Seizing Life, episode 93
A Parent's Guide to Your Child's Epilepsy Diagnosis and Treatment
Guest: Dr. Doug Nordli
(Transcript)

Kelly Cervantes:	00:00	Hi, I'm Kelly Cervantes, and this is Seizing Life. A biweekly podcast produced by CURE Epilepsy.
Kelly Cervantes:	00:17	Today on Seizing Life, I'm happy to welcome Dr. Doug Nordli. Dr. Nordli is a pediatric neurologist at the University of Chicago Medicine, where he is also Chief of pediatric neurology and the co-director of the Comprehensive Epilepsy Center. Dr. Nordli is here to discuss the diagnostic and treatment journey for children with epilepsy and their families.
Kelly Cervantes:	00:39	Dr. Nordli, thank you so much for joining us today. I'm so excited to jump into this conversation because for all of our parents and caregivers out there, please bookmark this episode, flag it, there are so many questions that we are going to get into that are going to be so valuable across the length of an epilepsy journey. And I'm just so grateful to be able to ask you all of these questions. I admire and respect you so very much.
Kelly Cervantes:	01:10	To begin with, aside from an obvious seizure, what should parents be on the lookout when wondering if perhaps their child has had a seizure?
Dr. Doug Nordli:	01:25	Well, thank you so much, Kelly, for inviting me to be here. It's a pleasure. And let me return that compliment. I admire the work that you do on behalf of all people with epilepsy tremendously. So I think everybody is aware of the most overt manifestations of a seizure. What we call atonic clonic seizure and what that refers to is the sudden stiffening of all the body followed by clonus which is rhythmic jerking. And that's the classic image probably that comes up in all of our minds when we think about a seizure. But in reality, that's only a minority of seizures and many of them are subtler, particularly in babies. And so what parents need to be on the lookout for is any sudden change in the behavior of their child, particularly when it's associated with some type of unresponsiveness. So an easy thing to do, it's not uncommon for everybody to daydream a little bit or get drowsy. So an easy thing to do is to try to engage the attention of the child, to see if they're responsive and if they can look at the parent and then utter some response to questions.
Kelly Cervantes:	02:44	Okay? So the parent now is suspecting abnormal behavior. Be it a seizure or something else, behaviorally something is going on, flags have been raised. What should the parent do? Should they immediately take the child to the emergency room? Should they contact their pediatrician? What's the next step?

Dr. Doug Nordli:	03:04	Yes. I think in a minority of circumstances, let's say if it's a convulsion, many times, what happens is that EMS is called and then the response from there is to take the child to the emergency room. So that's often what happens, but let's take maybe a more common scenario where the parents who know their child's behavior. So well suspect that something is wrong. Then the thing to do is, number one, if they have this capability, like we are now, is capture that episode on a video. If they can use their phone and capture it. The video quality of phones is amazing, and that's so helpful to us if the events are recurring in again. If not, then definitely calling the pediatrician and then explaining like, "Oh, I saw this sudden change in behavior." And again, if they were able to capture it on video, that would be great. But even if they can't, describing it to the pediatrician who can then take it to the next step.
Kelly Cervantes:	04:09	Okay. And then are there some conditions out there that could be confused for epilepsy? So you think your child has had a seizure or maybe they have had a seizure, but it's not epilepsy.
Dr. Doug Nordli:	04:24	Absolutely. And over the years of doing this, I've come to trust parents. Parents have, in my experience, a really good sense of when something is wrong. But not all the time is that thing that's wrong, a seizure. So there are many things that can mimic it. And even to skilled observers, fool us. And we think, "Oh, that looks like a seizure." But in fact, it's not. So some common things that come up when people pass out and sometimes after passing out they faint, they may have brief movements and that sometimes gets suspected that, "Oh, that's a seizure." So a very simple rule of thumb is, almost always, when an individual is having a seizure, their eyes are open. If their eyes are closed, it's probably something else. So that's a very helpful hint that we use a lot when we're looking at videos.
Kelly Cervantes:	05:21	Oh, that's actually really fascinating. That's a good tell. You discover that the child is having a seizure or strongly suspect it, the pediatrician refers you to a neurologist or the ER, says to schedule an appointment with a neurologist. I can't tell you how many parents I've had conversations with where they tell me that they've tried to get an appointment and it's going to be months. Now, the language that we're putting out there is that seizures are a medical emergency. And then to try and schedule an appointment and find out that it's going to be months before can get in to see a doctor, can be alarming. What should a parent do when faced with that situation?
Dr. Doug Nordli:	06:07	Well, first of all, I think the message that you are sending is a good one. That it is good to get prompt attention for something

		that's suspected of being a seizure. Because we have to figure out what's going on. Is it a seizure? And then if so, if we can, what's causing it. So I think several months wait is not acceptable. So I think there's two things that parents could do. One is to, if they got referred to the pediatrician, they called the neurologist office and they said, "It'll be several months." Is call back the pediatrician and say, "I need a more urgent appointment." And then the pediatrician can usually put pressure on the neurologist to say, "This is a new onset. Can't you get them in sooner?"
Dr. Doug Nordli:	06:49	If that doesn't work, one silver lining from this horrible pandemic is that most of us are doing telemedicine. So there may be resources within your state at for example, an epilepsy center within the state that offers telemedicine. And it's not quite as good as being in person, but for epilepsy, it can be a very good substitute at least to get the ball rolling. So I would tell parents, don't get discouraged, reach out to the pediatrician. If that fails, then look up some resources in your state or close by and see if they offer telemedicine consultations.
Kelly Cervantes:	07:33	Yeah. And I would probably add to that also that if you are fortunate enough to live in an area where there are multiple hospitals or multiple pediatric epilepsy or pediatric neurologists to try a different healthcare center and see if you can get in somewhere else and keep the other appointment that's a few months later because you can always use a second opinion, just keep trying different centers as well to see if you can get into another hospital, another doctor.
Dr. Doug Nordli:	08:08	Yes. That's a really good suggestion. And on the CURE Epilepsy website, there's information that lists all the centers. The epilepsy centers in the United States. So that's easy for parents to do. They could go to that and then see a list of all of the approved comprehensive centers. And probably, I would guess virtually, all of them have some form of telemedicine now.
Kelly Cervantes:	08:39	That's an excellent idea. I want to piggyback on that a little bit. A two part question, we throw around the terms, neurologist and epileptologist, as well as you may go to a neurologist's office versus going to an epilepsy center. What are the differences in these terms?
Dr. Doug Nordli:	09:03	So most of the time I believe most children should see a child neurologist. Now there are enough of us that there's over a thousand of us in the United States that are active. So I think that the expectation should be to see a child neurologist. So

		what is a child neurologist. A child neurologist is somebody who's done specialized training for that specialty. They've done two years of pediatrics, a year of adult neurology, and then two years of child neurology training. And in that training, we as child neurologists get a lot of exposure to children with seizures and epilepsy. So they should expect that the child neurologist should have a very high level of competence in caring for children.
Dr. Doug Nordli:	09:50	Now, an epileptologist, a pediatric epileptologist is the same as a child neurologist, so that same training. But then they've done an additional one or two years of training. So now seven years of training after medical school, many times. And then going beyond that, they tend to focus their work on just patients with epilepsy. So every year, they keep increasing their skill set and just focusing on that aspect of child neurology. So many of them are in Comprehensive Epilepsy Centers, the epileptologists, although some may be outside of those comprehensive centers.
Kelly Cervantes:	10:29	And what is the difference between a Comprehensive Epilepsy Center and your general neurologist office?
Dr. Doug Nordli:	10:37	So comprehensive epilepsy center has met the criteria. There's a national organization that surveys all of our centers and has a certain bar for qualifications. At the highest level, that's a center that has the capability of doing absolutely everything that is needed to care for a child with epilepsy, whether it's dietary, medications, surgical approach, et cetera.
Kelly Cervantes:	11:05	And when should a parent push for their child to see an epileptologist over a neurologist? Or to visit an epilepsy center versus the general doctor's office?
Dr. Doug Nordli:	11:19	I would say, for the most part, I would expect that they would see a child neurologist. There are some exceptions, and not to complicate things, but many epilepsy centers have opened up what we call new onset seizure clinics. And many of those, the expectation is that the child is seen within one week. So getting back to our earlier comments, if they're disappointed in their appointment with the child neurologist, call to see if there's an epilepsy center. They may have a telemedicine and they may also, many of these may have new onset seizure clinics where they fast track children in.
Dr. Doug Nordli:	11:53	That aside, let's say that the child is seen by a child neurologist and all goes well, that's great. If there are speed bumps in this journey, then that's when that parents should think about going

		to a pediatric epileptologist. And we could talk about what those speed bumps may be.
Brandon:	12:19	Hi, this is Brandon from CURE Epilepsy. An estimated 3.4 million Americans and 65 million people worldwide, currently live with epilepsy. For more than 20 years, CURE Epilepsy has funded cutting edge patient focused research, learn what you can do to support epilepsy research by going to cureepilepsy.org. Now back to Seizing Life.
Kelly Cervantes:	12:42	So Dr. Nordli once a family has visited the neurologist's office. What tests can they anticipate that the doctor is going to order and how will they come to a conclusion or a diagnosis of epilepsy?
Dr. Doug Nordli:	12:58	There are three tests, I would say nowadays that have become so common. The first and the most important is an EEG. That's a brainwave study where electrodes are gently placed on the child's scalp and then we record the brain electrical activity. It's been around for a while and it remains the single most helpful test. If that shows abnormalities and the first event was say an unprovoked seizure, then even with that information, nowadays, we can diagnose epilepsy. Which we all know, is defined as a condition of [inaudible 00:13:36] where someone is predisposed to recurrent seizures. So that's changed nowadays. So EEG is one of the most important. It not only tells us, is someone at risk for another seizure, but also, many times can give us a clue as to what kind of a seizure or what epilepsy are we dealing with, if it is epilepsy?
Dr. Doug Nordli:	13:56	So that test is very helpful. I won't say, almost all the time. They could expect that there will be a brain MRI and an MRI it basically a simple principle where someone's put in a magnetic field and then a little radio pulse is put in and then a signal, believe it or not is released from our tissues in our brain, and then computers can analyze those signals. And it's amazing. Probably people are pretty familiar with MRIs, but it's amazing the quality of the structural images that we get nowadays.
Dr. Doug Nordli:	14:34	And so I'd say, with some exceptions, they should expect that probably the neurologist will order an MRI. And then last, and this has become so important to us nowadays is genetic testing. And particularly when the epilepsy is starting relatively earlier in life, genetic testing has really transformed our landscape. Not everybody is a good candidate for genetic testing, it would be only a subset of the patients. But I would say that's the third commonest test that we're ordering nowadays.

Kelly Cervantes:	15:08	I hear from a lot of families as well that maybe the MRI came back fine. The genetic testing was inconclusive or normal, but the EEG, they're uncertain. What are the next steps there?
Dr. Doug Nordli:	15:28	So first of all, I think it's important that we remember that even in this modern age where we have all these wonderful tools, epilepsy is still a clinical diagnosis. So if we're convinced that the episodes were seizures and recurrent. Once they've been two, we can still then accurately diagnose epilepsy. But beyond that, we want to try to characterize it further to try to get a better understanding of exactly what type and what was the underlying cause of that. So here's the thing that I'm sure parents struggle with, I struggle with, which is, I always want to know the answer, right? I want to know why did this happen? But here's the paradox. It's better if I can't figure it out.
Dr. Doug Nordli:	16:18	If I can't identify a brain MRI abnormality, there's no genetic abnormality. Generally speaking that fits into a category of what we used to call primary epilepsy or idiopathic epilepsy. And as a rule, there are exceptions, but as a rule, the chance of remission of spontaneously growing out of epilepsy is higher. So I always struggle with that. Like on the one hand, there's a part of me that was like, "I want to know why this child's having seizures." And another part of me is, "Gosh, I hope we don't find out why this child is having seizures."
Kelly Cervantes:	16:53	Right. Then it's more likely a more serious issue.
Dr. Doug Nordli:	16:58	Yes.
Kelly Cervantes:	16:58	At what point in the journey should the parents or caregivers start seeking out a second opinion?
Dr. Doug Nordli:	17:06	Most epilepsy comes under control pretty quickly and without a lot of difficulty, assuming that the selection of the medication was correct. So I would say that parents should expect their child to be well controlled within a few months. I'm saying a few months, because sometimes it takes a little bit of time for the concentration, let's say if they're put on a medication for the concentration of the medication to come up to an appropriate level. And then it takes a little bit of time to see if it's going to work. So I'd say on the order of months, and certainly if two well chosen treatments haven't fixed the problem.
Kelly Cervantes:	17:48	Okay. So you talk about, it can take a month or two or even three I know for sometimes those medications to reach a therapeutic level and for anyone to even understand if it's

		actually doing what it should. How long then before you decide, if we need to try a new medication, and then what happens if that medication doesn't work? How many options are there?
Dr. Doug Nordli:	18:16	Really good questions. So let's talk about the first one. And this has changed for me also. When I first started, I would insist on pushing the medication to its absolute highest level. And now, newer research suggests that's not the best approach. That once you get to a reasonable level, there's probably no need to push that medication to a toxic concentration. So I would say, once that medication's at a reasonable level where you'd expect that it should work and it's not doing a trick, time to move on. Don't keep working and working and pushing that too high.
Dr. Doug Nordli:	18:58	There are many options. We had made these helpful cards for our residents. And I think there are over 30 cards that I made for the different medications and their attributes. So we have a lot of choices. If the second one does the trick, great. If it doesn't, then statistically, it's less likely that the third is going to work. And that's where we need to pause, hit the pause button and say, "Okay, what's wrong here, do we have the wrong diagnosis? Is there some other test that needs to be done? Is there an alternative type of treatment that we should think about?" And I think getting back to your earlier question, if the child neurologist is helping to guide through all those aspects, great, if not, then that's the time for a second opinion.
Kelly Cervantes:	19:54	And what other options are there outside of medication?
Dr. Doug Nordli:	19:58	We have at least three other options nowadays. One is diet. And diet has come a long way. When I was in training, our only dietary option was the full ketogenic diet. And now we have many different versions that are much better tolerated and much easier to use compared to way back when. Second big option is, if we're dealing with a focal type of epilepsy is surgery. Obviously that's frightening, it's something that we never embark on early on, but if it looks like medications aren't working and there's a single source for the seizures, and we can see it basically on imaging studies, then that child may be a good candidate for a focal resection. And I should mention that our resources there have increased dramatically. So nowadays many times we don't even need to do a large operation. We can use a very small diameter laser to oblate the tissue if it's not too big of a size.
Dr. Doug Nordli:	21:11	And then the third, and this is probably after those other options are various forms of neurostimulation where using a device, like the idea of defibrillating or a pacemaker idea. But

device that constantly sends some electrical signal to the brain or nerves that supply the brain to try to dampen down the epilepsy.

Kelly Cervantes: 21:37 Would that be like a VNS, a vagus nerve stimulator?

Dr. Doug Nordli: 21:40 Yeah, exactly.

Kelly Cervantes: 21:41 Yeah. Okay. So family goes in to the neurologist office and they're trying these different treatments, they have this epilepsy diagnosis, but so often they come out with more questions than answers. What information should their neurologist be giving them? What questions should they be asking?

Dr. Doug Nordli: 22:07 Yeah, this is a really important topic. So let me tell you how I as a pediatric epileptologist approach things. I fundamentally want to know three things. I want to know precisely what type of seizure or seizures am I dealing with? What kind of seizures? And there's a variety of ways that we classify seizures and for parents who are listening to this again. I would say go to the CURE Epilepsy website on the information page for patients and parents. There's really nice section that talks about the different types of seizures. So that's the first thing I want to know.

Dr. Doug Nordli: 22:43 The second thing that I want to know is, what is the epilepsy syndrome? So the epilepsy syndrome is a thing that is particularly important in pediatric epilepsy where it's a way of taking everything together, information about the patient, the seizure type, the EEG, and putting it all together in one package, that's called a syndrome.

Dr. Doug Nordli: 23:07 And back in the day, we used to treat patients based on the seizure type. Increasingly, to get more precision, we are looking at the epilepsy syndrome. So that's the second thing that I want to find. The last and maybe the most important is the cause if I can. I want to know the cause because now we have certain select treatments for specific causes and you can see the handwriting on the wall. We're going to have many more options for specific treatments as time goes by. So those are the three things, seizure type, epilepsy syndrome and cause.

Dr. Doug Nordli: 23:42 With regard to the epilepsy syndrome, if people go to epilepsy.org, there's a ILAE section. And within that, there's a thing called epilepsydiagnosis.org. It's a little wonky. It's like getting a lot into all the details, but if they've been told an

		epilepsy syndrome and they want to double check it, that's a good resource to look into.
Kelly Cervantes:	24:06	Thank you. And rewind and make sure that anyone who's listening, write down those websites. Those are great resources to go to get that information if you're not getting it from your neurologist. So another tricky question here, but so unbelievably important. When should the neurologist mention SUDEP to the family sudden unexpected death in epilepsy.
Dr. Doug Nordli:	24:34	Right away. Maybe not the first minute of the conversation, but as soon as possible. Dealt with tens of thousands of families, and it's hard to hear the news about even that their child has epilepsy. So sometimes it takes time just to process that. One way that I like to introduce it is, there's a couple of ways, but one way sometimes is, particularly if somebody is new to this, the experience of seeing their child have a seizure is one of the most traumatic events anyone's probably going to have in their life right? And one of the things that I think that bothers all of us about it is that this fear that the child is dying. It's in our unconscious that's what's happening. It's so frightening.
Dr. Doug Nordli:	25:27	And many times what I've observed is people will break down when they're describing that. And then I think it's good to pause. And then at that point say, "Bring up this." That a lot of people think that their child is dying. So then people usually say, "Yes. That's exactly [inaudible 00:25:44]." "Okay, let's talk about that. Let's talk about the risks of that." Because it's fresh in their mind, right? If the interview allows it, then you can get right into it at that point. Let's say if it doesn't then another way to introduce it is maybe towards the end of that interaction is to say, parents will often ask, "What thing should I do? Like how should life change?" And then that's another nice time to say, "Let's talk about the risks of seizures."
Dr. Doug Nordli:	26:12	And we can go through all things like risk of injury, risk of drowning, risk of SUDEP. And I think that's a nice more it has less emotional valance to bring that up and discuss it. And here's the thing that surprised me as a professional doing this is that this is not the thing where you're scaring people. They're already scared. And they already are aware that something's wrong. So I think bringing it up and having a straightforward discussion, if anything, helps in terms of calming, "Okay, here it is. These are the risks, this is what we're going to do about it."
Kelly Cervantes:	26:51	Okay. So now not just all epilepsy, caregivers and parents need to watch this, but we now also need to make sure that all medical students are watching this as well. So they know exactly

what to say to their patients in the room. Because you're 100% correct. The parents are already scared. They're already frightened. So be real with them, be honest, let them know the risks and then talk to them about all of the different ways that they can mitigate them 100%. I don't think I've ever heard it articulated so clearly before. Dr. Nordli I also wonder, is this something that a patient or caregiver can bring up with their doctor bring SUDEP up with their doctor?

Dr. Doug Nordli: 27:32 Absolutely. And I think if parents listening to this, haven't heard that discussion with their physician. Then I would encourage them to do that and they could bring it up and say, "Can we talk about the risks of epilepsy. And I've heard about this thing called SUDEP." And that would be a perfect opportunity for that discussion to take place.

Kelly Cervantes: 27:55 So ideally, and in most situations, the epilepsy and seizures will be controlled with one of the first two medications. If they're not, we have lots of other medications that we can try. There's also these other treatments that we've discussed. So we go off on two different avenues here. I feel like we have two different groups. We have the people who are medication resistant, intractable epilepsy, and we have the people who are controlled. For the people who are controlled, what does their relationship look like with their epileptologists Moving forward?

Dr. Doug Nordli: 28:28 For the patients who are controlled, it's important to stay in contact with let's say the epileptologist or the child neurologist, because we know from a lot of research, that there are other conditions that can go along with epilepsy. We call them comorbid conditions. And so even though the epilepsy is well controlled, we still need to be alert to other things that are important to manage. So what are these? These could be things like attentional problems, difficulty performing in school. Maybe there's a little bit of a learning disability. We need to stay alert to mood and behavioral issues. We don't want to miss an opportunity to intervene with somebody who may have some depression. So the majority of people won't suffer from these things, but a subset of children will. And what we learned is that it's important to get on top of those issues right away for the best possible outcome.

Kelly Cervantes: 29:29 I love that you are bringing up the mental health aspect of it because that's something that we have discussed so much on this podcast. And I think often gets overlooked. But they truly do go hand in hand epilepsy and mental health and making sure that the neurologist is on top of that as well. And that the parents and caregivers are on top of that. For the patients who

		have the intractable epilepsy, we've talked about the epilepsy centers. I know a lot of times parents and the patients; they get comfortable with their neurologist. And they think that they know their child best or they're worried about hurting the feelings of this doctor who has been helping them. But at what point do they need to seek out that second opinion. At what point do they need to go to that epilepsy center?
Dr. Doug Nordli:	30:18	The vast majority of child neurologists that went into this profession, really care about children. And what we like is when we feel like we've made a lasting impact in the life of a child. So if something's not going right, and child's continuing to suffer seizures, it's very bothersome as well to the child neurologist. So if the parents bring up and say, "Hey, do you think it's time for a second opinion?" I would say the vast majority of child neurologists, their ego is not going to get bruised. They're going to actually be comforted to in most circumstances say, "That's a great idea. Let's do that." Maybe there's something that somebody else could help us with that could make the child better. And then in an ideal world, once that happens, then the care could be returned again to the child neurologist.
Kelly Cervantes:	31:13	Oh, I think that's really important. You have this comfort with this doctor. It doesn't mean that just because you're getting a second opinion that you're transferring your care, it just means that you're getting more information. And then you can still come back to that doctor that you know and are comfortable with. Girls with epilepsy, when you bring in reproductive health, into the conversation, it further complicates these discussions around these medications. It's hard to be thinking about your future daughter's reproductive health when they're six months old, three years old, six years old. But is this a conversation that you need to be having with their neurologist or at what point do you need to be having that conversation when discussing meds about their reproductive health?
Dr. Doug Nordli:	32:02	Absolutely. It is a conversation that needs to happen. And I would say even in preteen girls we need to think about this. We do as child neurologists, as we've learned more about the side effects of certain medications, we're very skittish about introducing certain medications in girls, even as preteens, because thinking like, "What if they have to stay on this as they enter their reproductive years?" You're right. And you have to keep in mind, I am a father of two girls. So I understand it could be a delicate issue to bring up. So I usually introduce it and say, "I know pregnancy is a long, long way away. But we need to start thinking about this." So there are things that are very important to consider. And I think that if that hasn't come up

		with parents in their discussions with their child neurologist, that they should bring it up about, "Hey, I'm concerned about ultimately reproductive health."
Kelly Cervantes:	33:16	Another question that I get a lot is around the transition from pediatric to adult care. It is very overwhelming, especially if it's an earlier onset epilepsy. And you've been with this doctor for ages, or, health insurance, all of these things. There's so many changes that come about living independently, what have you. Going from that pediatric to that adult transition in care? When do you recommend that that happens? What tips do you have for parents and patients to make that transition as smooth as possible?
Dr. Doug Nordli:	33:54	I would say, in general, sometime between 18 to 25 years depending upon what's going on with the individual is a general rule of thumb. As child neurologists, I mentioned that we spend a year in adult neurology, so we're pretty comfortable dealing with a lot of adult neurology conditions. What I think we're less comfortable dealing with is adult medical issues. We train for two years in pediatrics, so we're good with that, but we don't know an awful lot really when it comes to adult medical conditions. So I think so long as the person is generally physically healthy, we're in good shape for monitoring them and caring for them. And lots of times I'll use it'll depend upon where, let's say they're 18, they're going off to college, let's say, and then it'll depend on like, well, where is that? And then are they coming back home afterwards? So sometimes that gets into it.
Dr. Doug Nordli:	34:53	Another aspect can be that we talked about some of these genetic conditions and we are on the front line of dealing with, and uncovering these genetic conditions. So, we, as child neurologists know a lot about them. Our adult neurology colleagues are increasingly learning about these. So sometimes it could be helpful for us to stay involved a little bit later than we normally would just because the conditions are relatively unusual for an adult neurologist. That being said, what do we do? I think we studied this when I was on an ILEE commission, a pediatric commission. We studied transition programs around the world. And there were two things that I found were helpful.
Dr. Doug Nordli:	35:39	One is, start preparing early. And you can do that by making sure that the child, knows basic information about epilepsy. They have epilepsy, what kind of epilepsy, and then maybe at the next visit, what medication are you taking? And then at the next visit, what are the doses of the medication that you're taking? And then increasingly devote a little bit of time

		specifically in the interview to that adolescent so that they get increasingly comfortable telling this story about what's happened. And then the other thing that we learned is, sometimes you can have conjoint situations where both the child neurologist and the adult neurologist can see the patient at the same setting. If that can't happen, what I like to do is to have one more visit after they've met the adult neurologist, just to make sure there are no loose ends. So in other words, some overlap is ideal.
Kelly Cervantes:	36:40	I like that. I especially love about empowering the child earlier on with their own medical information. I think that's so useful. As a doctor who has treated countless children and had goodness knows how many conversations with parents and caregivers over the years. What tips and recommendations do you have for the parents and caregivers in those conversations to get the most out of them in negotiating different treatments or asking the questions, what's the best way?
Dr. Doug Nordli:	37:16	Two things come to mind about that. One is, it's very helpful as questions come up to write them down. And so that we can make sure that we've addressed all the questions that have come up. And I think not to be afraid to bring up topics. If there's something out there that you heard about and you want to have a discussion, then do it. Likewise, if somebody has a thought about something, bring it up. I can't tell you how many times that the thing that has been helpful has been listening to parents and some nuances about what they have discovered or their impression about what's working or not working. It's so valuable. And I rely a lot on parents and I'm particularly keen to pay attention to maternal grandmothers.
Kelly Cervantes:	38:13	That's fascinating.
Dr. Doug Nordli:	38:16	Yeah. Here's my theory on that one. I feel like maternal grandmothers have good communication with the mother and they also have a little bit more objectivity because more time on the planet. And so my advice by the way, that I often tell physicians in training is, go against the impressions of a maternal grandmother at your own peril.
Kelly Cervantes:	38:47	You have just made my mother a very happy woman, and I may not hear the end of it. That is brilliant advice. Dr. Nordli I'm so grateful to you for your decades of practice and treating so many children, helping so many families and coming on and sharing your vast knowledge and experience with us today. I truly believe that this episode is going to help so many families,

		whether they're beginning this journey or well on their way. Thank you so very much.
Dr. Doug Nordli:	39:22	Oh, it's been my pleasure and thank you for suggesting it. And I hope it has been useful to parents.
Kelly Cervantes:	39:31	Thank you, Dr. Nordli for your thorough explanation of the diagnostic and treatment journey for children with epilepsy and their families. Locating accurate information about epilepsy and understanding your diagnosis are vital to making decisions about care and ensuring that you are getting the best treatment possible. To learn more about epilepsy, visit the understanding epilepsy section of the CURE Epilepsy website at cureepilepsy.org/understanding. Through research, there is hope. Thank you.
Brandon:	40:11	The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. The information contained herein is provided for general information only and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs. CURE Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual specific health situation.