

Peace WITH ENDO PODCAST

PWE56: Latest Endometriosis Research with Mary Lou Ballweg

Aubree: Hi, love. This is episode 56 of the *Peace with Endo Podcast*. I'm your host, Aubree Deimler. I am an author, coach and energy healer who helps women with endometriosis naturally manage pain, increase energy and find peace with endo.

Today's show features Mary Lou Ballweg, the president and executive director of the Endometriosis Association, an organization she helped to start in 1980. She also helped find the world's first research registry for endometriosis and has been responsible for major breakthroughs in endometriosis research.

In the episode today Mary Lou shared a bit of her story with endometriosis and what inspired her to start the Endometriosis Association, which has played a key role in endometriosis awareness. Mary Lou shared her experience with the evolution of endometriosis awareness and the issues that can come up with that. She spoke about new, exciting research that's happening around endo, and the role of environmental factors. I hope you enjoy our conversation, now on to the show.

Hey Mary Lou! Thanks so much for being on the show today.

Mary Lou: Hi Aubree! Thank you for the invitation.

Aubree: So will you share a little bit of your background and what inspired you to start the Endometriosis Association?

Mary Lou: Well I was clicking along in a wonderful career in my twenties and into my early thirties. I was a filmmaker and writer. I had a national consulting business, lots of work out in DC in particular and whamo suddenly I was bedridden with extreme exhaustion, extreme pain. To go from a high-flying, wild busy person to a day where it was an accomplishment just to get a shower was pretty terrible, and this is back in 1979, and as you can imagine I really had a hard time getting any kind of help with a diagnosis.

Eventually I had helped start a women's health clinic some years earlier and realized that at least some of my symptoms really matched up to this thing called

endometriosis, and I kind forced my OBGYN to diagnose me even though she said well it really won't do any good to diagnose you because there really is nothing that can be done, which I wasn't willing to accept that.

So, once I was diagnosed and started to figure out how to get back on my own feet little by little, I thought I can't be the only woman in the world with this. I researched the medical literature, which there was very little, and decided that I would find other women with endometriosis so we could compare notes, and also secretly I thought somebody might have the answers.

So, we started meeting in January 1980, which means now that we are closing in on our fortieth anniversary. So we came together, eight women at first meeting, second meeting 22 women, and it just kept growing from there. I went out to the NIH in DC and said what are you doing in terms of research? They were doing nothing! Zero. (laughs) So I came back to the group and they said well we'll do the research, which was wonderful and hopelessly naïve, but I'm so glad that we were naïve.

So I put together an extensive questionnaire, which looking back was highly scientific, because it had no suppositions in it... it just was very straightforward. The women and her family, their full medical history, everything was in there. Then remembering this is the days before computers, just big mainframes and institutions, we had volunteers who put in over a thousand hours each to manually tabulate the data. By the time we were six, seven months old, we had more data than had ever been gathered on endometriosis, and looking at the data we said, Wow! This is an immune system disease. This isn't just endocrine, hormonal. It's immune.

So we kept gathering data. Eventually we had 8,500 cases, way beyond what we could cope with manually, got connected to some people at the medical college of Wisconsin, the medical college students, nurses, all kinds of people got involved, starting publishing from that database and eventually, ironically, actually published... published I think about eleven research papers with the NIH, which is a big honor and also fun, because when you publish with the NIH no one argues with you. Now of course I've published many other things too, and as any scientist, you get (laughs) attacked. It's part of the scientific process, except for NIH papers.

So, we then started helping women who were contacting us sometimes from all over the world. Sometimes we didn't even know what language a letter was in. I remember one really long one. This poor woman obviously had taken a lot of time to write us. It was Romanian. So we started translating our brochure. It's in 31 languages now. We started setting up chapters and support groups. This is all pre-Internet, so these are in-person groups. We had over two hundred in the US and Canada alone, at one point, and I organized in Asia, where there's a lot of endometriosis. I actually think more even than here and then in South America and Europe and a few parts of Africa, and so that's how we grew. That's how we got into it.

Aubree: That's great. So this was pre-Internet, so lots of grassroots, it sounds like happening there with you.

Mary Lou: Yeah. Well people did know how to organize before the Internet (laughs)

Aubree: Right?

Mary Lou: Which may be hard to believe now, but yes it did happen.

Aubree: So will you share a little bit more about what the Endometriosis Association does?

Mary Lou: Yeah. We have three main programs: support, education, and research. So, in the support program we provide every kind of individual assistance that we can. We have crisis... trained crisis call listeners, some of whom will take calls at three in the morning, which given the suicide issues that some of the women face, it's really wonderful that these people are available, prescription drugs savings plan, we have nutritional supplements that are generally only available through practitioners. We have an essential oil based roll-on pain reliever, so that's all part of the support program, and there are other things, but I'll move on to education program.

As I said, we have brochures in 31 languages. We have a teen outreach program, which has covered 33 states right now. We're stuck in Texas at the moment, which is very large and hard to get this program into the schools because there's actually a law in Texas that you cannot teach sex... sex education and people get this mixed up with sex education, although I wouldn't call it that.

Also in the education program we have the endometriosis awareness month, which is a big deal all over the world and we were involved in starting the collaborative on the health and the environment and also healthcare without harm. So, we get involved in some of those activities. I'm excited in the last few years to be involved in the international menstrual health efforts to de-stigmatize menstruation and that's really interesting to see how things are happening even in places like India and parts of Africa.

And then in the research program, of course, I already mentioned the registry. We funded... for 14 years we funded a special program at Vanderbilt. We also funded twenty research projects in seven countries through our open research fund, and a number of other research funding. We also provide research assistance, so people come to us with all kinds of questions and concerns, and because we've been at this so long, we can usually help them, and we can help them find subjects for their studies.

So that's kind of it, in a nutshell.

I forgot to mention our books, sorry. We have four books, one in Spanish, and members get our third book, the complete reference, which is almost five hundred pages for free if they become a member, and I'm working on our fourth book, which I suspect will be my last endometriosis book.

Aubree: Nice. It sounds like you're doing a lot out there in the world, so thank you for doing that and for being such a big, key player in spreading awareness about endometriosis. So how have you seen that evolve over the years as you started the endometriosis awareness month. How have you seen that change since you first started the association?

Mary Lou: Well when we first started my professional colleagues, because I... I was fairly well known as a filmmaker and writer and affirmative action consultant... my professional colleagues were very angry at me and they let me know (laughs) that they thought I was throwing away a good career, for what? For this endo whatever the heck it was? You know it was still a time when you really didn't talk about periods and menstruation or female sexuality or female biology and every time we managed to get something in the media we considered it a huge achievement. Now of course there's a lot more awareness, also a lot of misinformation out there, but that's always been the case with endometriosis. When you don't have answers, you make them up, right?

And of course because drug companies, surgeons, even alternative practitioners have discovered that there's money to be made in the field and that there's so many women with endometriosis. It's really getting a lot more attention because of that. I wish they had paid attention a lot earlier, but better late than never.

Aubree: Absolutely. So are you seeing that shift of there being a little bit more comfort in speaking up about some of these things?

Mary Lou: Yes and no. There are very many different cultural differences, you know, throughout the country, even in the US. You have different... I don't want to say subcultures. That almost sounds like they're not as good as main culture, but we still hear from women and girls who have been chastised or sort of alienated from their families because they dare to talk about this stuff.

I remember one former board member from Canada whose aunts pretty much disowned her because she dared to talk about something like this, hush, hush, you don't talk about this, but for the most part I think I see more willingness, but on the other hand, certainly online, a lot of what you see is preaching to the choir, so it's hard to judge what's happening just in the general population.

Now there are thousands of diseases. How many of us pay attention to a disease that we don't have? So I think that's pretty... pretty common that... you know... if you don't know somebody with it, you're not going to pay attention. Now the reality is

probably everyone really does know someone with it, so the real key is that we women and girls' family have to speak up.

Aubree: Exactly, and I think it's good that there was the big campaign that happened at least on television, so I think more people are searching. I think endometriosis was one of the most searched word last year, so people are looking more into it, which is good.

Mary Lou: Right, and there was the whole speak endo site, which I think is still up, which really helped women get over their reluctance to complain (laughs) to their doctor. That's the person you should complain to. So I just love it, because I hear this. I've heard these kinds of things forever, you know, go in to see the doctor all gussied up. First of all I tell women, don't get gussied up, because they'll just look at you and see a young woman. They won't see the pain or other problems you're having, and in the speak endo, what is it... speakendo.com, I think.

She's on the examination table and she says... the doctor asked her how she's doing. Well I have a few cramps (laughs) and her alter ego says tell him it feels like a thousand stabbing knives! That's what we have to do to get past this, sort of crazy idea that menstrual pain is normal

Aubree: Mhmm. Absolutely. So are you aware then of any new research that's happening with endo?

Mary Lou: Oh, there's tons of it. So, for me that's so exciting and rewarding that all over the world there's so much research that probably most people can't keep up. I'm lucky since I started when there was almost nothing, but there's a lot of research looking at the immune aspects of endometriosis. There's research looking at the early development of the disease. Our new vice president of research on our board has looked at the very beginning development of lesions. I, myself would say the disease process was there first, or the lesions couldn't develop, but she's shown that it's the immune system that's critical at that stage, before the hormones actually make a difference in the disease.

There is research showing that the pregnancies of these women are much more complicated than people realize previously. There's the whole area of epigenetics, which our team at Vanderbilt really became world experts in... in other words they... the environmental and the genetic problems that you and I and the father of a baby have will be passed on. In this case you may know that it was our discovery that dioxin, which is a contaminant in pesticides and herbicides, plastics burning, municipal incineration, a couple other sources, very... it's called the most toxic chemical ever produced by man, that was our discovery, and we paid the price for it.

The chemical industry did everything in their power to stop us, but with dioxins in the body, which build up over time in both the mother and the father, you will get an impact on five generations, which is pretty scary to think about, and just today over

my desk, two emails came from mothers who'd had severe endometriosis, who are now trying to figure out what to do for their daughters.

Now in the book I mentioned before, the complete reference, *Endometriosis: The Complete Reference for Taking Charge of your Health*, I have a large section on prevention drawn from many different fields of science. I do believe that we can prevent the disease, but it means taking a lot of action, but isn't it worth it for our kids? So, my own daughter was my only live experiment (laughs) because I had no one else to experiment on, and she's fine, and recently gave birth to our first grandchild, a beautiful little granddaughter.

Aubree: That's great. Well hopefully that repeats then into the next generation.

Mary Lou: Yes. I hope so. I don't have as much control as I did with my own daughter (laughs).

Aubree: But I'm sure you've taught her well, so hopefully she passes along some of that.

Mary Lou: Yeah. I hope so. I hope so. One thing I see in the homes of so many people, especially young people now is all the WiFi, and all of the electronics, and I mentioned before we went live, Aubree, that I wanted to tell people about this extremely important summit with phenomenal speakers. It's called the5gsummit.com, and they have really excellent speakers explaining scientifically and in other social ways what's happening to our children and to us with the amount of radiation that we're being exposed to.

What I've found is that people don't even realize that these devices radiate, and that radiation is cumulative and we know of course radiation is linked to cancer. I'm worried about women with endometriosis because some of the newest research I've seen recently, and haven't completely digested it, has looked at the electrophysiology of women with endometriosis. We're different (laughs). We're unique and also those who are more chemically sensitive, which is very common in women with endometriosis have a much greater risk of becoming electro hypersensitive, although everyone is sensitive, just on a degree, but there are people who become completely incapacitated, completely unable to be around even a TV.

So, I'm asking people please take action. I'm seeing in my neighborhood how the 5G small cells are going up, and it really scares me, especially the one down the road by our school.

Aubree: So, do you... have you heard of any ways that you can help combat some of that?

Mary Lou: Yes, actually they have people who... on the summit who have figured out legal ways, although it's very hard because the telecommunications industry, the

FCC, which is supposed to regulate this industry is what's called a captured agency, which is exactly what it implies. So, it's hard, but if we don't fight it we're going to be much sicker.

Aubree: Right and I've heard of some of the initiatives happening to stop some of those new towers from going up. Is there anything you can do, like in your home to help?

Mary Lou: Yeah. There's actually a lot that you can do and when you sign up for this free summit you can get some free books, including seven essential booklets... seven essential ways to make your home safe from 5G and EMF radiation and another one: 5 simple ways to protect yourself from cell phone radiation.

Aubree: Ok. Excellent. That's good to know. So, it sounds like there's a lot of exciting research that's happening around endo, which is good, and I think it's good that we're focusing more... more on the immune system component, because I feel like overall maybe there's a little too much focus on the reproductive aspect of things, which is when it tends to come up a lot of times, you know, if someone's having trouble trying to have a kid, or can't have a child, and that's when they start exploring more, so it's nice that they're expanding beyond just that and looking more at it systemically.

Mary Lou: Well I always tell the doctors when I'm doing talks for doctors, look if we diagnosed and treated that 15-year-old well, she might not be infertile at 25.

Aubree: Right.

Mary Lou: So, let's straighten people's health out and not wait until it's, you know, a crisis of infertility or severe pain or women who can't hold a job anymore, are on disability. What I find is, you know, it's human nature to go into denial. Oh it's not that bad, it'll get better, whatever I can still manage. I can pop a bunch of pills, whatever it is. The thing about endometriosis, darn it, is that it really can get much, much, much worse, so we have people who are bedridden. We have people who are disabled. We have suicides, and I can only guess that the ones that come to our attention are just the tip of the iceberg.

So, when your body is speaking to you, listen. It's the only one you get, right?

Aubree: Yep. Absolutely. And it would be nice yes if they did catch it earlier, and some of that comes from that stigma, like you just said of painful periods are normal. I know I was told that growing up, going to see the doctor, that oh it's just a normal part of being a woman. You get pain with your periods, so there's a bigger issue at hand that needs to shift.

Mary Lou: A lot of that thinking came into play in the 1920's and 30's, because the feminists at the time, maybe that's not the right word, were trying very hard to get

women into various jobs that had been closed to them, so they... you know... were up against this myth, oh women even in my memory they... I would hear things like oh women can't be pilots because they're hormonal once a month, to which I say well men are hormonal just about every day... no (laughs).

Aubree: (laughs)

Mary Lou: But it's just the stigma around that, so to counter it, and you can understand how these movements happen in history, they basically said that if a woman complains of her period it's psychological, which that... there's still vestiges of that myth hanging on and certainly we hear from women who are told, unfortunately all too often by doctors, that it's psychological or in their heads, as one woman said to me. I wish it was in my head, because then I could do something about it (laughs).

Aubree: Right. It's a physical thing, but it does impact your mind as well, so it's... there's a... it's kind of a double edged sword in the sense that yes your mind does play a role, but it's not... it's a physical thing. So, I get that from both angles.

Mary Lou: Well I think the hard thing psychologically is that with the dropping age of menarche and the younger age of menarche in... in and of itself is a risk for endometriosis. That comes on so young that that poor child has not sometimes had that chance to develop a strong sense of herself, which is needed to fight a society that says this is not important and to fight for the kind of care that we need, and to be able to sort through the confusion. That's... that's a lot to ask of someone who just got sick, you know, at nine or ten.

Aubree: Right and I saw an article about that in one of the major news outlets about how the... women are menstruating earlier and earlier and I do... I think there's some type of environmental impact on that, as you were talking about the dioxins earlier and more and more hormones we're picking up in the environment.

Mary Lou: Exactly.

Aubree: So definitely a trend that needs to be addressed (laughs).

Mary Lou: I would like to reverse it. I would like to go back to the days when women had their first periods at 16, you know, give people a chance to grow their minds and their personalities first and it's particularly prevalent among African American populations. There's a... to have a very early puberty and menarche, which is the last thing anybody needs when they're already just trying to grow up.

Aubree: Right.

Mary Lou: And have older boys paying too much attention to them in the wrong way. There's a researcher who's done a lot of research on this, Herman-Giddens,

really phenomenal work and has shown unequivocally that there are African American girls going into puberty at seven years old, which is really, really sad and as people probably know, the disadvantaged communities are more likely to live in polluted areas.

Aubree: Right. So, it's just a whole environmental type thing that's happening.

Mary Lou: Yeah. Exactly. Exactly.

Aubree: So, I appreciate you playing the part in at least spreading the awareness about that and hopefully something changes along the way.

Mary Lou: Yeah. I think only if we all stand up. Think of how many we are, just tens of millions, we don't know for sure the exact number, we need some of the non-invasive diagnostic type testing to come to fruition, but it does look like it is, so we have tens of millions of women and girls and families affected around the world. If we all stand up and start to demand a healthier environment, healthier food, food without pesticides, which actually kill off some of our healthy gut microbiota, where 70% of the immune system lives. **If we stand up and say, enough! We can change this.**

Aubree: Right and I think that's... endometriosis is... I feel like it's almost like the canary in the coal mine (laughs).

Mary Lou: Yeah.

Aubree: It's a sign and more and more women are getting it, and the fact that women are getting their periods at seven, that's just frightening to me. It needs to change.

Mary Lou: Yeah. No kidding.

Aubree: Well, I appreciate you Mary Lou for coming on and sharing some of your wisdom and some of this recent research that's happening on endo. Do you have any final words of inspiration for our listeners today?

Mary Lou: I think the most important thing is probably not what people want to hear, you have to take charge of your own health. There isn't any magic practitioner out there, despite some of the advertising online. Please call us before you fork over tens of thousands of dollars. You really have to do the homework, you have to read the books, as I said our complete reference for taking charge of your health is free with membership, which is only \$35, and there are other benefits with that.

Because if you don't understand what is going on with your body, it is so easy to be victimized by all kinds of people out there now that they've come to realize there's money to be made and I'm just so sick of hearing people who've had 10, 15, 20

surgeries and of course are now in worse condition than they were to begin with, and **I encourage people to look at what they can do. It's amazing once you start to make friends with your immune system and your gut microbiota. What a difference nutrition, for instance can make**, dealing with your allergies, which you may not even realize you have because the wave hypersensitivity seems to be a big for us, which means that you don't react to something until some time within 72 hours later. So you don't know that what you're reacting to today was because two days ago you ate some... I don't know... gluten, dairy, whatever it is that sets off your immune system.

There is no one endometriosis diet because all of us do have very different immune systems, but if you can find an environmental medicine practitioner, a pelvic floor therapist, energy work, things that can make you healthier as a whole person, you will find that you will be healthier with your endometriosis.

Aubree: Absolutely. Yeah there's definitely ways to manage it, so for those who are listening (laughs) Don't give up.

Mary Lou: Absolutely.

Aubree: You can definitely start to feel better.

Mary Lou: Absolutely. Right. There is lots of hope. But you can't just throw yourself at the feet of the doctor and say cure me (laughs). Not, unfortunately now. Maybe... I don't know... 40 years from now? (laughs).

Aubree: Right. Unfortunately there's not the best choices out there right now when it comes to Western medicine.

Mary Lou: Right. Absolutely important to remember, and also remember that Western, Conventional medicine is oriented to symptoms, rather than the root cause. Myself, I try to get to the root and fortunately I've had some marvelous people to help me, so if you met me today you'd have no idea how old I am, and I'm still going strong with this work. You can do that too, but you have to take charge.

So, if you want to connect with us our website is www.endometriosisassn.org, in other words the abbreviation for association endometriosisassn.org and our Facebook page is Endo... where is it? Endo Assn.

Aubree: Excellent. And how can people pick up your books?

Mary Lou: They're online. They're on Amazon, but if they contact us and become a member they'll get the complete reference for free. The companion book called *The Endometriosis Sourcebook*, which is different because (laughs) because I have to much to say, covers different topics than the complete reference.

Aubree: Well thank you so much Mary Lou for being such a strong advocate for endometriosis and being such a key player in spreading awareness and continuing to educate women that really very much need it. I appreciate you.

Mary Lou: Wonderful. Thank you Aubree for what you do.

Aubree: And thank you so much for coming on today.

Mary Lou: Good health to all of us.

Aubree: If you enjoyed this episode I invite you to subscribe to continue on the journey. Please leave us a positive review, and share with your friends, so more endo sisters can find the show and get on track to finding peace with endo.

If you want to connect with me further and see how we can work together, you can find me at peacewithendo.com or over on Facebook, Twitter and Instagram @peacewithendo. Pop on over and share your thoughts on the show, or simply say hello.

Thank you so much for tuning in. I hope you find some peace in your day today. Sending you so much love. Bye for now.

All information provided within is for informational and educational purposes only and should not be construed as medical advice or instruction. No action should be taken solely on the contents on this podcast. Please consult your physician or qualified health professional on any matters regarding your health and wellbeing on any opinions expressed.

When trying any suggestions posed, please do so at your own risk. You are responsible for consulting your own health professional on matters raised within.