

CURE Webinar
Epilepsy's Impact on Learning and School Performance
(Transcript)

- Brandon Laughlin: [00:05](#) Welcome everyone. And my name is Brandon Laughlin and I'm the Research Manager here at Citizens United for Research for Epilepsy, otherwise known as CURE. I want to thank everybody for joining us today. We are proud to present our next webinar, which is in a series of our 2018 Leaders in Epilepsy Research Webinar Series. This series is going to consist of multiple webinars throughout the year. That's really there to highlight some of the key research that's being done in the field of epilepsy.
- Brandon Laughlin: [00:38](#) First off, I do want to thank our sponsor for helping us present this series to you. Our sponsor for today's webinar is Sunovion. And the webinar that they're helping us bring today is Epilepsy's Impact on Learning and School Performance. CURE's mission is to identify and fund cutting edge research in the search for a cure for epilepsy.
- Brandon Laughlin: [01:04](#) We are currently celebrating, actually this year, 20 years of impact in the field of epilepsy. CURE has been instrumental in advancing to science in a variety of different fields, including post-traumatic epilepsy also infantile spasms, devices and technology, SUDEP and epilepsy genetics, just to name a few. This webinar is going to outline some of the cognitive issues that the estimated 470,000 young people under the age of 18 experience as a result of their epilepsy.
- Brandon Laughlin: [01:38](#) We're also going to discuss some of the latest research on cognition and epilepsy and also identify some of the potential resources that might be available to individuals and their families. We at CURE, we are concerned about all the ways epilepsy impacts individuals including its effects on learning and their success in school. Our featured expert today is Dr. Madison Berl.
- Brandon Laughlin: [02:04](#) Dr. Berl is a board certified pediatric neuropsychologist at Children's National Health System and the director of research for the Division of Pediatric Neuropsychology. She is the neuropsychologist for the epilepsy team at Children's and serves on several committees within the American Epilepsy Society and also the International League Against Epilepsy. Before Dr. Berl begins, I do want to encourage everyone to ask questions. We do want to make sure that this webinar is as interactive and informative as possible.
- Brandon Laughlin: [02:37](#) So you can go ahead and enter your questions anytime by typing them into the questions tab in the GoToWebinar control

panel and just clicking send. I'll go ahead and get to as many questions as I can in the time period that's allowed and read them out loud during the Q&A portion of the webinar. We do ask to respect everyone's privacy that try to make these questions as general as possible and not specific to yours or a loved one's epilepsy.

Brandon Laughlin: [03:07](#) I also want to mention that today's webinar as well as the entire Leaders In Epilepsy Research Webinars Series will be available for later viewing on the CURE website. Now I will go ahead and turn it over to Dr. Berl.

Dr. Madison Berl: [03:26](#) Thank you. I appreciate you guys inviting me and I hope this information is useful to as many families as possible. And it's an important topic. So my plan today, really the scope of what comorbidities are has really expanded to not only cognitive problems but social problems, other risks such as mortality risks, accidental risks, those kind of things. We'll talk a little bit about that. But my focus today is really on cognition.

Dr. Madison Berl: [04:06](#) We'll go over what the risk factors are and maybe have an eye toward predicting and thinking about whether your child might be more at risk than other children. And then I really hope knowing that people are listening from all over, that there's enough general recommendations out there and resources that you could use anywhere. But there's probably a lot of specific recommendations for your local area as well and finding those can be really helpful as well. And then we'll go to questions.

Dr. Madison Berl: [04:40](#) So again, the scope of comorbidities is really quite large now. We don't think of just the seizures but we think of the impact of the seizures and the disease itself across a lot of different areas, including cognition, your psychiatric or behavior which is acting and feeling issues, depression, anxiety, even non-epileptic seizure events. So some children express their distress psychosomatically by having a seizure that really isn't a seizure that is associated with ultra brain activity but they are mimicking what they've seen or what they do at other times and that definitely needs to be addressed.

Dr. Madison Berl: [05:29](#) Other risk factors that I'm not going to get to today but you should be aware of are, reproductive risks, sleep disorders and just any of the other medical disorders that are associated with epilepsy. So the importance of comorbidities is definitely well recognized by several institutions. One of them being a landmark report by the Institute of Medicine. And really the recognition that the burden of epilepsy is more than just controlling the seizures.

- Dr. Madison Berl: [06:03](#) If we know that medicines can help about 70% of children with epilepsy in terms of stopping the seizure, but then there's so much more that families and children need to deal with. And that burden can sometimes be lifelong. And so knowing about that and recognizing it and putting more resources towards it is definitely an aim that is ongoing. The National Institutes of Health, an institute that's focused on neurological disorders really has put research monies and efforts towards really figuring out what these comorbidities are, how to prevent them and really trying to get better prediction on who's going to have these difficulties and what to do about them.
- Dr. Madison Berl: [06:57](#) So just in terms of an overview, there really is no one profile set of strengths and weaknesses that exist for people with epilepsy. And even for the same people that have the same epilepsy and seems very similar, they can present very differently. And so one of the assumptions that people make is that if you have focal seizures that start in one area of the brain are mostly limited to one area of the brain, then you're going to have a very specific deficit.
- Dr. Madison Berl: [07:33](#) And that's just really hasn't been found to be true. And the reason why, is that we know that seizures involve a network of areas in the brain and so does cognition. And so what this picture up on the corner shows is that those often overlap. And so just because it starts in one area, maybe connected into many other areas of the brain that are involved in different areas of functioning. And so that's why it's not limited.
- Dr. Madison Berl: [08:03](#) This picture down on the bottom here of the horse track is really a part of my training, is that one of my supervisors would always say, "If you think of a network as a race track, it doesn't matter where on the race track the horse might trip or fall, it's not going to finish the race." And this is the same principle that work in the brain as well. And so that's one way I think of it or remember it.
- Dr. Madison Berl: [08:27](#) So the factors that we consider and I'll talk about this a little bit more later about what is associated with outcomes are really what is the underlying pathology? What's causing the seizures? And that can be predictive and let you know what difficulties the child may have or what strengths they may have. And all the events that happen during a seizure they're specifically having more episodes of status epilepticus or prolonged seizures certainly can lead to worse outcomes. And then seizure medications or the antiepileptic drugs can definitely impact cognition as well. And so we try to consider all of those different pieces that go into play.

- Dr. Madison Berl: [09:06](#) The other thing I just want you to be aware of is that when you're reading and sometimes you'll be reading a study or something and it's really talking about adults. And adults don't necessarily follow those... I mean, children don't necessarily follow those adult profiles. So I would just be cautious about when you're reading work that's really primarily with adults. That may not hold true for children and it can be a positive thing.
- Dr. Madison Berl: [09:30](#) Children have very plastic brains and can reorganize and adapt in ways that adults can't. And so it may be an advantage. And so just to keep that in mind when you're reading. So the different areas of functioning that we talk about with a neuropsychological evaluation are many. And I'll go through a little bit of the data that's out there specific to these areas. So basically you have your general IQ or intellectual functioning, attention, executive control, language, visual or nonverbal processing, memory and learning, which is super important for school, motor skills, academic skills and definitely social emotional. I'll touch on that a little more.
- Dr. Madison Berl: [10:15](#) So in terms of global IQ, intellectual functioning, what we know from population studies or epidemiological studies is that about a third of children with epilepsy have an IQ that's below 70. And that cut off of 70 is used for intellectual impairment or what used to be called mental retardation. About a third of children really the risk factors for those are primary generalized epilepsy more than catastrophic epilepsies, Lennox-Gastaut.
- Dr. Madison Berl: [10:50](#) It can be focal epilepsy especially when the seizure focus is hard, difficult to isolate, which may be an indicator of something more general or broad going on in the brain. If a child has severe abnormalities in their brain, volumetric abnormalities, if you have a left brain, you obviously have less that you're working with in order to do your thinking skills. Early onset of epilepsy is associated with worse outcome. That's usually because those are often when the catastrophic epilepsies do start.
- Dr. Madison Berl: [11:22](#) But also if you think about the earlier onset as associated with more lifetime number of seizures usually. And so the more that you have frequent seizures or more severe seizures, again back to that status epilepticus where you have a prolonged seizure that is going on for 30 minutes or more, that is not good for your brain.
- Dr. Madison Berl: [11:45](#) This also presents an opportunity for prevention of IQ decline. We do have some evidence that if you treat the seizures, if you

know. So tuberous sclerosis complex is highly associated with seizures and you sometimes know that before the seizures start. So some people are thinking, "What if you treat prophylaxis with antiepileptic drugs before the seizures start, could you stop that IQ decline that's associated with that?"

- Dr. Madison Berl: [12:14](#) So we're trying to be better about how we think about this. Again, if you have to take polytherapy or more than one drug and you have tried several drugs, that's just an indication of the severity of your seizures. And that is also associated with lower IQ, intellectual impairments.
- Dr. Madison Berl: [12:37](#) So the next slide is just an indication of IQ across different epilepsy types. And what you can see is just the blue line is the average range. And the real dip there, the generalized symptomatic epilepsy is just what I said. It's primary generalized with lots of abnormalities, symptomatic meaning there was something that was causing it whether identifiable. But the other thing to notice is that across any population we do have a downward slope of IQ. And so it's still in the average range.
- Dr. Madison Berl: [13:13](#) So negative ones is zero is still average. So many children have average range or better IQ, but there's this lowering of IQ that we want to try to work on to prevent. And again, whether that's medication, seizures, those are the things that we're trying to identify so that we can prevent that as much as possible.
- Dr. Madison Berl: [13:37](#) So moving to another area, ADHD or attention hyperactivity deficit disorder is one of the most common comorbidities in epilepsy. There's lots of studies depending on the population, it can be very prominent up to 70%. But I would say as a whole, the population, 30% of children probably qualify for a disorder of ADHD. And again, we're talking about those other two thirds of kids that are not necessarily lower IQ that are average IQ or better. And what is different from developmental ADHD or the ADHD that you hear about with the kids that are more hyperactive and jumping around and all over the place.
- Dr. Madison Berl: [14:33](#) Children with epilepsy tend to have more the inattentive presentation. And really this is more about the symptoms of making careless errors, being a little bit forgetful, a little bit of hasty and attention problems as opposed to that hyperactive, impulsive fidgety. There may be cognitive impulsive fidgety where a child is jumping ahead and doing things before hearing things but not necessarily out of their seat.
- Dr. Madison Berl: [15:01](#) And so that is much more common. Not to say that both symptoms don't occur but the more common is inattentive

presentation. And I do want to say and be an advocate for... I know that many of you are on medications already and are hesitant to add medications, but if your child has ADHD and is having symptoms that interfere with their learning, please don't be afraid of considering medications for their attention symptoms.

Dr. Madison Berl: [15:30](#) There's lots of studies out there that show that they're effective and it does not impact the seizure threshold or the likelihood of increasing seizures. There's lots of work out there. There's even an FMRI study that shows similar response to stimulants both behaviorally and neurologically in the brain between standard ADHD, developmental ADHD without epilepsy and kids that have ADHD and epilepsy.

Dr. Madison Berl: [15:57](#) So it can be a great tool and so don't be afraid of that. And so another question that comes up with ADHD is what's the cause of just the epilepsy itself? Or is this really a factor of, "If I can stop the seizures, that'll stop." Or, "If I take less medications or don't take the medications at all, then I won't have these attention problems." And there's actually evidence for both sides.

Dr. Madison Berl: [16:25](#) So one thing we would think of is that if you have frontal lobe epilepsy or childhood absence epilepsy, maybe even have ADHD more. And actually, even though there's not a higher likelihood than other epilepsy types, if you look at just frontal lobe epilepsy and childhood absence epilepsy, that is the problem that they have. So there's some evidence that there is specific learning attention issues to a disorder or a type of epilepsy that really affects those frontal lobes and those attention networks.

Dr. Madison Berl: [17:00](#) Also some of the ADHD symptoms maybe secondary to that ongoing seizure activity or medications. And some evidence for that is that we do see improvements in attention for those children that have undergone surgery and their seizures have stopped and they've been removed from medication. So then you do see that improvement in attention over time that is really evidence verbal. We took a look at... The ADHD we see didn't feel the same. And so we really wanted to look at that.

Dr. Madison Berl: [17:34](#) And we looked at different components of attention. And we looked first over here, what you can see is the epilepsy patients that are in blue controls are in green and so the average range is this dotted black line. And so what you can see is that both groups do pretty well, including the epilepsy. And the epilepsy group really is no different than control when you do very

simple searching for targets, which is the visual accuracy or on the third set of columns, listening and counting targeted.

Dr. Madison Berl: [18:10](#) One thing they have to do for a few minutes, they do it just fine. Simple primary attention is okay. Where we see the differences is here, where the asterisks are is that the pace at which they find those targets or the speed, those visual targets is slower. And so the processing speed might be an issue there. And then on the last two sets of columns it's really when we ask them to do two things at once.

Dr. Madison Berl: [18:36](#) So not only do they have to search for those targets but they also at the same time have to listen for target. And then there was another one where they had to listen for two pieces of information at once. And both of those, that's when our children with epilepsy really fell out. And so that's the complexity. What this means is that sometimes these attention problems don't present in first, second grade like other ADHD but it's really later on that when complex attention is required that you really see these problems pop up. And so to be on the lookout for that.

Dr. Madison Berl: [19:14](#) So along with attention are the executive functions. And again, this is another area. Executive function is an umbrella term, that means all those skills necessary for purposeful goal directed and independent activity, which is what we hope for all of our children. And we really want to put all that knowledge that we have into action. There's several components to executive functioning. There's a behavior side which is inhibitory controls shifting attention and flexibility as well as emotional control. Your emotions are regulated in the same way that your attention is.

Dr. Madison Berl: [19:51](#) And then there's a cognitive regulation side, which is working memory or keeping information in mind, initiating tasks, planning organization as well as self-monitoring. And so we also have studied these before and what we see across our population of kids is that, yes, the green percentages show the percentage of kids that have clinically significant problems above clinical range. So this red line is an indication of clinical range. So you can see on an average the group is below.

Dr. Madison Berl: [20:30](#) So there's many kids that don't have any of these problems, I wonder how. But there's other kids that are in that clinically significant range and it's really impacting their school. So what we see here is that, that cognitive regulation, so that initiation working memory, that really is associated with those inattentive

subtypes. So those careless errors, those kinds of things, planning and organization.

- Dr. Madison Berl: [21:33](#) And those are the most problematic and actually goes up to about 40% of kids that have difficulties in working memory and planning in the organization in the clinical range. And so again, being on the lookout for those executive problems that really come into play later in childhood. And so that's what the next slide talks about, is this times in childhood when executive functions really jump off on you.
- Dr. Madison Berl: [22:04](#) And so you may be on the lookout more for problems. And I would say that many children with epilepsy really get by fine for kindergarten, first grade, second grade, but it's not until third, fourth and above that they start to have serious academic problems because the executive demands for that planning and organization really go up. So when you're in kindergarten and you just need to keep control of your body and sit in a circle. In first grade you got to sit in a seat all day, that kind of thing. And then it's not until fourth grade where you now have to read to learn. You have to organize your learning and you have to...
- Dr. Madison Berl: [22:42](#) In middle school you have seven teachers, you have to keep track of many more binders on books and assignments. And then in high school you're asked to do all of that much more independently. And then in college you're doing your learning, but now you have to do your laundry, you have to do meal planning, all that kind of stuff. And so these are all times and transitions that we really think about and wouldn't be surprised that sometimes things are going along fine even through elementary school. But middle school is really when things come tumbling down because those executive weaknesses are really pushed.
- Dr. Madison Berl: [23:18](#) So in terms of another area is language. It's often talked about with temporal lobe epilepsy because the temporal lobes are fundamental in how language networks. Also frontal lobe epilepsy is where we do express some language in the frontal lobe. When we're planning for surgery, we're definitely trying to avoid these areas and protecting them. There's other disorders like Landau-Kleffner that has a specific piece of language regression that is diagnostic. And so we definitely pay attention to language and epilepsy and language problems
- Dr. Madison Berl: [23:58](#) Maybe specific to the side of seizure focus. So sometimes there's an assumption that if you have a less seizure focus, that language is going to be more of a problem than others. And again, that's not necessarily true in children. Some children may

have reorganized language to the other side. Also just in general, we use language a lot. And so if you have any learning problem, language may be a factor because we use language to learn. What we have found is that again, like attention, children with epilepsy often have pulled core language skills.

Dr. Madison Berl: [24:39](#) These aren't kids coming to us at age two, three, four with language problems, with learning to talk. It's just later on when language becomes more complex. We use it for social functioning and we have to explain more complex ideas to other people. And so it really maybe related to that as executive functioning that I talked about earlier. In terms of reading too, it's the comprehension, it's not learning to decode but it's really the reading problem.

Dr. Madison Berl: [25:06](#) So usually the other piece that plays into there is processing speed. So again, language usually needs to be quick and timely and especially in a social conversation. And then if you're slow to catch on or to keep up, then that can be a bigger problem later.

Dr. Madison Berl: [25:37](#) The next area is memory. And again, like language there may be differences between what you hear about with adults and children in terms of lateralizing effect of the seizure focus. So left hemisphere, again associated with verbal memory problems, right hemisphere associated with nonverbal memory problems. And for adults there is an association with that in terms of left temporal lobe epilepsy being verbal memory. But that's not necessarily the case for kids.

Dr. Madison Berl: [26:10](#) And really the consensus across many studies is that verbal memory just is at risk regardless of the final focus. The other thing is again, attention maybe playing a role in this because if you're not paying attention that information is not going into your head. And there's one study that found that once those attention problems really resolve or are not as big of a problem, because we all get better at attention as we age, from a four year old to a 15 year old, that really then that's when maybe those global memory problems are more evident and more specificity. Again, what we found is that most of the memory problems in children are really associated and predicted by those executive and attention problems.

Dr. Madison Berl: [27:02](#) So another area of concern is psychiatric comorbidities. And really what we know is that there is an increased prevalence in people with epilepsy. These go back to studies from a long time across epidemiologic studies, population studies. And the risks for having a psychiatric disorder is about 35% of the population

of people with epilepsy will experience a psychiatric problem in their lifetime. And that is higher than the general population. Just to be aware of depression, anxiety are most common.

- Dr. Madison Berl: [27:44](#) Most of you are dealing with stopping the seizures, school problems, that kind of thing. And again, these are the things that can get overlooked at time. And mood problems really can sometimes be the thing that affecting cognition in schoolwork and can particularly also affect attention, executive function, processing feed, these things that we've been talking about.
- Dr. Madison Berl: [28:06](#) Again, if that ends up being the issue, I know sometimes they're hesitant to do another medication. But treatments that worked for depression also worked for depression and epilepsy. And so working with a professional to decide if that's the right step is really important. Again, just some populations studies to show that it may be the neurophysiology of the epilepsy that put kids at risk.
- Dr. Madison Berl: [28:31](#) So it's not just having a medical condition, chronic medical condition. There's a higher risk for people with epilepsy that's uncomplicated. And then that even shoots up more with complicated epilepsy. Another study I just want to show you is the functional outcomes from a large national study of children. And for children with epilepsy you have a higher risk, yes, of school problems, parents stress, those kinds of things. But the thing that I find surprising and something to always remember is there's a nine times higher risk of that child being the limited in their activities that they do. And that is so important for kids.
- Dr. Madison Berl: [29:12](#) And so I'm going to return to that one when I talk about recommendations. Again, thinking about how often your kid is really isolated from what other kids do. All right, let's move to recommendations. Again, I tried to make these as applicable as possible to many people. And so the first thing you want to do, especially for attention and processing speed, is make sure that your school knows about it and is helping you do something about it.
- Dr. Madison Berl: [29:46](#) And you can do that through a 504 Plan which is through American Disabilities Act, that anybody with a disability should have equal access to government facilities including a public education. And so that's where 504 Plan comes in with the same regulation that you put on so that people have to put ramps, so that people with wheelchairs need to get into a public building. This is the same idea that any child with a disability has access to educational curriculum. And so whatever

accommodations need to be done to make that happen are required.

Dr. Madison Berl: [30:23](#) And so that means maybe preferential seating. These are all things that could be done by the teacher in the classroom and doesn't require anybody extra. It can be extra time, it could be a reduced worksheet. So they're doing a few five problems, 10 problems, those kinds of things. The other way to go is you're an individualized education plan. And the advantage of that is that you're going to have goals that then the school is required to monitor and keep track of your child's progress towards those goals.

Dr. Madison Berl: [30:59](#) And so some people think it's better that you could have a very heavy 504 Plan that does just fine for your child. It really depends on your child's needs. There's some IEP Plans that gives your child five minutes of a speech language person once a day and that's it. And that may not help your child as much as having all the time in the world to do their tasks and being able to take it in a quiet room. So it really depends. But again, those are two ways to go to get the accommodations you need.

Dr. Madison Berl: [31:30](#) And these are just, again, some common accommodations that we talk about. Breaking down tasks, repeating instructions, those kinds of things. We talked about medication for ADHD already. You can consult with a neurologist, a psychiatrist and then sometimes a pediatrician. Sometimes a pediatrician may not feel as comfortable given the epilepsy part but talk to them definitely. If you do go with a stimulant, that's something that you have to go to the doctor's office quite often. Usually you need to see them every three months for that. And so maybe having somebody close by to you is a little bit more convenient.

Dr. Madison Berl: [32:06](#) Again, I just wanted to give you some books as well as access to websites. That can be really helpful. LDonline.org has a ton of recommendations and articles for the processing speed. These timer apps can be wonderful and great. It helps the child know when the task is going to be over as well as how much time they should be spending. Technology is also really great and kids like it in terms of...

Dr. Madison Berl: [32:33](#) My teenagers always like it when I recommend something. I say, "I guess, you have to get a smart phone or an Apple watch in order to make it happen." The other areas, executive functioning. And again, you can put goals specifically into your IEP about this. Avid is actually a school wide curriculum that is being picked up and if you go to this website, www.avid.org you can look up your school to see if it's available for you.

- Dr. Madison Berl: [33:07](#) Sometimes the school doesn't always have the right knowledge and right personnel. And if you have the resources to get a tutor who really understands executive functioning and how to help your child, that may be the best way to go. And I do recommend it. It can also reduce homework battles at home that causes stress in other ways. Using tutors can be a useful tool.
- Dr. Madison Berl: [33:31](#) Again, more apps and websites and using technology. Note taking as a tough thing to do. You have to listen and pay attention and keep information in mind that working memory while understanding what the teacher says. You can't write down every word. So you have to summarize it and then continue to write it down and then keep up with the teacher when they're talking. And if they talk as fast as I do, that's hard to do.
- Dr. Madison Berl: [33:58](#) So note taking apps can be great. They can be linked to a pen where you can go back and listen to just to that part of the lecture that they missed or their notes are weird and those kinds of things. Again, lots of tools for that. Lots of books about how to use different strategies for homework, longterm planning, those kinds of things that are there. One thing I do want to mention is Cogmed (www.cogmed.org) or any of these brain training programs. There's some evidence, we did run a trial here, that it can be helpful for some children.
- Dr. Madison Berl: [34:32](#) But it's not a lot of children. And the one issue is that it's not generalizable to other skills as far as we can tell. And so for a lot of money people are spending time and I'm not so sure that's necessarily the best place to put your money. A great EF (executive functioning) tutor, I would go with first. But having said that, again, sometimes kids really respond to it and the structure of doing the task five days a week, it structured the rest of the kid's day and homework time. And so it did help some families. Again, I would be cautious about whether it's really worth it for you.
- Dr. Madison Berl: [35:14](#) So the other area I want to talk about are memory recommendations. And again, at this model at the top, I want you to notice that, again, paying attention. Sometimes the breakdown is just getting that information in. So any recommendations for attention can be helpful. And then the other two steps later, the working memory or keeping information in mind, that rehearsal and repetitive exposure, any recommendations for repeating information can be helpful and then that longterm memory store where there's organization. So there's retrieving and then coding.

- Dr. Madison Berl: [35:56](#) What I talk about for is that if I have my filing system, my filing cabinet and I just throw all my papers in there randomly, when I'm going back to look for that one piece of paper, I have to shuffle through all those papers. I have no system for picking it out and retrieving it. So if you put the information in an organized fashion, it's much easier than to go back and pick out that one piece of information you need or you're being tested on. So organization really comes into play with memory and where it might break down.
- Dr. Madison Berl: [36:31](#) So these are just some recommendations for that input and coding. And then the next page is really about the organizational piece. So one thing that happens is, we've learned from our other colleagues that work with children with traumatic brain injury that have a lot of memory problems associated with that. And one technique is errorless learning.
- Dr. Madison Berl: [37:21](#) So sometimes we think is best to learn is to quiz. Our teachers will quiz their students. And that may not be the best thing because the child is making all these associations and guesses because they really haven't learned the information. So errorless learning is really this technique of when you're asking that question, you're really giving the information to them right the first time and they're rehearsing it that way. Or you're giving them multiple choices where the answers are right there and you're not making as many bad associations with their learning. You always want it to be the right learning.
- Dr. Madison Berl: [38:04](#) Rehearsal and practice, again, verbalizing and visualizing and coding at different levels is really helpful. You want to make things an active process. So turning flashcards into a match game which can increase their interest and attention, all kinds of things. The retrieval problems, again, using cued recall, also external prompts. Again, technology comes into play. If you want your child to walk the dog every day, and get them a watch that beeps at them to walk the dog. Those are great and there's really lots of opportunities and options now.
- Dr. Madison Berl: [38:42](#) Again, more books and websites for you. Again, some strategies for improving communication, doing homework. This last bullet point is repetition of basic skills or repetition of books then listening. I really love audio books for kids. Most people with epilepsy can go to bookshare.org and qualify. There's a very short application about two pages that your neurologist or another professional you work with can help you fill out. And it really gives them the access to thousands of textbook titles as well as free reading titles.

- Dr. Madison Berl: [39:16](#) So many kids really can't read at the same pace and enjoy it, but if they're doing the readings then listening to the book at a level of interest. Harry Potter, when other kids or peers are reading Harry Potter, is great. And so that can be a great way for people to reinforce learning in a fun way and to enjoy reading.
- Dr. Madison Berl: [39:43](#) Again, these reputation of basic skills, using computer games. There's lots of fun ones for math skills, math facts, those kinds of things. Spelling and learning to type can be a huge benefit for kids that have motor problems and that gets in their way of doing their written work. So all of these can be really helpful.
- Dr. Madison Berl: [40:03](#) Psychosocial. Last one. So when I talked about the limitations, what I'd really like you to think about, I know safety is certainly number one. But if you can really think about whether you are limited in activities because you're afraid or really because your child can't participate, it's pretty rare that a child really can't do even sports and things like that.
- Dr. Madison Berl: [40:34](#) And so can you add in supervision to make everybody feel safe? Is there an alternate activity to the first choice? So even if they're not doing football, can they be the student trainer and be involved? Just the importance of being with their peer group, doing something active and feeling involved can go a long way in terms of their social, emotional happiness and then being creative.
- Dr. Madison Berl: [41:00](#) So for the teenagers around here in urban and suburban settings, you have Uber, you have Lyft. Can that child get themselves somewhere even if they're not driving without necessarily having mom and dad drop them off. Those kinds of things. And trying to be creative and helping that child be independent when they need to be independent and join their peer group in an appropriate way and get them out there and not have them isolated.
- Dr. Madison Berl: [41:27](#) Again, empowering them to discuss and educate others about their seizures. What if I'm going to have a seizure, nobody knows. Well if they have a best friend, let them in. Let them know about what would need to be done and that can... Kids are more responsible and I think they give them credit for. Again, seeking support if there is an issue or problem. Yes there's a traditional individual therapy or social skills group, but sometimes it can be something more informal than that.
- Dr. Madison Berl: [41:56](#) So peer groups, parent groups, camps, there's lots of epilepsy camps around. Maybe it doesn't have to be epilepsy specific at all but, again, some sense of belonging. Maybe they're just

dealing with some stress. It can be all different kinds. And just having that child feel like they're not alone and not the only one dealing with it, again, can go a long way for their social emotional health. And then finally, again, medication may be needed in the more severe case. Now I think that's it. Thank you.

Brandon Laughlin: [42:28](#)

Great. Thank you so much Dr. Berl. There was a lot of great resources in there. And actually a lot of questions that came through while you were talking. But you actually did a wonderful job of answering a lot of the questions as your presentation went along. So we'll go ahead and begin the questions portion of the webinar. We'll get through as many as we can like I said. And again, if you have any last minute questions you can actually render them like I said through the questions tab in the GoTo meeting control panel.

Brandon Laughlin: [43:00](#)

First question actually comes whereas dealing with what you just discussed as far as the CogMed programs. And do you have any sense on how successful the percentage of cases are aided by programs like CogMed and how great the impact is?

Dr. Madison Berl: [43:18](#)

Yeah. So for our study and I think there's one other published study in Epilepsia, it's about 20% of the kids that were in the study showed a significant improvement. So it's not nobody, but it's not a majority either. And so that's a concern. And I think we don't have enough information of why those kids responded and the other kids didn't. So that may be something else about it to learn about too.

Dr. Madison Berl: [43:47](#)

And then the second factor is, okay, they improved. Usually they're improving on the measures that are very specific to that task. So they can repeat more numbers backwards or something like that. But how that actually translates to real life school skills or other skills is really lacking. The other thing that we've seen with longitudinal studies, because these programs have been tested a lot more thoroughly in ADHD populations, is that even if they show significant gains on something like math fluency, which we actually found too, it goes away after six months.

Dr. Madison Berl: [44:29](#)

So it's very short lived. And so does that mean that you have to keep doing this training? Does it really change things long term or not? And so those are some questions that are still concerning that it really doesn't generalize or last in the way that we hope it does.

Brandon Laughlin: [44:47](#)

Great. Thank you. Another question actually deals with 504 and IEP. They stated that advocating for 504 and IEP combinations

seems to be a daily challenge. And so they wanted to know how they can get better resources for the teachers in their schools.

Dr. Madison Berl: [45:08](#) Yeah. So that can go in a lot of different levels, right? So, yes, we need more funding for our education system, hands down. I am an advocate of that. In terms of getting the resources for your child, I think you also come to a point where you just have to fight for your own. And use of advocates is wonderful. They can be expensive. It's like hiring a lawyer.

Dr. Madison Berl: [45:36](#) But there are often, at least around here, organizations that have access to advocates that are free or at least at a reduced costs because their nonprofit mission is to help children access the curriculum. And so if you can get an advocate, if your school is not being responsive, really the parents that are the loudest, the squeaky wheel gets the oil, be like a pit bull and just be after them. And nobody likes that when it gets contentious, but sometimes that's what you need to do for your child.

Brandon Laughlin: [46:17](#) Good. Thank you. Are there any thoughts on what it indicates if a child makes huge cognitive gains on seizure meds and with every increase in their seizure medication?

Dr. Madison Berl: [46:28](#) So that's a great question. I think that's a great reminder to know that if there's great gain, that probably means that was interfering with your child's ability to learn. And so the medicine's quieted down that brain activity. I would be very cautious about saying that then more medicines mean better cognitive skills because that can go the other way too. Like making them blotto by giving them too much drugs. And you really have to work with your neurologists about that.

Dr. Madison Berl: [47:04](#) They usually are working with you by doing routine EEGs to see what the EEG looks like. And if some of the problems are like attention, that's where, again, maybe going to the stimulant medication and it's not necessarily more anti-epileptic medication but it may be a different medication that could be helpful.

Brandon Laughlin: [47:32](#) Great. And that actually ties into my next question. Are there any other options when stimulants don't seem to work for ADHD? And specifically this person is talking about in frontal lobe epilepsy.

Dr. Madison Berl: [47:46](#) Yeah. So there's a couple of things. There are non-stimulants ADHD drugs. So those could be helpful. Again, depending on what is going on, sometimes I've seen really the inattention is

around sleep. And so I've had some parents feel like melatonin at night actually does wonders for the attention during the day because now they're sleeping better. So I really think you need to dig in to know maybe why that stimulant wasn't effective and that might open up some other options for other drugs or maybe other interventions.

- Dr. Madison Berl: [48:26](#) And really then just the behavioral interventions in school are definitely something that needs to be carried out. Whether that's smaller class size, working in small groups, those kinds of things.
- Brandon Laughlin: [48:42](#) Great. And actually the last question I have falls into that same line. And the person asked, "Does failure to medicate for the purpose of mitigating inattention have any impact on longterm development IQs?"
- Dr. Madison Berl: [48:58](#) I'm sorry. So if you didn't medicate, would it have an impact?
- Brandon Laughlin: [49:08](#) Yeah. Does the failure to medicate for the purpose of mitigating inattention?
- Dr. Madison Berl: [49:12](#) Yeah. I mean, I think what if your child is not available to learn? Whether they're sitting in the classroom and not listening or never attended school, it would be the other extreme, then, yes, that can impact their development. So, yes, if you are afraid of medication and decided not to, you may be hampering them because they are just not available to learn. But again, I'm not saying that it's the only way. It's just that it is a tool.
- Dr. Madison Berl: [49:46](#) And I feel most of the parents I work with are more hesitant to add a medication. And so that's why it sounds like... I'm just telling you not to be hesitant and to consider it. It doesn't mean that has to be the only way. But for sure, I would just think it should be considered more and I think many parents that I work with are a little bit more afraid than the typical parent because they already are on medications.
- Brandon Laughlin: [50:12](#) Gotcha. And actually, I'm going to throw one more question in there because we did get a few questions dealing with this subject area. This particular question deals with a thought of actually possibly homeschooling their child. At what point do you think that homeschooling is a viable option for a particular child or student?
- Dr. Madison Berl: [50:39](#) Yeah. So I think that as much as I said, working with an advocate can be helpful. Fighting that process can be long and hard. And

even what's an acceptable amount of time that your child is not accessing the curriculum? Is one year too long? Is two years too long? And so I can sympathize and empathize with parents that say, "You know what? I can do this better and I can do this at home and we don't have to waste all this time."

Dr. Madison Berl: [51:11](#)

And I have had lots of families that have done a great job at that. I think you have to think about you and what you're able to do and your willingness. I think there's lots of tools and resources. We have lots of co-ops around here, so you don't have to do it on your own. And then again, I would just make sure you at least worked with an advocate or a professional to make that decision just to have the discussion with somebody else so that an issue you hadn't considered or options you hadn't considered, that everything was turned over before you made that decision.

Dr. Madison Berl: [51:52](#)

Again, some kids it's just they need to because you know the school that you have access to. Or you know your child. We have some children that really, they're so variable that they need to sleep till 10 o'clock in the morning and they can work and then they need to take a nap or they are going to be seizing every two hours. And so just because of them, they may do some of their best learning at seven o'clock at night and school's not open. And a child that really needs that much more flexibility might be another reason to decide to do homeschooling.

Dr. Madison Berl: [52:30](#)

So there's lots of factors that go into it. But I would mostly just recommend that having that discussion maybe with several people so that you're considering all the options. But again, I've seen wonderful teachers, parents that are way better teachers than what's in the school system. So it can definitely be a good decision.

Brandon Laughlin: [52:55](#)

Great. Well, this actually will conclude our webinar today about the effect of epilepsy on learning and school performance. I want to thank Dr. Berl again for a wonderful presentation. I also want to thank Sunovion for sponsoring today's webinar. Also finally I'd like to thank the audience today for remaining very engaged and asking some great questions. I'm sure many of you may want to view this presentation again or pass it along to your friends. So this will be available on our website at www.cureepilepsy.org.

Brandon Laughlin: [53:29](#)

And if you do have any questions do feel free to reach out to us at infolectureepilepsy.org. Thank you again and please be on the lookout for some more scheduled webinars to come. The

next webinar in our series will take place on April 18th at 3:00 PM Eastern time. And that's going to feature Jackie French from NYU, who will be discussing promising antiepileptic drugs in development. Have a great day, everyone. Thank you.