CURE Epilepsy Webinar
Surgical Treatment Options as Tools to Reduce the Risk of Mortality in Epilepsy
(Transcript)

Dr. Laura Lubbers: Welcome everyone to today's webinar. I'm Laura Lubbers and I'm the Chief Scientific Officer for CURE Epilepsy. I want to thank you for joining us today. Last week we recognized SUDEP Action Day. A day to raise awareness of Sudden Unexpected Death in Epilepsy or SUDEP and epilepsy deaths worldwide. Today's webinar is entitled, Surgical Treatment Options as Tools to Reduce the Risk of Mortality in Epilepsy. And it's conducted in partnership with our friends at Partners Against Mortality in Epilepsy, also known as PAME.

Dr. Laura Lubbers: The pediatric epilepsy journey can be very challenging and very scary. Surgery has been less utilized as a treatment option, but research has shown that it can be an effective treatment, especially for those living with drug resistant epilepsy. Surgery can reduce seizure frequency and lessen the risk of seizure related death. While surgery may not be an option for every person, it is important to advocate for timely, comprehensive surgical evaluation for all people struggling with epilepsy.

Dr. Laura Lubbers: And reduce the known disparities and access to surgical treatment options. This webinar is a part of our 2023 CURE Epilepsy Webinar series where we highlight some of the critical research that's being done on epilepsy. Today's webinar, like all of our webinars, is being recorded for later viewing on the CURE Epilepsy website. You can also download transcripts of all of our webinars for reading. CURE Epilepsy is proud to celebrate our 25th anniversary this year.

Dr. Laura Lubbers: Since our founding in 1998, we've raised millions of dollars to fund epilepsy research that supports our mission, which is to find a cure for epilepsy by promoting and funding patient-focused research. CURE Epilepsy provides grants that support novel research projects and advance the search for cures and more effective treatments. In today's webinar, we'll discuss how surgery is one of the tools available to treat epilepsy and why having a surgical evaluation is important.

Dr. Laura Lubbers: Attendees will also learn about how different treatment approaches can improve survival and contribute to improved healthcare outcomes. This webinar is presented by Dr. Sandi Lam, the Division Chief of Pediatric Neurosurgery at Lurie Children's Hospital in Chicago, Illinois. She also serves as a Professor and Vice Chair in the department of Neurosurgery at Northwestern University Feinberg School of Medicine, which is also in Chicago.

Dr. Laura Lubbers: Dr. Lam will also be introducing to us an inspiring mom who chose surgery for her son who is suffering from seizures. Dr. Lam's clinical focus encompasses pediatric epilepsy surgery and cerebrovascular surgery, and she has expertise in surgical innovation, neuroendoscopy, minimally invasive surgical techniques, and the development of multidisciplinary patient-centered clinical programs. Before I begin, we'd like to encourage everyone to ask questions.

Dr. Laura Lubbers: We'll address the questions during the Q&A portion of the webinar. Keep in mind, you can submit your questions anytime during the presentation by typing them into the Q&A tab located on your WebEx panel and click send. We'll do our best to get through as many of the questions as we can. We do want this webinar to be as interactive and informative as possible.

Dr. Laura Lubbers: However, to respect everyone's privacy, we ask that you make your questions general and not specific to a loved one's epilepsy. So with that, I'll turn it over to Dr. Lam.

Dr. Sandi Lam: Thank you. It's an honor to be here and spend this afternoon with you. We have a special guest today, Jamilah Doyle-Walters, who I actually know as RJ's mom. And we have had a journey together where I had the privilege of gaining the trust of RJ's mom and family so that I was able to join their epilepsy journey. This was after already some years of RJ having seizures and Jamilah is going to share some of their epilepsy journey and really the family's perspectives in this fight against epilepsy together. So I'm honored to welcome Jamilah.

Jamilah Doyle-Walters: Thank you, Dr. Lam. It's a pleasure being here and Sean, and actually just speaking about my son and our family and our journey. That was unexpected, but it's been amazing and once you get over the part of processing the disease process and over the hump of the surgery, the road to recovery is pretty smooth. So my son, he is nine now. At the time, he began to have seizures at the age of four, normal growth and development up until then.

Jamilah Doyle-Walters: His first seizure was in April of 2019 at exactly 7:31 in the morning. I would never forget it. And of course we went to the emergency room and the process was every child has a seizure every now and then. We'll see if it happens again. Unfortunately, it did happen again. It continued to happen after countless amount of medications. We have been on previously, seven controlled substances all at one time to control his seizures.

Jamilah Doyle-Walters: None of them completely worked. And it wasn't until my son began to have numbness and tingling in his legs in November of 2019 where things just got worse. Fast-forward to post Covid to June of 2020, we received the diagnosis of Rasmussen's encephalitis. His brain at the time showed right frontal lobe, brain atrophy, meaning the right frontal of his brain was dying. It was attacking itself.

Jamilah Doyle-Walters: I searched high and low for a cure, a treatment because immediately my thought process was, what does life look like for my son? I'm not going to be here forever. What do we do? I reached out to several hospitals. I interviewed several doctors before I found Dr. Lam because I wanted somebody who worked on children's brains. I did not want a general neurosurgeon. I wanted a pediatric neurosurgeon. And that's when I found Dr. Lam.

Jamilah Doyle-Walters: And I called Lurie's Children's, told them about my son and that we had a referral. And from there I interviewed Dr. Lam. It was easy. She's very trustworthy, very honest, gave me all the information that I need to make a very prudent and wise decision to proceed with surgery for my son to give him the best quality of life. And since then, my son has been seizure-free since December of 2020. Me and my husband, we decided to keep him on at least one medication just for precautions.

Jamilah Doyle-Walters: But he lives a completely normal life. He plays basketball for Special Olympics. He runs track with Special Olympics. He's in TaeKwonDo. He is currently a yellow belt. He is full of just smiles and love. Recovery, it wasn't easy, but it was doable. Lots of just being patient would definitely get you through that part. And the amount of research that I did prior to finding Dr. Lam and the amount of research that is ongoing, I don't regret my decision at all. So yes. Any questions right now? I know.

Dr. Laura Lubbers: Thank you so much, Jamilah, for sharing your story. I know we don't have much time for questions, but in a minute that we have. I'm wondering if you can speak to the biggest challenge you had in this.

Jamilah Doyle-Walters: The biggest challenge I would definitely have to say was recovery. Recovery definitely was the biggest challenge. I tried my best. Me and my husband together tried not to put so many expectations. We tried to be realistic with our thoughts of what we wanted, and ultimately we just wanted him to just be healthy. I called my son my third child because although I only have two, I received three kids and one. I received the little boy that I birthed up until four.

Jamilah Doyle-Walters: Around four, his personality changed, and with the medications I received another child. And then after surgery I received my third child. And to have his laughter back that we lost unfortunately in that second phase was amazing. To see him ride a bike again because he did not ride a bike once his seizure started. That left side constantly just giving out on him, that weakness. He was not able to ride a bike, so he gave up on that.

Jamilah Doyle-Walters: It was a lot of things. He had to learn how to read again, write to everything. But despite all of that, I don't regret my decision. And I know that's not the case for all parents, but I would like for my family to be an inspiration to you guys and let you know that it's possible and it's doable.

Dr. Laura Lubbers: Thank you, Jamilah. It sounds like it's been a remarkable process, but also remarkable recovery. So we really appreciate you sharing your story. I'm sure others will have questions and we are happy to collect those questions. We know you can't stay on with us, but again, we really appreciate you sharing your story and RJ's story, your family's story on this and giving us much to think about. With that, I can turn it over to Dr. Lam.

Dr. Sandi Lam: Thank you so much and thank you RJ's mom. Hi to RJ family.

Jamilah Doyle-Walters: My pleasure. We're always here for you. Thank you.

Dr. Sandi Lam: Thank you. Really a remarkable family. I've met RJ's mom and dad and siblings and grandparents, and it really takes a village and a community to battle a chronic disease like epilepsy and to see the seizure-free outcomes and see children and families go on with their lives and reach their fullest potential. That is what keeps us going. That's what motivates our team clinically and research wise. So I'll share some broad perspectives both as a pediatric neurosurgeon and as a health services researcher.

Dr. Sandi Lam: So my name's Sandi Lam. I'm the Division Chief of Pediatric Neurosurgery at Lurie Children's Hospital here in Chicago. And I'll start with the burden of epilepsy in the first slide. Epilepsy is a big deal. Epilepsy costs the healthcare system an enormous amount, and that's only what we know how to measure, right? And that really does not take into account that the caregiver and the family related costs of taking care of children and loved ones living with epilepsy.

Dr. Sandi Lam: And there are also many medical comorbidities with other diseases that go along with epilepsy including mental health disorders. And what we see is actually an increased risk of death, an increased risk of premature death. And that's not only related to seizures, it's also related to accidents and suicide and other causes of death. So I know that the last series talked about SUDEP. This kind of builds on that.

Dr. Sandi Lam: If you look at the next slide, the mortality risks associated with children with new onset childhood epilepsy. Some are related to seizures and some are not. And if you compare people living with epilepsy and the mortality risk that they face, all comers, children and adults actually face a two to four times higher overall risk of death than people without epilepsy. And in children, that is actually five to 10 times higher compared to children without epilepsy.

Dr. Sandi Lam: And in the next slide you'll see just kind of overall for the US. Epilepsy is much more common than one would think. There are over 3 million people in the US living with active epilepsy. And when you break it down to the pediatric population who I treat, it's over 200,000 children with epilepsy. If you look at the next graph there is... You'll see that about 4% of people may develop epilepsy at some point in their life, and there's different age groups.

Dr. Sandi Lam: So I treat children. So I actually see children presenting before 18 years of age, and there's quite a lot right within the first year of life. And then it tapers off, and then the rate of incidences of epilepsy rises again in adulthood. The next slide will show us... Also, the first encounter that you'll see with seizures is what Jamilah just talked about, right? Having the workup and trying to see is this going to happen again? Are we going to need medications?

Dr. Sandi Lam: And then the medications. There are many, many medications that are available on the market now, about 30 or more. So it is quite common to try a first medication and then a second medication and then maybe more. But after two appropriately dosed medications, that would be considered drug-resistant epilepsy. So if you look at the numbers here, at about three quarters of people will respond to their first and second medications. And beyond that, the chances of achieving seizure freedom start to decline.

Dr. Sandi Lam: So next slide will show us actually a consensus recommendation from the International League Against Epilepsy. Where 61 experts treating epilepsy from around the world actually came up with recommendations for who should be referred to be evaluated for epilepsy surgery. And if you look at this, it actually is quite expansive, which says every patient up to the age of 70 as soon as drug resistance is determined.

Dr. Sandi Lam: So usually after two well dosed medications, that can be a candidate for a surgical referral. And that is to look at if surgery is an option. And that will be one of my themes today, that really surgery is part of the toolbox that we have against epilepsy and really can be considered just like any other medications or diet modifications to really see if this is something that can help stop the seizures or decrease the seizures.

Dr. Sandi Lam: And when epilepsy is lesional, so when there is a brain lesion on an MRI that we can see a cause for the seizures. Patients don't even have to be on the two medications or more to be considered an appropriate referral for surgical evaluation. So this comes from experts all over the world. And so if you go to the next slide, to summarize, really it's every patient who has seizures despite being on seizure medications, should have a workup for having the option of epilepsy surgery.

Dr. Sandi Lam: And every family with a patient with epilepsy should be empowered with the knowledge of these options. So when I first started training in neurosurgery and in the medical field, epilepsy surgery was considered a last option and a very scary option. But when we think about being empowered with understanding options and the choices and understanding that poorly controlled ongoing seizures is actually very dangerous.

Dr. Sandi Lam: Then we should be able to have a good conversation to understand is there a role for surgery and how? So that we can make choices together. If you look at the next slide, this is a kind of typical workup or rubric where you would do your first or second medications and the rate of reported seizure freedom is 60 to 75%. And then if there are more seizures, then you would be referred to an epilepsy center where you undergo a workup with many diagnostic tests to see if epilepsy surgery is appropriate or if you would be a candidate for epilepsy surgery.

Dr. Sandi Lam: So as I alluded to this imagery of this kind of toolkit against seizures. And the next slide you'll see kind of the rationale for epilepsy surgery. You'll see that there are detrimental effects of ongoing seizures to the brain and for children to the developing brain. So having recurrent seizures really holds people back in terms of development of the brain and kind of neurocognitive achievement.

Dr. Sandi Lam: And then there's also anti-seizure medication side effects that will also have detrimental effects. So really to have the option of surgery and maybe having a surgical cure or having the surgery be able to effectively decrease the seizures could really help achieve goals of either seizure freedom, fewer seizures, a higher quality of life, and really for children to give them that opportunity for the brain to really develop and reorganize and achieve its full potential.

Dr. Sandi Lam: So in the next slide you'll see kind of a whole spectrum of epilepsy surgeries. There are many and they're targeted at different things with different diagnoses. And in the next slide you'll see that it'll look very busy, but really it's looking at all of the data and all of the information that you get from the epilepsy workup from an MRI and from all of the other tests that are done really to try to figure out where the seizures are coming from.

Dr. Sandi Lam: And how best to try to address where the seizures are coming from in a safe way. So that's where you'll actually see all of these different surgical options. It's really tailored to the patient to try to maximize the chances of seizure freedom and also to make sure that we can do this safely. And for the next slide, you'll see that as we think about expanding our surgical options, it's tailored to the patient.

Dr. Sandi Lam: So some patients are relatively straightforward and some are relatively complex depending on the cause of the seizures and where they're coming from. But in appropriately selected candidates up to 80% of seizures, actually 80% of patients with epilepsy can have a very successful result from epilepsy surgery and achieve seizure freedom. And there is ongoing research all the time to help us think about how to do this better and how to have better options for everybody.

Dr. Sandi Lam: So you'll see that there are many surgical innovations that have happened for epilepsy over the past two decades. So even in the course of my career, we've been able to do this better and safer, and even patients who weren't candidates for epilepsy surgery in the past are now candidates for epilepsy surgery because we have minimally invasive options or we have neuromodulation where we actually don't think about where's the seizure coming from and resecting or removing the part of the brain causing the seizures.

Dr. Sandi Lam: Now we're able to say, you know what? If the seizures are coming from a part of the brain that is necessary for say, talking or moving and things that really make you you. Is there a way that we can tell the brain to calm down with other technologies like neuromodulation and really stimulate the brain to try to decrease the chance of seizures? So you'll see at the beginning when we had the randomized controlled trial almost 20 years ago, published in the New England Journal.

Dr. Sandi Lam: You'll see that there's a randomized control trial for temporal lobe epilepsy that really compared a surgically treated group to a medically treated group. And you'll see that the surgically treated group very clearly had better rates of seizure control, and this was for temporal lobe epilepsy when the treatment was to remove the temporal lobe where the seizures were coming from.

Dr. Sandi Lam: So with really the best scientific evidence that we have, we were able to really think about helping more patients with epilepsy with surgery. And even having that definitive evidence, you'll see in the next slide that we were able to do more surgery to try to help more people and help more kids to achieve seizure freedom. And when you look at how epilepsy surgery is used or deployed to help people, we know that based on Anne Berg's Connecticut study of epilepsy.

Dr. Sandi Lam: That epilepsy surgery is very underutilized. So estimates are about maybe one in three children who could benefit from epilepsy surgery are actually getting epilepsy surgery. And there are actually broad disparities to this. You'll see in the chart on the next slide that who gets epilepsy surgery can actually be dependent on sociodemographic factors and also based on sex, race and insurance, whether it's public or private insurance.

Dr. Sandi Lam: The next slide please. So this is not just in the US, we've actually seen these types of reports from different areas of the world and different insurance systems such as Canada. So disparities in access is a real issue. You'll see in the next slide, which was provided courtesy of my colleague, Dave Clark at UT Austin. We collaborate a lot if we know that we have good treatments to offer for patients that may be able to give seizure freedom and that may be in the form of epilepsy surgery.

Dr. Sandi Lam: How can we actually get more people to know about these treatments and how do we get more people to be able to benefit from these treatments? So when you look at ideal, which is everybody would understand that there is an option for epilepsy surgery after a workup if appropriate and then be able to choose this together. But you can see that actually in the literature, there's many studies that show that there's actually quite a delay.

Dr. Sandi Lam: When you receive a diagnosis of epilepsy or drug resistant epilepsy to actually get the workup with the EEG and the MRI and the referral to specialists and then having all of the other workups and having the appropriate specialists be involved, there can be a delay of ideally maybe one to three years. And up to 10 to 17 years has been reported in adult centers. So when you heard from Jamilah, they took fewer than two years to be able to get the multidisciplinary evaluation and surgery.

Dr. Sandi Lam: But I think if we asked Jamilah, that probably felt like a lifetime during the period of her second child having ongoing seizures and declining. So when you look at estimates for this country, we may be able to help a hundred thousand people with surgery. But when you look at adults and kids, we're helping maybe 6,000 people with surgery and only fewer than a quarter of people are seen at level three and level four epilepsy centers that have that comprehensive epilepsy team for evaluation. Next slide.

Dr. Sandi Lam: So there's many areas where we can have delays and deficits, and you saw that in a different graphical format in the previous slide. So that's at kind of every step along the way of the workup. And then in the next slide you'll see that there may be actually many other factors that are built into our healthcare system. And also kind of into our society where there may not be access in terms of geography. Not everybody lives right by a level three or four epilepsy center.

Dr. Sandi Lam: And there's also language barriers, where if English is not the primary language, it's actually much more difficult to access the healthcare system in a way that is comfortable for families. And we already talked about the role of insurance and other kind of socioeconomic factors, and there is a real issue of trust and really being referred in a timely manner. So in the next slide, it's a reminder for me to say, you know what?

Dr. Sandi Lam: We can actually do epilepsy surgery safely in very young children. And that's actually where we want to be able to help when families already know that they're seeing seizures 20 times a day, a hundred times a day. Moms and dads know that something is wrong. So really having a comprehensive evaluation and if appropriate, actually getting to surgery sooner so that the brain can be free of seizures and actually develop to its full potential is certainly an option.

Dr. Sandi Lam: And certainly something that we want to be able to have all families benefit from if appropriate. So we actually did an international study to show that at certain centers that do this all the time. We can actually do epilepsy surgery in babies safely and effectively with good seizure outcomes. And in the next phase, I'll talk about my research and how I think about helping more people who are living with epilepsy.

Dr. Sandi Lam: So when you look at different research in epilepsy, we talk about seizure reduction, healthcare utilization, maybe coming to the ER, emergency room or using less anti-seizure medications and quality of life and neuropsychological and neurocognitive development. We don't talk about survival as much, right? We talk about SUDEP and we talk about risk of SUDEP. But in the next slide, this was a recent publication for my team.

Dr. Sandi Lam: We actually looked across the United States at a multicenter study looking across over 40 centers, taking care of children in the US over a period of over 10 years. And we compared people who are already on two medications. So either adding a third medication or adding vagus nerve stimulation, which is an implant around the vagus nerve that is part of the choices for neurostimulation or neuromodulation.

Dr. Sandi Lam: And then compare that to epilepsy surgery on the brain. So we don't specify exactly what type, but either brain surgery for epilepsy, vagus nerve stimulation or adding more medications. And you can see in this graph that the patients who were treated with medicines only actually had a lower survival and the patients who were treated with brain surgery for epilepsy actually had the highest survival. So if you look in the next page, the graph here is larger.

Dr. Sandi Lam: So you'll see that the patients who had brain surgery for epilepsy, when you look at... We had a 10-year time point and then beyond. But if you look at the 10-year time point, the probability of being alive after epilepsy surgery on the brain is 98% at 10 years, the probability of being alive after the VNS is 92% at 10 years, and the probability of being alive on medications only was 83% at 10 years.

Dr. Sandi Lam: This is very, very different and statistically significant. That if you have a 90 something percent chance of being alive at 10 years versus an 80 something percent chance of being alive at 10 years. If you look at the next slide, this is across actually a very large sample size. So we had over 10,000 children with epilepsy in the anti-seizure medication cohort, and over 5,000 patients in the VNS cohort and over 3000 patients in the brain surgery cohort.

Dr. Sandi Lam: So sorry to review the numbers. The probability of being alive at 10 years is 89.93% for seizure medications. VNS is 93% and brain surgery is 98%. So sorry, I just adjusted the numbers a little bit here. And then if you look at the next way to kind of think about it is how do you reduce the risk of overall death when living with drug resistant epilepsy?

Dr. Sandi Lam: So compared to the medication only cohort, the risk of overall death were reduced by 35% in the VNS patients and reduced by 83% in the brain surgery patients. In an editorial that accompanied our manuscript, our colleagues from Canada actually thought about how to frame this. So when we think about the choices of continuing anti-seizure medication strategies and adding more medications or to think about operating, that epilepsy surgery could save lives.

Dr. Sandi Lam: And this is for if the patients are candidates for epilepsy surgery, if we can define a tailored surgery that would be safe and effective. And if you look at the public health way of thinking about it and a survival advantage in the cohort that had brain surgery, the opportunity to prevent preventable deaths in epilepsy is actually similar to what we see in public health campaigns for the whole numbers of sudden infant death syndrome, fire safety, fire prevention.

Dr. Sandi Lam: This should be something that we all know in the epilepsy community. Should we be evaluated for epilepsy surgery and can we know about these options? Just that babies sleep on their backs is the recommendation and that we should all have fire safety training. So if you look at the next click. What we know is that epilepsy surgery is underutilized. There's disparities and access to getting to surgical referrals and getting to surgical care.

Dr. Sandi Lam: And we don't know if we really have an accessible road for everybody to understand if they're a candidate for epilepsy surgery or to actually undergo epilepsy surgery. So in the way I think about it, knowledge is power, right? If we know that children with drug-resistant epilepsy who had brain surgery for epilepsy or VNS surgery had higher survival rates than those who received only medical treatment.

Dr. Sandi Lam: There is a role for at least increased access to surgical care. More evaluations and more referrals to comprehensive epilepsy centers that have teammates that represent every single tool in the toolbox against epilepsy so that people can understand if surgical treatments are a good option for them. So in the next rubric, you'll see in a multidisciplinary comprehensive epilepsy team, we really think about a lot of things, right?

Dr. Sandi Lam: Are we doing things safely? Are we offering things that are better than your current state than your alternatives? And then, are we giving you personalized care? So when you look at kind of establishing shared values together in the next slide. The care team should really try to think about taking care of patients well at the right place, at the right time with the right care. And we really want to know outcomes that matter to families.

Dr. Sandi Lam: So if you look at some questions and answers, we want to know, can we do this better? And are we doing it in a timely manner? And I showed you research that shows that there's really delays and getting to surgical evaluation and surgery for the people who are benefiting from it. So how can we improve integration of this into our conversations? And things that honestly, I don't feel that we ask enough in the clinical world is how do we fit into patients' lives?

Dr. Sandi Lam: How do we fit into your medical journey, your social journey within your family dynamic? It's financially challenging to take all of this time off work and try to take care of the rest of the family while coming to the hospital for all of these workups and all of this care. So there's really direct costs like when you show up at a hospital, but a lot of indirect costs and a lot of things that families give up to go through their epilepsy journey.

Dr. Sandi Lam: So how can we do this better? So you'll see that in the next slide. I really think of this as more than just brain surgery. If you go to the next slide, you'll see that it's... To me, it's more than just good surgery. How do we get good timely referral? Good patient selection? What happens to families in their journey and how do we lower the barriers? If you go forward to the next slide, it's really right place, right care, right time.

Dr. Sandi Lam: And then the next slide is how do we put this into action? So next slide is showing what I do in terms of looking across the country at how healthcare is delivered. And you'll see that in a study that I did about a decade ago now. In the next slide, when we compared everybody in the Children's Hospital Association database, we just looked at medical versus surgical treatment for kids who were treated with continued medication versus surgery.

Dr. Sandi Lam: We showed other types of outcomes. So in addition to survival, we showed going to the emergency room, inpatient and outpatient visits, and being on prescribed medications for seizures. We actually saw that the surgically treated group had fewer inpatient hospitalizations, fewer clinic visits, fewer emergency room visits, and lower amounts of anti-seizure medications and higher survival rates.

Dr. Sandi Lam: So in the next slide, you'll see this shown kind of in a summary format. If you look at five years after the surgery or adding medications, it really has decreased use or decreased needing to go to the hospital or the doctor. And if you see the next slide, the first, second, fourth and fifth years look like after the treatment, the surgery or the adding the medications.

Dr. Sandi Lam: You'll see every single year actually the use or encounters with the healthcare system actually shrinks. So if you look at the next slide, what does this look like for one care team? So if you look at... We actually did a review of how we did surgeries in Texas at my last practice. We looked at almost a hundred patients with the same diagnosis, cortical dysplasia.

Dr. Sandi Lam: When we looked at people who got the diagnosis of epilepsy surgery, sorry, of epilepsy that was drug resistant and getting to surgery, we found disparities actually. If you look at the next slide, it's actually patients who are not white, had a longer duration of epilepsy before getting epilepsy surgery. And the patients who are less likely or to have that delay in epilepsy surgery were more likely on Medicaid and actually lived closer to the hospital.

Dr. Sandi Lam: So there's a disparities in access to getting epilepsy surgery. So it's really hard to interpret those findings. What is it that is causing the delays and how do we actually get to more timely referral? And in the next slide you'll see, I'll talk about this in a little bit. We're actually working with families in a grant that I have with the Patient-Centered Outcomes Research Institute.

Dr. Sandi Lam: To actually work with families with Lennox-Gastaut syndrome to understand how to answer questions of that choice between when do we add more medications? When do we do surgery? And how is this care being done all over the country? Then how do we measure outcomes that matter to families, not just going to the emergency room or being in the hospital. Those are big deal things, not just seizure freedom or kind of decrease in seizure rates.

Dr. Sandi Lam: But how does this affect the child's ability to communicate? And how does this affect behavior and how does this affect quality of life? And lastly, I'll talk a few things about just the healthcare system. I think every encounter that you have with a healthcare professional in a clinic is actually an opportunity for health, not just sickness. So if you look at this next study, we looked at just insurance transitions in terms of healthcare utilization for children with drug-resistant epilepsy.

Dr. Sandi Lam: So if you look at the next slide, we actually looked at two different cohorts. So patients who had insurance transitions more than twice in the time that we looked in the study. So if you changed insurance, whether it's Medicaid to private insurance or private insurance to Medicaid or back and forth. You look at the patients who had to change insurance twice actually had a much higher chance of ending up in the emergency room because of their epilepsy.

Dr. Sandi Lam: So it's actually essential for us to think about, it's not just, can I help you with surgery or not? It's actually making sure that whenever you come to the hospital or the clinic that we check on you to make sure, are you okay? Is your insurance okay? Are you going to lose coverage or not be able to fill your prescriptions? So in the next slide I'll show you just for our Lennox-Gastaut syndrome project is our comparative effectiveness.

Dr. Sandi Lam: And we'll skip over a little bit. You'll see Lennox-Gastaut syndrome is usually a childhood onset and the seizures are relentless. If you look at the next slide, many families actually have described having seizures seven days a week. And if you look at the choices that are there, if you look at the blue, it's actually adding medications and the green is actually adding vagus nerve stimulation or corpus callosotomy, which is the most commonly offered for Lennox-Gastaut syndrome.

Dr. Sandi Lam: The next slide shows the project, which I explained is really looking at on a national level that the choices that families face, when do we make this choice? And we have a multidisciplinary team. You'll see pictures of our team, which is a neurologist informatics pediatrician, myself and Tracy Dixon-Salazar, who runs the LGS Foundation, who is a mom of a daughter with LGS. And we're doing a comparative effectiveness study together over the next four years.

Dr. Sandi Lam: And you'll see in the next slide that one of the first things we did actually is this graph shown in purple. To actually ask families how well we do in terms of how well we assess patients. You'll see in the next slide what families tell us is that we are so focused sometimes on just the clinical things getting through clinic. That we don't do as much as what families want, which is to measure communication, behavior, quality of life, explaining the surveys, or really integrating this into how we do this.

Dr. Sandi Lam: So we're learning a lot. And lastly, I'll talk about how do we think about helping more people? We already have a lot more work to do. We're already not reaching everybody that we need to in Chicago or in the US. But when you look across the world, the World Health Assembly actually passed a resolution talking about integrating action for epilepsy and other neurological disorders around the world. So you'll see that in the next slide that there are huge epilepsy treatment gaps.

Dr. Sandi Lam: So over 80 million people in the world suffer from epilepsy and people in low and middle-income countries actually suffer disproportionately. So we have a program where we're working with a team in Uganda actually helping them identify patients living with epilepsy who can be surgical candidates. You'll see in the next slide, it's through an Institute of Global Health grant with one of my collaborators in Global Health.

Dr. Sandi Lam: And this is a picture, next slide from a recent trip that we did doing epilepsy surgery in Uganda. So this is not a fancy thing that only the most elite centers can do. If you identify patients with lesional epilepsy who can benefit from surgery, we can do this safely and effectively and help patients who are living with epilepsy possibly being able to achieve seizure freedom and be able to have seizure-free lives and better quality of life for the patient and the family and the entire community.

Dr. Sandi Lam: So in summary, you'll see in the next slide, there are just so many opportunities together that I'd really love to continue the conversation together. How to address some of these deficits and delays in the way that we deliver healthcare to really make this more accessible the entire journey. There are so many terms, so many specialists, but we really see that there are treatments that can help people and help people have a better quality of life achieve seizure freedom.

Dr. Sandi Lam: And now I think this is a major point, is that we have something that can have a higher survival and really try to have people have a longer survival and live a better quality of life. So this whole teamwork together with patients, families, the healthcare system is essential and I want to learn from you how I can be an better advocate. Thank you so much.

Dr. Laura Lubbers: Thank you so very much, Dr. Lam. I love the concept of working together and collaborative and comprehensive care as you've been talking about. It's so important to approach epilepsy treatment holistically. I think that that's how you've been thinking through this. So we have a few minutes for questions that we can address. One is a sort of a combo question.

Dr. Laura Lubbers: It relates to surgery as an option. And is it an option for drug-resistant patients who have seizures as a result of FIRES? And perhaps you can explain FIRES in NORSE that are triggered across many parts of the brain. And similarly, is it helpful in the case of generalized seizures, which are really...

Dr. Sandi Lam: That's a great question because these are very, very challenging diagnoses. So I would say from a traditional surgery standpoint, it is kind of the most straightforward when there is one area of the brain causing seizures and we can do surgery to remove that area. So that is kind of the most straightforward. And I had mentioned that we need to tailor epilepsy surgery options to the patient. And some are much more complex.

Dr. Sandi Lam: And the scenarios that you talk about, I mean generalized seizures or FIRES are really much more complex, but we actually have more options than when I first entered the field, which is we're looking for this lesion, the one guilty area, and removing the guilty area that's causing the seizures. And now we have neuromodulation, so vagus nerve stimulation, which is kind of a more broad way of stimulating the vagus nerve with broad projections to the brain to really kind of try to tell it to calm down.

Dr. Sandi Lam: But now we have other ways with brain stimulation, having deeper either targeted ways when we know that there's a certain area we can put the electrodes there to do stimulation in a targeted area. Or we can actually have thalamic stimulation, which actually tries to help the whole network. And we really don't, in those scenarios, we don't know one area where the seizures are coming from.

Dr. Sandi Lam: It's actually a more kind of generalized epilepsy where we're actually targeting deep targets in the brain to actually tell the entire brain to have neuromodulation effects. So patients were not candidates for epilepsy surgery 20 years ago, or even 10 years ago or maybe even five years ago. Our thinking and our ability to do these surgeries safely and use these technologies more effectively is evolving and we're getting better and better and we're learning together.

Dr. Laura Lubbers: Right, so perhaps for those who might've had this discussion five years ago, it's a good opportunity to now think, should I have this discussion again with my care team and see if there's something new for me? I just want to remind everybody that actually we're using not the Q&A function, but the chat function today. And so if you have questions, you can put them in the chat.

Dr. Laura Lubbers: And the next question is actually a great segue on what you were talking about. At what age can you be a candidate for DBS or RNS? So deep brain stimulation or neuromodulation responsible.

Dr. Sandi Lam: That is a great question. From my standpoint, we don't give up. We are always looking for is there something that we're missing or something more that we haven't tried or something that we haven't thought of that could really be, that we can think of. Do we have more tools in our toolbox? So surgery is a tool, and we've thought about different types of surgery for patients who are even the youngest patients.

Dr. Sandi Lam: So when you think about a DBS, a deep brain stimulator or an RNS, a responsive neurostimulator, technically the US FDA approval is actually for adults, for patients 18 years old and above. We have actually implanted these device in children and even school aged children or a little bit younger. So while the companies will have to kind of stick to compliance and regulatory approvals, there are just human factors.

Dr. Sandi Lam: Where we tailor the treatment that we give to patients in a way where we decide as a whole team along with the family, if we think that there is a good chance of this helping have seizure control, then we actually consider it all together. So from a care team standpoint, there's good precedent that at my center and actually multiple specialized centers in the country, we are doing cranial stimulation for children.

Dr. Laura Lubbers: So many great options. And it's great to know that yes, given regulatory approvals that these can go to different age groups. Let's see, other questions.

Dr. Sandi Lam: While you're reading the questions, we've actually seen very good results from neurostimulation and cranial stimulation for patients who just weren't candidates for epilepsy surgery before. So I am very hopeful that we're able to offer these options at specialized centers.

Dr. Laura Lubbers: Great. And that actually another ties in nicely to the next question, what is the frequency of DBS and RNS now? How common is it? Is it still considered exploratory or new?

Dr. Sandi Lam: That's a good question. And I guess it depends on who you ask, right? So it is relatively new, but it has been used for... I guess when you look at the trials and onward, I would say I have seen data that's at five years and 10 years. I would not call it experimental at this point because there have been trials and studies that are ongoing as well. I would say it would depend on the patient and the family and also your care team.

Dr. Sandi Lam: So I think that the patient and family have to be comfortable with their care team, and there has to be that trust. And also the care team has to be comfortable with what they're offering. So they have to have that level of experience with the treatments that they're offering. So it really is a combination of factors, but at a place that is really thinking about being innovative and really just not giving up and not taking, we don't know or no for an answer.

Dr. Sandi Lam: And having that hope and curiosity to see are there things that we can do to help patients? That's actually how we get better. And as I told you, when I first trained in this field and when I first started my practice, a lot of these were not actually even available. And now that they're available, I've been lucky to be part of teams and centers that have been among the first to apply these technologies such as laser ablation or putting in responsive neurostimulation into children and doing endoscopic epilepsy surgeries.

Dr. Sandi Lam: And now we actually have quite an accumulated experience where my partners and I probably have one of the largest experiences among pediatric centers. So there is a certain level of comfort and experience to understand what are the tools in our toolbox. We don't want to offer a tool that we don't have, and we want to offer the tools that we know, right? That we know what the result is going to be and be able to really look you in the eye and work with families and say, you know what?

Dr. Sandi Lam: I believe this is going to help. And I know that in my experience I can say that I can do this safely, and I really have that hope of being able to help you. And we need the whole team to do this, and we need to be able to make those choices together.

Dr. Laura Lubbers: Great. I think it's great to share that perspective on what people should expect from their care team. Thank you. So I know we are running up against time, but I did just see Jamilah say that she could take a question. And so I would like to ask, there was a question that came up. Jamilah, are you still there?

Jamilah Doyle-Walters: Yes.

Dr. Laura Lubbers: So there was a question about how long did it take for RJ to recover? Could you address that quickly for us?

Jamilah Doyle-Walters: Sure. RJ was at Lurie's for one week and then we went straight over to inpatient rehab at Shirley Ryan for exactly 30 days and then we were home. We did intense PT, OT, and speech three days a week for three hours, one hour each section. And that was for about six months or so. And then we graduated to outpatient PT, OT and speech. And I would definitely say just a word of advice to those who are intense physical therapy, occupational therapy and speech therapy.

Jamilah Doyle-Walters: Start looking in advance because I know where I'm from, it was a long waiting list. However, like how Dr. Lam said that advocating for your child, I advocated heavily. I searched high and low, I put him on multiple waiting lists and it was first come first serve.

Dr. Laura Lubbers: That's great advice, Jamilah, and we're so glad that he's doing well. And we thank both you and Dr. Lam for being a part of this presentation, sharing your story and giving advice to our audience. So we thank you for that. We also want to thank our friends at PAME for partnering with us on this webinar today, and also to our audience, always has amazing questions. And we will go through and see if they have been questions that have not been addressed and do our best to get those answered for you.

Dr. Laura Lubbers: If you have additional questions about this topic or wish to learn about any of CURE Epilepsy's research programs or webinars, please feel free to visit our website or email us at research@cureepilepsy.org. And then please stay tuned for our announcement of our final 2023 webinar, which will be held next month in November. So I'd like to wish you all a wonderful weekend. Happy and safe and fun, and thank you again for your participation in this webinar. Be well.