

[Your Complex Brain theme music]

00:00:01 Dr. Esther Bui

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00:00:21 Heather

This is Your Complex Brain, a podcast all about the brain, the diseases that impact it, and the path to finding cures.

I'm your host, Heather Sherman, and I have the great pleasure of working alongside the team at the Krembil Brain Institute in Toronto, Canada. A leader in brain research.

In each episode, we'll take you behind the scenes into our clinics and our research labs to meet the game changers of the future. We'll also empower you with the latest research to help you take charge of your own health. You'll hear directly from patients who are living with brain disease as well as their loved ones and the care teams who support them. Join us on a journey to unravel the mystery of your complex brain. [theme music continues then fades out]

00:01:13 Nikki Ashworth

[gentle electronic music] My name is Nikki Ashworth, I'm 40 years old, and I have temporal lobe epilepsy on my right side.

My seizures always manifest themselves the exact same way. They're about a minute long. Nine times out of ten, I'm outside. Being outside is my trigger. These symptoms happen all at once. I immediately get a sense of overfamiliarity of things. I would describe it beyond casual déjà vu. This is a profound understanding that everything you're experiencing in the present, as it happens, millisecond by millisecond, has happened before and before and before. It's this deep spiritual knowing, for lack of a better word.

Another symptom I experience is a sense of dread. I'm not afraid. I feel like something very bad is going to happen, but it never does. Simultaneously at the same time, I get physical symptoms. So, it starts with a warming sensation in my lower abdomen and this radiating sensation travels up my abdomen very, very slowly. And as it's working its way up my torso, I start feeling nausea. I'm usually standing when I have a seizure, so it's almost like your body is physically being elevated. I don't feel like I'm floating off the ground. I feel more so like I'm going up a roller coaster anticipating this drop.

As the heat travels up my body, by the time it gets to about my shoulders, that's when I know the drop is going to happen. I can actually calculate how many seconds left I have in a seizure based on where the heat is in my body. So, you know, if it's at, like, chest level, I know I have about 20 seconds left. It's almost this sensation of falling, so it's a rise, like a [inhales deeply, then high-pitched exhale], and then you drop down.. And by the time the drop down ends, it's over. It's completely over. The nausea is gone. It can leave me fatigued. Not confused, just tired sometimes, especially if I have several in a row.

[music fades out]

My triggers are crossing streets, and it can be any street, at any location, at any time. Any corner. It can be a busy intersection with people and traffic. It could be crossing a quiet, little sleepy street in a residential area with absolutely no one around and no lights whatsoever. I know it's not caused by lights, or flashing, or noises of traffic. It's just the physical act of anticipating crossing a street from a corner. So I'll go to the corner, and then it hits me right away. and I will continue to have the seizure as I'm crossing the street, and then usually I need to kind of lean on a lamp post or something by the time I get across the street.

People would not notice I'm having seizure at all. I've hid them my entire life. I've had seizures at work. I've had seizures to and from getting coffee at work with coworkers. There really are no symptoms with me. That's why I wasn't diagnosed until— I think I was 37 when I was diagnosed. What prompted me to first seek diagnosis was having many more seizures than I used to. It got to the point where I was having about three to four a day, and always at intersections or crossing streets, always crossing streets.

And one day I'd had quite a few. I'd been with my boyfriend, and I even had a seizure on my way to his house. And when I got there, I felt like I just had to say something about it. And I said, "Does— does that ever happen to you?" And he just looked at me and said, "I think you need to speak to a doctor." I found that comical, because it honestly never occurred to me it was medical. And I said, "Oh, yeah, what am I going to do? Google 'deja vu but medical'?" And so, I actually typed in "deja vu medical" in Google on my phone, and the very first thing that popped up was an epilepsy website from the UK. And I looked at it and I laughed again, and I went, "Ridiculous. Like, that— no, I don't have epilepsy." Because as far as I was concerned, the only type of epilepsy I knew was what I now know are called tonic-clonic seizures. But I knew them as grand mal, so in my head, I was like, "Well, that's obviously wrong. You know, I'm not having grand Mal seizures. How utterly ridiculous." Didn't think two thoughts about it.

[light electronic music] Until a couple of weeks later. I was having seizures again that whole time. Still hadn't done anything about it. And then one day, when I was at work on my break, I got up the nerve to look it up again. And I went to that same British epilepsy website, and I read about what they referred to as focal aware epilepsy, and they had a list of symptoms. And I was reading about myself. I knew immediately deep, deep, deep in my gut, it was right. And I immediately left work and I went to a walk-in clinic, because my family doctor is very far away.

I described my symptoms, and I told the doctor, "I believe I have focal aware epilepsy. I would like to see a neurologist, please." And I was very adamant and, of course, he suggested, "Oh, maybe you're having panic attacks," and I said, "No. I've never had those in my life. I know what those are. This is not what's happening." I said, "You have to understand, I've been having these my whole life. I've just figured this out right now. I need to see a neurologist." And I just kept saying it over and over again. "Please, I'd like to see a neurologist. Can I see a neurologist, please?" So, then he finally said, "Okay, sure, I'll put in a request for you to see a neurologist." And that's what got the ball rolling.

[uplifting electronic music] By the time COVID started and the world drastically changed, I was having about ten seizures a day, and I still didn't know what was wrong with me, so it was incredibly surreal. My biggest concern for myself at that time, my own health, was my seizures, because I didn't know if they were harming me at that time. I didn't know what it meant to have so many seizures. I didn't know if

something bad would happen to me before I got the diagnosis. When I was finally able to have my appointment with my neurologist, it had been about a six-month wait by the time I met him, so I was very, very eager. And within that first appointment, based on my descriptions, he felt very confident I likely was having focal aware seizures. That was the first time it was suggested to me that I probably had temporal lobe epilepsy. And we did some tests, got some MRIs done.

So, I got my MRI results back, and it ended up that I had a little brain tumour on my right temporal lobe in the exact spot that is known to cause focal aware seizures. I was not expecting that at all. And, again, oddly, I was happy about it because it was real proof. It's not that people didn't believe me necessarily. Like, I never had someone straight up say, "You're lying," or, you know, "I don't believe you," but I think there was some healthy amount of skepticism from people.

[bubbly electronic music] The most profound thing of this whole experience has been, to me, the way I've reacted to it, because I wouldn't have thought if someone had told me, you know, five years ago, "You're gonna find out you're epileptic, and there's going to be a pandemic, and you're going to learn you have a brain tumour, and you're going to be on medication," that I would be oddly content with it. I think in hindsight now, I understand that it probably, in many ways, shaped who I am as a person in general, as a whole. And I was very calm. I've always been weirdly calm, full of wonder and excitement, almost, about this, because I've learned about myself. I've learned about my brain. I've learned things about my memory that most people never get the chance to experience. Never! Like, actually learning about how my mind remembers things— fascinating. Absolutely fascinating. And I've been continuously fascinated throughout this entire experience. I've looked at this whole thing as an adventure, which I know, again, is unusual. [chuckles]

But I tend to be a pretty positive person, in general, and this has just been so damn wild. Like, when I talk about it, I feel like I'm talking about a movie I saw. I just find it so interesting. And to really know myself that way, it's really a gift.

00:11:37 Heather

[light electronic music] Nikki's experience is much more common than you might think. Though women make up nearly half of the world's population, and have higher rates of neurological disorders, there is still a gap when it comes to better understanding and treating women living with brain-related illnesses. So why is that? Well, to begin with, brain diseases such as epilepsy, stroke, Parkinson's, and dementia, as well as many other neurological conditions, affect women differently at various stages of their lives— from puberty, to pregnancy, to menopause. And like Nikki, many women face systemic barriers and biases when they seek help, often leading to a delay in diagnosis and treatment. Our guests today want to help change that by advocating for more awareness and education in the field of women's brain health.

I'm thrilled to welcome Dr. Angela O'Neal, Director of the Women's Neurology program at the Brigham and Women's Hospital in Boston, and Assistant Professor of Neurology at Harvard University. Also joining us is Dr. Esther Bui, a neurologist and epileptologist at the Krembil Brain Institute in Toronto. Dr. Bui is an Assistant Professor at the University of Toronto, and the founder of Canada's only women's neurology clinic.

Thank you so much for joining me today.

00:13:08 Dr. Angela O'Neal

We're excited to be here.

00:13:09 Dr. Esther Bui

Thanks for inviting us.

00:13:14 Heather

It's great to have you. So, I know that the two of you have collaborated on research projects in the past, and you seem to have a great vibe between you. I'm curious, how did you first meet?

00:13:24 Dr. Esther Bui

I specifically sought out Dr. O'Neal. She has really pioneered a lot of the work worldwide but has made such a big impact with Harvard's program. And when I first started setting out to see how we can do a similar program in Canada, I first looked to Harvard.

00:13:42 Dr. Angela O'Neal

It's a mutual love affair. Dr. Bui is absolutely wonderful. I'm really enthusiastic of what she has created in Toronto. It's a fabulous program.

00:13:54 Heather

Well, that's one of the reasons why we're getting together today, to talk about the issues affecting women who live with brain diseases and some of the challenges that they face in getting help. Women's neurology is finally gaining some traction. So why has it taken this long? Dr. O'Neal.

00:14:10 Dr. Angela O'Neal

Well, I think that we didn't recognize the gap until we started really working in the area. And so for me, this was 2010 that I really started working in this area. And before that, I

00:14:22 Dr. Angela O'Neal

Would have said, "Oh, of course, I understand women's issues," but I didn't know what I didn't know. And so I think that starting working in this area, you really recognize what a gap there is. Many of my subspecialty colleagues had been working in this area long before I joined, but there was this huge gap within general neurology, for sure.

00:14:43 Dr. Esther Bui

Certainly, we study what we care about, and certainly, the last few decades, women have grown more and more into leadership positions, both in academia and in research leadership. And I think that has really opened up the gateway. In the early years, like, Dr. O'Neal and Dr. Janet Waters really understood its inherent value, but myself and many others, including our trainees, have really reaped the benefits of all the incredible hard work when, really, there was nothing that pre-existed our understanding of women's neurology. I think one of the most important things that people don't recognize, as Dr. O'Neal hinted at, is that we don't know what we don't know. And the absence of data doesn't mean the data of

absence. And this really reflects what is the iceberg of sex and gender issues in neuroscience. 50% of the data that exists now in the last few years really don't even factor in sex or sex-related biological factors that are neuroscience research. So, we have a long ways to go, but we are beginning to recognize how important this topic is.

00:15:53 Heather

Dr. Bui, earlier in the episode, we heard from Nikki, who's one of your patients. After years of experiencing symptoms that went unrecognized by her doctors, Nikki was finally diagnosed with epilepsy in her 30s. How common is her story?

00:16:07 Dr. Esther Bui

Nikki has a, first of all, spectacular story because she's such a great storyteller as an individual, but unfortunately, it's far too common. And there's an aspect of epilepsy that's unique in that people can tell you their internal feelings of their seizures, and it will feel very bizarre and fictional at times. And if you think back on what Nikki tells, it sounds like it's from a storybook.

00:16:34 Heather

It does.

00:16:36 Dr. Esther Bui

But the reality is it's simply an electrical phenomenon called a seizure. Physicians need to better recognize that seizures can manifest as really anything. The brain is capable of any electrical activity that can malfunction and cause a seizure, and when the speech areas are not involved, and we're not having a convulsion, which is the most common seizure type that the public recognizes, being able to describe your internal feelings like Nikki does so well, doesn't negate the fact that this is still a medical phenomenon. One of the complicating factors of Nikki's story is that she was a young woman. And I think, in my experience, and there is data out there, is that there is a sex and gender bias towards women having a higher likelihood of being diagnosed with anxiety, or depression, or other neuropsychiatric disease.

00:17:29 Dr. Angela O'Neal

I would say, to echo what Dr. Bui said, is that I think women often are dismissed, and simply because you have anxiety, depression, or post-traumatic stress disorder doesn't mean that these symptoms are not real and certainly can be devastating. So, I hear it a lot that patients will feel like they're not listened to. And I think that's really important to hear what the patient's story is and support them to get better.

00:18:01 Heather

[light electronic music] And how does that make you each feel as clinicians when you hear these stories from your patients?

00:18:07 Dr. Esther Bui

I'm quite saddened sometimes, and there are some devastating consequences, and many of them are unintentional. But women who tell me that they've been told, specifically as young women, that they should never have children, or that if they took their medication, their children would be damaged or

severely injured. And it goes counterintuitive to everything I know of, having met hundreds of women who genuinely care about, one, remaining seizure free, but also having a pregnancy that is giving the best chance of their developing child a chance to not be injured and be healthy.

00:18:43 Dr. Angela O'Neal

I think several things happen. Either the women are counseled incorrectly that they cannot have a healthy pregnancy, or they're often undertreated. It's very common for disorders like migraine for patients to be undertreated. I remember distinctly a very sophisticated male colleague once said, "Well, they should just bite the bullet." And that just— it's just not right, nor reasonable. We have safe medicines. We can treat these women, and they should be counseled as such.

00:19:16 Heather

I wanted to ask you as well about the whole idea of fertility and pregnancy. A lot of patients who are living with these illnesses may want to have a family and they may be dissuaded at some point in their journey. So, what do you have to say about that, in terms of the option of fertility for many of these patients? Dr. Bui?

00:19:36 Dr. Esther Bui

It continues to be a passion project of mine to emphasize that because we don't have data, doesn't mean that it's unsafe, and also to balance the costs at stake. And breastfeeding is an example that there's not a lot of information out there on medications and lactation, but because there's not enough medication, doesn't mean that a one-size-fits-all type of example can fit for women who are wanting to breastfeed their child with medications on board. And the same can be said about fertility medicines. There is really very limited data on how fertility medications, especially the hormones needed to support early stages of fertility treatment, can impact diseases like epilepsy, where we know estrogen can potentially worsen seizures, whereas progesterone can potentially protect women from seizures. But because we don't know that information doesn't necessarily ring true that fertility treatments are unsafe. It's simply we don't have enough data, and Dr. O'Neal and I, and many others across North America, are working hard to get that data.

00:20:42 Dr. Angela O'Neal

I think when we're talking to a woman who desires a pregnancy, we have to think about the huge benefit that is.

And when we don't know the risks, I think it's best to say that these risks are probably small, or at least the benefit outweighs those risks. And we really need to put that equation in mind, because the absence of data doesn't mean it's not safe to do it.

00:21:09 Dr. Esther Bui

I'm having patients tell me their doctors are telling them they should not get fertility medicine, or that because they have epilepsy, they shouldn't go through fertility treatment. That is devastating to any human being, you know, if you want a child and you cannot have access to medical care. And I think doctors are saying that because there's no data. It's basically altering our entire life course of one human being because of the absence of data.

00:21:36 Dr. Angela O'Neal

I've heard it even as simple as things with migraine with aura. "Well, maybe you shouldn't go through these hormonal treatments because there's a high amount of estrogen." It's like, that's absolutely crazy. I'm sorry, the risk is small. The benefit is huge.

00:21:50 Heather

Dr. O'Neal, can you actually explain what an aura is in case listeners aren't familiar?

00:21:55 Dr. Angela O'Neal

An aura is a transient neurologic symptom that is associated with a headache, which is migrainous. And that transient neurologic symptom is most often positive. So, we see flashing lights or zigzag lines that move across the field, or pins and needles that move down the leg. So, there's a number of different neurologic symptoms that occur associated with migraine. Usually aura happens before the migraine, but it can happen with the migraine, or it can happen even in the absence of headaches.

00:22:28 Heather

Why don't we take a step back for a moment, and let's talk about why is it so important to consider the experience of women differently than men, especially when it comes to brain disease? Dr. Bui?

00:22:38 Dr. Esther Bui

Yeah, I think one of the factors that really changes the trajectory of health for women is just purely the biological component. We have monthly fluctuations in hormones, but those fluctuations have important health implications, whether it's important to our mood, to our epilepsy, to our migraines, as well as pregnancy. Pregnancy is very important to many women, and that brings in a lot of interesting and important aspects, which is whatever's happening to a woman's body at this time impacts another human being. The health of a developing fetus, a newborn child in the postpartum stage is intricately linked, so whatever decision you make is doubled in terms of its impact and importance.

00:23:29 Dr. Angela O'Neal

The other thing that we're finding the more we study it is that complications and things that go wrong in pregnancy have implications for women decades later. So, the fact if a woman has preeclampsia, that increases her risk significantly of cardiovascular disease decades down the line. Gestational hypertension increases your risk of having cognitive complications decades down the line. So, it's a very complex life stage that not only affects two individuals, but it has impact on a woman's health decades down the line.

00:24:05 Dr. Esther Bui

And just to springboard from that really important point, you know, we're coming from an era where pregnancy was an exclusion factor in research, and we're coming into a new era where pregnancy is an inclusion factor in research, where we better understand what happens in pregnancy and its long-term implications.

00:24:25 Heather

Can you tell me a little bit more about that? How are things changing in the research landscape when it comes to women and pregnant women, as you mention?

00:24:32 Dr. Esther Bui

I think we're being more explicit about studying what happens during pregnancy, and as Dr. O'Neal has mentioned, many times in the past, researchers did not want to put a pregnant woman at potential harm during that pregnancy. So, if there are drug trials, or if there are interventions, participant safety was an important and understandable concern. But research goes beyond drug trials. It goes into observational studies. It goes into long-term outcomes. And because of that inherent absence of data, it kind of extended to all research in excluding pregnancy, and that's not necessarily the case. We know that we can safely research pregnancy states and learn better so we can inform our pregnant patients on what to expect. And this is very well demonstrated in the world of epilepsy, where there are registries that are just blossoming worldwide that follow women through their pregnancy and outcomes for their offspring as well as themselves during pregnancy, and also in the six to eight years following.

00:25:38 Dr. Angela O'Neal

As Dr. Bui mentioned, epilepsy has really led the way here, but there's very scarce data on things that are just really common, like headaches and pregnancy. We have retrospective studies, but, you know, often none of the new medications that we're using for migraines have been studied in pregnancy or lactation. So, we have a lack of information to give our patients, and since we don't have safety information, we have to say let's avoid those things for now. In the area of stroke, all the stroke trials for thrombolytic, that is clot-busting therapy, pregnancy was excluded. And now we're coming to a point that, you know, the characteristics of the stroke should drive what we do for our pregnant women. It's really taken decades and a lot of push from leaders in the field to start to look at women who are pregnant because they deserve to have information and be treated appropriately.

00:26:35 Heather

Well, especially as you say, as the consequences of what they experience at these different stages can be even manifested later in life. So, it seems that there's more at stake than ever.

00:26:44 Dr. Esther Bui

Well, one really important example is how women experience stroke and cardiovascular disease. The classic kind of Hollywood presentation of a middle-aged man with all the vascular risk factors like high blood pressure, smoking, being overweight, and then the crushing kind of "elephant on my chest" pain. Many women don't experience that. For example, women may experience a different set of symptoms, like chest pain or nausea, shortness of breath, or fatigue. These aren't as typical as the sudden onset numbness or weakness in the face, arm, or legs that we generally know about acute stroke. And so, they may be having a serious cerebral vascular or cardiovascular event that is life threatening that has excellent evidence for treatment, but they don't seek treatment because we don't understand as a public enough how women experience the same illnesses as men.

00:27:43 Dr. Angela O'Neal

I'd also like to add that stroke risk factors are quite different for women. So, for example, migraine with aura is a very common risk factor for women, as is depression, and atrial fibrillation is a higher risk for

women than for men. So, there's differences not only in how they present, but the risk factors are different. And then, as I mentioned earlier, the fact if you've had preeclampsia, that's a risk factor for stroke. There's also a treatment bias by physicians here women are undertreated for their neurologic conditions, such as stroke. They're less likely to get appropriate stroke therapies than a man, so it has important outcome problems.

00:28:26 Heather

Well, you mentioned bias. We've also talked about this whole idea of many women getting diagnosed later, in some cases getting misdiagnoses. And then, of course, there's hormones to think about. So, with all of these gaps, I mean, what is the real risk to a lot of the women that you treat, and women living with brain disease overall, if they don't get the proper treatment?

00:28:45 Dr. Esther Bui

I think one of the important changes in medicine is moving towards precision medicine. And we've moved in this example using genetics and having such a highly individualized, tailored treatment, but we're neglecting 50% of our population. And so women's issues is part of precision medicine. And so recognizing the values women have, and not only just the sex factors, the biology and hormones, but also the gender factors. Women are, in most households, the primary caregiver. Women have been more heavily affected by COVID and the pandemic. More women have lost presence in the workforce, and so in addition to recognizing that there are biological factors to the patient that you're caring for, there are psychosocial factors as well. And having that integrated approach, both sex and gender in neurological care, provides the chance to give true precision-based medicine.

00:29:46 Dr. Angela O'Neal

Oh, I so agree. Women are more likely to be caregivers. And so the burden for women who are taking care of a spouse with Alzheimer disease is huge. So, it's not just the sex, but it's also the gender and the roles, and very important to support our patients in getting the best neurologic health it can.

00:30:07 Heather

Women, as you mentioned, are so often in the position of caregiver. Do you find that a lot of your patients will actually avoid treatment when it could be helpful to them?

00:30:16 Dr. Esther Bui

You know, avoiding isn't really the right word, because avoiding means that you're purposely not doing something, and I think it's simply you can't. and I'll give you an example of appointments being set at 8:00 o'clock in the morning or after-school pickup times. There are challenges with not just childcare, but also elderly care. And so, women are caregivers to both levels of generations. And so, having simply the time is very difficult for lots of primary caregivers. And if you have to choose between going to work and providing care, and groceries, and pickups for your young children, and driving your parents to their doctor's appointment— and I'll say firsthand that I was literally at the doctor's waiting room with four other women and their elderly parents, that I let out a good chuckle that, you know, our “n of five” study on that particular day at the eye doctor's reminded me that women do do a lot of hidden kind of unrecognized work. And so, we don't avoid going to doctor's. We simply don't have the time, for many of us.

00:31:21 Dr. Angela O'Neal

I would echo what Dr. Bui so eloquently said— that they're not avoiding care. They're simply placing others' care above their own needs. So, their care gets delayed. And I hear that every day. You know, I didn't have time because of XYZ, but now I'm coming back to it. And subsequently, they're suffering.

00:31:42 Dr. Esther Bui

When they do seek care, recognizing that this patient in front of you has gone to extraordinary lengths to be there and prioritizing their wellness, it is not to be dismissed.

00:31:55 Heather

Dr. Bui, I understand Nikki, who we heard from earlier, came and presented her story to your class. So, what was that like for the students who listened to her story?

00:32:04 Dr. Esther Bui

I have to say, every teacher hopes and prays for that moment when all the light bulbs kind of flash on in their students' learning experience, and this is exactly what happened. And in fact, I think multiple students said to me afterwards that the hair on their neck rose because of how compelling and concise Nikki was with her experience. Nikki's story is really a gift that Nikki can provide to advocate for other patients, other young women who may have been neglected and not listened to, but also to other physicians, to recognize that seizures can sound exactly like what Nikki has described.

00:32:44 Heather

And there was one medical student in particular who was there that day and wanted to tell us how he felt listening to Nikki talk about her experience. Here's what Roshan had to say.

00:32:55 Roshan Malhan

[upbeat music] My name is Roshan Malhan. I'm a second-year medical student at the University of Toronto. Over the course of our first and second years, we have the opportunity to engage in a number of clinical skill sessions that touch on a variety of areas of medicine. And as part of our neurology block, we had the pleasure of learning from Dr. Bui. And Dr. Bui was great because she made it a point that after the end of our sessions, we would go and visit one of her patients and get the opportunity to connect what we were learning in our textbooks and our lectures to a real patient and their experience in our healthcare system. When I heard Nikki tell her story, I thought it was particularly impactful because the majority of our learning at this stage is all through PowerPoints and readings, and we don't get a lot of face-to-face interactions with patients, at least not yet.

And so, to connect the things that we were learning to a real person, I thought that was incredibly valuable. Something that struck me about Nikki's story was her difficulty in navigating the healthcare system, in that for a very long period of time, she was either not believed, or ignored, or dismissed, perhaps, and it really required a lot of onus on herself in order to get the level of healthcare that we assume that all patients should be receiving and should get. And I think that if Nikki didn't really take it upon herself to go the extra mile, to sort of force her way into seeing the specialists, like Dr. Bui, who

she eventually saw, she probably would still be undertreated or not treated at all. And that would have a drastic impact on her quality of life.

We don't assume the patient should have to advocate for themselves. I think we believe that the system should take care of a lot of that, that any patient should be able to enter the system from a primary healthcare standpoint and get to where they need to go. But I don't think that's true. I think it really requires a lot of patience to force open those doors, and I'm glad that Nikki did. It really struck me, though, that she had to, because if she didn't, she probably wouldn't receive the level of care she needed. [light electronic music]

From the perspective of a future doctor, I learned how important it is to engage patients and empower them to feel like they can demand a certain level of care, particularly if they feel that they've been dismissed or not taken seriously by the healthcare system. The time we spent with Nikki, even though it was probably just under an hour, really stuck with me. I think connecting these ideas to the patients and their experiences in a face is really quite a powerful thing. [music fades out]

00:35:42 Heather

Dr. Bui, how important is it to provide this kind of access to young medical students and to be able to change the paradigm when it comes to education around this issue?

00:35:52 Dr. Esther Bui

I feel very passionate about this, mainly because as educators we will never build, you know, the towering structures that others can build, but we plant the seeds. And sometimes, if we're lucky, those seeds outgrow those towers. And so this is, for me, foundational in that whatever we do for our patients, we need to continue to advocate at multiple levels, and spreading knowledge and having a patient-centered focus and a patient-led focus is one of the ways that we can advocate for our women's issues in neurology.

00:36:31 Dr. Angela O'Neal

So, I was just thinking and reflecting that I'm participating in a Harvard sex and gender course, and we are going to present the patients' focus, you know, to make the point that what happens, you know, when the patients aren't front and centre, and how that can affect their care, and how these things are so important to take into account when we see young women.

00:36:55 Heather

Well, Nikki talks, also, a lot about feeling like she was bounced around to different doctors who she felt never really took her concerns seriously. So, I guess I'm curious, you know, how often do you hear stories like that?

00:37:06 Dr. Esther Bui

All the time, unfortunately, and it's routine for me at the end of every clinic day to have at least one, if not multiple, people say thank you, to take the time. "The time is worth its weight in gold," is what I tell our students. If you take the time, every subsequent visit will be more impactful, more efficient, more

worthwhile of your time and the patient's time to direct the care that is individualized and specific to their needs at this moment in their life, so it's worth the time to invest.

00:37:39 Heather

And how does it feel when you have a patient who you're able to treat in a way that helps them medically but also helps them emotionally, psychologically? How does that feel as a physician?

00:37:50 Dr. Angela O'Neal

Feels like I've finally done my job. As Dr. Bui says, when you can listen and help patients, and really move their care along, I really feel like I've done my job as a neurologist.

00:38:02 Dr. Esther Bui

I'm usually the third, fourth, or fifth neurologist people have seen, mainly because of this subspecialty, and I'm sure Dr. O'Neal is the same. And I think the concept of, you know, your story and this new chapter in your life begins today at this visit is something that, almost universally, every single person has welcomed hearing from their physician.

00:38:26 Heather

So, based on everything we've talked about today, how important is it to offer programs that are specific to women's neurology? For example, Dr. Bui, I know you're involved in this very unique program called the Lullaby Project for Women with epilepsy. Can you tell us a little bit about it?

Absolutely. It's another passion project of mine, and it's really to explore what is inherently part of the fabric of women's neurology, which is patients are much more than their disease. And if we can somehow fit those pieces of the puzzle together, we have a full picture of who they are and how their illness may impact who they are as a person. And using music therapy, and we've been able to partner with Roy Thomson Hall, which is the equivalent of Carnegie Hall in the States, has really empowered participants in our study to explore themes of how music and music creation, and specifically creating a lullaby for their unborn child throughout the process of navigating, managing their epilepsy, has been an incredible journey to watch. And one of the highlights of my work is to see these women bring in their beautiful babies and have this perfectly written lullaby for this child.

00:39:40 Heather

So beautiful. I can see you're both smiling right now because you can't not smile when you hear about a story like that. [chuckles]

So, I want to ask you both, where do we go from here? Why does women's neurology need to be a subspecialty, and how are you going to make it happen?

00:39:55 Dr. Angela O'Neal

Well, we're already making it happen. Doctor Bui, myself, and Doctor Waters have fellowship programs in women's neurology. And it was a very interesting journey— I can speak for myself— to get that approved through Harvard, because when I first went forward with this idea, I actually got a fair amount of pushback. Like, “Well, our residents already know this. You know, 50% of the patients are women.” And it's like, no, they do not know this. And I work with some of the brightest neurology residents on

the planet, and it's just that there's so much to learn. There's, again, a lot of nuances to this, whether it be an epilepsy, or migraine, or stroke. There's just a huge amount of information, and so to move that ahead has been a fantastic journey for me.

00:40:46 Dr. Esther Bui

We are beginning to develop the women's neurology program here in Toronto, and there is an accredited women's neurology fellowship, and we've graduated two fellows, with our first fellow coming to join us and creating our first obstetrical neurology program, which is incredibly exciting to see. But there's more work to be done, and I think having women hear that our programs exist, finding ways to support it, even if it's following us on Twitter or being aware as public knowledge that this program exists, and to ask their physicians for referral to one of the many physicians who manage women's issues in neurology in Canada and the US, is the beginning of something greater than just our individual programs.

00:41:34 Heather

Well, and we should mention your Twitter is @WomensNeurology, in case anybody is interested in following.

Okay, I think it's fair to say that the two of you didn't set out to be pioneers and advocates for change in women's health when you first got into this, but that's certainly where you found yourself. So, what has made you so passionate about women's health issues, and what have you learned in your journey? Dr. O'Neal?

00:41:58 Dr. Angela O'Neal

I think that this is a new field, and to be able to be impactful in this field has made it really exciting for me. Again, the more we explore, the more we understand that there's a huge gap and need. One of the things that Dr. Bui and colleagues and I are working on is developing a women's neurology curriculum, because many medical schools have very little in the way of teaching of this. And so, we really want to expand the knowledge and make this, you know, something that's commonplace for all our residents in neurology.

00:42:32 Heather

That's terrific. Dr. Bui?

00:42:34 Dr. Esther Bui

Yeah, I'll have to say that I'm, kind of, constantly energized by seeing other women, and it's a remarkable transformation. I can't say enough. And I share with my own students how you meet a woman who might be frightened or traumatized by her experience, perhaps as a child or as a teenager, and now newly pregnant. There's a lot of frightening aspects of revisiting this and at a high-stakes situation. And then within the course of our year journey together, during the pregnancy and welcoming a newborn child, these women transform. And I remember my own transformation with my own child, and how beautiful that transformation is, but to be able to witness that on a daily basis is really the fundamental reason why we do what we do, because our patients really inspire us.

00:43:23 Heather

And many of them, they've been through a lot by the time that they see you. I mean, they've been dealing with these illnesses for many, many years.

00:43:30 Dr. Esther Bui

Nikki is a perfect example of that.

00:43:33 Heather

So, what is your final message to anybody listening right now who might be out there and suffering needlessly? Dr. O'Neal?

00:43:39 Dr. Angela O'Neal

Well, I think if you can find a neurologist who specializes in the areas that they're having problems with, that is key, a neurologist who understands how hormonal sex and gender issues impact you. That is really important. And again, I can only echo what a joy it is to take care of some of these women. I mean, I love my obstetrical clinic because I get to see women and their lovely babies. I mean, it's just a joyful experience.

00:44:09 Heather

Isn't that ironic? Because I remember you telling me that in medical school, you definitely did not want to be an OB-GYN. You wanted neurology.

00:44:16 Dr. Angela O'Neal

Yeah, well, I knew—when I went into medical school, I knew I wanted to be a neurologist. And what I did not want to do was obstetrics. [Heather laughs] And so, my last rotation in medical school as a fourth-year student was obstetrics, and I've come a full circle.

00:44:33 Heather

Doctor Bui, what's your final message to listeners today?

00:44:35 Dr. Esther Bui

No, I'll have to echo that. There's nothing scarier to an obstetrician than a woman with a neurological condition, and nothing scarier to a neurologist than a woman who's pregnant. And I think this is where we bridge the gaps. I would say we're early, we're nascent compared to programs like Harvard and the University of Pittsburgh. But Canada has a role to play, and I'm very fortunate and I feel very privileged to be working with Dr. O'Neal, and Dr. Waters, and many others who are emerging out of the woodwork very clearly and eloquently, to echo kind of what our mission statement is, which is to provide women with care that is specific to them as an individual. And I think any support that's provided, whether it's just retweeting or keeping an eye out on happenings of our women's neurology program, would be, you know, a lot of inspiration to keep us going.

00:45:32 Heather

Well, I'm sure there are many listeners who feel empowered by what they heard today, and inspired about some of the advances that are being made in women's neurology. I know I am. Thank you both so much for speaking with me today.

00:45:43 Dr. Esther Bui
Thank you for inviting us.

00:45:46 Dr. Angela O'Neal
Thank you for having us.

00:45:52 Nikki Ashworth
[mid-tempo electronic music] Definitely when you're on the type of adventure I've been on, you need to be mouthy. You have to be persistent. You need to make yourself clear. It's not just about advocating for yourself, but recognizing you deserve to advocate for yourself and not putting it off. It's so hokey, but knowledge is power. [music fades out]

00:46:38 Heather
[mid-tempo electronic music] Thank you to Dr. Angela O'Neal and Dr. Esther Bui for joining us on the podcast today. Special thanks to Nikki Ashworth for sharing her incredible story, and to Roshan Malhan for offering his perspective, as well. If you'd like to hear more about Nikki's journey, head to our website uhn.ca/krembil and click on the show notes for today's episode.

This episode of Your Complex Brain was produced by Jessica Schmidt. Our Executive Producer is Carly McPherson. Thanks also to Dr. Amy Ma, Twayne Pereira, Suzanne Wice, and Meagan Anderi for their production assistance.

I hope you enjoyed today's episode, and if you did, I would love for you to tell your family and friends about Your Complex Brain. And don't forget to leave a review on your favorite podcast app.
[Your Complex Brain theme music]

Thanks for listening. We'll be back in two weeks with another exciting episode. Have a great day.
[Your Complex Brain theme music fades out]