

My Condition Isn't Generic: Why Changes to Insurance Coverage Matter

- Kelly Cervantes: 00:00 I'm Kelly Cervantes. This is *Seizing Life*, a weekly podcast produced by Citizens United for Research in Epilepsy, CURE.
- Today, I'm joined by Joanne Guthrie-Gard. She is a mother and advocate who helped push forward legislation in Illinois to prevent insurers from changing the terms of prescription drug coverage in the middle of the year when consumers are already locked into their plan. When the insurer changed the coverage for her daughter Erin's epilepsy medication, she was forced to take a new med or pay \$10,000 for the original med.
- Kelly Cervantes: 00:43 With few options available to her, Erin tried the new med. The side effects were so severe that Joanne feared for her daughter's safety when sending her to school. Eventually, Joanne was able to work with the insurance company to get coverage for the treatment her daughter needed. This process took months. With the help of the Epilepsy Foundation of Greater Chicago, Joanne was able to be the face and voice of Illinois House Bill 4146, culminating in its successful passage into law. Joanne, thank you so much for coming and chatting with us today. I am always thrilled to be joined by another super mom.
- Joanne G.: 01:19 Well, thank you.
- Kelly Cervantes: 01:21 I want to start by getting your story. How did epilepsy enter your life?
- Joanne G.: 01:28 When Erin was eight years old ...
- Kelly Cervantes: 01:30 Erin is your daughter.
- Joanne G.: 01:31 ... Erin is my daughter. At eight years old is actually when she was first diagnosed. We think that, possibly, she was actually having what are called absence seizures, or staring seizures, for maybe even a year in advance. Then, that culminated in a big, what they call grand mal seizure, when she was in school. Once she was diagnosed, we started her on... You know, of course, they start with one medication. As with probably 99% of the parents out there with children, or even adult-onset epilepsy, it almost never works with the first one or the second one or the third one.
- Joanne G.: 02:10 We went on a journey of four years before we found a cocktail of medications that didn't keep her seizure-free, but kept her fairly controlled where maybe she would only have two or three a day. She was in school, and they would happen there. She would get through the seizure, and then go on with her day. It

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took us four years to find that. I know that a lot of people with those specialized conditions, not just epilepsy, but a lot of different conditions, when you find that medication that works for you, you don't want to lose it.

- Kelly Cervantes: 02:45 No.
- Joanne G.: 02:45 You don't want to lose it. We were on a good trajectory for a while. Then, when she got into high school, she started having very bad dizzy spells like vertigo where she was nauseous, and she said her legs would feel like noodles where she couldn't even stand up. It would put her down for probably about two to three hours.
- Kelly Cervantes: 03:07 Oh my gosh.
- Joanne G.: 03:08 If it happened when she was already in school, she would go to the nurse's office, lay there for a couple of hours, and then go back to class. Sometimes it would happen on her way to the bus. Sometimes it would happen before she left home. This went on for probably six or seven months. The doctor then said what they felt was happening was one of her medications was being metabolized differently now. You know, the body goes through changes when you become a teenager.
- Kelly Cervantes: 03:38 Yes. Now you're dealing with, how is the body reacting to what had worked for six years?
- Joanne G.: 03:48 We had to deal with it. We couldn't change the medication, so we just had to deal with this side effect, sometimes missing school completely, and then sometimes missing maybe just a couple of hours in the morning.
- Kelly Cervantes: 04:02 Okay.
- Joanne G.: 04:03 You know, we were more for trying to get the seizures controlled. That's the top thing with a parent too. Are you willing to deal with the side effects that are keeping them from having too many seizures? Or do you not give them that medication because of how it makes them feel, but now you're dealing with the seizures?
- Kelly Cervantes: 04:21 The age-old, quality-of-life question.
- Joanne G.: 04:24 Exactly.
- Kelly Cervantes: 04:24 Finding that magical balance.

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- Joanne G.: 04:27 Most of us don't find that balance. You're just sort of fudging along the way. Every day is a little bit different. You really don't know what the day is going to bring to you. What happened when she was in high school, with that same medication, the pharmaceutical company came out with an extended version, or an XR, extended release. It would have a coating on it. Then the coating would just kind of wear away after she took it, and the medication was put into her system at a slower rate than just taking the tablet that she was taking. I called the doctor as soon as I saw that the extended release came out. I think I knew before he did almost.
- Kelly Cervantes: 05:13 Super mom.
- Joanne G.: 05:13 He said, "Absolutely. Let's try it." He wrote a prescription for it. The day Erin started taking that extended release medication is the day her symptoms stopped.
- Kelly Cervantes: 05:23 Wow. It was the exact same med she was on before. It was just a slightly different delivery system.
- Joanne G.: 05:29 Yes. Exactly. It worked phenomenally. Of course, we were very happy. About three months in, I get a letter from the insurance company saying that they are no longer going to cover the extended release, and that she had to go back to the tablet version. The issue with that is there was no generic for it. It's not even that I could say, "Well, why don't we try the generic?"
- Kelly Cervantes: 05:56 What was the insurance company's reasoning?
- Joanne G.: 05:58 There really wasn't a reason. I knew that it was very expensive. When I did look into what it would cost for retail, it was \$10,000 for each prescription.
- Kelly Cervantes: 06:13 Because that's reasonable.
- Joanne G.: 06:14 Of course. Since I didn't have \$10,000 laying around just begging to be [crosstalk 00:06:20].
- Kelly Cervantes: 06:19 Why not, Joanne?
- Joanne G.: 06:21 We had to go back to the other medication.
- Kelly Cervantes: 06:25 You have to go back to this med, which has side effects that are, frankly, dangerous.
- Joanne G.: 06:30 Absolutely.

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- Kelly Cervantes: 06:32 You call the insurance company and they just say, "Nope. Sorry. There's nothing you can do."
- Joanne G.: 06:37 Nope. Sorry. Yep. When the symptoms came back again ... It's one of those things where, as a parent and as an advocate, you have to be the voice. I think there's a difference between someone who comes in like a bull in a china shop. I also don't think that you need to come in and be all meek and timid and ask that way. I really think that there's a balance between the two. I think that's where I've also learned that I am a squeaky wheel, but I don't do it to the point where people are shutting me out. I think that if you go in and you're educated ... even if you have to educate yourself on things. Make sure that you know what you're talking about.
- Joanne G.: 07:26 I went into our doctor's office. I really encourage people to use their medical community. Use your nurses. You know how amazing they are. They know a lot. They see a lot. What I did is, I went in and talked to our epileptologist's nurse. I said, "This is not acceptable. I'm scared for Erin. There's got to be something that we can do." She actually wrote a letter and appealed to the insurance company. The first appeal came back rejected. Then what do you do? You go back a second time. Again, the argument was that it is putting her in danger. Her safety is our utmost concern because of falling, maybe going down stairs when she's dizzy and she can't catch herself.
- Joanne G.: 08:19 That second one did come back approved. That is actually called "prior authorization." As long as you've got the backing of your doctor, I would encourage people just to keep pressing forward if they really feel that there's a medical reason. They call it "non-medical switching." You've got people on the insurance side that are making decisions based on business, not based on the medical decisions. Sometimes there are good reasons to change. If you do have a condition where you don't necessarily have to have the cost of a brand name, and you can switch over to a generic, then more power to you. If you can spend \$20 instead of \$100, why wouldn't you?
- Kelly Cervantes: 09:07 Sure.
- Joanne G.: 09:07 Why wouldn't you? Right?
- Kelly Cervantes: 09:10 Right.
- Joanne G.: 09:10 I think what's difficult is that the people who are making those decisions behind the scenes are not making them based on

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what the medical decision is for why that person is taking that drug, especially in situations where they may have spent years going through multiple types of prescriptions to figure out what that one is that works. Now you have someone telling you, after your four-year search, we're not covering that anymore.

- Kelly Cervantes: 09:41 In the middle of your contract with this insurance plan. It's not like you can get out of it and switch to a new insurance plan.
- Joanne G.: 09:50 You're caught between a rock and a hard place. Especially with the way the medical care works now, like with Obamacare, where people are actually purchasing their own insurance policies. When you've got someone that has a special need, or has a certain kind of condition within your family, of course, part of your research is you're going to make sure that medication that they're taking, keeping them functional and alive, is covered by that plan.
- Kelly Cervantes: 10:17 Of course.
- Joanne G.: 10:18 You buy into the plan. You sign on the dotted line. January 1st, it starts. Right? You're now locked in until open enrollment the following January 1st. You get a letter in March that says, as of July 1st, we're not covering your medication anymore. What happens? You have a really difficult decision to make. A lot of times what they'll do is, instead of covering this, we'll cover you on this.
- Kelly Cervantes: 10:51 Right. We've gotten those letters before.
- Joanne G.: 10:53 It may be the generic, but that person behind the scenes that isn't the medical person doesn't know that. With Erin, because her epilepsy is so difficult to treat, whenever a new medication would come out, a lot of times that's what the doctor would try her on. By the time a generic would come out, she's already been on this medication for six years.
- Kelly Cervantes: 11:18 Right.
- Joanne G.: 11:19 I'm not switching her.
- Kelly Cervantes: 11:21 No. No, of course you're not.
- Joanne G.: 11:22 Just to see if it works. Again, those people that are back there that are going, "Oh, there's a generic for this now. That's the one you need to take."

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- Kelly Cervantes: 11:31 Yeah.
- Joanne G.: 11:32 A lot of times what they'll do too is they'll change the tiers. It'll be moved into a tier that, all of a sudden, maybe the tier that that medication was on before, or the formulary, is \$40. Now, in the middle of the year, they're moving the formulary and they're putting you on a different tier. Now it's \$120, or \$400, or whatever that combination is. You've got people who go to fill their prescription and, all of a sudden, the cost has quadrupled for them.
- Kelly Cervantes: 12:01 I think it's also important to remember that a lot of epilepsy patients are not on just one med.
- Joanne G.: 12:07 Right.
- Kelly Cervantes: 12:08 You're talking ... You're like, "Oh, \$120 a month for a med." You get that's still a lot of money, but it's not the only one.
- Joanne G.: 12:15 Yeah. Erin is on six, which is the most of any patients of the epileptologist that she currently sees at Northwestern.
- Kelly Cervantes: 12:23 How is Erin doing now?
- Joanne G.: 12:25 She's doing better than, let's say, two or three years ago, believe it or not. We do a lot.
- Kelly Cervantes: 12:31 She's 20 ...
- Joanne G.: 12:31 She's 27. She was diagnosed when she was eight. We've been going through it for a really long time. We're really trying to work on trying to get the medications, the dosages, and everything lowered so we can see where that threshold is, so if we know that if we go down here, this is seizures. If we're right here, this is seizure-free.
- Kelly Cervantes: 12:53 Right.
- Joanne G.: 12:53 We don't want to be up here if we can be here.
- Kelly Cervantes: 12:57 Right.
- Joanne G.: 12:58 That's kind of what we're working with now. We're at the point now too where she's embracing, even after all these years, also being an advocate. There was a time where it was just a dirty word to her. I couldn't have a conversation with anybody about her epilepsy without really upsetting her. We went through a

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period of time where she didn't go to any epilepsy events with me. She didn't do any of the educational things that I like to do and learn about. She didn't want any part of it. I would say, probably about four years ago, she started embracing it. I was very proud of her this year when we had the opportunity to get involved in the Bill. She stepped up.

- Kelly Cervantes: 13:49 She sure did. I really want to talk about that, and how that came about. You had this experience. Eventually, with assistance from your doctor's office, you were able to get insurance to cover that med.
- Joanne G.: 14:01 One of the medications she takes is still that same medication.
- Kelly Cervantes: 14:04 That's amazing.
- Joanne G.: 14:05 Yeah.
- Kelly Cervantes: 14:07 How does that experience translate into the legislation that you helped pass? What started that journey?
- Joanne G.: 14:15 It started with the House Bill. There was actually a Representative, Laura Fine, who had this happen to her husband. It was when they changed the formulary in the middle of the year, and when he went to pick up his medication, the price had quadrupled. She was like, "This isn't right." She was the one that sort of spearheaded and wrote the bill. Lots of support from both sides of the aisle. There was a medical coalition in Illinois that was put together of all these different medical organizations, including The Epilepsy Foundation, The Arthritis Association, and The Heart Association, because these are all conditions where patients are very dependent on medications, sometimes very specific medications. They had this medical coalition, and they contacted the Foundation. They said, "Hey, do you know of any families who may have gone through this that would be able to tell their story?" When I got the phone call, it was kind of like, "You know, you and Erin have gone through so much so I figured that you guys have probably gone through this." It was like ...
- Kelly Cervantes: 15:24 As a matter of fact, we have.
- Joanne G.: 15:25 Yeah. Yeah. They put me in touch with this Tribune journalist and writer. They did an article, and it included the information about the House Bill 4146 and what the issue was and what had happened to us. Then, I went down to Springfield and went to the House Committee. I didn't get to talk to [inaudible

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00:15:51], but I did go down to show support. I did write up a little thing about Erin. They did actually tell her story, and what had happened with us. It went through and was passed on the House floor, which then goes over to the Senate. You learn a lot about Springfield, and how laws get put in when you get really involved in that. Right? You don't really know how it all works until you are actually there.

Kelly Cervantes:	16:13	Yeah.
Joanne G.:	16:14	Then it goes over to the Senate committee, the Health Committee. Since we had a little bit more advanced notice, we were able to arrange for Erin to actually testify in person.
Kelly Cervantes:	16:25	Oh, that's amazing.
Joanne G.:	16:25	I could not have been more proud of her to sit up there. We went around and talked to the Senators on the committee in advance. We actually got one of them to change his vote. He was getting a lot of pressure from insurance lobbyists to not vote for it. We actually got him to change his vote, which, of course, she was just so excited about.
Kelly Cervantes:	16:54	She should be.
Joanne G.:	16:55	Yeah. Yeah. Then it went to the Senate floor, and it actually passed unanimously through the Senate. Ironically enough, the day that it passed, I got an email that two of Erin's medications were not going to be covered as of July 1st.
Kelly Cervantes:	17:16	Stop it.
Joanne G.:	17:17	Yeah. Yeah. The day. The day.
Kelly Cervantes:	17:21	Did you call the insurance company and say ...
Joanne G.:	17:23	You betcha I did.
Kelly Cervantes:	17:24	They're like, actually you're going to because I personally...
Joanne G.:	17:29	Guess what? [crosstalk 00:17:31]. I know this is going to get signed. The thing is, is that I got it as an email. It was not a hard letter in the mail. I got it as an email.
Kelly Cervantes:	17:37	You're kidding me.

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Joanne G.: 17:37 The email subject ... This is a lesson for anybody who gets email communication from their insurance companies or whatever. Open it. Open it. It came across to me as a market ... At first, in the subject I thought it was more of a marketing thing trying to get me ... They've always been trying to get me to switch over to generic.

Kelly Cervantes: 17:58 Sure.

Joanne G.: 17:59 I only do brands. Like I said, that's why she's been on it for six years.

Kelly Cervantes: 18:03 It works, and you're not messing with it.

Joanne G.: 18:04 No. I almost didn't open it. For whatever reason, I opened it. It was as of July 1st.

Kelly Cervantes: 18:14 I'm floored that they're allowed to send that in an email.

Joanne G.: 18:15 That was in May, so I had five weeks before they weren't going to cover that medication anymore.

Kelly Cervantes: 18:23 You can't get them off of ... No. It doesn't work that way.

Joanne G.: 18:27 I also knew that there's something called "prior authorization." I went through the same process with the doctor's office as what I had gone through 10 years earlier to have the medical reason for why she needed to be kept on the brand. It was approved the first time through as well.

Kelly Cervantes: 18:48 If you had so much time to be spending on things like this, it frustrates me that the doctor's office has to spend time on this also. That takes them away from the patients.

Joanne G.: 18:57 Absolutely it does.

Kelly Cervantes: 18:58 They shouldn't have to be fighting and arguing medical care with an insurance company. I digress.

Joanne G.: 19:04 Yeah.

Kelly Cervantes: 19:06 The Bill is passed.

Joanne G.: 19:08 The Bill is passed, and then it goes to the Governor's desk. Of course, then there's this lag time in there. Right?

Kelly Cervantes: 19:18 Yes.

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- Joanne G.: 19:19 Then, of course, you never know what a governor is going to veto.
- Kelly Cervantes: 19:25 Sure.
- Joanne G.: 19:25 It could be a Bill that makes all the sense in the world and, for whatever reason ... At least we knew the opposition had been removed because of tweaks that they had made.
- Kelly Cervantes: 19:36 Okay. What was the opposition? What reason did these governmental officials have to not vote for it, or for the Governor to not sign it?
- Joanne G.: 19:46 Right. You've got insurance companies that, what they do is, they would move the formulary around. Again, putting things on different tiers.
- Kelly Cervantes: 19:56 Okay.
- Joanne G.: 19:57 Okay? If you have something that is down a lower tier, that might be your generics, that type of thing. If you have something that's on the much higher tier, those would be the more expensive medications. The whole thing about them being able to move things around tiers midyear. That was a big part of it. You can't change someone's coverage in the middle of the year. What they now are able to do is, they would still have to make the offering. They would be able to move a tier at the beginning of the next year. They would be able to move around the formulary. You might still get an email in May that will say, "We're no longer covering this medication for Adelaide." But now you've got until January 1st to be able to find that replacement, or go through the prior authorization and that type of thing. You're not under the [crosstalk 00:20:58].
- Kelly Cervantes: 20:58 If the insurance ... you go through all of it, and they're still not going to cover it ... Usually, if you fight you can win if you stick your feet in. But, then you know, and you can start hunting for the next insurance company.
- Joanne G.: 21:13 For the next insurance company. Exactly.
- Kelly Cervantes: 21:15 What advice do you give to patients or caregivers out there who see a legislative concern in their community? I know that the House Bill that you were a part of came to you.
- Joanne G.: 21:32 Right.

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- Kelly Cervantes: 21:33 Having been in this world, for the patient or the parent that wants to get into political advocacy, what avenues do you recommend?
- Joanne G.: 21:45 I think first, get involved in foundations and organizations. Typically, they will have a lobbying group or an advocacy group. Maybe they have an employee on their staff, someone who just does Springfield advocacy or DC advocacy. I think tapping into those people to see what kind of legislation there might be out there where maybe you can add something to it. Even just learning what's out there so, if you know there is a Bill in Springfield, maybe it's already a Bill that is in a committee somewhere. Then find out who's on that committee. Pick up the phone and call him/her. Especially if it's your own Representative or Senator. They will listen. They really will listen. You are their constituent. You're a vote.
- Joanne G.: 22:44 You have a Senator who lives in your area or has an office in your area. Then you have a Representative who is also in your area. They keep offices in both places. When Springfield is not in session, when the General Assembly is off, they're usually keeping office hours locally. You can go online to find out what their schedule is so you know exactly when they're not in session. Your Representative typically might be much closer to your home because they cover a smaller area. Your Senator covers a much larger area so their office may not necessarily be right in your community. That's where I would go. I would find out when they are going to be in the office. I would make an appointment. Make a 15-minute appointment to go in and introduce yourself. Let them know about some concerns that are happening in your life with prescriptions or with anything that would be going on. It's their job to know what the issues are in their own area and with the constituents that are around.
- Joanne G.: 23:55 I did that with my Representative. Actually, after Erin and I were in Springfield, when she testified in front of the Senate committee, I made an appointment with my Senator and went and spent time with her to make sure that she understood that it was super important to me for her to vote yes for that Bill. Then, also, if you've got younger children or, like with Erin, once I realized that she had gotten out of that funk, she came with me to everything. She saw how I talked about it and how passionate I was about it. Of course, with how long it's taken us to get here, I'm starting just to see her confidence building up, which just means everything. I think that the most important thing is that you can't be silent. You just can't be silent.
- Kelly Cervantes: 24:49 I couldn't agree more.

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Joanne G.:	24:50	I always felt other people ... How can I expect someone else to do it for me and my benefit, and have Erin benefit from someone else's work, if I'm not willing to go out and do it myself?
Kelly Cervantes:	25:02	You are a wealth of information. I am so happy you were able to come and join us today. The true epitome of a super mom.
Joanne G.:	25:10	Well, thank you.
Kelly Cervantes:	25:11	Thank you so, so much.
Joanne G.:	25:12	Thank you for having me. I appreciate it.
Kelly Cervantes:	25:17	Thank you so much, Joanne, for giving us on <i>Seizing Life</i> advice on how to be a political advocate. It is so important that we understand the power we hold as voters and citizens of our country. Please share Joanne's story with other epilepsy families so that they can learn to be a voice in their own local governments. Finally, don't forget to visit and follow <i>Seizing Life</i> podcasts on Facebook and Instagram and <i>Seizing Life</i> pod on Twitter. Thanks so much.
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