

More Than Fibroids Podcast

With Sateria Venable

<https://rss.com/podcasts/thefibroidfoundation>

Conversation with Dr. Erica Marsh: January 18, 2021

Transcript (auto-generated by RSS.com)

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Welcome to the Fibroid Foundation podcast. Today we have the pleasure of speaking with

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Dr. Erica Marsh. Dr. Marsh is a friend of the Fibroid Foundation. She is one of our trusted

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medical advisors. She is an associate professor of obstetrics and gynecology at the University

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of Michigan Medical School and chief of the division of reproductive endocrinology and

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fertility. Dr. Marsh's research is amazing. It focuses on uterine fibroids and reproductive

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health disparities. She seeks to understand the challenges of fibroids from a 360 degree

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perspective by investigating, addressing their pathophysiology, their epidemiology, and

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clinical impact through a patient-centered lens. Patient-centered is just wonderful because

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that's our focus as well. Dr. Marsh, welcome.

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Thank you so much, Sateria. It's an honor to be here. You know, I'm a huge fan and we

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both are fibroid warriors. So I'm always happy to be a part of anything that's fibroid foundation

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related. Thank you so much for that. And we're a fan

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of yours as well. And we rely on you for great information and to be able to chart our course

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for helping the patient community. So today I thought it was interesting because I think

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your background is just incredible. If you would share with us more of what brought you

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to medicine and specifically reproductive medicine.

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Yes, I had a little bit of a circuitous journey to medicine. I had always been fascinated

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in a kind of romanticized way with becoming a doctor. But while in college, kind of saw

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the pre-med scene and said, okay, that's not for me. And ended up trying to pursue health

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care through other means, specifically on the business side. After college, I did management

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consultant for a few years and had an incredible time, learned a lot. But really at that point

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I realized that I wanted to take care of people in that company. And went back to school,

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took my pre-med courses and went to medical school. And years later, here I am now. So

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like I said, it was a security story, but I think the destination was always the same.

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That's really interesting. And I'm sure that you found that those detours here and there

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get your own incredible value as well.

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Absolutely. Absolutely. Like I said, I learned a lot from spending time in the business world,

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specifically the strategic management space. And also, I think another kind of planned

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detour that helped a lot on my journey was the opportunity to spend time in the research

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space while I was applying to medical school, enduring medical school. Because that really

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opened doors for me on understanding the importance and power of research. And also the importance

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and power of who was included in research, who was represented by the research and who

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was benefiting from the research. So I have to credit my research mentors, particularly

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my early research mentors, Dr. Janet Hall in particular, who I worked for at Mass General

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Hospital while I was applying to medical school. And I think her, the foundation that she helped

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me lay in terms of setting a very high bar for excellence and quality has stayed with

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me on my research journey and basically is a big reason why research continues to be

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a part of my career to this day.

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That's really interesting. And you have led some incredibly groundbreaking studies, particularly

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around health disparities and uterine fibroids. I know when I first met you, you were working

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on a huge study, which was like the first of its kind at that time. And I think probably

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even since in specifically in fibroid research. Can you tell us about a couple of your studies

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and did any of the findings in your Hallmark studies shock or surprise you?

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Absolutely. I'm always happy to talk about research and kind of the doors it opens and

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the minds it opens. I think one of the first studies that really was an aha moment for

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me was work I did while at Northwestern as a relatively new faculty member. I was seeing

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a lot of young African American women in particular who were coming to me not only with symptomatic

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fibroids, but symptomatic fibroids that they had had surgery for already and they were

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in their 20s. And some of them had had two surgeries already and were just in their 20s.

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And I went to the literature, most of the papers on the epidemiology of fibroids showed

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that the racial disparity that we've long known about kind of popped up in the 30s and

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particularly the mid to late 30s. But because I was seeing so many young African American

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women with fibroids, I did a study where we recruited about 100 women, half were white,

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half were black, who were between the ages of 18 and 30. They had no symptoms of fibroids

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and we did that intentionally. We selected that way intentionally so that we weren't

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biased for recruiting a group that had an artificially high prevalence of fibroids.

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So these were young women who had normal menstrual cycles, were using a normal amount of product

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each month, leading a normal amount of days each month, had no symptoms of fatigue or

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anemia. And we had them come in for a pelvic ultrasound and ask them a few demographic

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questions and health related questions. And what our study found was that the disparities

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we see in fibroids don't start in the late 30s and early 40s. They actually start even

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before women know they have fibroids. So what we found was that while about 7% of the white

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women that we scanned with an ultrasound had fibroids between the ages of 18 and 30, 26%

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of the African American women had fibroids. And no fibroids were seen in women between

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18 and 20. We started seeing them when women were in their early 20s, so 21 and older.

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And there was an age related increase going from 20 to 30 in black women and a pretty

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steadily low prevalence of fibroids in white women. And so what that showed me was that

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the 89% prevalence that you hear about in black women by the time we're 50 starts in

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our early 20s. Those fibroids start to develop. They're not symptomatic necessarily. None

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of the women in my study even knew they had fibroids. They had to actually, we asked them

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if they had fibroids and if they said yes, they were actually excluded from the study.

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So these were women who were asymptomatic to their knowledge and not have fibroids.

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And we found that 26% of the African American women have fibroids at this young age. Those

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fibroids grow over time. Most fibroids grow. Some don't. Some even shrink over time. But

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for the ones that grow, they become problematic and lead to all types of life-disrupting symptoms

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that you and your followers well know. Fatigue, anemia, soiling of clothes, lightheadedness

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and dizziness, let alone the emotional and mental health impacts of feeling depressed,

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isolated, dealing with poor body image, those types of things. So this is a problem that

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starts early in life. And we have to address it as such. And as we think about ways to

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combat fibroids and in fact to prevent fibroids, which is the space we all ultimately want

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to get to, we have to realize that that journey starts not in the 30s and 40s, but actually

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in the early 20s.

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That's really powerful information because you described my journey. You know, I didn't

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know at the time that I had fibroids when I was probably around 20, but looking back

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with my symptoms, I could tell that something was starting to change in my body. And I actually

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had my third fibroid surgery at Northwestern because as you described, women have had procedures

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that were not effective or not comprehensive, and that was me as well. So the most problematic

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fibroid that I had was not removed until 10 years later at Northwestern. And you think

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about that I had had two procedures since the diagnosis, but by that time I'm going

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into surgery number three and that one problematic fibroid was finally removed. So you're looking

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at 10 years of suffering and heavy menstrual bleeding. So what you've uncovered with that

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study is going to help a lot of women moving forward.

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We have started to focus on college campus outreach to be able to inform women about

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the potential onset of fibroids and or endometriosis and kind of what to look out for, to better

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care for themselves and to hopefully not be as encumbered with it at all. So that's really

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good information for our listeners to hear and so that they can share it with others

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as well, their daughters or sisters or granddaughters because this helps us all to thrive.

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Absolutely. I remember one of my first conversations with you, you recommended or told me about

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a medical therapy that I was not aware of. And I ended up asking my doctor for that medical

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therapy. I actually asked more than one because when I moved, I had to ask another doctor

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for the same medication. And that medication is helping me through perimenopause or helped

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me with perimenopause when I was symptomatic. And it's just not talked about. And I often

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think about back to that conversation with you where you were just talking about various

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therapies but after I was able to use that therapy, take that therapy, it helped me tremendously.

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It helped me avoid another surgery. And I just wonder why even now some of these medical

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therapies are not widely utilized or prescribed. Do you have any thoughts around that?

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I think that's an important question, Seteria, and a hard one to answer to be honest. I think

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part of the challenge is that fibroids have historically been considered very much bread

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and butter over Gyn and there was a time in women's health where the expectation was that

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women would just get hysterectomies when their quote female parts started misbehaving end

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quote. And thankfully a lot of that mentality has changed in women's health. I think a large

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part due to the fact that there are a lot more female providers and also due to the

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part that training has changed and has become a lot more patient focused and patient empowering.

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And I think there's been a long history and quite honestly present of fibroids being addressed

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by surgery and specifically hysterectomy and in fact fibroids continue to be the leading

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cause of hysterectomy in the United States. I think there's some women for whom surgery

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and specifically hysterectomy is the perfect treatment for. It has transformed the life

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of many patients. And I think that there's some patients that are not good candidates

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for surgery, want to continue to have the option to bear children and carry a pregnancy

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or just simply even if they're done with childbearing they just want to keep their uterus. They

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don't want surgery. And I think we have to be a lot more intentional as a field about

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saying these are all of your options and tell me what your goals are, your life goals are

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and we can overlay these options with your life goals and understand which ones may be

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more appropriate given your life goals or less appropriate given your life goals. I

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think within that talking to patients about the pros and cons of medication therapy and

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medical therapy, medical therapy can be something as straightforward as taking an NSAID, a
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steroidal anti-inflammatory drug like ibuprofen for example. It can be taking a birth control

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pill that helps with bleeding. It can be getting a legal no-dress girl releasing IUD that can

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help with bleeding. It can be taking an injectable medication that can help with bleeding and

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transiently shrink fibroids. It can be an oral medication that helps with bleeding by

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also putting you in a state similar to menopause and lowering estrogen and progesterone levels

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which are the two hormones that feed both the fibroids and feed the tissue called the

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endometrium that we shed each month during our period. So I think there are a lot of

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medical options. There's some medical options like trans-hexamic acid that target how we

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clot blood in our body and can lower the flow of blood during our menstrual cycles. I mean

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I'm not naming all of them but there are a lot of different classes of medications that

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we have to offer patients now and I think some of the challenges is that some of them

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you can't stay on for more than six months but some of them you can stay on for longer.

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The important thing is to share with the patient what the options are, what the risk and benefit

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of each of the options are and let the patient decide what works best for them given their

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lives, given their goals. I want to put that answer on a loop because it's so comprehensive.

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I know that our listeners will get a lot out of that as did I so thank you for that. So

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in the recent article or blog that you wrote you talked about potential risk factors for

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developing fibroids. Can you touch on a few of those? Absolutely. I think that two of

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the most significant risk factors we've talked about already and that's age and race and

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those are probably the two most known risk factors. I think that we also know that an

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increasing number of pregnancies actually appears to be protective against fibroids.

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That's not to say that we're encouraging women with fibroids to go out and get pregnant just

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to treat their fibroids but that's an association that we've seen. We know that beer can, you

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know, several servings of beer can, is a risk factor for fibroids. We know that being overweight

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specifically being, having obesity is a risk factor for fibroids and obesity is disproportionately

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exists disproportionately among certain racial and ethnic groups and that likely contributes

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to the disparity. It's not necessarily the driver of the disparity but it contributes

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to the disparity. We know that higher levels of or we know that progesterone and estrogen

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feed the fibroids and we and so they're not risk factors per se but being in a position

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where you have increased estrogen and increased progesterone levels may contribute to fibroids

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and we see that African American women most notably have higher estrogen levels at certain

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times of the menstrual cycle than when compared to Caucasian women. There's some epidemiological

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data that has shown association between having high blood pressure and having fibroids, having

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a history of STIs and having fibroids as well. And again those are associations so we don't,

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you know, they haven't proven causality yet but they're associations that have been observed

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in large epidemiological studies. Wow. I find the higher estrogen levels with women

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of African descent at specific times during the menstrual cycle to be higher than some

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other ethnicities to be absolutely fascinating and I think that there might be a lot there.

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Wow. That's a lot to ponder. So one of the key messages that I think really needs a lot

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of uncovering is the emotional impact of suffering with fibroids and you raised that in your

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blog and thank you for that. You know, I know I didn't really know the full scope of what

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I was dealing with when I was highly symptomatic. I, you know, because your, your every, all

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of your movements are scripted based on where you can go, where you can't go, you know,

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finding the right sanitary supplies and feminine care supplies and it really takes over your

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quality of life. And so I'm brainstorming on ways that we can help our community. I

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know that telling stories is very important. Having a community of support is very important.

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Do you have any thoughts on that you'd like to share on what shape emotional support of

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fibroid patients might take moving forward? I think a big piece of that is, is honestly

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just acknowledging that fibroids do have an impact on emotional health and something that

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I think it's important for us to do is to one, acknowledge that and two, incorporate

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that into a new interdisciplinary or transdisciplinary approach to fibroid care. And move away from

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a model where it's just about, you know, what treatment am I going to get? Am I going to,

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you know, what procedure am I going to get to treating the whole woman? Because some

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patients are, are less focused on, on treatment than they are on just wanting to feel heard

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and wanting their journey acknowledged and how we care for patients and how we heal them

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may or may not involve therapy, you know, medical therapy or surgical intervention.

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We found in one of my qualitative studies that specifically looked at emotional and

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psychosocial impact that almost a hundred percent of the women that we talked to reported

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some type of psychological distress from their fibroids. And half of them reported a sense

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of helplessness about a third of them, a little more than a third of them reported negative

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feelings about body image, negative feelings about sex, their sexuality. And I think in

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some ways most concerningly about a quarter of them reported a lack of, a lack of support.

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So I think that, you know, even though, and I've said this time and time again, even though

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fibroids don't, don't typically kill women, they create a lot of morbidity, a lot of, of,

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of women not being able to lead their full lives and be their best selves.

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Absolutely. Wow, that's profound.

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And we have to, we have to, you know, we have to step in and say, it's, it's, that's not

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okay. You know, that's, that's not okay. And, you know, one of the quotes that I used in

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my paper from one of the subjects, you know, talks about the, the, the, the participant

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says, I think that there's this aspect to having fibroids that some women feel that

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is a secret topic and you don't discuss it until you have had the surgery. I think there

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needs to be more communication. So women feel comfortable just to talk about it. That's

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from a participant's voice, you know, from someone who is a, who is a patient somewhere.

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And I think it, you know, she couldn't have been more correct. We have to create a space

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00:25:12,520 --> 00:25:21,200

where, where women, and I, and I, I want to be clear, I'm using the word women broadly

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00:25:21,200 --> 00:25:26,920

to, when I refer to fibroid patients, I realized that, that not everybody who has fibroids

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00:25:26,920 --> 00:25:35,240

self-identifies as a woman. And so I want to be clear that I understand that and, and

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00:25:35,240 --> 00:25:43,920

am inclusive, being inclusive of anybody who's born with a uterus. When I talk about, when

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00:25:43,920 --> 00:25:54,720

I talk about fibroids, but I think we have to, to move beyond, you know, surgery check,

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00:25:54,720 --> 00:26:01,720

you know, medicine check that we have to treat the whole patient, that we have to empower

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00:26:01,720 --> 00:26:14,840

women to, to, which involves educating them, making them aware, to, to engage more in the

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00:26:14,840 --> 00:26:24,200

process, and to, to choose their own treatments, to choose the best treatments for them, and

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00:26:24,200 --> 00:26:32,640

to make sure that they're in a, in a patient care provider, patient relationship where

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00:26:32,640 --> 00:26:39,720

there's trust. Because I think that is the foundation that allows for all the other things,

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00:26:39,720 --> 00:26:45,120

that, you know, the safety of asking questions, the being educated, the feeling empowered

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00:26:45,120 --> 00:26:55,360

to speak your voice. But I, I, you know, women can't, this fibroid should not be a mark of

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00:26:55,360 --> 00:27:00,440

shame. And having heavy menstrual periods cannot be a mark of shame. I get it. They're

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00:27:00,440 --> 00:27:07,160

not sexy to talk about. They're not, you know, nobody, you know, even when you're amongst

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00:27:07,160 --> 00:27:11,520

your crew, your squad, you know, it's not like, hey, you know, how many tampons did

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00:27:11,520 --> 00:27:18,240

you use today? How many PaxiPads did you go through? It's even, even amongst your closest

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00:27:18,240 --> 00:27:24,560

friends, you don't, it's not something that comes up because there's, there's a, there's

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00:27:24,560 --> 00:27:33,400

a, I think culturally and almost anthropologically, we've been socialized that, you know, in a

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00:27:33,400 --> 00:27:42,800

very negative and, and, and self, negative self image way around periods in general,

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00:27:42,800 --> 00:27:46,680

whether they're normal or they're abnormal, and particularly so when they're abnormal.

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00:27:46,680 --> 00:27:52,600

So, you know, we have to encourage women to come out, talk about it, share your stories,

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00:27:52,600 --> 00:27:56,880

because you're by doing that, they're not only helping themselves, but you're helping

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00:27:56,880 --> 00:27:57,880

other women.

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00:27:57,880 --> 00:28:08,800

And you helped us today because those statistics hopefully will help a lot of our listeners

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00:28:08,800 --> 00:28:17,840

to exhale because it really, when you talk about those huge numbers of people experiencing

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00:28:17,840 --> 00:28:27,600

the same symptoms and the same emotions around those symptoms, it's eye opening. And I appreciate

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00:28:27,600 --> 00:28:34,640

you sharing that and for really designing a research study that really delved into the

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00:28:34,640 --> 00:28:43,880

heart of what we experience and feel so that we're no longer, you know, feeling that isolation.

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00:28:43,880 --> 00:28:50,360

So I think I'm, I'm very reassured by what you shared that that's going to help to move

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00:28:50,360 --> 00:28:58,200

us forward in a lot of ways. And we'll be, this broadcast will post during our anniversary

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00:28:58,200 --> 00:29:06,160

week. So hopefully, a lot of listeners will have an opportunity to hear it. So where can

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00:29:06,160 --> 00:29:11,040

our listeners find out more information about your practice, Dr. Marsh?

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00:29:11,040 --> 00:29:18,720

Well, the University of Michigan Medical School website is probably going to be the best source

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00:29:18,720 --> 00:29:28,240

of information in terms of clinical, you know, my clinical enterprise, the ODGYN department

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00:29:28,240 --> 00:29:33,560

at the University of Michigan Medical School or Michigan Medicine, which is specifically

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00:29:33,560 --> 00:29:40,920

the clinical enterprise, is very committed to treating women with fibroids across a number

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00:29:40,920 --> 00:29:47,280

of divisions, not just my division, which is reproductive endocrinology and infertility,

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00:29:47,280 --> 00:29:54,000

but also the women's health division, which is the general ODGYN division and our minimally

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00:29:54,000 --> 00:30:06,120

invasive surgery group, as well as our general gynecology division. So we have the team in

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00:30:06,120 --> 00:30:17,200

place to really provide, you know, 360 degrees of that care, including social workers, and

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00:30:17,200 --> 00:30:25,200

you know, we partner with our hematologist as well to help women who have, you know,

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00:30:25,200 --> 00:30:32,880

severe anemia get to a space where they feel better and feel well enough to actually contemplate

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00:30:32,880 --> 00:30:38,360

the options versus just being so fatigued and so wiped out that they're in a place where

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00:30:38,360 --> 00:30:43,920

they say, I don't care anymore, just do what you need to do. And that's not a space of

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00:30:43,920 --> 00:30:51,000

empowerment. That's a space of defeat. And that's not okay. That's not okay. So.

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00:30:51,000 --> 00:30:59,760

And that is a practice that is really patient centric and is covering all of the aspects

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00:30:59,760 --> 00:31:05,240

of our care because it is so important to not make decisions while you're not feeling

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00:31:05,240 --> 00:31:11,360

well. And if you're helping the patients to get to a place where they're stable and can

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00:31:11,360 --> 00:31:17,360

make an educated decision because there's a lot to learn about, you know, Fibroids diagnosis,

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00:31:17,360 --> 00:31:23,680

I think that you are really creating an environment that's really beneficial for all of us. So

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00:31:23,680 --> 00:31:30,000

I appreciate that greatly. And thank you so much for speaking with us today.

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00:31:30,000 --> 00:31:34,440

Thank you so much for having me, Sateria. And thank you for the incredible work you

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00:31:34,440 --> 00:31:42,960

are doing with the Fibroid Foundation on behalf of all of us. We appreciate you. We appreciate

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00:31:42,960 --> 00:31:51,640

your hard work and your commitment to this condition and to, you know, the many of us

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00:31:51,640 --> 00:31:58,200

who have had to deal with Fibroids in our lives, either personally or via family members

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00:31:58,200 --> 00:32:01,340

and friends. So thank you.

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00:32:01,340 --> 00:32:05,360

Thank you so much.