Seizing Life, episode 49
Seizing Life Highlights: Epilepsy Surgery
(Transcript)

Kelly Cervantes:	00:00	Hi. I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by Citizens United for research in epilepsy cure. This week on Seizing Life, we present a special compilation of previous episodes focusing on epilepsy surgery. For some epilepsy patients who are eligible for surgery, it can be a truly life-changing procedure resulting in significant reduction or, in some cases, elimination of seizures. The path to determining eligibility and ultimately deciding to undergo surgery is a long journey of consultations, tests, and ultimately personal introspection and considerations.
Kelly Cervantes:	00:47	In this episode, we present the medical and patient perspectives from pre-surgery testing through recovery. We begin with Dr. Joffre Olaya, board certified pediatric neurosurgeon at Children's Hospital of Orange County who spoke with us at Epilepsy Awareness Day at Disneyland about surgical approaches to epilepsy and how the new ROSA robot is impacting those procedures. What makes someone a candidate for surgery?
Dr. Joffre Olaya:	01:12	There's a big workup that's done to determine if somebody is an epilepsy candidate or not. First, someone with epilepsy would be worked up by an epileptologist, and the epileptologist would order an imaging study. They'd get an MRI to make sure there's no underlying brain lesion that could potentially be causing the seizures. They would get an EEG or a long-term EEG or VTM to get telemetry to see if they could lateralize, or localize, what part of the brain the seizures are coming from.
Dr. Joffre Olaya:	01:41	In addition to that, we may get some additional studies, such as a PET scan, a SPECT, MEG, and these are all other studies that can be used to help localize where the seizures are coming from. At that point, patients would also get a neuropsychiatric testing, and that helps us to localize any sort of deficit and can sometimes can help lateralize seizures, as well. So, all that information is then taken together and, typically, we would meet as a group with a surgeon, the epileptologist, the neuropsychologist, the radiologist, go over all the studies and then determine if someone is a candidate or not.
Kelly Cervantes:	02:13	It sounds like in order to be a candidate, you really have to be able to zero in on exactly what part of the brain those seizures are originating from.
Dr. Joffre Olaya:	02:23	Ideally but, once we have the information, we come up with a hypothesis of where we think the seizure may be coming from,

and there may be multiple different areas. So, to gather more information, then we can place electrodes directly into the brain or around the brain, either on one side or bilaterally, depending on the hypothesis, to then try to capture a seizure and see where that electrical activity is coming from.

Kelly Cervantes: 02:46 What kind of surgical procedures can be done in that case?

Dr. Joffre Olaya: 02:52 Classically, we would do what's called a craniotomy. We make an incision. We elevate the bone. We open up the dura, or the covering over the brain, and then we place electrode directly on the brain and particularly the areas of the brain that we're concerned where the seizures are coming from. We can also place electrode directly in their brain so, instead of doing a large craniotomy through a few millimeter burr hole or opening, we place an electrode direct stereotactically, so using a special neuronavigation software directly into particular parts of the brain, and this is much better tolerated, there's less blood loss, less pain.

Dr. Joffre Olaya: 03:27 Then we can still gather a lot of important information to help, again, pinpoint where the seizures are coming from. In order to do this, at our institution, for example, historically people would use frames. They're special frames and you have to calculate exactly where you put the electrode in, but now we use a robotic arm. The tool we use is the ROSA robot so, prior to surgery, I can plan exactly where I want the electrodes to go and then, the day of the surgery, I basically make a small opening, I put a little bolt in the bone and then pass the electrode down to the target. I try and avoid any important structure, the vascular structures, to prevent any bleeding or causing any damage to the brain.

Kelly Cervantes: 04:09 So, is the ROSA robot that you work with, is that for diagnostic or are you actually removing part of the brain using that robot?

Dr. Joffre Olaya: 04:16 That's a great question. As I was describing it, in this particular case, it would be diagnostic, so it's to gather more information and figure out where the seizures are coming from. Once we figure out where the seizures are coming from, then we remove the electrodes and then we have another conversation as to what the next step in treatment would be. Potentially, if it's an area that can be resected, we would remove it.

Dr. Joffre Olaya: 04:39 If it's a place that can be ablated, we could put a laser ablation probe and burn the tissue to get us a similar effect or, if it's in an eloquent part of the brain, some part of the brain that helps us with language, with movement, and we decide we can't take

		that part of the brain out, then sometimes we can put electrodes directly on or over the brain that are permanent electrodes. They are then connected to a generator, which is called the RNS, and that basically detects the electrical activity on the brain and, when there's a seizure, it'll send a signal to help stop the seizures, as well.
Dr. Joffre Olaya:	05:12	So, the ROSA can actually be used for implanting the electrodes initially. They could also be used to help target and place the ablation probe or it could be used, actually, to place the depth probe if we're doing an RNS, so it could be used for a lot of different steps in the surgery.
Kelly Cervantes:	05:30	Dr. Jeffrey Loeb, the John S. Garvin Chair, Professor and Head of the Department of Neurology and Rehabilitation at the University of Illinois at Chicago, provided us with an in-depth description of EEG testing and how it is used to localize seizures. One of the end goals here is to try and localize where those seizures are coming from.
Dr. Jeffrey Loeb:	05:53	For surgical workup, that's what we do. Most of the time we do EEG, we put electrodes on the scalp with various adhesives to make them stick, sometimes stronger ones when we do longer term EEGs. A routine EEG is often anywhere from 20 minutes to an hour. You only see what's going on during that window that you're looking so, if there happens to be an electrical discharge within that short 20-minute period, you may capture it.
Dr. Jeffrey Loeb:	06:22	If it happens five minutes after you disconnect the wires, you miss it so, during a routine EEG, we may flash lights, we may ask you to hyperventilate, breathing really hard until you get a little woozy, and those are things that can actually induce some of those abnormal waveforms.
Dr. Jeffrey Loeb:	06:38	During the longterm studies, we'll make you stay up all night, all the things that you're told not to do because you'll have a seizure. We'll stop your medications. We'll make you stay up all night. You say, "I only get seizures when I get stressed," so we bring their ex-boyfriend in there at some point and say, "Now there's stress." We want to see the seizures while the EEG is on so we can characterize them, localize them, and make sure we're doing the best treatment.
Kelly Cervantes:	07:00	So, the EEG is completed, you have your data. How are you reading that data? How do you use that to then help treat the patient?

Dr. Jeffrey Loeb:	07:12	We sit in rooms with computer screens and we click page by page by page by page. Each page may have about 15 seconds of the brainwaves. If you are there for 24 hours or four days, there's a lot. Sometimes, we click the pages quickly. We have people who are experienced, electroencephalographers, who read the EEGs who have a lot of experience seeing the different waveforms and patterns, and then we draw up a report that goes back to the doctor and says this is our opinion of what we saw.
Dr. Jeffrey Loeb:	07:43	If we're lucky, we capture the epileptic discharges and/or seizures that allow us to localize where they're coming from. The closer you are to an electrode that produces that signal. The closer in the brain that is and, because we put the electrodes all across the brain, say it's coming from your right temporal lobe, we'll see the electrodes on the right temple area have a lot more amplitude of the signal than, say, the left side or other parts of the brain, and that's how we localize where the seizures are coming from.
Kelly Cervantes:	08:11	Wow!
Dr. Jeffrey Loeb:	08:12	The other thing we do is, we never do EEG by itself. We will do an MRI. We will do PET studies. We will do other studies that corroborate what...
Kelly Cervantes:	08:19	What is a PET study?
Dr. Jeffrey Loeb:	08:21	Positron Emission Tomography, so one thing we do is look at the metabolism of the brain. You inject it with glucose, which is food for the brain and, if its uptake goes higher or lower in some areas of the brain, you see that on the PET scan. That can correlate with an area that has those epileptic waveforms. When things are concordant, when you see the PET scan abnormality, when you see something on the MRI like sclerosis or dysplasia, that is the same location where you see the electrical signals. Then you say, "Aha! We've got it!", and we can go after it and do surgery and help that person.
Brandon:	09:02	Hi. This is Brandon from Citizens United for Research in Epilepsy, or CURE. For the 65 million people worldwide living with epilepsy, progress is unacceptably slow. At CURE, our mission is to find a cure for epilepsy by promoting and funding patient-focused research. Learn more at cureepilepsy.org. Now, back to this episode of Seizing Life.

Kelly Cervantes:	09:24	Epilepsy Foundation of Chicago Board Chair, Howard Zwirn, provided us with a patient perspective on surgery, describing his personal experience from the initial determination that he was a candidate through his recovery process. You're going through and you're trying all of these meds and nothing's working. You're still having the seizures. When did surgery first enter the conversation as an option?
Howard Zwirn:	09:48	I think it was maybe around the five year time frame. My parents wanted me to get a second opinion at Mayo, so we went up there. After the two-day session that you have up there, their first recommendation was to have surgery.
Kelly Cervantes:	10:02	I imagine because they could localize where those seizures were coming from.
Howard Zwirn:	10:06	Exactly.
Kelly Cervantes:	10:07	Unless you can localize that place, then you can't be a candidate for the surgery. So, you find out that you are a candidate. What goes through your head?
Howard Zwirn:	10:19	I mean, the first response was, "No. I just can't do it." I was so scared and then, one day, one night, I had a grand mal seizure. After I had the grand mal, the next day I went in and spoke with the doctors, and he said, my doctor, "Howard, listen. I think it's really time that you consider having surgery again. You're a candidate. They know the area. It's localized. There's always the pluses and minuses, but I really think that you should consider it."
Kelly Cervantes:	10:52	What did they tell you in terms of what the risks were and what they thought the cone of possibility was for your outcomes.
Howard Zwirn:	11:00	There's always risks with surgery.
Kelly Cervantes:	11:02	Of course.
Howard Zwirn:	11:02	In your brain, there's always a risk but, because of the testing that I went through, that if there were more concerns or problems with the left side that the right side would handle it because a lot of it is the rehabilitation that you go through about speaking and writing and doing everything that your brain just doesn't do at a certain point. That is really a part of the rehab. At that point, that was the risk. I felt extremely comfortable from the beginning after meeting the surgeons, and it was a joint decision. Jeannine and I, we said yes.

Kelly Cervantes:	11:42	Okay, so you have decided to have surgery.
Howard Zwirn:	11:45	Right.
Kelly Cervantes:	11:46	You're walking into the hospital. What is that day like for you?
Howard Zwirn:	11:50	We were very, very nervous. I mean, we had just found out that Jeannine was maybe a month into having our first daughter at the time.
Kelly Cervantes:	12:00	Oh, my gosh!
Howard Zwirn:	12:01	So, I mean, I signed all the paperwork, God forbid.
Kelly Cervantes:	12:06	And you have a child on the way.
Howard Zwirn:	12:07	And we have a child on the way.
Kelly Cervantes:	12:09	And you're having part of your brain removed.
Howard Zwirn:	12:11	And I'm having part of my, yeah, part of my brain removed. It's a lot of risk, a lot of concern, so the pressure... I was, obviously, not only thinking about myself, but my family.
Kelly Cervantes:	12:22	How long did the surgery take from beginning to end?
Howard Zwirn:	12:25	I believe it as approximately five hours that I was under.
Kelly Cervantes:	12:34	I mean, I don't know how long I would...
Howard Zwirn:	12:36	Not a full day.
Kelly Cervantes:	12:36	Right. I don't know how long I would expect it to take to have that procedure done, but not excruciatingly long.
Howard Zwirn:	12:43	No, not a full day.
Kelly Cervantes:	12:45	So, you come out of surgery. I mean, then it's just sort of a waiting game, I guess, to see if it worked.
Howard Zwirn:	12:53	Right.
Kelly Cervantes:	12:53	You don't know immediately if it's worked.
Howard Zwirn:	12:56	Correct. I mean, I was in the hospital for approximately five to six days afterwards, going through some testing about how are

you feeling having to use the facilities by yourself? Can you walk? How far can you walk? Yeah, five to six days, went home.

Kelly Cervantes: 13:21 Wow! What was the recovery period like? Did you have to do PT, OT, speech therapy?

Howard Zwirn: 13:28 I did them all. I think that I was home approximately... I was off of work for about three months.

Kelly Cervantes: 13:33 Oh, wow!

Howard Zwirn: 13:34 Right. Through that time, I was going through some physical therapy, speech therapy for approximately two to three times a week at the hospital, writing, all of it because there's no doubt that it's funny to think about. You quit having trouble writing, having trouble talking. After the therapy, I definitely got back into that, and it felt really good after three months of being at home.

Kelly Cervantes: 14:05 You haven't had a seizure since.

Howard Zwirn: 14:08 Fifteen years it's been since the day I had surgery. I've had two girls, healthy girls. It's been an incredible 15 years.

Kelly Cervantes: 14:21 Surgery is often not considered as a frontline treatment for obvious reasons, the expense. The potential risks are incredibly high but, in some cases, it could be considered one of the first two or three available treatments out there. I think that we're starting to see that wave change so that it's not the last available option. Nothing else works, so then you try surgery, and you're starting to see that conversation shift a little, which is really interest.

Howard Zwirn: 14:58 Right. I think it's a great point to bring it up a little more in the beginning of it so you're not waiting five years or seven years...

Kelly Cervantes: 15:08 The amount of damage that could be done or the risks that you're taking just by living with seizures over that time.

Howard Zwirn: 15:15 Every seizure has an impact on your system, every one, so all the people that we know that, again, have a seizure, 10 seizures a day, 15 seizures a day, it just hurts them more and more and more every time. So, if surgery is one pathway to cut back on that, it's a better thing for the future to hopefully make their life better in the longterm.

Kelly Cervantes:	15:49	The choice to undergo epilepsy surgery is a personal decision in which the patient must weigh the potential benefits and risks in careful consultation with physicians. For some, surgery can provide relief or even complete freedom from seizures but, for too many people dealing with epilepsy, there is no relief, but we have made great progress discovering new therapies and medications. Over 30% of those with epilepsy do not respond to traditional treatments. That's why CURE is dedicated to supporting patient-focused research to find a cure for epilepsy. To help us achieve our mission, please visit cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
Brandon:	16:38	The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained herein is provided for general information only and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs. CURE strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with the patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.