

CURE Webinar
Transition Care
(Transcript)

- Dr. Laura Lubbers: [00:00](#) Welcome, everyone, to today's webinar. I'm Laura Lubbers, and I'm the Chief Scientific Officer for Citizens United for Research in Epilepsy or CURE. I want to thank you all for joining us today.
- Dr. Laura Lubbers: [00:12](#) Today's webinar is entitled Transitioning from Pediatric to Adult Epilepsy Care. It will discuss how people with epilepsy, their family, and their pediatric neurologist or epileptologist can develop a plan to prepare for this critical transition, the factors they must consider when transitioning care, and the research guidelines that have been established to guide that transition, as well as the resources that are available to assist all of those involved.
- Dr. Laura Lubbers: [00:41](#) This is our second installment of our 2019 Leaders in Epilepsy Research webinar series where we highlight some of the critical research that's being done on epilepsy. Today's webinar is being sponsored by our friends at the BAND Foundation. We're grateful for their support.
- Dr. Laura Lubbers: [00:59](#) CURE's mission is to find a cure for epilepsy by promoting and funding patient-focused research. CURE's robust grants portfolio has advanced epilepsy research across areas such as infantile spasms, post-traumatic epilepsy, sudden unexpected death in epilepsy or SUDEP, and epilepsy genetics just to name a few of the areas.
- Dr. Laura Lubbers: [01:24](#) Today's presenter is Dr. Joseph Sirven, who is Professor of Neurology and the Chair Emeritus at the Department of Neurology and the Director of the Epilepsy Program at the Mayo Clinic's Arizona Campus. Dr. Sirven has published extensively on epilepsy and its treatment. His interests include status epilepticus, surgical approaches to epilepsy, epilepsy in older adults, and psychosocial issues, particularly those involving Hispanic populations and transportation issues.
- Dr. Laura Lubbers: [01:57](#) Before Dr. Sirven 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 at the bottom of the Zoom panel on your screen and clicking send. My colleague from CURE, Brandon Laughlin, will read them aloud during the Q&A portion of the webinar.
- Dr. Laura Lubbers: [02:21](#) 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 and not specific to a loved one's epilepsy. I also want to mention that today's webinar, as

well as all previous and future webinars, will be recorded and are available on the CURE website. So with that, I'd like to turn it over to Dr. Sirven.

- Dr. Joseph Sirven: [02:48](#) Laura, thanks so much for having me. It's such a pleasure to be here doing this webinar for the listeners today. As you see on the title slide, what I'm going to be talking about today is a transition. It's a transition that oftentimes doesn't get as much attention as it probably should, and that's the transition from a pediatric to adult epilepsy care.
- Dr. Joseph Sirven: [03:19](#) I will tell you ... I'll start off from when ... From a personal standpoint, I am an adult neurologist and I see adult patients. But I receive many young adults, even late adolescence, that come under my care, and I can tell you that the process for which they've arrived at my doorstep is somewhat variable, to put it in the very least.
- Dr. Joseph Sirven: [03:51](#) Sadly, I will say that the most common thing that I notice is that oftentimes that someone shows up at my door in the office, I ask them, "Why are you here?" and basically demand, and oftentimes with parents, will say, "Well, we're here so that you can take over our care," and that's the first time I've met them within that first few minutes without anything to guide us.
- Dr. Joseph Sirven: [04:17](#) So what I want to do today is at least walk you through that there's actually a process and there is a way to go through this.
- Dr. Joseph Sirven: [04:41](#) So what is the problem? Well, I gave you the sense of that problem by just the nature of how I started off with when I first meet patients, the fact that many youth with epilepsy and others that need a transition don't receive enough transition planning which can lead to problems, if all of a sudden the pediatrician ... And I've met so many wonderful ones so I haven't actually seen this, but it could happen ... says, "You know what? You're an adult now. You need to go with an adult person."
- Dr. Joseph Sirven: [05:22](#) Well, we have health issues that arise because when you're an adult, there are certain expectations that come with it. The expectation is that the person can speak for themselves. If they can't speak for themselves, there's a formal power of attorney, there's a formal level of everything there so that the voice of the person in front of you can be helped. Without those items, we basically are stuck in a quandary, and you can't precipitate a health crisis that is entirely preventable.

- Dr. Joseph Sirven: [05:57](#) This then also means that you have to address the legal and financial needs of the person who you're helping to take care of. For some, it may be very few, but for others, that can be a big deal. So that's one of the issues that we want to address in this transition because, again, it doesn't get the attention that it really deserves.
- Dr. Joseph Sirven: [06:26](#) Now one of the things that is very nice, and what I'm going to be sharing with you today, is the fact that many great organizations have really thought through this process, the Child Neurology Foundation, the American Epilepsy Society, the American Academy of Neurology. They've actually outlined a very nice guideline that helps to, in essence, layout the steps necessary for when you should start talking about transition to when you actually have turned this over to the adult neurologist.
- Dr. Joseph Sirven: [07:11](#) Now it may seem for some that it is not something that they have dealt with or they just don't want to deal with, because I know that I have met people who continue to see their pediatrician in their late 20s and 30s and I've met others that have stopped seeing the pediatrician very much as soon as they got into adolescence. So there's a lot of variability here, but I will try to outline those steps.
- Dr. Joseph Sirven: [07:39](#) I'm going to sound like one of those typical internet-related things. There are eight steps today that we're going to walk you through that is really the key to reaching that point of finally successfully transition to that adult neurologist. So let's start out with the first of the steps.
- Dr. Joseph Sirven: [08:20](#) The first step in this particular situation is setting expectations for the talk. That expectation-setting is huge because it should occur no later than the 13th birthday. So most experts and some of the organizations in pediatric neurology believe that by the age of 12, we should be having a discussion about the fact that, at some point in the future, you're going to be transitioning from a pediatrician to an adult neurologist.
- Dr. Joseph Sirven: [09:11](#) Now in this talk, you're going to have a lot of different types of discussion, and it's going to vary depending on the severity of the epilepsy or the condition of the child that we're talking about. The main thing with this is to discuss the fact that there's going to be a transition that's going to occur in the future. That's going to be very important to lay that out, that basically to point out to the family, to the patient that as much as I love taking care of you as a pediatrician, that you're going to be

graduating to someone else that is going to be there for you for the rest of your life at the right time.

Dr. Joseph Sirven: [09:55](#) So you talk about future meetings. "When should we plan to have this thing or plan done so that we can move forward?" We really put a stress on the importance of shifting your care from the pediatrician to adult neurologist, because I know I get attached to my patients and the patients get attached to their physician, and I know that typically what happens in the exam room is if I bring up anything about a transition, it's like, "What are you talking about? Are you leaving me? Are you going somewhere?" "No, no, no. Let's all take a deep breath. This has to be done step-by-step, point-by-point. Yes, there will be a change." I think that's one of the important parts of that point.

Dr. Joseph Sirven: [10:48](#) Then comes very pragmatic and key issues that get to be brought up oftentimes with the family, but sometimes with the patient too, which is, "You know what? As you get older, we start talking about things such as your health insurance. What happens when you turn 26, which right now that's the age that anyone can stay under their parents' insurance? What happens after age 26? What happens if you're in a different situation and you require lots of care? Maybe you already have some form of Medicare now and a disability thing. So how does that transition as you grow older to the adult provider?"

Dr. Joseph Sirven: [11:40](#) You also want to really start instilling to the child, to the patient, to the teen to the level that they can best do this the fact that you're going to want them to, as best they can, to take responsibility for their own health. You want to make sure that you're training your child to the degree they can to be the best advocate they can be for themselves to manage their own care, and you want to have that out there.

Dr. Joseph Sirven: [12:20](#) So this is a big important talk, mostly because it's very emotionally laden. Oftentimes when you're talking about becoming an adult at the age of 12 or 13, with parents in the room and the child in the room, I can assure you it will have a lot of excitement and just concern. You want to allay that, and not so much about abandoning, this is not what this is about, but just how we're going to get to there, to that next step, and that that may be able to bring at least some semblance of peace when this occurs.

Dr. Joseph Sirven: [13:00](#) So once you set that expectation and you've had the first talk, so that's step one of this process, you're going to go to step two.

- Dr. Joseph Sirven: [13:15](#) So in step two, here's where the neurologist or other physician, whoever you're seeing, starts getting into the nitty-gritty of trying to assess from your child, from the patient, their ability to self-manage. Epilepsy is a big spectrum of disease or condition and, as a result, there are some that have a seizure once or twice a year, some that have seizures every day multiple times a day.
- Dr. Joseph Sirven: [13:52](#) So what we try to do is to get the assessment of how well does that person, that patient, can they figure out what's going on with regards to taking care of themselves. This is what starts at the age of 12, and it needs to get documented. That's what the doctor will do to figure that out.
- Dr. Joseph Sirven: [14:16](#) Now there's a few things that we're looking for when we're doing this assessment. We're looking at how well does that patient understand the condition and/or any limitations the condition will provide. So seizures, do they get where seizures can be a problem? I mean I'm not here to point out limitations, but more do they understand what they can and they can't do to some degree? Do they understand the responsibility for their own care? Do they get I have medications I may have to take or I have a device that I may need to upload something to or over a phone? Do they know what is the plan in an emergency? Do they have a way to get identified in that way?
- Dr. Joseph Sirven: [15:11](#) It also brings up the concept where you're trying to figure out the ability of the child to be able to give informed consent, not that the parents doesn't have a role here, but the ability to ... Maybe there's a trial, a research trial. Well, how well do they get the risks and how well do they understand those issues?
- Dr. Joseph Sirven: [15:32](#) So we try to get an inkling of how well they pick up on that. Research has shown that for many, at the age of 12 is when you start getting a sense of how well they consent to things or not. That's one of the elements that we try to always go from there.
- Dr. Joseph Sirven: [15:53](#) The other piece about the self-management skills isn't about the assessment, but it's also about the encouragement, and that is we always want to encourage our kids to begin taking control to the degree they can of basically what is going on and how to best manage this.
- Dr. Joseph Sirven: [16:25](#) Now there are a couple of situations where you say, "Well, does this even apply to me?" Let's say that your child has a fairly striking intellectual disability or something along those lines, and it's not really changing year to year.

- Dr. Joseph Sirven: [16:39](#) So the point of this assessment may not, in that situation, be so much about the child, how they're changing, if it hasn't changed year after year, but it may be also to gauge how well is the caregiving going in terms of the caregiving being able to be done.
- Dr. Joseph Sirven: [16:59](#) In other words, I know when I have people in my office and I see caregiver and I see the patient, and sometimes the patient would say ... Like the child and everything is good, seizure is controlled as best they can.
- Dr. Joseph Sirven: [17:16](#) But I look at the caregiver and they look exhausted, worried. They haven't slept. You're like, "I'm not their doctor, but I really need to ask what's going on with them," because they don't look like they're healthy or sleeping or anything.
- Dr. Joseph Sirven: [17:30](#) So this is also the other shot, to assess the caregiving analysis, is that planning underway? Because I know that's a big deal and that's a big sense of worry for so many folks. And so, I think that is where we really go.
- Dr. Joseph Sirven: [17:48](#) Again, this is something that starts around the age of 12. What's really important, it gets documented, or should be documented, in the medical record to help for some other context that's going to be popping up as the child grows older.
- Dr. Joseph Sirven: [18:08](#) Let's go to number three, our next one, which is after that, you're going to do a yearly discussion of the medical condition and age-appropriate concerns. This is something that many good pediatrician, pediatric neurologists, a neurologist, or anyone should be doing.
- Dr. Joseph Sirven: [18:35](#) So here you're going to be walking through a discussion of, in this case, since you're at a CURE webinar, it's going to be seizures and epilepsy, but medical conditions. You're going to talk about what medications they're on. Do they understand the side effects of these medications, both short term, long term, and how it impacts their life? What are the signs and symptoms that a seizure's going to occur? Maybe they have clusters. Do they know when that's going to happen? Do they realize that maybe this was a time to take cover or do whatever necessary to best help?
- Dr. Joseph Sirven: [19:16](#) Then you get into some of these very also emotionally laden topics, which for some families can feel uncomfortable, but they have to be talked about. What about reproduction and genetics? What about that issue of contraception,

relationships? What does it mean? What does it not mean? Because there are so many myths that occur, and you have to get that corrected at an early point so that that issue is brought up as appropriate.

- Dr. Joseph Sirven: [19:52](#) You'll also need to talk about puberty and sexuality and understanding feelings of changes. I mean it's hard enough to do it when you don't have any conditions neurologically to deal with, so you add this, everyone's so nervous and it brings in a lot of their own feelings about it. But it has to get discussed.
- Dr. Joseph Sirven: [20:12](#) This is part of that age-related medical annual discussion that is a part of the transition process so that everyone knows what we're talking about in this direction. I know a lot of times I've watched families and I've watched mothers and fathers and they put their heads down. I don't want to be pursuing this line of discussion either, but you've got to. At the end, we get through it and we put it all out there. But it's also a very good point.
- Dr. Joseph Sirven: [20:45](#) Then it gets us to some other issues that, especially in the world of seizures and epilepsy, have to be discussed. I get the driving almost all the time, on the daily, from everyone that I see, young, old, anyone.
- Dr. Joseph Sirven: [21:05](#) And so, understanding how does the driving laws in your state work as they vary from ... All 50 states have their unique driving law because it is a state issue. How does that work? At some states, you can get a permit at the age of 15. Every state lists out seizures and epilepsy. How well controlled can you be? What are the issues of medications? How is CBD viewed in the state with regards to driving, if you're taking that?
- Dr. Joseph Sirven: [21:41](#) Then you have to look at other issues such as alcohol, its avoidance and what are the issues and how it can impact the child and things of that sort. So these questions have to be addressed.
- Dr. Joseph Sirven: [21:57](#) Last but not least, you have to be looking at the emotional and psychological concerns that can arise. I spend so much time hearing about stigma, loneliness, social media, all these pieces that interplay that make ... Things are just so complex as it is, we need to make sure that we're bringing this up and understanding how these things can have its own role.
- Dr. Joseph Sirven: [22:34](#) Now I'm saying all of this and there's this other part of me as a practicing physician that's saying, "Wow! Aren't most follow-up

appointments 30 minutes? And he's saying you're going to do all of these significant major discussions."

- Dr. Joseph Sirven: [22:51](#) Well, I want to point this out that this stuff should not be brought up while we're talking about an emergency management of a condition or when we're talking about a big medication change. That appointment is not going to be appropriate for this.
- Dr. Joseph Sirven: [23:08](#) In the best of situations, a specific appointment that is just for transition planning and assessment should be made so you have time to go through these things with your doctor, with your nurse practitioner, with your PA, whoever it is.
- Dr. Joseph Sirven: [23:26](#) If they don't have the time or they don't have a special called out appointment for this, certainly it's to be done when there's not an emergency situation or not an acute situation that needs to be managed that day, because this will get lost.
- Dr. Joseph Sirven: [23:44](#) So I can say all of this, and it's lovely, but you also have to make time for it. That's something that both doctor and patient have to ask for specifically oftentimes just to make sure that nothing gets lost. Let's go to our fourth step in this transition.
- Dr. Joseph Sirven: [24:07](#) So here we segregate out to a very different part of medicine, which isn't really medicine, but it's related, and that is evaluation of legal competency. It sounds so scary, it sounds so serious, but here is a conversation that typically occurs around the age of 14. At that age, we have to get a discussion going where you really answer two big questions about the child or the teen in front of you.
- Dr. Joseph Sirven: [24:50](#) The first question, is there going to be a need for legal guardianship or power of attorney, or is the epilepsy decently controlled enough that that is just not a big issue and the child, the teen will be able to have that aspect of their control with their life, if you will? So that discussion needs to be made just so that an understanding that that's the case.
- Dr. Joseph Sirven: [25:19](#) You also have to document the decision-making capacity of the teen in front of you, to the degree ... And there are tools that the doctor uses, but I think it's in the conversation, in the question that they ask. But that capacity becomes really important because, again, we start getting into adult issues a little later on. At age 14, you're pretty close.

- Dr. Joseph Sirven: [25:46](#) Now you may say, to those of you listening to this, "I can't tell. Maybe this is all going to get better in a year or two." Well, if it's unclear, then understanding that this is going to take a yearly evaluation, and we're going to have to come to this, that this is going to be an important point that we return to that we're going to have to document in some way or another.
- Dr. Joseph Sirven: [26:15](#) And so, I just put that out there because I know legal competency sounds so unpleasant, but it is a question that has to get addressed. It's something that has to get addressed by age 14 or so because it really gets to really some of the issues that come up. Let's go to our fifth step in this particular issue.
- Dr. Joseph Sirven: [26:42](#) So by the fifth step, by the age of 14 going on 15, the big thing is that there has been a transition plan that has been written up, it's in the medical chart, and the doctors, the patient, that's you, the family, everyone knows that this exists and is going to be there.
- Dr. Joseph Sirven: [27:13](#) We also have identified the responsible doctor who's going to help complete the plan. In other words, let's say that you don't have one. Well, this is the point they're like, "Well, doctor, you are going to do that, right? You are going to lay this out?" It's not the doctor, it's the social worker that's in the office. Is it going to be the nurse? Is it going to be ... Who's going to lay this out for the physician taking care of the patient? Because this has to be completed and it has to be in there.
- Dr. Joseph Sirven: [27:46](#) This plan is going to address a lot of issues. It's going to address the healthcare. So what's the plan of care? Who's going to address the finance, legal concerns? Has this been brought up? Has this been discussed? What about education? What's going to happen there? What's the schooling issue? Maybe there's no schooling issue that has to be worried or ... But maybe there is a schooling issue that has to be created.
- Dr. Joseph Sirven: [28:13](#) What about later? Is there concerns about employment? Housing? Where will they go? Maybe they'll be in the home with you, maybe not. The question is this has to get brought up.
- Dr. Joseph Sirven: [28:28](#) Then all of this is to bring all the physicians there. Maybe your child has multiple conditions and there's multiple specialists involved. Well, here's where this plan addresses all of those together in one place because the idea is that the transition's going to occur from pediatric to adult, all subspecialties should be addressing it all at the same time so that it can go to the adult. Of course, there are always exceptions to the rule, but that's what we're trying to do.

- Dr. Joseph Sirven: [29:05](#) Now as a neurologist, and, again, we're talking about epilepsy and seizures, we also want to update the neurological component when it comes to this. What's going on on the neurology? What's going on with the development? What's going on with their education and intellectual capacity? Those things are all there, and that's a very important piece that we want to bring on. Let's go to our sixth step.
- Dr. Joseph Sirven: [29:37](#) In our sixth step, what we try to do here is that we are now approaching that magical time of when this transition may occur, 18, 19, 20. So what we want to make sure is that the child neurology team has completed the main responsibilities that are spelled out in this transition plan. We've laid out the neurological component. We have a summary of what the child's goals are. If they want to go to college and it's something that they can do, then let's do this. How are we going to lay that out? What are the additional testing that needs to occur?
- Dr. Joseph Sirven: [30:25](#) I've had kids that ... Like they had a shunt placed, as an example, at the age of 10 or 12. For the adult neurologist, they're going to want to know when was the shunt changed? When was the last operation? What was the thinking at the age of 10 or 12 from that neurosurgeon/neurologist about what do I need to do? Do I need to have a planned MRI at some point in the future? Do I need to have a planned neuropsychometric testing for the child?
- Dr. Joseph Sirven: [30:59](#) Just as importantly, what are the emergency plans? This is something that gets so overlooked, even in adult. What is the goal in the situation of maybe your child has seizure clusters? How do we handle that? Do they carry some additional medication on board? Do they take extra of their typical prescription? Maybe they have a special compounded pharmaceutical that they use for emergencies. What's the plan of action for that?
- Dr. Joseph Sirven: [31:33](#) Then we want to lay out the advanced plan of care in terms of what's going to happen. Then the guardianship plans, and that is mostly if your child has a lot neurological issues, we want to make sure that power of attorneys and guardianships have been sorted through and completed, because, remember, if one needs to get that before they turn to be an adult, on average, it's a two-year process to get a power of attorney or legal guardianship. So that needs to be done before they are legally considered an adult in their state. And so, that plan has to be executed in advance of those years in order to be ...if it applies.

- Dr. Joseph Sirven: [32:28](#) If it doesn't apply and, if they're on the side of spectrum of epilepsy where things are fully well-controlled to some degree, it may not be so applicable. But this is for those where it is. Let's go to step seven.
- Dr. Joseph Sirven: [32:47](#) So step seven is really the lynchpin. This is where you identify the adult provider. Now I started off this webinar by telling you a lot of times people show up with like a, "Hi, I'm here to see you because you're going to take care of me for the rest of my life." Other than, "Wow! Okay, fine. We're here help to you." We don't want to get surprised neurologists involved. We want to have that identified as early as possible.
- Dr. Joseph Sirven: [33:22](#) And so, the identification of the adult provider is huge because not only is it big for the pediatrician that knows this is who they're going to send this person to, but it's a huge relief to the family, to you, to the patient that I know who my doctor is come age 18. I know who I'm going to turn to at age 19. You can begin to build a rapport or relationship.
- Dr. Joseph Sirven: [33:53](#) This is also the time where the child neurologist can coordinate the transfer for this. It becomes very important to do that in that situation so that we are basically in a place where the adult neurologist has a plan of action that can, in essence, outline and tells them this is their meds, these are the medications that've been tried, these are the surgeries that have been done, these are the major problems that have been ongoing, these are the tests that need to be done. This is what ER emergency plans that've been rendered. This is what works, what doesn't.
- Dr. Joseph Sirven: [34:42](#) Those type of sheets, of forms, that's a godsend to the receiving neurologist, adult neurologist, and healthcare practitioner because it gives you that opportunity to know what's been tried, what doesn't, and it gives the guide to you so that we could best help you. That, I think, is one of the biggest issues that I think that we want to do.
- Dr. Joseph Sirven: [35:13](#) Now we go to our eighth and final step, and that is the actual completion of the transition. This is where there's now a direct communication between the child's neurology team and the adult neurology team. There's now a handoff that has occurred, that there's a documentation of that handoff, and that's the case.
- Dr. Joseph Sirven: [35:44](#) Now you may say, "Okay, that's great. How wonderful. But maybe I live in a rural area and there isn't someone taking care of me so quickly." Well, then the bottom line is that we make sure that the child neurology team, they're there to answer any

question for whoever's going to care for your child or you, that they will be there should any question arise for whomever is going to help take care of you.

Dr. Joseph Sirven: [36:19](#) Now I know some pediatricians and pediatric neurologists are taking care of patients that go into their 30s and 40s, and that's fine if that's how it's turned out. But know that there's not exactly a huge number of pediatric neurologists in the United States, so oftentimes they will transition to adult. If not, it's just that there's some connection made in that documentation for smooth transition.

Dr. Joseph Sirven: [36:53](#) Now as I go to our next slide, the question comes is that, well, what do we know about this? I've been talking about a process that some of you may or may not know a lot about. We know one thing is that when formal transition processes such as this have been implemented, it at least seems to alleviate fear, anxiety, concern on behalf of parents, family, patient, child. And so, on one hand, we know that piece is fantastic.

Dr. Joseph Sirven: [37:37](#) What we don't know is a lot of the research, and this is an area that is ripe for healthcare research, if you will, to answer the question, well, how well does this work? What is the number of kids that bounce back to their pediatric neurologist because they can't get an adult neurologist? How difficult is it to get a transition? How does health disparities play into this equation? Is there certain groups that are more prone to have a transition plan and others that aren't? These are questions we don't know.

Dr. Joseph Sirven: [38:19](#) How does quality of life improve? I mean I mentioned anxiety and relief for those involved because a plan is in place. But there's so much we don't know. We know that, as I mentioned, the plan I just outlined came from the Child Neurology Foundation, the American Epilepsy Society, the American Academy of Neurology. All of these groups have endorsed these plans, but there's so much we have yet to just pinpoint and perfect. I think that's something that we look to the future.

Dr. Joseph Sirven: [38:58](#) So in our next slide, I offer you some references from the NIH, from the Child Neurology Foundation. I have this fantastic website that is only related to transitioning. It has a lot of questionnaire and tools that you can easily download. I'm sure that you can find many more. Dr. Google is never short of answers for all of us. So we want to know that there are a lot of opportunities.

- Dr. Joseph Sirven: [39:33](#) But I think that should give you a sense of the formal way that you should be thinking about transition, the big picture that it covers in the life of your child and your family, and that this is something that is not a small trivial point. It's one that you have to really ask about and self-advocate for because that's what helps to improve everyone's quality of life.
- Dr. Joseph Sirven: [40:04](#) So with that, I just want to say thanks so much again to my dear friends at CURE, to Laura and team, for being so wonderful and inviting me to speak. I'm happy to answer questions in a moment.
- Dr. Laura Lubbers: [40:19](#) Wonderful. Thank you so much, Dr. Sirven. That was incredibly helpful. I think it will give families a lot of reassurance on how to move through this process and how early you have to start in this process to really have it executed well for those who can do this. So thank you again.
- Dr. Laura Lubbers: [40:38](#) So we can now begin our Q&A session. I know that there are some questions already in the queue. But if you have questions, please submit them using the Q&A tab located at the bottom of the Zoom panel and then click send. Brandon will go ahead and read them aloud. So, Brandon, I'll hand it over to you.
- Brandon Laughlin: [40:58](#) Yes, thank you, Laura. We actually got a good many questions about dealing with specific steps within your plan, Dr. Sirven. But actually, I'm going to start with a question that came in from one of our viewers about how great this plan seems. If you have a neurology team that really hasn't been following this plan, then how do you actually communicate this as a need as the parent?
- Dr. Joseph Sirven: [41:28](#) Yeah. Well, here's the thing. This is considered a vital aspect of the care of a child with epilepsy or with any neurological condition. And so, it's important ... I guess two ways to answer the question ... to know that this is ... Dr. Sirven and CURE and other teams are putting together. Hey, what a cool concept. This is actually considered a guideline of standard of care.
- Dr. Joseph Sirven: [42:03](#) And so, if you're not having this discussion, I would say you've got to bring this up. You've got to ask, say, "Can we have a formal transition type of meeting?" Now to a pediatrician, they're probably going to get that and they'll understand.
- Dr. Joseph Sirven: [42:22](#) But maybe you're not seeing a pediatric neurologist. Maybe you're seeing an adult neurologist already because that's who's in the community, or you're seeing your family care. This is to

be brought to them. That's why I gave you some of those resources. Some of those are actually handouts you can print out, especially at the transition site, that you can actually even bring to your physicians with questions so you can begin answering these.

- Dr. Joseph Sirven: [42:50](#) So as I mentioned earlier, a lot of this has to do with self-advocating and also planning. Like any good parent, ask the questions. If they're not coming to you with this, know that by the age of 13, this should begin to be brought up and bring this up, because even for busy clinicians, they will stop, they care, they want to help. They just needed to be reminded sometimes, because you're so busy and focused on the acute issue that you forget that there's a future big picture that we need to address. Sometimes asking for a time appointment for that is going to be the way that you get there.
- Brandon Laughlin: [43:36](#) Great. Thank you, Dr. Sirven. The next question actually is going to deal with insurance issues. The audience member asked if there are already insurance issues or even possible legal ramifications, if people wish to stay with actually their pediatric clinicians if they're very comfortable with them?
- Dr. Joseph Sirven: [43:59](#) Yeah. There's no insurance ramification per se. The pediatricians will be covered under the same plans as an adult neurologist. I've not seen in my career a situation where I have seen lack of payment or not paying because an adult is with a pediatric neurologist. It doesn't work that way. It certainly doesn't work that way in the current laws.
- Dr. Joseph Sirven: [44:32](#) Having said that, there are some pragmatic issues, and I'm delighted for the person who has that pediatric neurologist. But the fact of the matter is if there is a huge shortage of pediatric neurologists, and then if you expand that out, there's an even bigger shortage of pediatric epilepsy neurologist out in the United States.
- Dr. Joseph Sirven: [44:59](#) And so, oftentimes you may see that it's not that the pediatrician wants to let go of you or anything along those lines. Most pediatricians, they love taking care of their patients. It's just that, at some point, because the lines are so long and there are so few of us, so few of those physicians out there, that the transition may come up to you.
- Dr. Joseph Sirven: [45:24](#) Now maybe you're in a community that that's who you're going to see because that's all you have, but know that that's the reality. Insurance sticks its neck in many things, but, fortunately, has not stuck its head in this equation just yet.

- Brandon Laughlin: [45:43](#) Great point. The next question actually comes along those same lines. But what do you suggest if your pediatric team has not yet identified, an adult neurologist and does insurance play a role in choosing those physicians?
- Dr. Joseph Sirven: [46:02](#) That's a fascinating question. First of all, you ask the pediatric team to help choose who are my choices out there. You don't have to ask them for a specific person, even though you're going to get one, but can you give me a list of names that you think may be good for my transition?
- Dr. Joseph Sirven: [46:24](#) Now insurance, they indirectly play a role here. One of the things that is occurring in modern healthcare now is fairly large networks of doctors. If you think about it, most of us get insurance through our employers, and employers, they get their insurance coverage through a network. So you work for a company, the company has networks.
- Dr. Joseph Sirven: [46:59](#) Well, the network may say, "These are the people in my plan." So you may be on the kid plan, the pediatric plan, these are the doctors on it. But then for adults, the plan is whatever they spelled out that they're going to cover as being within network.
- Dr. Joseph Sirven: [47:21](#) So I guess, indirectly, how your insurance is structured, how tight do you have to go with the network. If you have a PPO insurance, that means you get to choose fairly broadly. If you're in a health maintenance organization or a version of that type of organization, you may not have a broad choice as that, and that may impact how much out-of-pocket you have to put out for continued care in the hospital.
- Dr. Joseph Sirven: [47:58](#) So the network, the insurance plan may not do it, but the network may. I hope that I picked out that nuance for the listener out there.
- Brandon Laughlin: [48:12](#) Thank you, Dr. Sirven. Our next question actually deals with medical records. This parent has addressed the fact that they keep pretty good records, but they wanted to know to what extent are records transferred over to you providers. Do they have to handle this or does their pediatric neurologist take care of this?
- Dr. Joseph Sirven: [48:37](#) Okay. That is a fantastic question. That should be a simple answer, and it's not going to be. So I'm going to try and talk it through at the end.

- Dr. Joseph Sirven: [48:50](#) Medical records are technically owned by the patient, but housed by the physician, hospital, and all those folks. They can only travel to a new doctor with the permission of the patient. So the patient has to give permission. Patient or parent, whoever is in charge, have to give permission for those records to travel from doctor A to doctor B, from pediatrician to adult. So that has to be instituted from there.
- Dr. Joseph Sirven: [49:31](#) In some cases, it's really easy. For instance, where I work, I'm on a large electronic medical record known as Epic. One of the benefits of Epic is the fact that anyone who's on Epic, by clicking a button with the patient, the records will automatically open up from one institution to a completely different institution if they're both on.
- Dr. Joseph Sirven: [49:58](#) Now if you're not on Epic, then physical records have to be sent, either paper or electronically, to the doctor in some way. But the permission, regardless if it's electronic or paper, is the same. It has to come from the patient. The patient technically owns those records.
- Brandon Laughlin: [50:23](#) Great answer. The next question actually deals back with the legal issues. The listener asked if a legal power of attorney is required for joining her adult child who's over the age of 18 at her doctor's appointments.
- Dr. Joseph Sirven: [50:41](#) Well, the fact of the matter is that at the age of consent or the age of majority, which is defined state-by-state ... 18 is the typical one for most states in the United States. I can't think of one that isn't, so I'll just say age 18. They're legally adults unless there's a power of attorney that says that someone else is there.
- Dr. Joseph Sirven: [51:12](#) Now to your listener's question, if they don't have a power of attorney and the child or your child, even though as a parent, they're always your children, but your child can say they don't want you there and the healthcare group has to honor that.
- Dr. Joseph Sirven: [51:45](#) So to your listener, yes, legally, if they're 18 and the child has consent regardless and there's no power of attorney, it's up to the child to say whether they want them there or not. That's legally. I mean it doesn't have to be ugly or anything along those lines, but, yes, that is true from a legal perspective.
- Brandon Laughlin: [52:18](#) Okay. We have time for, I think, one more question. So we'll deal with one that deals along with epilepsy and the association with autism. In your opinion, if there are different steps

involved when transitioning a child who might be diagnosed with both epilepsy and autism spectrum disorder.

- Dr. Joseph Sirven: [52:43](#) I get a lot of kids or young adults that have both. In fact, as an adult epileptologist, autism comes into the exam room, the clinic office very frequently together. What the transition is in that situation is that you spelled out not just what you're doing for the epilepsy, but what's the plan for the autism, because we focus so much on the epilepsy that sometimes the autism piece gets almost placed on the side, and yet that may be the bigger issue and the epilepsy's not such a huge one.
- Dr. Joseph Sirven: [53:36](#) So the short answer to the question is that those have to both be laid out. What do we do when there's issues with behavior? What do we do when there's issues with regards to management? That has to be spelled out because oftentimes they get conflated in the exam room, in the office, and they're not.
- Dr. Joseph Sirven: [54:02](#) It's just laying out what's my course of action for each of these. That's important because the management are very different, and understanding where the medications may play a role, what's been tried, what's worked, laying those things out can be a godsend in that reaction.
- Brandon Laughlin: [54:22](#) Great. Thank you for your informative responses, Dr. Sirven. Laura, I'll turn it back over to you.
- Dr. Laura Lubbers: [54:28](#) Thank you. I'm sorry for any questions that we haven't been able to get to. I know that there was great interest in this webinar. So this does conclude our webinar about transitioning from pediatric to adult epilepsy care. A special thank you to you, Dr. Sirven, for sharing such great guidance to our listeners and viewers.
- Dr. Laura Lubbers: [54:49](#) I also want to thank the BAND Foundation once again for sponsoring today's webinar and our entire webinar series. I'd also like to thank our audience for your attention and your great questions.
- Dr. Laura Lubbers: [55:01](#) If you have additional questions about this topic or wish to learn about any of CURE's research programs or future webinars, please visit our website at www.cureepilepsy.org. I also encourage you to check out our Seizing Life podcast, which is a relatively new offering for CURE at seizinglife.org, which our most recent episode addresses the academic issues associated

with transitioning from secondary to higher education. So it parallels this quite nicely.

Dr. Laura Lubbers: [55:37](#)

We also hope you will join us for our future webinars, including Dietary Options on Epilepsy, which is on June 13th, and Surgical Approaches in Epilepsy on July 10th. So with that, I hope everybody has a wonderful rest of your day. Thank you.