

0:00:16 - Adele Scheiber

Welcome to your Health Unlocked, a podcast that empowers you to make better healthcare decisions by elevating accurate, unbiased information about today's most pressing health topics. This podcast is produced by the National Women's Health Network, a non-profit group of activists fighting for better access to high-quality healthcare across the nation. We do not rely on big pharma, medical device companies or insurance companies, meaning we answer only to science and healthcare consumers like you. If you'd like to support us in our work, head on over to nwhn.org/donate and make your contribution today. Hi there, I'm Adele Scheiber, the host of the Your Health Unlocked podcast on the Director of Communications here at the NWHN, also known as the Network.

Endometriosis is a condition in which tissues similar to the lining of the uterus grows outside the uterus, resulting in chronic pelvic pain, excessive bleeding and other life-altering symptoms, described by today's guest as like a cancer that never kills you. This devastating illness impacts one in 10 women nationwide, and yet we know almost nothing about it. Today, I sat down with Dr. Jocelyn Fitzgerald, an assistant professor of obstetrics and gynecology in the Division of Urogynecology and Reconstructive Pelvic Surgery at the University of Pittsburgh School of Medicine. As you'll soon discover, Dr. Fitzgerald is extremely passionate about endometriosis research and getting endometriosis patients access to the care they need.

Dr. Fitzgerald completed her female pelvic medicine and reconstructive surgery fellowship at Georgetown University, MedStar Health and her gynecology and obstetrics residency at the John Hopkins Hospital. She attended medical school at the University of Pittsburgh and graduated from the Physician Scientist Training Program. Before medical school, Dr. Fitzgerald attended the Schreyer Honors College at Penn State University and earned dual degrees in neurobiology and women's studies, with an emphasis in women's health. Her research has focused on mechanisms of female chronic pelvic and bladder pain, patient-centered outcomes of gynecologic surgery and predicting how women seek care for pelvic floor disorders, with a particular interest in the role of social media in women's health. Keep listening to learn more about endometriosis causes, symptoms, treatment and the work that still needs to be done in this space. Welcome, Dr. Fitzgerald, to the Your Health Unlocked podcast. We're so happy to have you.

0:02:57 - Dr. Jocelyn Fitzgerald

Thank you so much for having me. I'm so excited to be here.

0:03:01 - Adele Scheiber

So why don't you tell us a little bit about yourself? You know what are you a doctor of? That kind of thing.

0:03:04 - Dr. Jocelyn Fitzgerald

Yeah of course, I am like you said, my name is Dr Jocelyn Fitzgerald. I am a board-certified urogynecologist, also known as a female pelvic medicine and reconstructive surgery specialist. Most people in the community know urogynecology a little bit better. I practice at the University of Pittsburgh, at McEwen's Hospital. I'm an assistant professor of the above that I mentioned in the Department of OB-GYN and reproductive sciences. I did my, you go to a lot of school to become a urogynecologist. So, as you might have said in the introduction, I went to the University of Pittsburgh for medical school. I was trained as a physician scientist in they have sort of a specialized, almost like a mini-intern MD-PhD program, and then I did my residency in OB-GYN at Johns Hopkins and then I did my female pelvic medicine and reconstructive surgery fellowship at Georgetown before coming back home to Pittsburgh to McEwen. So that's kind of my background and now I've been in practice. This is my third year.

0:04:17 - Adele Scheiber

Wow, well, congratulations. That sounds like that is quite an accomplishment. What is it? 35 years of school, roughly about. It's a long time.

0:04:27 - Dr. Jocelyn Fitzgerald

Yes, I got my first grown-up job at 34.

0:04:32 - Adele Scheiber

It happens. I know how that feels. So either. A couple of things. So I've heard of a gynecologist, I've heard of an OB-GYN. What is a urogynecologist exactly Like? What's the difference?

0:04:46 - Dr. Jocelyn Fitzgerald

Yeah, that's a great question. So your general OB-GYN and there's a lot of variation in general of obstetrics and gynecology, but those are the physicians and surgeons, who have four years of post-medical school training and their proportion of obstetrics and gynecology practice can be variable but those are the people who deliver the babies, who you see in the office. They do your pap smears, they do maybe a little bit less complex pelvic surgery. So you see a lot of, like I said, management of peps and hysteroscopy and some fertility issues and some fibroids and bleeding. But you'll see them for your yearly checkups and also, like I said, they do a lot of obstetrics, more low risk obstetrics. There's maternal fetal medicine which would take care of lots of advanced genetic type things.

Ob-gyn is a field a lot of people don't realize just how many advanced fellowship trained physicians and surgeons lie under the umbrella of OB-GYN, and urogynecology is one of those. So, you do four years of OB-GYN training and then you do a subspecialty fellowship and mine is in urogynecology and the real

difference in what I do is that I do more advanced pelvic surgery for pelvic floor disorders. So those include prolapse, which is when the vagina and the pelvic organs behind the vagina sort of bulge out of the vaginal opening, incontinence, which people leak with COFLAF-C so they can't get to the toilet in time. I treat those conditions with medications or procedures or surgeries. I also do a lot of pelvic pain, a lot of just difficulties with toileting, both urinary and fecal, and then some more rare but more advanced things would be like a fistula from birth trauma. I do a lot of work in that sort of area. So, yeah, someone came to see me. They in general wouldn't be getting a pap smear but they would be seeing me for dysfunction of their pelvic organs.

0:07:05 - Adele Scheiber

Right, I see. So you're like the second to third referral kind of sounds like yes, I got you.

0:07:11 - Dr. Jocelyn Fitzgerald

Yes, that's right, I get a lot of referrals from general OBGYN and also from internal medicine, family medicine, urology, sometimes as well.

0:07:22 - Adele Scheiber

So thank you for explaining that, because that really does clear it up. You're also I mean, you are primarily surgeon, which, am I right? Is that kind of a male dominated field still, or what's the deal there, yeah?

0:07:34 - Dr. Jocelyn Fitzgerald

So yes, I am predominantly a surgeon. I do medical management of recurrent UTIs and urgent continents, that kind of thing, but we work with a lot of mid-level providers who kind of help us with those things so we can focus on patients who need to go to the operating room. So, yes, predominantly a surgeon and urology. Just now we are finally sort of in an era where I would say certainly the people coming out of fellowship are predominantly female.

But it was only until very recently that the people at the highest levels of our professional societies, of our division leadership, are becoming predominantly female as well. But I will say OBGYN as a whole and I mentioned that there's a very large umbrella. People think people don't realize, just like, how much falls under OBGYN and how much specialization there is inside of our field. The majority of our leaders in our medical schools in OBGYN are still men.

0:08:39 - Adele Scheiber

Wow, that's interesting. That's a whole different talk show on what it was like to go through OBGYN in school and there are a lot of great men.

0:08:48 - Dr. Jocelyn Fitzgerald

We want a men in OBGYN. We don't want men to be afraid of women's bodies. That's part of it.

0:08:53 - Adele Scheiber

Part of the problem. Part of the problem.

0:08:56 - Dr. Jocelyn Fitzgerald

Part of the problem. But it is true that our field has been majority female since probably the mid to late 90s and the leadership hasn't necessarily reflected that, which is interesting because OBGYN is kind of the only field of surgery, that's like that.

0:09:12 - Adele Scheiber

Yeah, cool. Well, we'll put a pin in that, because I have another one.

0:09:16 - Dr. Jocelyn Fitzgerald

Put a pin in that one.

0:09:20 - Adele Scheiber

I hear tell you've been doing a lot of work recently with endometriosis patients. What exactly is endometriosis and how prevalent is it?

0:09:28 - Dr. Jocelyn Fitzgerald

Yeah, so, yes, when I was again this is like another thing that goes back to my very formative college years it was really interesting double majoring in biology, neuro, it was neurobiology and women's studies, because the two, the two sort of conditions, I walked away thinking like I need to go to medical school and I need to make a difference in these, the understanding of these processes. One was menopause and the other one was endometriosis, which is a sort of very complicated, absolutely devastating disease that we know so little about relative to the fact that 10% of people born with the uterus have it. To answer your first question, so what is endometriosis? And I remember learning about this and being saying, oh my God, this is a problem, this is a big problem. It's a condition where tissue

similar to the endometrium, which is the lining of the uterus, that's what sheds every month when you get a period that tissue, tissue very similar to it winds up in a part of the body that isn't the uterus.

And I say that very carefully because for centuries I have a textbook I want to think it's a honey right here, right here textbook of practical gynecology.

It's like a vintage book from the early 1900s that I bought and there's a chapter in there on endometriosis and you would have thought it was written within the past five years, because that is how little we have progressed in our understanding of this disease. But the theory behind it was this retrograde menstruation theory that in the process of expelling the endometrium during menses you get back flow of this tissue through the fallopian tubes and it winds up in the abdominal cavity, implants itself and then becomes hormonally active every month when recycle. That theory may have some plausibility, but now we at least you understand a little bit more that these implants probably get there another way, because many patients become symptomatic and I'll talk about the symptoms in a second from this condition before they ever start getting a period. Young girls can have it and then also it can affect women into the menopausal transition and it can show up in places like as the brain, the lungs, places that aren't immediately accessible by the retrograde menstruation.

0:12:02 - Adele Scheiber

Pause. Even this tissue can show up in your brain and in your lungs.

0:12:07 - Dr. Jocelyn Fitzgerald

It's rare, but it has been found in the brain and it has been found in the lungs.

0:12:12 - Adele Scheiber

I only see that I've been reading up on this because I was like I should probably learn a little bit. That's news to me. Wow, that's sci-fi stuff right there. Okay.

0:12:22 - Dr. Jocelyn Fitzgerald

It is sci-fi stuff. It's a really a full body disease that we don't fully understand and in order for me to explain it to people in a way, so I'll be back up really fast and just say what are the symptoms. So, like the classic symptoms are debilitatingly painful periods. The classic story of like we all have, like a girl in our middle school classes who, like, missed school because of how bad their period cramps were we all know, we could probably all picture like who that person is, and painful period cramps have been passed off as a normal ticket into adolescence for women forever. But that is absolutely not normal. To miss school or to not be able to physically get out of bed, because the amount of pain you're in from menstruating is not normal at all, and I think we finally are recognizing that that's a really big red flag. So, a lot of times those are sort of the classic starting symptoms.

But a lot of the other symptoms that might even be more common are urinary pain, pain that feels like a UTI and then after an extensive workup you aren't finding that the urine cultures are positive.

A lot of IBS type symptoms, like a lot of GI and gut symptoms painful intercourse is a huge one, painful bowel movements and then some really strange symptoms. I mentioned the lung, saying some mutations can get like lesions higher up in their abdomen so they can get pain in some other weird places and then in like really rare circumstances, they can get like collapsed lungs every month from like this tissue bleeding into their chest cavity. I mean that's really really rare, but the more common things are these pelvic symptoms that we tend to overlook. And if you can imagine the tissue that becomes your period or that responds to hormones every month, if you have that in your abdominal cavity, you have like bleeding and blood and inflamed tissue firing up like on your intestines every month. And so the way I really have to explain it to people I'm like "it's like a cancer that never kills you."

0:14:31 - Adele Scheiber

That's exactly what I was just thinking. It was like it sounds like a cancer. It sounds like what cancer does it invades.

0:14:36 - Dr. Jocelyn Fitzgerald

That's right but it's not malignant, so in general it doesn't kill you. It just it kills you slowly in like the way that it makes everything hurt so badly. I explained it actually to my dad recently. It's like what did he heard of someone he knows this condition. He was like, "what is this?" I was like, imagine, once a month you feel like you have appendicitis, like that is what it can feel like, but we don't know anything about it, and we don't have a cure for it.

We have treatments that are pretty invasive, surgical, laparoscopic surgeries but it's still a big surgery to remove all the endometriosis. Usually by the time it's diagnosed I know this is one of your questions you wanted to talk about today seven or 10 years on average. So, at that point, like the amount of inflammation that's in the abdomen and the scarring that can happen can wreak total havoc on your gut health, your bladder, your reproductive organs. I didn't even mention infertility. I didn't mean to skip over that, but one of the biggest symptoms is infertility. So, it's a big problem and I try my best to raise awareness and there's a lot of people now raising awareness thanks to social media and the fact that there are some women with this condition that have big platforms and we're just really behind.

0:16:00 - Adele Scheiber

Yeah, well, so that you know, you kind of half answered most of my questions with that, which is great. So, it sounds like the challenges with diagnosing this and that seven to 10 year gap, it's because these

symptoms could be anything and everything right? We actually had somebody. Her name is Hannah George. She's a Harvard graduate or a soon to be graduate. She wrote a young feminist article for us because she has endometriosis and her doctor kept being like your toilet paper is too rough, like you just have a UTI. You listen to that, and they just kept dismissing her because she had the pain from urination symptoms and like so would you agree that the biggest confounder for diagnosing is that these symptoms could be anything right and there's no test, right? It doesn't sound like there's any test that'll get you.

0:16:45 - Dr. Jocelyn Fitzgerald

There's no test besides surgery.

Exploratory surgery which, you know, in the hands of a well-trained endometriosis surgeon, we can come back to that. There aren't many of them. The way that women's health has been structured has been set up to fail this disease because of the way surgeons are trained to deal with it and the training path produces so few of them. But in the hands of a well-trained surgeon, the biopsy and the removal of the endometriosis itself is the only test. And as a urogynecologist I'm actually not that kind of surgeon. I work very closely. This is another type of fellowship trained OBGYN. They'd go on to do advanced training in endometriosis excision, specifically because it is like taking out of cancer. It's very complex surgery, very similar to being a cancer surgeon, even though it's a benign disease. But I often see these patients first for their urinary symptoms, because that is what sends them into the doctor's office. They're like it burns when I pee, but more than that, I have this horrible squeezing pain, burning sensation in my bladder. I sometimes have incontinence and that brings them in and they are worked up and very little is found.

One of my I think, hopefully research hills that I will die on in my career is showing how closely linked urinary symptoms, which are often called something called interstitial cystitis, which is another umbrella term for this sort of diagnosis of exclusion of urinary pain. It's tied so closely to endometriosis, especially in reproductive age women, and so we're actually working on that. Now. I have a multidisciplinary clinic where I work very closely with these incredibly talented endometriosis surgeons and the patients that come to me first for their urinary pain. I get them in the hands of the endometriosis surgeon and I always go to the operating room with them to see am I on the right track? Like, are we doing the right thing for these people? Surgery is not a small deal. I'm not just shipping people off to surgery, like I have to feel really compelled that their urinary symptoms are related to this condition, and I will tell you anecdotally that I go and they all seem to have it.

0:19:17 - Adele Scheiber

So we're working on it. Well, and that leads me to kind of a follow-up, which is you said we don't know anything about it and it's under researched. Why do you think that is? What are some of the challenges researching this condition?

0:19:30 - Dr. Jocelyn Fitzgerald

I mean that is also another, probably whole discussion. But we do know that if you look at NIH research dollars and the percentage of them that go to OBGYN departments, it is less than 1% of all the money that the NIH spends. The amount that is spent on endometriosis is, frankly, negligible.

0:19:57 - Adele Scheiber

So let me just break that down. We have 50% of the population who needs an OBGYN. Less than 1% of that money... Got it. Cool, amazing.

0:20:06 - Dr. Jocelyn Fitzgerald

That's something if the NWHN wants to work on something that would be like at the very, at the very, very top of my party list, policy-wise.

0:20:18 - Adele Scheiber

As we interviewed folks because, like I didn't know that, you know what I mean.

0:20:21 - Dr. Jocelyn Fitzgerald

It's absolutely crazy. That paper was published last year, the year before, in the American Journal of Obstetrics and Gynecology. I'd be happy to send it to you. But less than 1% of the total funding. Yeah, for doctors they take care of 50% of the population, so that is probably the number one reason. But you know, other reasons are that we've normalized things like painful periods.

For so long there hasn't really been a field of medicine that's really owned this condition. Urology certainly doesn't own it but, like general OBGYN doesn't really own it either. And the field of medicine that specializes in endometriosis removal is new. It's small and if you want to look at or watch a fascinating documentary maybe you've heard of it it's called Below the Belt. It was produced by Hillary Clinton and Orrin Hatch and it's all about endometriosis and the payment complex that has come out of it.

So, this is also something that, if NWHN wanted to make a big impact in women's healthcare and how it's delivered, is reimbursement for women's health and women's complex women's surgery. There was the Centers for Medicaid and Medicare services, based their billing off of a Harvard report that came out in the 90s, I believe, and if you compare the amount of money that a surgeon gets paid to do complex gynecologic surgery versus, say, complex urologic surgery, for example. There've been lots of papers that have been published comparing like male and female equivalent procedures. Female procedures get reimbursed significantly less and when everyone thinks it's like, oh, gynecologic surgeons are mad, they're like not getting paid more. That's not true.

What matters is how much, in the way healthcare is set up now and many for profit health systems, even if not truly for profit like resources are going to go to the types of surgeons that generate the most

revenue for a hospital. So, if in your hospital you're doing these complex surgeries that take sometimes six or eight hours but the way the billing structure is set up to reimburse for them is minimal and endometriosis doesn't have these complex codes that you don't get, the surgeons don't get reimbursed hardly anything for these really complex endometriosis surgeries. I don't blame the hospitals. I wouldn't pour resources into employing those surgeons because they're taking up a lot of operating room time and they're not generating a lot of revenue because of the way the billing is set up. So, what the documentary is all about is how the really advanced endometriosis surgeons go into private practice and they charge cash. They don't even take insurance.

0:23:10 - Adele Scheiber

So I've been hearing that more and more and more lately.

0:23:13 - Dr. Jocelyn Fitzgerald

Yeah, women are taking out like mortgages to get these endometriosis excisions done by someone who is trained to truly do them in the right way and they're going into debt and also a lot of times that these surgeries are not pain relieving. They don't take away all the pain or all the urinary symptoms or all the gut symptoms when your body has been in pain for a decade. You know what I mean. So, there's a lot of things, long answer to your question,

0:23:42 - Adele Scheiber

No that's you really hit on a lot of what you're describing. It's not that the surgeons are mad. It's not a personal, it's a systemic incentive. It's a negative incentive.

0:23:57 - Dr. Jocelyn Fitzgerald

We lose out on talent if how are we going to recruit the best and the brightest MD PhD students to set up a lab in endometriosis if, number one there's no money, how are they going to you know there's no, it's like snowball effect, you know. If there's no, they tend to go into fields where they know they can get grants and pay for a lab and employ the people that work.

0:24:23 - Adele Scheiber

Because school's expensive and people got in the lab. I get it.

0:24:26 - Dr. Jocelyn Fitzgerald

no one Great why would you go into endometriosis if you're not going to make any money? You're going to be totally overwhelmed with patients and there's no infrastructure for research. So, I get people have to survive. You have to really be so committed to this disease.

0:24:43 - Adele Scheiber

That's fascinating and thank you for explaining that so fully, because I do think you know we tend to. We like it when there's someone to blame, right, and we like heroes and villains in our stories, and I think we often miss out on the systems and the institutions that are kind of making this hard for everyone, right?

0:25:03 - Dr. Jocelyn Fitzgerald

So, speaking of that, it's not, I think, malicious. I don't believe that, but these are systems that were set up 100 years ago and they might need a little updating and might need some new ideas for how we approach science or groups that have been left behind.

0:25:27 - Adele Scheiber

Ten percent of women. I mean, this is something that affects 10%, 10% and it's a hidden disease and it's totally debilitating.

0:25:34 - Dr. Jocelyn Fitzgerald

I mean, I wish that's. The other thing is, I'll say you have to really feel as though this is like your life's work. These patients being in pain for 10 years is not making you into a pleasant person. Right? Patients are very difficult to deal with. They are in so much pain, they have so many, they have so much PTSD. Their visits are exhausting for doctors. Most doctors do not want to touch endometriosis patients with a 10 foot pole because they dominate your clinic. They cry a lot, understandably. They have been gaslit by the medical system. They have been traumatized in the emergency room. So having those patients in your clinic is hard as a doctor, you have to have support. You can't take care of them alone and one of the only reasons I feel like I've been able to do it is because I have support from my institution. I work with these other surgeons. I have in-house physical therapy and behavioral health. I have relationships with, I hate to say this, but really committed young female doctors in other specialties like gastroenterology and physical medicine and rehab and pain medicine. Now that there's just more women doctors, it's easier to take care of these patients.

0:26:50 - Adele Scheiber

You know what you tell it like it is. You're just calling it like you see it. My job is to give you a platform to call it like you see it, so you kind of this leads perfectly into my next question is what are some tips you have for your provider colleagues, OBGYN and otherwise, for treating endopatients, whether it's somebody who walks in the door and they suspect, or whether they want to, like, make this their life's work?

0:27:16 - Dr. Jocelyn Fitzgerald

Absolutely Okay. So, the first thing I guess is if the patient walks into your office, validation is free and it's therapeutic. You know there's actually good data that saying to the patient, I believe you, I believe your pain is real actually has therapeutic value and the relief that they feel from having someone believe them and listen to them actually helps their pain. So, it's like that the ramp up of like being afraid that they won't be listened to actually makes pain worse. So, validation is free, Prescription for validation.

The second thing I would say is to a patient who is coming back and back with these strange abdominal pelvic symptoms keep endometriosis on your differential. You may not know all of the symptoms, but referrals are also free and just know who you're referring to. And that can be really challenging because there are, and this is where I'm going to poke a little bit at like some, there are a lot of like old school community OBGYNs who treat endometriosis who aren't fellowship trained and don't completely excise endometriosis or don't necessarily treat it properly or they do a diagnostic laparoscopy without the advanced surgical skills to actually remove it and it can be difficult to know where to go or if the surgeon you're seeing is considered to be reputable in this arena. So, there are a lot of really good community resources that I recommend that people use. There's a community called Nancy's Nook that was started by Nancy, she's a nurse but also has endometriosis herself and has dedicated her whole life to building this massive network of millions of women. And they actually vet MEG surgeons. Meg stands for minimally invasive gynecologic surgery. Those are the surgeons that have advanced fellowship training after their OBGYN training to remove endometriosis. They kind of have a whole repository of people, and so I would say

00:29:25 – Adele Scheiber

We'll find that for the show notes for sure.

0:29:26 – Dr. Jocelyn Fitzgerald

A little bit of research will be needed, but just knowing the type of surgeon that actually removes endometriosis is probably the first step. So if you're a physician, okay, this patient has these big, strange symptoms. I don't really know what's going on, but endometriosis is on my differential. I've worked this patient up as far as I can go. This is where I'm going to refer them, and that would be the next thing I would say is that there's just like people practice medicine with their egos a lot, and when it's I even experienced this when you don't know what's going on and the patient has all these symptoms and you have no idea what to do, which sometimes I truly do not.

It is very tempting to blame the patient, and you're not really blaming them, but in your head you're like, well, your body is just weird. Like those are internal things that you think, and then you're like, okay, no, no, gut check. This is just something that you aren't unfamiliar with and the best thing you can do is help this patient navigate to the right place. And that's not a perfect system, because patients get really frustrated. They're like, oh my God, I'm being sent to another doctor. But what I find is helpful is just to admit to the patient that I don't know and I'm so sorry, and I'm going to help them to the best of my

ability get to another smart person who might have some ideas. It can be really hard to admit to a patient that you don't know what's wrong with them.

0:30:53 - Adele Scheiber

I'm so happy that you say that and that, as a doctor, you're kind of normalizing that thought pattern. Because, I don't know if you've seen, there's that New York Times show it's on Netflix called Diagnosis. You should watch it. It's really good. It's interesting because I see that play out. I watched the two seasons already. I'm addicted to it. And it's these people who look for years for a diagnosis, essentially. And you watch like the doctors go from like hopeful to frustrated, to like, and then they move and wrap or like trying to fit their theory in. You know what I mean Like, and as I'm watching it, what strikes me is, it's clear to me two things. One, difficult diagnoses are more common than we realize and that's not really reflection necessarily on the system or the doctors. It's just bodies are weird, bodies are complex. We don't know everything.

0:31:49 - Dr. Jocelyn Fitzgerald

We don't right, especially about women. Especially about women, we don't know.

0:31:54 - Adele Scheiber

Yeah, yeah. And then the second thing is that you know it's almost like in those cases. You know it's like you're caring and your investment is almost working against you, right, because you're getting frustrated, because you do care and you do want to help this person and you want to be the one who helps them. You know so exactly.

0:32:11 - Dr. Jocelyn Fitzgerald

Yeah, no, I think there is. You are so taught that patients are not questions on a medical board exam, and it can be difficult, as someone who is taught to have all the answers, to not have all the answers. But it's okay to tell patients that you don't know. I do it all the time and they appreciate that rather than I've heard so many horrible stories from people, doctors just saying I don't know what you want from me, like I can't tell you how many times a patient's been like I saw this doctor. They made me feel horrible and I kept going back to them and they finally said I don't know what you want from me.

0:32:50 - Adele Scheiber

We hear that all the time. We get members telling us that that's the treatment they get. All the time they're afraid to go to the doctor because their doctor is almost mad at them that they haven't solved the problem. Yes, and that's not acceptable, right? No, that's not. We do not endorse that behavior.

0:33:06 - Dr. Jocelyn Fitzgerald

That is terrible, terrible behavior. But maybe we need more classes in med school for how to deal with the mystery or how to talk to patients when we've reached, you know, the edge of what is known.

0:33:21 - Adele Scheiber

Yeah, no, I think that's a great. That's great something to reflect on, for sure. Okay, so we've talked about what providers can do, and that was great, and I'm going to target providers all of these ads for this episode amazing. What about you know, for women who suspect they have endometriosis or are experiencing some of these symptoms, what are some things that they can do to increase the chances that they will have a better experience or get a diagnosis faster?

0:33:50 - Dr. Jocelyn Fitzgerald

Yeah, a lot of the same things that I've kind of mentioned. When it comes to women's health, we all just need to accept that we're our own best advocates and, I guess, expect to be frustrated. Hopefully you won't be, and that really upsets me and makes me sad. But I think we need to go, especially women's health, like go into things knowing that you might need a second opinion and be ready to get one. Online resources and community groups are vastly important. They're a bit of a double-edged sword. I spend a lot of time as a doctor on social media reading what patients are saying.

0:34:38 - Adele Scheiber

Reddit. Reddit slash endometriosis. Definitely.

0:34:41 - Dr. Jocelyn Fitzgerald

Yeah, I think it's really important that doctors are part of these communities and read what patients are saying so that we can decide which ones are good and which ones are not so good, because, of course, in a vacuum of knowledge, pseudoscience is going to proliferate, no question about it. So, there's some bad information out there. There are some TikToks that I have watched that I'm like, oh my God, I hope no one believes this. And there are some really good doctors who spend their valuable time and it is hard to make online content and find time in your busy schedule to address some videos that people make about women's diseases that are not factually correct and bat down a lot of pseudoscience, but those are really valuable resources I mentioned.

Nancy's Nook is a really good one. There's a lot of other great Instagram accounts for endometriosis awareness and advocacy that I think are excellent and I think we as a field I know you asked like what can

patients do, but part of what the reason I always do podcasts and I always go to any like speaking engagement or platform I'm offered is to educate about the structure of OBGYN. Yeah, so I really do want patients to understand, like, all the specialties that exist within OBGYN, because then you can kind of direct yourself to the right place. I think a lot of people get very frustrated when they go to see their regular OBGYN.

And a lot of them are truly tremendous and excellent. I would say especially like, I hate to put it this way, but like the younger, more modern OBGYNs who have trained with all of these established specialties are able, then we're all each trained at least a little bit in each of these, so we know that there's patients Well, it's the folks who have the most updated training.

0:36:44 - Adele Scheiber

Right, it's not about age, it's about the era in which they were brought up in medicine.

0:36:50 - Dr. Jocelyn Fitzgerald

Absolutely. That's what I'm not trying to be ageist at all, it really is, because the American Board of OBGYN has boarded and recognized these fields as separate subspecialties all within the last like 20 and 25 years. Like my field didn't even have its own boards until I should really know the dates. It was like the early 2000s, I believe is the first time that they offered board certification in urogynecology, which, of course, is why women who are 60 now, which might be the average age of my current patient, they're only 40 years old when that happened, like how would they know that this field of medicine exists? So I tried to tell people like urogynecologists do pelvic floor. GYN oncologists do women's cancers, family planning, complex family planning, does contraceptive care and abortion, maternal fetal medicine, does high risk OB MIGs, minimally invasive gynecologic surgery, does endometriosis and fibroids. I'm sure I'm forgetting more of, oh, reproductive endocrinology and infertility. They do all the IVF stuff and all of the infertility. There's also pediatric and adolescent gynecology. All of these specialists are people who did extra training after their general OBGYN years. So, kind of understanding that you have like a specialized problem will get you to the right specialist.

0:38:08 - Adele Scheiber

That is super helpful. Is there anything else, Dr Fitzgerald, that you'd like our listeners to know? And this is your chance to plug basically whatever you want.

0:38:19 - Dr. Jocelyn Fitzgerald

Yeah, oh man. Well, I feel like I've plugged a lot of things, but if there's anyone out there who is works in health policy or law and wants to get involved, I do think there are two things I want to plug. One is that I think honestly, the most imminent threat to women's health care delivery is reimbursement, because that is how health systems allocate resources. They give more resources operating their time. Nurses,

staff, I mean like appointment scheduling makers, like all of it, like those things go to the money makers in health system. And because advanced gynecologic procedures and advanced women's health and I shouldn't say non advanced women's health, like all women's health is so devalued in terms of how much effort and expertise it takes to get to the health system it takes to provide that care. Relative to the amount of revenue that it generates, it becomes increasingly diminished within the way health care is structured today. So that is something that a policy person could really help us out with. I know this was not about reproductive justice. I think probably that's another podcast.

0:39:45 - Adele Scheiber

We try to work it into almost every podcast, actually.

0:39:51 - Dr. Jocelyn Fitzgerald

And then people always ask like you know, do you have a plug or a place that you can donate or, you know, put your resources? And I try to keep like a list of those. I think that probably this is I'm very biased because I work at this place but McGee Women's Hospital, where I work, the McGee Women's Research Institute we are really the only independently standing academic affiliate women's health research institute for basic science and I can certainly send you the link.

But the values of that research institution were established before the NIH Office of Women's Health was even established back in 1993, and they have developed over the past I guess 30 years like an infrastructure where money donated goes in the hands of scientists that are trying to bridge the gap between women's and men's health and to investigate these diseases. So that's sort of the best pipeline I know to be like where can my money go? So, it supports women's health research and I'd be happy to send the link because I think they're doing incredible work. I'm just lucky that I work here. I trained here and when I went to this is no, no bad on Hopkins, I loved training there but I showed up and was like, oh, where's the Johns Hopkins like women's research institute and there was not one. So, places that were ahead of the curve are now kind of like shouldering a lot of the right lift.

0:41:28 - Adele Scheiber

But you do, you do a good job. They give you more work, right, that's true and almost exactly you do a good job, they give you more work.

0:41:33 - Dr. Jocelyn Fitzgerald

That's exactly kind of what's happening. So, yeah, we need. We need to incentivize hospitals to support the surgeries that we do in the care that we provide, and also need more money for research. You know, money is important I am.

0:41:49 - Adele Scheiber

You know we do a lot of work on. You know Medicaid, Medicare, you know policy and funding these programs. We actually just wrote our appropriations letter for 2024 and, yeah, I mean, you have to follow the money right.

0:42:02 - Dr. Jocelyn Fitzgerald

You have to follow the money. Yeah, that's looking how much is generated just to like take care of a pregnancy. I mean it's frankly embarrassing compared to that's. Labor and delivery units are closing everywhere, everywhere, because they just cannot afford to keep the doors open, for the expertise of taking care of a pregnancy is like just lady stuff, you know. So, it's easy, right your body knows what. It's easy, totally yeah yeah, like you know, as maternal and infant mortality rises.

0:42:36 - Adele Scheiber

Well, thank you, Dr. Fitzgerald, for this very sobering and eye-opening look into not just endometriosis but into the health system in general.

0:42:45 - Dr. Jocelyn Fitzgerald

I believe in you. Let me know if the NWHN wants to any more on this because this is really the struggle that doctors face every day in women's health is to show that they have to, you know, work twice as hard for to make the same amount of value to the system they work in.

0:43:21 - Adele Scheiber

That does it for this episode of your health unlocked. If you enjoyed this free content or learned something new, we hope you'll consider helping us keep the mic on by donating at nwhn.org/donate. You can also review us and subscribe to the program on Apple podcasts, Spotify or wherever else you harvest your audio content so that we can reach more people with these important stories. And don't forget to follow us on Instagram, facebook and Twitter. At the NWHN, all one word have your own story to tell. We want to hear it. Pitch us today at nwhn.org/yourhealthunlocked. Thanks for listening.