And for me in Colorado, the Epilepsy Foundation of Colorado does have resources for siblings.
- Dr. Kelly Knupp: [30:42](#) In fact, one of our younger camps is an epilepsy camp for both children with epilepsy and their siblings so it's important to

know what those local resources are so that you can share those with families. Encourage families to validate their own feelings and their siblings' feelings. Again, they may all be feeling the same thing and the more they can talk about it with each other and recognize that they're not alone, that will go a long way.

Dr. Kelly Knupp: [31:06](#)

As pediatricians, as I said, at the beginning, we use a family model of care. And so we need to make sure that we don't forget that siblings are part of that model, siblings are part of the family and they need to be considered in this. So just some ideas for resources and then we'll open this up for questions. I think it's really important to look at your local epilepsy foundation.

Dr. Kelly Knupp: [31:27](#)

As I said, my epilepsy foundation has sibling sessions, has sibling camp and has educational resources. I think many parent organizations can be very helpful. You can network with other families who are probably trying to manage the same things as you are, may have educational resources and may actually have opportunities for siblings to meet with each other and talk with each other which is something that siblings have said that they would really like to do, particularly as they get older.

Dr. Kelly Knupp: [31:57](#)

Some of these siblings may actually need counseling and I think it's really important to normalize this. This is a lot to cope with. I mean, quite honestly as a parent, it's a lot to cope with to have a child with epilepsy. So imagine what that's like as a child when you don't have all of the adult coping skills yet. So I think it's really important to make sure that you're using those opportunities if you need them. And I think with that, we will open this up for questions.

Dr. Laura Lubbers: [32:28](#)

Terrific. Thank you so much Dr. Knupp. To our audience, if you have any questions, please submit them in the Q&A tab on the Zoom panel and then click send. I know that there are a number of questions that have already come up so we will start to address those. The first question that came in is for siblings of children who have frequent seizures or other types of associated unpredictable, visible medical things that need urgent care like respiratory events, is there a language, or are there tips to make this easier on the sibling?

Dr. Kelly Knupp: [33:03](#)

So I think it's really important to meet the siblings where they're at. But I do think it's important to talk to them about it. You may have some local resources with child life who may be able to come up with some very age appropriate terminology to discuss that. And I know at my institution, our child life personnel are

available to talk to siblings just as much as they are to talk to patients and are really good at figuring out how to turn that terminology into something that's child-friendly.

- Dr. Kelly Knupp: [33:37](#) So ideas like having an IV that goes into your blood vessels paints a very different picture for a five-year-old than it does for a 15-year-old. And so it's really important to think about the words you're using and how you describe it. But I think as a parent, what's also important is to ask clarifying questions to see if the sibling has really understood what you are trying to describe, or if they came up with something scarier in their head.
- Dr. Kelly Knupp: [34:05](#) And that's more often what happens, is we use words and children may misinterpret that as something scarier than what's really happening. But I think knowing your resources and trying to find help with that can be really helpful. There are a number of books out there that can help with some of these specific things as well. And usually child life is aware of those books, or if there's a family library at your hospital, they often have a number of these books around that can help describe those things.
- Dr. Laura Lubbers: [34:34](#) Great. Thank you. Another question, and this actually comes from somebody at a local epilepsy foundation. Are there other helpful literature or resources in general to share with families who are struggling? And I know that that's kind of a broad question, you've touched on that.
- Dr. Kelly Knupp: [34:48](#) Yeah. So again, I would probably go back to the child life specialists and the family library. They often have sort of the best group of books, the... We actually turned to our epilepsy foundation to provide those books about epilepsy. So I think... I wish I knew of a great resource that listed all of those books. And maybe if somebody has a good idea of those resources, they can post them in the chat to share them with us, that really would be an amazing resource for families if there was a website that they could go to and find those.
- Dr. Laura Lubbers: [35:31](#) Very good. Thank you. I think there are some great books out there and somebody just posted here in the question, let me see if I can find it. One person notes that she believes that there's a list of books on epilepsy.com.
- Dr. Kelly Knupp: [35:50](#) Great.

- Dr. Laura Lubbers: [35:51](#) Yes, that's a great resource. And as a sibling myself, I pay attention to this space and there are lots of great books that span the age ranges. I was just reading one actually over the weekend that was really targeted to the younger generation, the younger set to talk about a sibling with disability. And in this case it was somebody with autism, but clearly many of the context are the same. And really, again, talking about it, this particular book also had a workbook like a coloring book where a child could express their emotions. So there are some really great resources that are starting to come up in this space and we can see if we can get some of those listed on our website. Another question-
- Dr. Kelly Knupp: [36:38](#) Well, just along that line, one of the things I didn't mention, but I've had a number of siblings who have used an art therapist, which has been really helpful. And it's been really impressive to me to see some of the artwork that comes out of that. And what is most impressive to me is that oftentimes what the children think is going on is far worse than what's really happening.
- Dr. Kelly Knupp: [37:01](#) And so particularly when our patients are going through things like epilepsy surgery, we have found that it's really important for those siblings to be able to come into the hospital and see what's happening to their sibling because otherwise what they picture when they hear about things like intracranial electrodes and surgery is so much worse than what's really happening. And so it's really important for them to see the real thing and know that their siblings are safe, but art therapy can be particularly powerful and helpful.
- Dr. Laura Lubbers: [37:33](#) That's a great suggestion, that's a great suggestion. And people are posting suggestions in the chat too. So I would encourage people to take a look at the chat because there's some resources that have cropped up in that. We'll get back to the questions, and this is a great question. This person has found that her parents were also emotionally impacted, what resources are available for them?
- Dr. Kelly Knupp: [37:55](#) Yes. Parents definitely can be emotionally impacted by this. And this is... I think that every parent who has a child with a chronic illness really has to go through the whole grieving process. And I think it can be really helpful to talk to other parents. I think it's helpful to have a good social support network and it may require therapy.
- Dr. Kelly Knupp: [38:21](#) So it may be that they really do need to sit down with a counselor or a therapist to work through some of that, and also

have some insight of whether they may have some underlying anxiety or depression that could be contributing to this as well. And grieving is something that everybody does in different ways. And so some people move through the grieving process fairly quickly, some people stall at one of the stages. And so I think trying to get help to continue to move through that process and come to a place of acceptance can be really helpful for everybody in the family.

Dr. Laura Lubbers: [39:00](#)

Great. Great advice. And I just want to correct that in some cases, the chat is only going to the panelists. And so if there are resources available that we think will be helpful for our audience, I'll make sure that they get posted on our website along with this webinar so that you can take a look.

Dr. Laura Lubbers: [39:19](#)

And just to your point, Kelly, I think we are recognizing it as a community that this is not post-traumatic stress, this is traumatic stress and chronic stress and that process starts very early and it's good to start addressing it early for all members of the family. So here is a question. There are so many ways a severe epilepsy divides a family in an effort to maintain some normalcy for siblings versus keeping the child with epilepsy safe. How do families accept the new normal and not allow it to divide a marriage?

Dr. Kelly Knupp: [39:58](#)

Boy, that's a challenging question. And I think that's a very complicated question and we know that divorce rates are higher in families with chronic illness. And I think the more parents are aware of that, the more they are open to receiving some support and help through that. I think it's also important for parents to recognize that their own individual processes are going to be different between the two of them just like it is with any other crisis or trauma that they have to deal with.

Dr. Kelly Knupp: [40:37](#)

And some families really do better when they're apart than when they're together, which is hard to say but that is the reality sometimes. But I think trying to intervene and trying to find some time to focus on yourselves as a couple can be very helpful. And I think that's where extended family and friends often come in. It can often be very difficult to receive help from people outside your immediate nuclear family but I think that can be really helpful.

Dr. Kelly Knupp: [41:10](#)

And many of those people want to help you, they just don't know how to help you. And so trying to establish that communication so that you can be clear with them of it doesn't help me when you come empty my dishwasher, but it's really helpful if you can take the kids for three hours so that we can go

for a walk together and try to reconnect and trying to find ways to maintain your relationship that way. But I don't think that there's a perfect answer to this. Honestly, there are families with healthy children who struggle with this as well. So it's not something unique to children with chronic illness, it's just something that we see more often in children with chronic illness.

- Dr. Laura Lubbers: [41:49](#) Thank you. Here's a difficult one. Can you discuss strategies for talking about risks of death? For our eight-year-old with severe DEE has been near death multiple times and is in a hospice program. While those high risks for imminent death have been less frequent recently, should we still be open about discussing the risk with a five-year-old sibling?
- Dr. Kelly Knupp: [42:15](#) Boy, that's tough. And I think this is where things child life can be really helpful. I mean, this is what child life does, is helps you have these difficult conversations. I think for the five-year-old, it's really important to ask them where they're at. And I would keep in mind that many siblings do worry about this and they may be afraid to talk to you about it.
- Dr. Kelly Knupp: [42:39](#) And so it may be helpful to say, "Hey, when you think about your brother or your sister, what worries you are you? Are you worried that he can't run? Are you worried that he eats different food? Are you worried he's going to die someday?" And try to figure out where that five-year-old's at so that you can answer their questions in the place that they're at. And I do think it's important to talk about it and also to let them know that it's not their fault. Particularly for a five-year-old the world still sort of revolves around them and so things that are not their fault still feel like their fault. And I think that's really important to talk about that.
- Dr. Laura Lubbers: [43:18](#) Interesting, very interesting perspective. So here is sort of the intermediate age here. The siblings in our family showed previous unspoken anxiety and concerns as they began planning their own families, thoughts about this.
- Dr. Kelly Knupp: [43:36](#) That's very real, right? The question comes up is will this be what my family looks like and do I have to worry about my children having this epilepsy? And I think we're in a better place now answering those questions than we were 20 years ago, because we know so much more about genetics. But I think having open honest discussions about that, I know that in my practice I've met a number of families who had sort of stopped looking for the cause of epilepsy for several years because it

was exhausting, it was disappointing, it's expensive, and it didn't make a difference in the day-to-day care of their child.

- Dr. Kelly Knupp: [44:17](#) But when siblings started to approach sort of family planning age, it took on a new significance to reach out and have genetic testing done to figure out what were those risks really. So I think as much as you can provide information that usually is helpful, I think also having open discussions about expectations of whether who will care for this child as parents get older.
- Dr. Kelly Knupp: [44:50](#) And oftentimes it's very surprising because many times siblings will say, "That's what I've always planned to do." And the parents say, "Boy, I don't want you to have this burden." And so it's really important to have that discussion so that there's a clear plan and clear expectations. Because more often than not, that's the way that discussion goes, is parents are trying to find a way to reduce the burden and the siblings are saying, "No, no, no, I want to do this."
- Dr. Laura Lubbers: [45:15](#) Right, absolutely, there's a lot of discussions along the path for sure in the care of a sibling especially into older age. Here's a question. I'm not sure I completely understand it, but we'll see if we can get there. Our focus was on our child with epilepsy and the therapy for coping with his diagnosis. How do we introduce this with his older sibling after the fact and make sure we didn't neglect their feelings during this entire process of learning and understanding?
- Dr. Kelly Knupp: [45:46](#) Well, first of all, I would give yourself a break because you can't undo the past. So if you think that you may have neglected something, what's done is done and you can't undo that. I think it's important to focus on the here and now and moving forward and checking in with them and asking them, how are they feeling? Maybe if they're older, talk to them about how you're feeling and what it felt like in those times in the past that you felt like you had to do everything you can, and all of your energy had to focus on that and now you want to move forward.
- Dr. Kelly Knupp: [46:23](#) But I think it's really important to be forward-looking with this. And we're not perfect, none of us are perfect and we've all had those moments where you really can't undo that. But what's important is to recognize the situation you're in now and try to find the best path forward.
- Dr. Laura Lubbers: [46:40](#) Right. Thank you. So someone just noted in the chat and this did go to panelists and attendees, just to clarify that child life is usually services at hospitals. Is that the case?

- Dr. Kelly Knupp: [46:52](#) Yeah, child life is usually services at hospitals, the vast majority of children's hospitals have both inpatient and outpatient child life experiences. So they are... at my hospital they are able to meet with people before procedures, before appointments, they're able to meet with siblings to talk about things like this. We actually have our child life specialists come up to our epilepsy camp to help out there. So child life specialists are usually open to a broad range of supports that they're able to provide.
- Dr. Laura Lubbers: [47:25](#) Wow, wonderful resource to know about. And this might tie into that. So somebody is asking for ideas for affordable counseling for parents. It's definitely chronic anxiety and stress that would be lifelong. Is there anything available through hospitals for the parents?
- Dr. Kelly Knupp: [47:41](#) So I think that's hospital dependent. Here in my state, we would usually refer somebody to the Epilepsy Foundation for that as opposed to the hospital because we're a children's hospital. But I do think reaching out, and this again comes to sort of knowing your local resources. There often are sliding scale offerings for counseling available in a variety of places, and so it would be very helpful to start talking to your providers to see if they're able to identify those.
- Dr. Kelly Knupp: [48:17](#) Interestingly, usually your primary care provider has the best knowledge of what those resources are. So it may not be your neurologist, it may actually be your family practice doctor, your internal medicine doctor or your pediatrician who may be able to identify those resources for you.
- Dr. Laura Lubbers: [48:34](#) Wonderful, wonderful. Great to know because people might not naturally think that and have that that they go to. That's wonderful. I have a question for you. I wanted to learn more about the BLC. I think that's what the-
- Dr. Kelly Knupp: [48:52](#) Basic life.
- Dr. Laura Lubbers: [48:52](#) The basic life.
- Dr. Kelly Knupp: [48:54](#) Basic life support, yeah.
- Dr. Laura Lubbers: [48:56](#) Yes. Where does one find more about that? Is that something that might be available through hospital resources or hospice communities? But families are so burdened with all they have to do, how can we get them there quickly?

- Dr. Kelly Knupp: [49:10](#) So basic life support is usually offered through Red Cross. It can also be offered through your local fire departments, your hospital. So there's lots of different resources for basic life support. And as I have started mentioning this to families, it's something that teenagers have really been open to taking. And for many girls who may be taking babysitting courses or things like that, basic life support is usually part of that.
- Dr. Kelly Knupp: [49:37](#) But it's a very systematic approach to what to do when somebody is in trouble and really can go a long way to alleviate some anxiety of what will I do if my sibling runs into trouble. And so I've been really surprised that many of the sisters may have already taken it with their babysitting courses and things like that, but many of the brothers have been really excited to take these courses and really do think that it helps a little bit in alleviating anxiety.
- Dr. Laura Lubbers: [50:08](#) Great, great. Great to put it into that context. Here is... it's less of a question, more of a statement, but I think it's important to just share these things. So this person says that they have twins and a severely medically refractory child with severe SCN1A epilepsy and his needs completely consume me. I'm home schooling too to keep them healthy. I feel like I'm just meeting everyone's needs and not spending quality time with my medically fragile child along with the twins. I feel guilty.
- Dr. Kelly Knupp: [50:40](#) I acknowledge that. I don't have a way to fix that. I think that the truth is parents feel guilty all the time because we can't be everything to everybody all the time. And that sounds like a particularly stressful situation. I think the first step is recognizing that you feel guilty and if you're able to find ways to get some help so that you are able to first take care of yourself.
- Dr. Kelly Knupp: [51:13](#) Because if we're not able to take care of ourselves, it's really hard to take care of our loved ones. And we sometimes forget that because we're so busy taking care of our loved ones. But even if it's taking a 20 minute walk, taking a break for a cup of coffee, taking those moments and I really do encourage families to reach out to your friends and family for that type of help. They oftentimes want to help you and they just don't know how.
- Dr. Kelly Knupp: [51:39](#) And that's something that's fairly simple, that maybe you just go sit in the backyard. So sometimes I know it's hard to be away from your child with epilepsy because nobody else knows their seizures as well as you do and nobody else manages their seizures as well as you do. But if you can just get 20 minutes in the backyard to catch your breath, now they would probably be

more than willing to help you with that and to identify those resources so that you can take care of yourself in that situation. But I think parents always feel guilty and I'll be the first to admit, I don't have any children with chronic illness and I still have many, many moments of guilt for my parenting.

Dr. Laura Lubbers: [52:21](#)

Thank you for that realism. But here's an interesting point. While many families are able and want to help, this question is how do you get in-laws or extended family to believe that your child is having seizures and not faking it?

Dr. Kelly Knupp: [52:38](#)

So I've encountered this. And I think oftentimes in that situation, it's really helpful to invite them if you're willing to, to visit with your neurologist so that your neurologist can help out with this. I've seen this come up not just with are these seizures really happening, but is this the management that really needs to happen?

Dr. Kelly Knupp: [53:06](#)

Sometimes we see this with ketogenic diet management where grandparents just don't understand why they can't slip a scoop of ice cream to the child and why that would be so detrimental. And so in those situations, it can be really helpful to enlist some help. I would definitely recommend that you give your provider a heads up that that's what you want to discuss and what the concerns are so that they know to specifically address that during the visit. But that can be a really helpful way to manage that.

Dr. Laura Lubbers: [53:37](#)

That's a great suggestion. Thank you so much. Here is one. It's actually coming from a sibling and it's actually a medical question, so I just want to change gears but sometimes it's hard for siblings to get this information and so I do want to pose this question. Why would increasing dosage of medication be the go to answer when seizure frequency increases? Thank you in advance, worried older sibling.

Dr. Kelly Knupp: [54:04](#)

So often our thought when we're doing that is if the medicine's helping at a lower dose, it may help more at a bigger dose. We always have to be cautious though, because sometimes our medicines have the opposite effect. And so sometimes our medicine can trigger seizures instead of helping with seizures. But we always want to make sure we maximize the medication before we move on to another medication.

Dr. Kelly Knupp: [54:27](#)

And so usually that is our go-to, is to increase medications. The other thing that can contribute to that is particularly in our pediatric population, is that kids are growing. And so we may have to keep adjusting doses because the kids are getting bigger

and so they need more medication to account for that bigger body size.

Dr. Laura Lubbers: [54:46](#) Okay, great. Thank you. And as a sibling myself, I found it helpful to also go to medical appointments and learn more. So I encourage all siblings to do that, ask those questions. You may be taking on more responsibility and it's just helpful to have that relationship with the medical provider and be able to go to them with these questions. Yes.

Dr. Kelly Knupp: [55:13](#) Now I was just realizing at epilepsy camp, we have an ask the doc session where the patients, the campers who have epilepsy get to ask physicians questions because more often than not in the visit, their parents are doing the talking and not the kids. And I'm just realizing... and I had made a note to myself that we probably need to do a sibling ask the doc so that siblings have an opportunity to ask questions as well without everybody else interfering.

Dr. Laura Lubbers: [55:40](#) That's a great idea. Well, we were about at the top of our hour, so I would like to close this webinar and thank you Dr. Knupp for spending your time and your expertise with us and answering so many great questions. It was a terrific presentation and I thought it was a great dialogue with our audience members, great suggestions, which we will capture, and again, post whatever resources we can on the website along with this webinar, which will be available on the website in the next couple of days.

Dr. Laura Lubbers: [56:11](#) I'd also like to thank our sponsors Zogenix and particularly Lori Bailey whose work I have been following for many years now and so grateful that she was willing to allow us to share this incredible information. I found it an amazing resource that somebody would take on this challenge of describing the issues in the family in the way that she did so I want to thank her in particular. I also thank you for making the webinar possible, and I'd like to extend again, a thank you to the audience for the wonderful questions, wonderful engagement.

Dr. Laura Lubbers: [56:51](#) If you'd like to suggest any future webinar topics to our audience, please do feel free to reach out to us through the CURE Epilepsy website. You can email us at research@cureepilepsy.org and you can also learn more about CURE Epilepsy research program in there. Please do also stay tuned for our next webinar that will focus on late onset epilepsy, the timing of which we're still working out but should be announced shortly. So again, thank you Dr. Knupp, thank you

to our audience for such amazing engagement and resources.
Please be safe out there. Thank you again.

Dr. Kelly Knupp:

[57:30](#)

Thank you.