# SEIZING LIFE, episode 40
# No One Does It Alone: Finding Support to Navigate World of Epilepsy Care
## Guest: Patricia Gibson
## (Transcript)

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

Kelly Cervantes: Today, amid the COVID-19 pandemic, we bring you another remotely recorded episode of Seizing Life. As we all struggle through these uncertain times, individuals and families touched by epilepsy are facing difficult decisions [00:00:30] about putting themselves and their loved ones at risk in order to access the care and medications they need. Today, we speak with someone who has spent much of her professional life assisting epilepsy patients and families in accessing care, information and medications.

Kelly Cervantes: Patricia Gibson has worked within the epilepsy community for more than 40 years. She is an associate professor in the department of neurology at Wake Forest University School of Medicine and serves as the executive director of the Epilepsy Alliance of North Carolina. Pat is zooming [00:01:00] with us today to talk about challenges and strategies for accessing quality epilepsy care.

Kelly Cervantes: Pat, thank you so much for joining us today. We are just so honored to have you. You are a legend and a hero, certainly in the North Carolina epilepsy community, but I would argue throughout the country as well. And we are just beyond thrilled to be able to speak with you today.

Patricia Gibson: Thank you. It's a pleasure to be with you.

Kelly Cervantes: Thank you. So how did you [00:01:30] get started in the epilepsy community? Did you have a personal connection? What drew you to this amazing group of people?

Patricia Gibson: Well, actually, I have no personal connection. Many years ago when I first got out of school, out of graduate school in social work, I took a job with the State Health Department of Virginia. And I covered 14 counties and I was a medical and psychiatric consultant [00:02:00] to a large number of clinics. And one of those clinics was child neurology. And we were very lucky. We had a very well known epileptologist from UVA who came out and covered that into the state with a clinic, a child neurology clinic. And we would see 250 kids in two and a half days.

Patricia Gibson: And then he left and I was responsible for watching after those children. [00:02:30] And of all the clinics I worked in, defective hearing, rheumatic fever, a whole variety of clinics, the kids that really touched me the most were the kids with epilepsy. And the thing that bothered me more than anything, Kelly, was the unfairness, the stigma that was attached to this. And it was much more so then in those years than now.

Patricia Gibson: But that really attracted me to [00:03:00] those children and wanting to do something about this, this ignorance that surrounded epilepsy. And so, that's how I became first involved. And then I later left and went to direct a mental health center, and that doctor kept sending me patients to talk with. And then, when he got an NIH grant to establish one of the first comprehensive epilepsy programs in the country, [00:03:30] he called and asked me to come to North Carolina, because he really wanted to do a more regional program, include part of Tennessee, North Carolina and Virginia. And so, he sent me to North Carolina to help set up an epilepsy program here. And that's how I got involved.

Kelly Cervantes: And we are so grateful that you did. I want to go back to two pieces that you brought up and just get some clarity. The first is, you talk about a comprehensive epilepsy program. What does [00:04:00] that mean? What does that entail?

Patricia Gibson: Well, Dr. Dreifuss and Dr. Kiffin Penry, who was head of the epilepsy section at NIH at the time and who was responsible for getting the funding for these programs, they both felt strongly that the treatment of epilepsy was more than just handing over a prescription. There was so much more involved that you really needed a team to treat epilepsy. You needed the [00:04:30] pharmacologist, you need the social worker, you need the nurse, you need the VR counselor. You need a true team addressing this problem. It's complicated, it's complex. It involves so much more than just giving someone a prescription for medicine. And that's what a comprehensive epilepsy program was supposed to be all about. It's really to be treated by a whole team of people.

Kelly Cervantes: And I cannot even begin to stress [00:05:00] how important that mindset is. And it's not just, it is establishing from the get go a team mentality around the care. I think, obviously, the caregivers are aware as they are juggling clinic appointments with all of these different professionals, but it's also having clinicians that are willing to work with others and recognizing that they are one piece of a machine.

Kelly Cervantes: So [00:05:30] I think what you bring up there is incredibly valuable and important, because many hospitals, doctors work in silos. They treat their single condition. But especially when it comes to epilepsy and other neurological conditions, they are one clinician amongst a team keeping the machine of that human operating. And so, I think there's so much value in that.

Kelly Cervantes: [00:06:00] The other piece that I wanted to go back to is you mentioned stigma within the epilepsy community, or stigma not within the community, but for those who are affected by epilepsy. You mentioned that you do believe that the stigma has lessened in recent years. Can you explain what kind of stigma you had seen before and stigma that people experience [00:06:30] now, and why you think that transition has occurred? Why are we seeing less stigma?

Patricia Gibson: Well, let me put it, stigma is still alive and well, I'm sorry to report. But it has, from my experience, lessened. Years ago, one of the reasons I set up a nationwide telephone information line is that I wanted people to be able to call and get information [00:07:00] without having to reveal who they were. Because so many people at that time were not willing to tell people they had this problem. They were told by many people around them, families, even some physicians, not to tell anyone. They didn't want their child being treated differently, so they just simply didn't share that, especially if the seizures were controlled. And I heard many horror [00:07:30] stories. I mean, every day I would pick up the phone and hear something really just shocking to me.

Patricia Gibson: And then, over time, and the comprehensive epilepsy program is a big part of them, especially our program, is education. We do tremendous amount of education of all groups. One year I did 95 workshops across the state just for teachers. We covered every county except two [00:08:00] counties. We mixed them, they were very small counties. We did them all together. And I saw television things starting to mention epilepsy, or one of the cartoons had epilepsy represented in one of the people in it. And just little by little, it started changing.

Patricia Gibson: And so, now I see young people just talking openly about epilepsy. They [00:08:30] talk about everything now. Nothing is sacred. So I have seen a really big change in that regard. It's still there though. I did a 20-year project in my county focusing on fourth grade students and teaching every fourth grader in my county for 20 years about epilepsy in a really positive manner. And I saw a lot of changes during that time. [00:09:00] And I think it has improved. It's still not perfect and I think as long as there are people in this world, it won't be, human beings being what they are. But I have seen a lot of change and very pleased about that change.

Brandon Laughlin: 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 [00:09:30] slow. At CURE, our mission is to find a cure for epilepsy by promoting and funding patient-focused research. Learn more@cureepilepsy.org. Now back to this episode of Seizing Life.

Kelly Cervantes: Tell us about the Epilepsy Information Service, this phone line that you created, because parents do have questions. And of course there wasn't always the internet for us to go doing deep dive 3:00AM Google searches, as my generation has grown accustomed to. [00:10:00] That wasn't always the case, but also, you're sifting through pages on the internet. And to be able to have a phone number with someone on the other line that can answer your questions in an educated way, where did this come from? Is it still around? How-

Patricia Gibson: Yeah. Well, I opened this in 1979, and I did so because I was in a situation working [00:10:30] with the leading epileptologist in the world. And I would often find information that would be helpful to patients that hadn't been published yet. And I thought, I have so much information and I can help people. And I thought a really quick way to get this out it, rather than seeing everyone one-on-one, is that if I opened up a telephone line and made it open to anyone to call. You wouldn't have to give [00:11:00] me your name, you could ask me anything and I might be able to get some of this information out quicker. So I got the funding in 1979 and I opened that line. It was originally meant just for North Carolina, but one day, they came and worked on my phone and they accidentally opened me up to the whole nation.

Patricia Gibson: And so, since 1980, it has been nationwide. And that line operates today. I'm here answering calls today on that [00:11:30] line, and we get calls about everything. My two top calls, I get two categories of calls. One is newly diagnosed, scared to death people that are searching everywhere for answers and they don't know what to do. They're just so upset and afraid and they've just had the most frightening moment of their lives. Their child's had a seizure and [00:12:00] they're just scared to death. And then I get the other group, the people whose seizures aren't controlled, they're having a very bad time, they're having a difficult trying to figure out what to do. The medicine's not working and they're looking for answers everywhere. Those are the two categories I get.

Kelly Cervantes: And where can people find information about this phone line if they do have questions and they do want to reach out?

Patricia Gibson: Well it's called the Epilepsy [00:12:30] Information Service of Wake Forest University School of Medicine. It's an 800 number, (800)642-0500.

Kelly Cervantes: It's an incredible service that you are providing, to be sure. The other piece that you brought up that I absolutely love and I think it's so incredibly important is educating within our school system. What was some of the response that you got from these fourth graders?

Patricia Gibson: I have them write an essay, before and after. [00:13:00] What is epilepsy/seizures, in case they know one term and not the other. And one of the most interesting thing happened in one of the essays that I learned. I learned one thing, that we teach so much more than we know. Because this one child ... and I do have a whole section that talks about feelings and attitudes toward epilepsy and [00:13:30] what to do emotionally to help someone if they have a seizure. I talk about what it would be like to have a seizure, feelings and emotions about that.

Patricia Gibson: And I had an essay, I mean, one of the essays come back that said to me, thank you for coming to my classroom and teaching us about epilepsy. We knew almost everything. And they did. Before I got there, a child had had a seizure and the teacher who had heard me [00:14:00] for five years, 10 years, went ahead and gave all the information to the kids that I had taught. He said, but you taught us something else. How to care about people who have epilepsy. You taught us how to care. And I realized, you can go in and teach statistics, but you can also teach attitudes. And we don't know it, but a lot of us are teaching attitudes, good and bad, out there by [00:14:30] what we say and how we say it.

Kelly Cervantes: That compassion and the teaching, that's invaluable. And we are so grateful. But that's not all that you've done in your career, which is incredible. You've been the executive director of the Epilepsy Alliance of North Carolina for 15 years. What does that organization do? What are you doing for the community? Tell us about your time with the Epilepsy Alliance.

Patricia Gibson: Well, that organization [00:15:00] came upon bad times about 15 years ago and they were going to close. And the board came to me and asked my help, and I agreed to come on and to head up that agency as a volunteer. I don't get paid. But it's so much of what I was doing anyway and what I wanted to do anyway. And it's been a wonderful organization. [00:15:30] And I have found an incredible board made up of parents, mostly parents and people who have epilepsy, and we've really done a lot of things.

Patricia Gibson: I had set up an epilepsy medication fund back in the eighties and this organization has really helped me tremendously, especially when all of our funding was cut from the state budget. And we've been able to keep that medication fund going through fundraising every waking moment. [00:16:00] The board and this organization has been tremendous help for that.

Patricia Gibson: But I feel so strongly that nonprofit organizations should be spending every penny on patient services, on doing what they should be doing. So I'm really proud to head up an organization that's done a lot of work and we've seen that all the funds go directly to what the patient needs [00:16:30] are. It's been a real pleasure to see that.

Kelly Cervantes: With all of your experience within this community and helping the community, assisting the community, what do you recommend an individual or a loved one is diagnosed with epilepsy, what should they do? What do they need to know in the immediate aftermath of receiving that diagnosis?

Patricia Gibson: They need to learn as much about this as they can and to reach out [00:17:00] and learn about it in every way they can, whether it be through local organizations, national organizations, information lines like mine. The first step is learn as much as you can about it. And then, you need to begin developing a network, a network of resources. A network of friends and family who will support you and help you, because it is a long and lonely road to do by yourself.

Patricia Gibson: [00:17:30] There is so much to know and so much to negotiate, and there's the insurance to deal with and all these problems. You need as much support as you can get. And many times, there'll be local organizations, local epilepsy alliances, or other organizations that that can help. And they're out there and you just need to ask and to look around and search and Google.

Patricia Gibson: And be aware also, [00:18:00] I've run into this from time to time, if you find yourself in groups who are incredibly negative, get out. You don't need that negativity. You need people who are there to help, not to just bash or bang or say how horrible this group is or that group. Get out of that group. That's not what you need. You need real, good information and, and you need help that's very positive, that's going to support [00:18:30] you and help you feel more competent yourself.

Kelly Cervantes: Absolutely. And when you're talking about, we spoke earlier about these comprehensive epilepsy centers, which is incredible and amazing, but they're not always accessible.

Patricia Gibson: No, not at all.

Kelly Cervantes: Or sometimes it can be incredibly challenging. You're talking two, three month waits or even longer to get an appointment with some of these doctors. [00:19:00] What should these patients and caregivers do if it doesn't seem that that is an accessible option for them?

Patricia Gibson: Well, not everyone needs to be seen at a comprehensive epilepsy program. I follow lots of patients who have been followed in their communities by really good doctors who are doing well. You want to seek out a comprehensive epilepsy program when things are really not going well and you've tried a number of things. And [00:19:30] some of those centers have access to new treatments or different treatments or clinical drug trials that might be helpful.

Patricia Gibson: And sometimes you're not able to afford to go to one of those centers or have the money to travel. There are funds out there that you can access that may help you with this. Or sometimes people are able to get into NIH and get evaluated free. [00:20:00] That's a possibility.

Patricia Gibson: So there's always different programs that you might or might not be aware of that could help you. This is one of the things that I do a lot of times is help people get access to what they need. If they're really struggling and can't get an appointment, there's a backup. There may be another program nearby that they would be able to access. And sometimes they need help getting there.

Kelly Cervantes: It highlights [00:20:30] these ... there's a whole other podcast and a whole other conversation perhaps, but just these socioeconomic pieces that become glaringly obvious for those that speak English as a first language or who have access to the internet, who have connections to get that doctor's appointment. Whereas, someone else has all of these significant barriers and it's just, [00:21:00] that it's something that keeps me up at night. But I digress.

Kelly Cervantes: I would be remiss in the current state of COVID-19 that we were in not to ask you, with your pulse in the community the way that it is, how are you seeing this pandemic affect the epilepsy community? What are the biggest concerns out there?

Patricia Gibson: Well, the biggest concerns, I think for all of us, is getting the virus. [00:21:30] And, of course, if you are at high risk, it's very serious, a very serious problem. And I think that our big worry are parents who have lost their jobs or are having difficulty accessing care, accessing medicine. This is a big one for me, because we've watched all of our fundraisers, we've had to cancel them. [00:22:00] We are not seeing donations coming in. Our medicine program right now is being run by our fundraisers and, I mean, being funded by fundraisers and donations. And it concerns me greatly. So I think that access to what we need is one of the big worries in regard to this pandemic. And we have no idea what the future is going to hold.

Patricia Gibson: I do, the same time, have hope [00:22:30] that we are a resilient group. And I said before that there is no other group out there who is better situated to cope with adversity than my parents of kids with epilepsy. I have great faith in them. They have overcome so many things and have grown from it and done things that amaze me, that I think this group's ready to go to handle anything. And we'll be there [00:23:00] to help them as best we can be. But there is hope.

Kelly Cervantes: There's hope and help out there. We just need to know where to look and you bring hope to so many in your community and beyond, and we are grateful for you. And I am grateful to have shared some of your decades of wisdom with our listeners and viewers today. Thank you so much.

Patricia Gibson: Well, I want to thank you and I want to thank CURE for what you guys do. I've worked with your organization since the beginning and so [00:23:30] impressed. And you've made such a difference in the treatment of epilepsy and what it's going to be in the future, and I commend you. You've done a wonderful, wonderful job.

Kelly Cervantes: Well, on behalf of organization, we are thrilled and honored to be entrusted with funding the research that our community so desperately needs. Thank you so much.

Patricia Gibson: You're very welcome.

Brandon Laughlin: The opinions [00:24:00] 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 specific health situation.

Kelly Cervantes: [00:24:30] Your generosity is greatly appreciated. Thank you.

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