

Kelly Cervantes: 00:00 I'm Kelly Cervantes, and this is *Seizing Life*, a weekly podcast produced by Citizens United for Research in Epilepsy, CURE.

Kelly Cervantes: 00:18 Howard Zwiirn is the Board Chairman for the Epilepsy Foundation of Greater Chicago. He is also a senior project manager at TRC Corporation. After battling epilepsy for several years, Howard opted to have surgery to remove his left temporal lobe. Thanks to this surgery, he has been seizure-free for the past 15 years. Thank you so much for being with us today, Howard.

Howard Zwiirn: 00:40 My pleasure.

Kelly Cervantes: 00:41 First, I want to start by saying congratulations on being 15 years seizure-free. You have had the optimal outcome from neurosurgery. It's really amazing.

Howard Zwiirn: 00:51 It's been a tremendous ride for all of us.

Kelly Cervantes: 00:54 Can you take us back? You were 28 when you had your first seizure. What was going on in your life?

Howard Zwiirn: 01:02 I was working, and I came home from work one night and had a seizure in the middle of the evening. A grand mal seizure. And we really knew nothing about it.

Kelly Cervantes: 01:13 It happened out of nowhere?

Howard Zwiirn: 01:14 Out of nowhere.

Kelly Cervantes: 01:15 Does it run in your family? Was this something that you were on the lookout for, or was it just a complete surprise?

Howard Zwiirn: 01:21 I had a febrile convulsion when I was one year old, but that's really all we knew. There's nothing in my family history that's related or similar to it. It was nothing we considered needing to pay attention to.

Kelly Cervantes: 01:33 Was it terrifying?

Howard Zwiirn: 01:36 Completely terrifying.

Kelly Cervantes: 01:36 When you went to the doctor, what did they tell you?

- Howard Zwiern: 01:40 Well, my wife Jeannine had some experience with it. Her father was having heart surgery and had cancer, so he had had grand mal seizures and were familiar with them. So she knew what was going on. The doctor basically said, "You have epilepsy." Then, "Let's start on different types of medication and see what options are out there to treat it."
- Kelly Cervantes: 02:04 What did that process look like? What treatments did you try? How long was it before you got from "Howard, you have epilepsy" to you're walking through the door to have brain surgery?
- Howard Zwiern: 02:17 The first thing was that we knew nothing about epilepsy. Absolutely nothing. I remember my mother actually contacted the Epilepsy Foundation and spoke with the president at that time. That's how we learned a little bit about it because we really knew nothing. And then, when we started speaking to the doctors, I think I went through maybe seven different types of medications in the first five years.
- Howard Zwiern: 02:44 I was still having grand mal seizures. I think we realized that I was probably having a lot of non-grand mal seizures as well. I would space out for a second. I would stop speaking. My eyes would roll. But I didn't know it was happening, which is something that's so common with a lot of people who have epilepsy. We just didn't realize it, and that was probably the first five years, as I was saying.
- Kelly Cervantes: 03:13 Did you ever find out the cause of your epilepsy?
- Howard Zwiern: 03:17 I had the different types of tests, and the EEG. The doctors said that the left temporal lobe in my brain was damaged, but there was no reason or evidence as to how that happened. When we had that discussion after multiple meetings, it was like, "Is it the chicken or the egg?" We don't know how it happened, therefore you're having these seizures, which could contribute to and make the damage in the brain worse. They didn't know really what the start of the problem was.
- Kelly Cervantes: 03:49 Wow. So 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 Zwiern: 04:04 I think it was maybe around the five-year mark. My parents wanted me to get a second opinion at Mayo. So we went up there for the two-day session they have. I know you have

experience with that as well. Anyway, they come out and their first recommendation was to have surgery.

- Kelly Cervantes: 04:24 Wow.
- Howard Zwiirn: 04:25 Without a breath. We basically packed up everything, ran out, and said, "No, thank you." We were very scared.
- Kelly Cervantes: 04:34 Yeah.
- Howard Zwiirn: 04:35 We were very intimidated. We didn't even think of that as an option. I talked to my doctor about it, and his opinion at that point was that the different types of medication were controlling the seizures. That's why sometimes surgery isn't really considered as much of an option because of the different pathways of medication that a lot of people choose.
- Kelly Cervantes: 05:00 Obviously, brain surgery comes with a lot of risks attached to it as well. I know that there is extensive testing that needs to be done before the doctors can determine if you're even a candidate for surgery. What was that testing process like for you?
- Howard Zwiirn: 05:21 I don't remember all the tests, but I do remember one specifically, the EEG. What they do is, since for me the damage was on the left side of the brain, they go in and freeze the left side of my brain to see how the right side operates. Can the right side of the brain handle everything that the left side is doing?
- Howard Zwiirn: 05:41 So it's pretending that, in theory, I didn't have the whole left side of the brain. How would I react? How was my speech? It was like a 15-minute test. The prep is longer, but I went in, and they froze the left side.
- Kelly Cervantes: 05:54 How did they do that?
- Howard Zwiirn: 05:55 Through my leg, all the way up into my head.
- Kelly Cervantes: 05:58 Oh my gosh.
- Howard Zwiirn: 05:59 And it's a 15-minute exam.
- Kelly Cervantes: 06:01 Wow.

- Howard Zwiirn: 06:01 When the time ran out, I remembered hearing the doctor tell Jeannine and my family that "Howard did wonderful on the test. He talked about the Bears, he answered some good questions, and his speech was very good." So they felt that, because the damage was limited, and they could see this in the other testing of my brain, and that I did well on this test, that I would be a good candidate to have surgery.
- Kelly Cervantes: 06:29 I imagine also because they could localize where those seizures were coming from.
- Howard Zwiirn: 06:33 Exactly.
- Kelly Cervantes: 06:35 I know that's one of the issues with my daughter. They're like, "You don't know where they're coming from," and unless you can localize that place, then you can't be a candidate for the surgery. That's pretty remarkable. So, you find out you are a candidate. What went through your mind?
- Howard Zwiirn: 06:52 The first response was, "No, I just can't do it." I was so scared. I mean, it took a lot of discussions with Jeannine. When I had the second test, we started talking about it a little more. Then one day, one night, I had a grand mal seizure. I decided that I had to go after I had the grand mal seizures. So, the next day I went in and spoke with the doctors, told them what the normal process was.
- Howard Zwiirn: 07:24 We went in, and my doctor said, "Howard, listen. I think its really time that you consider having surgery. You're a candidate. They know the area. It's localized. There are always pluses and minuses, but I really think that you should consider it."
- Kelly Cervantes: 07:46 I think that's interesting. This is 15 years ago, and listening to you talk, and hearing from other parents that I've spoken to, or through my own experiences, I think the mindset around surgery has come a long way. Now I think it's a little bit more accepted. 15-plus years ago, it was such a new and scary thing. Now I talk to so many families who are like, "Oh my goodness, I wish we could just have brain surgery on my child," which is just the craziest thing to think about.
- Kelly Cervantes: 08:21 I think, "I wish there was just a lesion that they could remove, or something like that, that we could find." It's just the most bizarre thing to be in this position where you're actually talking about removing part of the brain.

| | | |
|------------------|-------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Howard Zwiern: | 08:34 | Again, I was one of the lucky ones. As I was saying before, even if you have the surgery, that's not necessarily going to be the answer, right? We both know a lot of people who, unfortunately, have had the surgery, and it wasn't a solution. It didn't stop the seizures. It didn't even control them. But for me, we knew about that risk going in. |
| Kelly Cervantes: | 09:03 | Sure. So, I guess that- |
| Howard Zwiern: | 09:05 | We knew about that potential. |
| Kelly Cervantes: | 09:07 | What did they tell you in terms of the risks and what they thought the cone of possibility was for your outcomes? |
| Howard Zwiern: | 09:16 | There's always risk with surgery. |
| Kelly Cervantes: | 09:18 | Of course. |
| Howard Zwiern: | 09:18 | With the brain, there's always a risk. However, because of the testing I went through, if there were more concerns or problems with the left side, then the right side would be able to handle it. One other major thing that not many of us know is that everybody uses maybe 3-5% of their brain. The rest of it is just sitting there. |
| Kelly Cervantes: | 09:40 | Yeah. |
| Howard Zwiern: | 09:40 | So a lot of it is the rehabilitation you go through for speaking and writing and doing everything that your brain just can't do at a certain point. That is really a part of the rehab. So at that point, that was the risk. Again, I trusted and felt very comfortable with my doctors and the surgeon that we interviewed and met. |
| Kelly Cervantes: | 10:06 | Sure, yeah. |
| Howard Zwiern: | 10:07 | You go through that process. |
| Kelly Cervantes: | 10:08 | Of course. |
| Howard Zwiern: | 10:09 | It was a risk, but I felt extremely comfortable after meeting the surgeons. It was a joint decision for Jeannine and me, and we said yes. |
| Kelly Cervantes: | 10:20 | Okay. So you have decided to have surgery. |

| | | |
|------------------|-------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Howard Zwiern: | 10:24 | Right. |
| Kelly Cervantes: | 10:24 | You're walking into the hospital. What is that day like for you? |
| Howard Zwiern: | 10:27 | That was brutal. We were very, very nervous. <i>Very</i> nervous. We had just found out that Jeannine was maybe a month pregnant with our first daughter at the time. |
| Kelly Cervantes: | 10:42 | Oh my gosh. |
| Howard Zwiern: | 10:42 | I mean, I had to sign all the paperwork, God forbid. |
| Kelly Cervantes: | 10:47 | And you have a child on the way. |
| Howard Zwiern: | 10:48 | And we have a child on the way. |
| Kelly Cervantes: | 10:50 | And you're having part of your brain removed. |
| Howard Zwiern: | 10:52 | And I'm having part of my, yeah, part of my brain removed. There were a lot of risks, a lot of concerns. The pressure. I was obviously not only thinking about myself, but also my family. |
| Kelly Cervantes: | 11:02 | It's a much different thing, when you are leading a successful life, have a marriage and a child on the way, to be contemplating surgery. That realm is so much different than me contemplating surgery for my developmentally-delayed child. The risk of something like loss of life is obviously awful. But the risk of her losing quality of life is almost minimal because of where she's at. For you, though, that loss of quality of life is drastic. It's huge. |
| Howard Zwiern: | 11:39 | Of course. I remember one of the things that Jeannine's mother said before we went into surgery was about me cutting back on my medications. She said that I was a new person. Even before the surgery, just by cutting back on the dosages and the quantities, which just put you out. Being able to get off some of that ... they noticed, "Oh, Howard's back to himself." |
| Howard Zwiern: | 12:09 | That was a comforting thing to hear, and another reason why we were saying, "Let's go with this. Let's try this." If it works, maybe I'm going to get back to who I was and learn to grow even further. |
| Kelly Cervantes: | 12:25 | The part of your brain that was removed, what was that responsible for? |

Howard Zwirn: 12:28 A lot of that responsibility, from the hippocampus and the left temporal lobe, impacts your memory. I would always think at that point, okay, you're going to lose some of your memory abilities. But some of that also goes because of the medication that you're on, right? The medication you're on just pounds your memory. It pounds your thought process. Is my memory better? I still forget things all the time. But I will not allow, nor will my surgeon, or Jeannine, to let me use that as an excuse. I refuse to use that as an excuse for the memory loss.

Kelly Cervantes: 13:05 Well there you go. How long did the surgery take from beginning to end?

Howard Zwirn: 13:09 I believe it was approximately five hours that I was under.

Kelly Cervantes: 13:16 So I mean not, I mean I don't know- [crosstalk 00:13:19]

Kelly Cervantes: 13:19 I don't know how long I would have expected it to take to have that procedure done. But not excruciatingly long.

Howard Zwirn: 13:28 Not a full day. When I got out, I remember being told that I was embarrassed to have my family come and see me. And I let them, of course. They wanted to. My family was out...

Kelly Cervantes: 13:44 Of course.

Howard Zwirn: 13:45 ... in the waiting room. I let Jeannine come in. My parents wanted to come in, but I said, "No."

Kelly Cervantes: 13:52 Do you remember this at all?

Howard Zwirn: 13:54 I remember it from afterwards, hearing about it. They were a little hurt that I didn't let them in. After a while, I did let them come in. But I was, not to say I was embarrassed, but I was overwhelmed ...

Kelly Cervantes: 14:09 Oh, I'm sure.

Howard Zwirn: 14:09 ... of coming out of being down for so long with the medication that you're on.

Kelly Cervantes: 14:16 Absolutely. So you come out of surgery, and then it's just sort of a waiting game, I guess, right? To see if it worked?

Howard Zwirn: 14:24 Right.

- Kelly Cervantes: 14:24 You don't know immediately if it's worked.
- Howard Zwiern: 14:27 Correct. I was in the hospital for approximately five to six days afterwards. I went through some testing about how I was feeling or having to use the facilities by myself. Could I walk? How far could I walk? Then, after five to six days, I went home.
- Kelly Cervantes: 14:52 Wow. What was the recovery period like? Did you have to do PT, OT, speech therapy?
- Howard Zwiern: 15:00 I did them all. I think that I was home and off work for approximately three months.
- Kelly Cervantes: 15:05 Oh wow.
- Howard Zwiern: 15:06 Right. Throughout that time, as I was going through physical and speech therapy for approximately two to three times a week at the hospital, I was writing all of it because there's no doubt that it's funny to think about. You could have trouble writing, have 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: 15:36 You haven't had a seizure since?
- Howard Zwiern: 15:38 15 years it's been since the day I had surgery. I've had two healthy girls. It's been an incredible 15 years.
- Kelly Cervantes: 15:52 So you get to bring your daughter into a world where you don't have to worry about being left alone with her.
- Howard Zwiern: 16:01 Correct.
- Kelly Cervantes: 16:01 Just the freedom from the anxiety that this has provided in your life, I can't even imagine. You have certainly given back tenfold to our community, and we are all so beyond grateful for that.
- Howard Zwiern: 16:14 Thank you. That was one of the things that we feel we owe other people. We are in a certain position that many others are not. We know other people who have unfortunately lost family members because of epilepsy. We know other people whose family is not doing well because of that. We had the resources, and a lot of other families don't have the resources to even consider surgery, the doctors, or even the recovery.
- Kelly Cervantes: 16:47 For the family who doesn't have the resources or the support, but who think that maybe there's a chance they could be a

candidate, who do they turn to? How do they get information?
How do they find out?

- Howard Zwiern: 17:00 I know that there are a lot of resources, besides the Epilepsy Foundation, in every state in the country. Even with the support of an organization like CURE, it's you who has to ask the question of your own doctor. Not every doctor in the United States is a specialist in epilepsy. And if they're not a specialist, then that pulls them even further away from considering surgery as an option.
- Howard Zwiern: 17:31 It's almost like having to take the next step for the family to contact someone, whether it's different hospitals in your area, or again, the different foundations. The Epilepsy Foundation ...
- Kelly Cervantes: 17:44 Finding those boots on the ground.
- Howard Zwiern: 17:44 ... CURE. You need to find the boots on the ground. At that point, it may not be your local hospital that has the surgeons who do that.
- Kelly Cervantes: 17:55 Which makes it that much more difficult [crosstalk 00:17:57] for those families who don't have the financial means, perhaps, to travel.
- Howard Zwiern: 18:01 Right.
- Kelly Cervantes: 18:02 I would say that so much of our health records have been digitized now.
- Howard Zwiern: 18:07 Correct.
- Kelly Cervantes: 18:07 It's probably incredibly helpful that you can send those records electronically. You can send that MRI, you can send that EEG to another doctor and give them access to those records. Maybe you can have that consultation before having to make an expensive trip.
- Kelly Cervantes: 18:22 So a slightly uncomfortable question ...
- Howard Zwiern: 18:26 Yep.
- Kelly Cervantes: 18:26 You have mentioned a couple times, 15 years seizure-free, knock on wood.

| | | |
|------------------|-------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Howard Zwiirn: | 18:31 | Right. |
| Kelly Cervantes: | 18:32 | I think it's important to point out that, even though you've had the surgery, and you have been seizure-free for 15 years, there is still the chance that it comes back. |
| Howard Zwiirn: | 18:44 | There is still the chance. For my doctor, and a lot of other doctors, there is the question, when can you be called seizure-free? His opinion was a five-year window to be seizure-free. But I don't acknowledge that. Someone has asked me before, "Since you have been seizure-free for so long, do you still have epilepsy?" And the answer is yes. Because it could still happen. Do I wake up at three in the morning and think about that? Absolutely. |
| Kelly Cervantes: | 19:30 | Yeah. |
| Howard Zwiirn: | 19:30 | I can't make it go away. |
| Kelly Cervantes: | 19:31 | Yeah. |
| Howard Zwiirn: | 19:32 | It's always going to be there. |
| Kelly Cervantes: | 19:35 | The truth of the matter is that, even with surgery, even with all of these pieces, we still don't have that cure. |
| Howard Zwiirn: | 19:40 | We definitely do not have that cure. We definitely do not have that cure. |
| Kelly Cervantes: | 19:44 | When I think about the future of epilepsy, research is pointing toward these alternative methods. You look at genetics , the gene editing, all of these things. We're pushing away from the pharmaceuticals and into these other treatments, which is really kind of exciting. |
| Howard Zwiirn: | 19:58 | It's very exciting. For the others, along with considering surgery sooner, they allow more people to be able to draw a line in the sand and go on with their life and continue to grow. |
| Kelly Cervantes: | 20:13 | I would argue that your story is incredibly important. It shows that there is hope. It is through epilepsy research that we were able to get to a place where you could be the husband and the father and the advocate that you are today. And be seizure-free. That you had the solution available that you did was because of the research that was done decades ago. |

| | | |
|------------------|-------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Howard Zwiern: | 20:40 | Absolutely. |
| Kelly Cervantes: | 20:40 | I think that epilepsy as a whole doesn't have a ton of success stories out there. So when we hear them, we want to latch onto them and use them to give everybody else hope as well. |
| Howard Zwiern: | 20:56 | I just want to continue to be an advocate for people to consider surgery. |
| Kelly Cervantes: | 21:02 | I think that's an interesting thing to bring up as well. Surgery is often not considered a frontline treatment for obvious reasons. The expense and the potential risks are incredibly high. But, in some cases, it could be thought of as one of the first two or three available treatments out there. I think that we're starting to see that wave change, where it's not the last available option when nothing else works. You're starting to see that conversation shift a little, which is really interesting. |
| Howard Zwiern: | 21:43 | I think it's a great point to bring up surgery a little earlier in the beginning of the treatment process, so you're not waiting five or seven years, or- |
| Kelly Cervantes: | 21:53 | The amount of damage that is done, and the risks that you're taking just by living with seizures over that time. |
| Howard Zwiern: | 22:00 | Every seizure has an impact on your system. Every one. All the people who we know who have a seizure, sometimes 15 seizures a day. <i>15 seizures a day!</i> It hurts them more and more and more every time. So, 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 long term. |
| Kelly Cervantes: | 22:31 | Thank you so much Howard for ... |
| Howard Zwiern: | 22:33 | No, it's been my pleasure. |
| Kelly Cervantes: | 22:34 | ... sharing with us today and teaching us all about surgery as an available treatment and an option. We're just thrilled to have you as a part of our community, and for everything that you and your family do to support us. Thank you so much. |
| Howard Zwiern: | 22:49 | Thank you very much. I appreciate it. |
| Kelly Cervantes: | 22:49 | Thank you for being here. |
| Howard Zwiern: | 22:50 | My pleasure. |

- Kelly Cervantes: 22:53 Thanks again to Howard for his insights into the process and the personal choices he made to have surgery to stop his seizures. The decision to undergo neurosurgery can be excruciatingly difficult, and it is incredibly helpful to anyone considering this procedure to understand the process from beginning to end. Howard's story is also a reminder of why it is so important that organizations like CURE continue funding research to stop epilepsy for the millions of people around the world who suffer from this condition.
- Kelly Cervantes: 23:24 If you want to improve research funding, small actions make a big difference. Today, I'm asking you to let us know your thoughts by commenting on our Facebook page about your experiences with epilepsy. Have you considered or undergone surgery? Do you have another treatment that helped you? We want to hear your story. You can find our Facebook and Instagram page @seizinglifepodcast, and on Twitter @SeizingLifePod. Thank you.
- Narrator: 23:58 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.
- Narrator: 24:16 CURE strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.