Seizing Life, episode 129

Epilepsy in Women: Challenges, Concerns, and Considerations Guest: Dr. Elizabeth Gerard (Transcript)

Kelly Cervantes:

Hi. I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy. Today, I'm happy to welcome Dr. Elizabeth Gerard to the podcast. Dr. Gerard is an epileptologist and associate professor of neurology at the Northwestern School of Medicine. She also directs the Women with Epilepsy Program at Northwestern Medicine's Comprehensive Epilepsy Center and is a nationally recognized expert in the care of women with epilepsy. Dr. Gerard is here today to discuss specific concerns and considerations around women's health and epilepsy.

Kelly Cervantes:

Dr. Gerard, thank you so much for joining us today. I'm really, really excited to share your knowledge on this topic because I really truly believe it's going to help so many women and families. So to start things off, you lead the Women's Epilepsy Program at Northwestern Medicine, which I understand was one of the first of its kind in the Midwest as a center that specializes in women's health with a focus on epilepsy. Can you explain what it is that you do and what the program was created for?

Dr. Elizabeth Gerard:

Yeah. Yes, we were one of the first when I first moved here to start the program in 2009, but I want to make sure that I say that there's so many more programs now. I think pretty much every epilepsy program in Chicago has a women's program and there are many more throughout the Midwest so it's really exciting that this field has grown both nationally and internationally. And I think what I'm passionate about and what we discuss in our clinic is the way that reproductive health for female patients or patients with reproductive capacity, how that intersects with epilepsy. And there's so many phases of life that I know we're going to talk about that intersect. And some of the ones that I've focused on are contraception and how contraception interacts with seizure medications and how that's important in planning pregnancy, and a lot of times alleviating patient's anxiety about what it might mean to be pregnant and reassuring them that they definitely can have healthy and safe pregnancies. But the intersection for female patients and epilepsy is at many places. Puberty, also menopause and it really is throughout the spectrum. There's also a lot of cultural differences as well that are really important to consider and societal differences of what it means to be someone who identifies as a woman and having epilepsy that also come up.

Kelly Cervantes:

Yeah. It takes on a whole new meaning when you are throwing hormones and pregnancy into the mix. So I would love to start chronologically and how does epilepsy, the medications, all of these aspects affect a young person in puberty?

Dr. Elizabeth Gerard:

It's a great question. And I do want to say that I'm an adult epileptologist, so I tend to see patients after they've gone through puberty, but I still get a lot of questions about this. I think the first thing that everybody recognizes is that many epilepsy syndromes, both in those who are biologically male and biologically female, can start around puberty. And we don't fully understand the

reasons for that. But certain epilepsy syndromes, particularly juvenile myoclonic epilepsy, other generalized epilepsy syndromes often start around puberty for both sexes. And for other patients with other types of childhood epilepsies puberty can actually be a time where seizures go into remission or even go away.

Dr. Elizabeth Gerard:

But for other patients, it may be that seizures can change around the time of puberty. As we'll be talking about, hormones can be one of many triggers for seizures to break through. And so for a patient with epilepsy or their family members, they may be concerned that things will change around puberty. And I don't think there's a ton of data on this, but in general, if you have well-controlled seizures before puberty, there's not a guarantee that things will worsen around puberty. It could happen for some individuals, but the majority, I'd say that their seizure frequency is usually pretty stable. Others, as we said, may start during puberty and some may get better. But it's definitely a time as every parent knows and somebody who's gone through puberty knows, there's a lot of changes in your biology and the way your brain works and your sleep patterns so puberty can be a time of change and a time where things can happen differently with seizures.

Kelly Cervantes:

I think that's such an important piece that you bring up because when I think of puberty and seizures, I immediately think of hormones as being the culprit. But you are. You're talking about all of these changes in the brain. You're talking about vastly different sleep patterns from what you experience as a child. And so it makes sense that all of those pieces are going to impact a young person going through puberty. Speaking to that, obviously for a woman, one of the biggest changes in puberty is that she begins to get her period. Can you talk to us about catamenial epilepsy? And am I saying that right, first of all?

Dr. Elizabeth Gerard: Mm-hmm.

Kelly Cervantes: What that is and how it is diagnosed and what it means?

Dr. Elizabeth Gerard: Yeah. We get this question a lot, and it's such a fascinating neuroendocrine

phenomenon, and yet unfortunately, we don't have all the answers, and it can be extremely frustrating for patients and for providers. So catamenial epilepsy, which I sometimes prefer to think of as hormone sensitive epilepsy, is epilepsy that has a tendency to track with the menstrual cycle. So in other words, I think anybody who lives with epilepsy knows that their particular seizures can have triggers. So sleep deprivation is a trigger for many, many, many people living with epilepsy. Alcohol can be a trigger for some people living with epilepsy. Stress is a trigger. For many people, and we identify it, it's easier to identify in patients who have menstrual cycles. But for a large percentage of people living with epilepsy who are female and have menstrual cycles, there can be a

correlation.

Dr. Elizabeth Gerard: And it's defined by having a twofold or greater increase either during certain

times of the menstrual cycle. The most common time is right before the

menstrual period about three days before to three days after. The other common time is around ovulation, and people may have one or the other pattern or both patterns. And so again, an individual who has catamenial epilepsy or hormone sensitive epilepsy, that's not their only trigger. They may be sensitive to sleep deprivation, they may be sensitive to certain medications, but they may also be sensitive to hormone fluctuations. So it's the kind of thing where you may know right before your period comes as a particular vulnerable time to you, and particularly if you miss your medicine during that time or you don't sleep during that time, you're going to be even more likely to have a seizure.

Kelly Cervantes:

So catamenial epilepsy, it is not a type of seizure. It is not a type of epilepsy diagnosis necessarily. It is just saying that these certain times during a person's menstrual cycle, they are at a higher risk of having an increase in seizure activity. Are there statistics around how many women experience catamenial epilepsy?

Dr. Elizabeth Gerard:

Yeah. It's a great question and there's actually some new research to present on that. So most of the research on catamenial epilepsy early on in the definition of the particular patterns was done by Andrew Herzog, a neuroendocrinologist in Boston. And early research by him and others had suggested that this may be present in about one third, about 30% of patients with menstrual cycles and epilepsy. There's a new paper just published this year by my colleague Emma Voinescu and also my mentor Page Pennell, looking at a group of women who tracked their periods in a iPhone app in a study of fertility. It was a small group of, I think about 26 women, but in that study, actually half of them fit into these catamenial or hormone sensitive patterns. So it was a small group, but I think we can say that 30 to 50% of patients who have ongoing seizures that are not medication controlled seizures will have a hormone sensitivity pattern.

Kelly Cervantes:

So one in 26 people will develop epilepsy, right? We're talking about millions of people. Half of those people we can assume are women because epilepsy is non-discriminating. It's about 50-50. It's doesn't lead one way or the other. So you're talking about a quarter potentially of people with epilepsy are affected by their hormones and menstrual cycles, and yet we don't have much research to show for this and that is just a major deficit. I suppose it's not surprising, but it is frustrating when you break it down. When you're talking about millions of people across the world that could benefit from this research. Are there particular medications that work better than others? If you know a specific trigger for your seizures, I would hope or think, and I imagine your patients hope or think that you can then identify or point them toward a drug that is going to better able to control them.

Dr. Elizabeth Gerard:

Well, I should qualify what I said before. I wouldn't say that we don't have any research on this topic. It's been very, very hard to track. One other thing that came out of this recent paper is that patient's self-report of hormone sensitivity is actually very different from what is tracked when we track in calendars, and it's very hard to track in calendars. Also, I should mention that patients

reproductive capacity and epilepsy are more likely to have irregular cycles, so that makes it even harder to track as well. So it's a very hard thing to study. But what is frustrating to many patients and their families is that our research hasn't yielded a aha treatment for this. And it seems that, oh, if it's a hormone sensitivity, then there should be a hormonal treatment. And I can't say that there's not, but there hasn't been a great one.

Dr. Elizabeth Gerard:

There have been some very small series suggesting that suppressing the ovulatory cycle with a high dose injection contraceptive, which is Depo Medroxyprogesterone, that would eliminate the cycle can also improve seizure control in patients with these types of patterns. But again, very few of those patients received complete seizure remission. They had a significant improvement in their seizure control. There is some research going on, small case series research on other types of means of suppressing the menstrual cycle, but suppressing the menstrual cycle completely can also have side effects. So I think these are things we have to balance. And going back to what you said before, at the end of the day, we're dealing with a patient with epilepsy and so we first, especially in the beginning, need to target the best drugs, the best medications, the best treatment, even including considering surgery for that person's epilepsy. The hormone sensitivity is so common that it's not really a unique form that necessarily has a unique hormonal treatment. We need to do the best we can to control the epilepsy.

Kelly Cervantes:

Right. Because the hormones are just one piece of the puzzle. It is not the underlying cause.

Brandon:

Hi. This is Brandon from CURE Epilepsy. Have you or a loved one been recently diagnosed with epilepsy? Are you looking for more information about epilepsy and available treatment options? Go to cureepilepsy.org/for-patients to get resources and information about epilepsy. Now, back to Seizing Life.

Kelly Cervantes:

Moving on our chronological journey, Dr. Gerard, can you speak to how an epilepsy patient might need to think about contraceptives differently than the average patient?

Dr. Elizabeth Gerard:

Sure. It's really important that physicians and patients who work with antiseizure medications know about these interactions. Because anti-seizure medications can affect our contraception, and our contraception can affect our anti-seizure medications. So some of the considerations for contraception is that a lot of the contraceptions we have are hormonally based. And hormonally based contraception, this includes pills, the vaginal ring, the contraceptive patch. These are all hormonally based contraceptive that depend on hormones throughout the body. There's also a insert that can be put in for long-term use that's also a hormonally based contraception. All of these medications, their efficacy can be affected by many of our seizure medications. Not all, but about half of our seizure medications are what we call enzyme inducing seizure medications. That means that the medication speeds up how the liver breaks down medications, including hormonal medications. So for patients who are

taking enzyme inducing medications ... We have many of them. Carbamazepine, Phenytoin, topiramate, to a lesser degree lamotrigine, but there's many, many more. Our enzyme inducing medications will make contraceptive hormones less effective.

Dr. Elizabeth Gerard:

And so it depends on the contraception and it depends on the medication. The seizure medication. But in many cases, somebody may be taking a birth control pill and thinking it's working and it's not going to work to prevent pregnancy. So it's really important to think about methods that are both highly effective and don't interact with seizure medications. But another important thing that I want to make sure people know about and I think causes some confusion is for many people living with epilepsy, the IUD is a preferred form of contraception. A lot of people think of the copper IUD that used to be available is still available, but we have much newer IUDs, intrauterine devices that are plastic devices and are designed for anybody at any age, including people who have not had children before.

Dr. Elizabeth Gerard:

And these are devices put by a doctor or usually a gynecological doctor in the office into the uterus. And they offer very, very high level of contraceptive protection. About 99% effective. Way better than condoms. Better than most of the hormonal methods that we talked about. And these plastic IUDs, which are the newer ones that can also make periods lighter and cause less cramps, these have a small amount of hormone in them. However, that's a progesterone hormone that acts locally on the uterus. And so unlike all of our other hormone medications, these progesterone eluting plastic IUDs are not affected by seizure medications. So the IUD is often, for most patients, a really good go-to option that's not going to be affected in terms of efficacy and pregnancy prevention by their seizure medications.

Kelly Cervantes:

That is so incredible for everyone to know and to have that information when they go in and talk to their gynecologist. And we'll get to this piece later. We've looked at this one directional. How do the epilepsy medications affect the contraceptives? But I have a funny feeling that it works the other way too. How do the contraceptives affect the epilepsy medications?

Dr. Elizabeth Gerard:

This was really important research and it's going to lead into a lot of the other things that we talk about. But we've learned that hormonal medications, particularly those that involve estrogen, can affect the metabolism of our seizure medications. And so this is most well understood and most important for patients taking lamotrigine, although it may affect other drugs as well. Lamotrigine is by far and away the most commonly prescribed medication to patients with epilepsy and gestational capacity because it's one of our medications that's considered low risk in pregnancy. But lamotrigine is cleared by a process called glucuronidation in the liver again. And what we know is that high doses of estrogen, either high doses of estrogen during pregnancy or synthetic estrogens such as that's in pills and patches and the vaginal ring, these high doses of estrogen will actually cause glucuronidation to speed up and it will lower the levels of lamotrigine.

Dr. Elizabeth Gerard:

So to illustrate this, I had a patient once who reached out to me because she had heard a podcast I had done 12 years ago on this topic. And she was a college student and she had been doing very well on lamotrigine, but then she started birth control pills because she was a college student and she was becoming sexually active. She had three seizures within the next six weeks and couldn't understand initially why that had happened. Well, what had happened is that the estrogen in the birth control pill had made her lamotrigine levels fall in half. And so what was previously working for her was no longer working. So in general, when we can avoid it, we don't usually use birth control pills with estrogen or patches or vaginal rings with lamotrigine, but in some cases we do combine them. And when they're combined, the lamotrigine dose needs to be adjusted. This can affect other seizure medications to a lesser degree, perhaps Oxcarbazepine can be affected. And there's some question about whether valproic acid can be affected, but it's most dramatic and most clinically significant with lamotrigine.

Kelly Cervantes:

So these are all factors that you really need to keep in mind when you have epilepsy and you have to really be aware and think about planning pregnancy or preventing pregnancy. And I wonder when you recommend that these conversations need to be starting with parents, with the patient, with their gynecologist or epileptologist.

Dr. Elizabeth Gerard:

I'm so glad that you asked that. I think it's a really, really important concept both for parents, for patients, and for doctors to think about. I think these conversations need to start when a female patient receives a diagnosis of epilepsy. The thought has to go into the first medication that they're given, and these conversations need to start. And when I started as a junior attending, I did what I was told in medical school. Ask the parents to leave the room and then talk to the individual one-on-one and talk about whether they're sexually active and if they're ready for this information. But I've actually changed my style over the years because I think everybody needs to know this information. And so I think even if you're a parent of a person living with epilepsy, be receptive to the information. Even if you don't think the individual is going to become sexually active anytime soon I think it's really important to know these interactions, that birth control can affect their medications, that their medications can affect their birth control. And I think it's really important to also talk about pregnancy early on because I'll think a lot of people hold the belief that pregnancy is not for them because they have epilepsy, and that's definitely not true.

Dr. Elizabeth Gerard:

And lastly, conversations around the IUD, which I certainly favor and start early are important even if somebody's not sexually active because there's a lot of benefits to the IUD. It can make periods less heavy. It can make cramps less bad, which is a big thing for many teenagers. And I should have said that earlier. I think periods can be a trigger for seizures for many reasons and we tend to think about the hormones, but there are some patients who have more seizures during their actual period. That actually tends to be more related to the cramping and the stress of actually just having a period and not sleeping well than hormones. Especially if it's several days into the period. So I hear that a lot

from parents. But anyway, so the IUD has other benefits. So I think these conversations should start with teens, with young people who are diagnosed with epilepsy.

Kelly Cervantes:

And it may feel awkward in the moment, but I think you're right. I think you are so spot on. These are such important conversations to have. I can imagine many young people hearing that they have epilepsy and just assuming that that means that childbirth isn't for them, and that's just not the case. There are so many ways that a person with epilepsy can have a safe pregnancy. It just has to be planned and prepared for, and there are all of these other factors that need to be considered. What are some of those factors that someone with epilepsy needs to think about prior to becoming pregnant?

Dr. Elizabeth Gerard:

Yeah. I couldn't agree more. And I think it's really important to give the message to all young people who might consider a pregnancy in the future that they can and they will be able to. It's all a matter about planning and weighing risks and benefits. So I think the first thing is to be working early on with a team member who is familiar and knows and comfortable talking about this. I think that it's also just important to be informed. And also to recognize that our knowledge is growing all the time. And so we know a lot about seizure medications during pregnancy. That tends to be people's first concern is what is the effect of taking seizure medications on pregnancy? Although there are many things to talk through. I often tell my patients that for some of our seizure medications, we've been studying them now for over 30 years. We're really lucky to have international pregnancy registries that have been following pregnant patients with epilepsy throughout their pregnancies on various seizure medications.

Dr. Elizabeth Gerard:

What we want to do, particularly for somebody who's presenting early, is we want to pick seizure medications that are known to be lower risk in pregnancy. So lower risk in terms of malformations for the fetus and lower risk in terms of neurodevelopment of the fetus. We also want to make sure that we can fully control the epilepsy if possible. And if we're not fully controlling the epilepsy or don't fully understand it, we need to do investigations, for example, like an epilepsy monitoring unit admission to see if there are other ways to control the epilepsy like considering surgery.

Kelly Cervantes:

So with that database, that information that we know how different medications affect pregnancy, can you give us a rundown of what medications are better for someone who is pregnant versus another medication that could cause problems?

Dr. Elizabeth Gerard:

Sure. I want to just specify that we've been studying different factors in pregnancy. And when I say we, there's an international group of neurologists who have worked on following these patients well before I was even practicing. But we have been studying many different data points so that we now have data. The most data is about major congenital malformations, which are structural abnormalities that affect the fetus usually and develop early, early in pregnancy in the first trimester of pregnancy, starting as often as soon as

somebody knows they're pregnant. We also have information now about small for gestational age. And for some medications we're lucky to have prospective studies that have looked at the children exposed to these medications and seeing how they do in terms of IQ testing, in terms of development, in terms of performance at school. What we know so far is that there is one medication that very much stands out in terms of being higher risk than other seizure medications.

Dr. Elizabeth Gerard:

Valproic acid is particularly high risk when it comes to exposure during pregnancy. We know that children who are exposed to valproic acid on average have a risk of malformations of about 10%, whereas it's about two to 3% in the general population. All pregnancies have some risk of malformations even if you don't take seizure medicines. We also know that valproic acid seems to have a negative impact on IQ, at least for some children who are exposed. So on average, some of our studies have shown that children exposed to valproic acid during pregnancy have IQs that are about 10 points lower than other children. Our controlled children or children exposed to other seizure medications. We also know that valproic acid's been associated with the increased risk for autism or autism spectrum disorder or other learning disabilities. And so for these reasons, whenever possible, we try to avoid valproic acid in patients who may consider pregnancy in the future. And certainly if somebody needs to be on valproic acid, we try to keep the dose as low as possible because that can also have effect as well. Although there's no dose at which these things are not a concern, but it's better to keep the dose low.

Kelly Cervantes:

I have a quick question. If someone has been on valproic acid, let's say as a teenager and they're off it now and they've started a new medication and now they're going to get pregnant, does it matter that they took it as a teenager or when they were younger and now they're off of it?

Dr. Elizabeth Gerard:

Our belief and our understanding from all our data is that it's really about the medications and the exposure during pregnancy. However, I want to again emphasize that even at six weeks of pregnancy, even when you first have a positive pregnancy test, these vital structures for the infant are already forming. And so it's not sufficient to get pregnant on valproic acid and then switch. This is the importance of planning. You want to be on a medication that we think is low risk before you get pregnant. There are some people where valproic acid is the only seizure medication that works for them. It's a small group of patients. And for those, what we do is we try to lower the dose as much as possible. It doesn't mean that they can't get pregnant. I think it's important to know that there are risks, but they're probably not as high as what people imagine when we say it's a high risk drug. It's a high risk drug compared to other seizure medications, not compared to some other drugs like Thalidomide that had been studied way back and very high rates of malformations.

Dr. Elizabeth Gerard:

However, we do find that this is a medication that we should try to avoid and we feel very strongly about that. In particular because of the neurodevelopmental impact. I will also mention that there has been some

increasing concern about topiramate. We don't have as much data as we have for valproic acid. The average malformation risk is not as high as valproic acid, but there is a specific association with cleft lip and cleft palate, and there's some early data to suggest that there may also be negative impacts on neurodevelopment as well and increased risk of learning disorders in children exposed to topiramate. Which is going to be really important for us to flesh out because a lot of people take this medication for migraines as well as for epilepsy. But the European medical agency is warning a bit about the use of topiramate in pregnancy as well.

Kelly Cervantes:

So we've covered those more high risk medications. Which ones show less risk or little to no risk?

Dr. Elizabeth Gerard:

The best studied medications that we have that show very low risk in pregnancy relative to other seizure medications and relative to the general population are lamotrigine and levetiracetam. There's still more we need to know, but the risk of malformations with these drugs is largely similar to the general population or just slightly elevated depending on which study you look at, but really to a very minor degree. Also, we have some data about impacts of lamotrigine and levetiracetam on neurodevelopment and overall the IQ of children exposed to these two medications seems to be similar to children in the general population and not elevated when compared to other medications. This is something we still need to study. We're fortunate to be part of a study that's following children until age six years, and there's still more nuances we have to look at about behavioral stuff and the effect of medication levels and dose.

Dr. Elizabeth Gerard:

But overall, when picking seizure medications, these are medications that we feel confident in are relatively low risk medications and good choices for patients considering pregnancy. I just also want to mention that there's a lot of seizure medications that fall somewhere in between what we just talked about and a lot more where we have literally no meaningful data. And so we really need bigger and better studies to follow a lot of the newer medications or the less commonly prescribed medications so we can inform patients better. But I think sometimes people conflate not having any bad news about a medication as that medication being safe, and it actually just means that that medication hasn't been studied. So we really try to explain to patients that we're trying to pick the medication that's best for them. Doesn't have to be one of the two on the list that I just mentioned. The data is currently considered low risk. And we also try to have that medication at the lowest dose or blood level that's necessary to control seizures in that patient.

Kelly Cervantes:

Excellent. We've talked about the ways that the medications can affect the pregnancy. I'm curious, has there been research showing how pregnancy can affect seizures?

Dr. Elizabeth Gerard:

Yes. Actually there has been. I think overall it's very reassuring data. I think in general, patients who can be reassured that their seizure frequency during pregnancy is not typically different than their seizure frequency when they're

not pregnant. There can certainly be certain individuals where that might not be true and it might get better or worse but on average, most patients' seizure control during pregnancy is predicted by the seizure control before pregnancy is really not different from the not pregnant state. There's a caveat to that, however. I had mentioned earlier the effect of estrogen on lamotrigine metabolism. And so lamotrigine is one of the medications where we've studied changes during pregnancy best, but we've also learned that other medication levels can change dramatically during pregnancy as well. So we know seizure control can be stable during pregnancy if medications are adjusted during pregnancy. If we don't adjust medications and follow medication levels during pregnancy, there is a risk of breakthrough seizures out of proportion to what's expected in the non-pregnant state.

Kelly Cervantes:

Which just goes to this point of how important it is to have an epileptologist that is either well versed in gynecological issues or vice versa, or having doctors who are willing to work together because this is 100% a team effort to have a safe pregnancy both for the mother and the child. We've spoken a lot on this podcast about the comorbidity between epilepsy and depression and anxiety. And thinking of postpartum depression, is there an increased risk there for patients with epilepsy to experience postpartum?

Dr. Elizabeth Gerard:

So there's been different studies on this. In the past there was a study that suggested that patients with epilepsy are at increased risk for depression. One of the more recent studies said that that frequency of major depression wasn't necessarily worse in patients with epilepsy, but some of the symptoms and severity, in particular anxiety could be a lot worse in patients with epilepsy. Particularly in the peripartum or postpartum state. We also know that maternal anxiety can have a significant impact on child neurodevelopment. So I think that both patients, their caregivers and their doctors really do need to be attuned to looking for signs of depression, signs of anxiety, and helping with that. And not necessarily waiting for the postpartum period. And to some degree, this goes for any pregnant patient, but it's definitely something we should be aware of because we know that depression and anxiety are more prevalent in people living with epilepsy anyway. And so it never hurts to really have a team in place, including a therapist or somebody ideally before pregnancy, during pregnancy. Don't necessarily wait. If you don't need it frequently, that's great, but if they're there, they're there. I think that can be really helpful.

Kelly Cervantes:

I think that's great advice. Now, something I found it fascinating. I'm reading a lot more about menopause in the news recently. Studies about menopause, women are talking about menopause, we're getting more scientific studies, which is amazing. And so I'm wondering what have been the effects or what have you seen of menopause on epilepsy and vice versa?

Dr. Elizabeth Gerard:

I will say this is an area that definitely ... All these areas, but particularly menopause needs to be more studied for this population. We're really lucky to have a couple of foundational studies by a few investigators, including Cynthia Hardin, that looked at this. But it really hasn't been looked at in a systematic

way recently. Some of the things that had been noticed in the past would be that some patients, particularly those who felt that they self-reported hormonal sensitivity would have increases in seizure or worsening of seizure control during perimenopause, which is the years where the cycles are much more erratic and you can have higher levels of estrogen. And some in these studies suggested things might get better once they had completed menopause. I have seen that. I have definitely seen the worsening during perimenopause in patients who were previously stable but not the majority. Like what we talked about with puberty. I have seen it where there's no other great reason why things are getting worse other than they're going through perimenopause. But I would say many of my other patients go through perimenopause without a change in their seizure frequency.

Dr. Elizabeth Gerard:

I have had a few patients who hope that when they get to menopause, everything will get better because they won't have hormonal fluctuations, and at least anecdotally, I have not found that to be the case or promised people that everything will get better once they go through menopause. But sometimes the worsening that we see for a few years, which can be up to 10 years, gets better. I think the other important research that was done and important for people to know about is that Cynthia Hardin, before the women's health study, which studied these hormone replacement, which is what's been in the news so much, it was shut down because of concern about health effects. She had been studying those hormone replacement therapies and whether they had an impact in seizures. This trial was shut down because of the shutting down of the women's health study. But in her smaller sample size, they did see a correlation with the dose of estrogen in hormone replacement therapy and worsening of seizures. And so that is something to be aware of. Now, a lot of the hormone replacement therapy we use today is lower in dosage than what was used at that time. But this is another consideration people should be aware of.

Kelly Cervantes:

So as someone who is considering puberty, who is thinking about pregnancy, who is looking and has these questions about menopause and all of the different phases and stages that occur in between, are these questions that a patient with epilepsy should be able to take to their epileptologist and get informed answers on? Because I can see them being concerned that their epileptologist isn't going to have this information, but then going to their gynecologist and their gynecologist isn't going to know about the epilepsy. Where should they begin and should their epileptologist have these answers for them?

Dr. Elizabeth Gerard:

Yeah. Of course, my bias is that I think we prescribe the seizure medications, we are the epilepsy providers, we should be holistic in our thoughts. But in the ideal world, it should be a team approach. So it would be really great if everybody is informed. But I think it's important to think about that the epilepsy provider sees only patients with epilepsy, whereas the gynecology provider sees patients with all different types of medical conditions. So the in-depth knowledge about our medications in particular, I think often lies on the neurology side, but we all need to work together. So I do think that patients should be able to bring these

questions to their epileptologist and ask for input on it. There are a lot of resources online both through your websites and also The Epilepsy Foundation. I'm involved in a project that's about to launch a website called epilepsypregnancy.com, which was intended to really try to bring everybody together and on the same page and provide resources for physicians as well as for patients and some tools for patients to bring these questions to their doctors. So I think it is really helpful for patients and their families to do some research and bring these questions to their specialist, to the neurologist or their epileptologist.

Kelly Cervantes:

Absolutely. Knowledge is power, right? So thank you so much for sharing those resources because I really do believe that they are going to be incredibly valuable to our listeners. Dr. Gerard, thank you so much for all of your knowledge and expertise and sharing it with us. I know it is going to help so many patients and families out there. We certainly appreciate your time.

Dr. Elizabeth Gerard:

Thank you so much for this opportunity and for everything that you've done for the epilepsy community. I really appreciate it.

Kelly Cervantes:

Thank you, Dr. Gerard for sharing your knowledge and insights about women's healthcare and epilepsy. Since 1998, CURE Epilepsy has raised more than \$90 million to fund epilepsy research and other initiatives that will lead us to a cure. If you would like to help us in our mission to find a cure for epilepsy, please visit cureepilepsy.org/donate. CURE Epilepsy, inspiring hope and delivering impact. Thank you.

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