Introduction and Megan's PCOS advocacy

Hi. Welcome to this episode of the PCOS SOS Summit. I'm your host, Dr. Felice Gersh. I am so excited to join with me on this interview episode. Megan Stewart, who has founded and has been the executive director of a phenomenal organization, the PCOS Awareness Association.

So welcome, Megan thank you so much for joining me for this interview. And I would love for you to talk all about the wonderful advocacy that you're doing.

I know that you're promoting, you know, like education and awareness around the globe and empowering women to take charge of their illness and to really control their destiny.

So I just love what you're doing. So welcome. And I'd like to have you share your personal story as much as you're willing and talk about your amazing organization and your road to how you created it and where it is now and where it's going.

Yeah, absolutely. I'm so honored to be on on this episode with you, Dr. Gersh. You know, you and I have been connected for about eight years now, and I really appreciate all the work that you've done for the PCOS community as well, and and just your wealth of knowledge and in your advocacy.

So thank you so much. Yes, hi. I am Megan Stewart, the founder and executive director of PCOS Awareness Association. We have been around now for about ten going on 11 years now, and it's been an amazing journey.

It starts with me and I started showing my symptoms of PCOS when I was about nine years old and from the ages of 9 to 16, my mom was my largest advocate and she was shuffling me from medical professional to medical professional, trying to figure out what was going on with me.

She got answers, such as? It was just normal adolescence. It was something that I just had to go through as a, you know, going into teens and as a woman.

And she was also told that I just needed to lose some weight. Anybody that, you know, that has PCOS and has the weight gain, you know, that being told that you just need to lose weight is not a viable answer.

It's not an answer that is easily, you know, that can't be empowered by it and you can't. Losing weight is not easy. So that was kind of a deterrent for me.

But then as well, my mom was also told that it was in my head and that I was trying to get out of going to school and being a normal, you know, adolescent gym class and whatnot.

Early symptoms, misdiagnosis, and diagnosis

Some of my symptoms that I had were weight gain, of course, and then the hair growth on the face. I also just the ups and downs of my hormonal, you know, changes and then anxiety and depression were huge in my life.

So from the time of age nine to age 16, I was dealing with so many different things. Actually, just maybe a couple of years ago, I learned something that my mom actually did.

And I she she's telling the story to somebody else that I'm over hearing her tell this story and I'm like, Wait, you did what? So she was telling somebody that when the one of the medical professionals had told her that, it was in my head that she decided that she was going to give me a placebo pill and she was going to figure out if that was true or not.

So she had given me a placebo pill, and she said that for about the first week that I was a whole new person and that it seemed like all of my symptoms were cured.

But she said about the second and third week, my symptoms were worse, my depression was worse. My anxiety was worse. Self-esteem was just not there. And then at that point, she realized that it just wasn't just in my head.

It was something that was serious, seriously going on with me. So a couple more medical professionals going to and finally found an OBGYN at the age of 16 that was able to diagnose me with PCOS at the time.

I was also diagnosed with cervical cancer. So it really kind of put PCOS to the backburner because I was told, as most women with PCOS are told, that it's just an infertility issue.

And of course, at age 16, I was like, You boys, I don't care about that. Like, it's not something I really want to talk about or think about at that age.

So cervical cancer was definitely high on the list at that point. Around the age of 21 is when my PCOS symptoms really started to weigh on my life. I'm going to date myself a little bit here, but years prior, age 21 was like the cutoff for parents to have you on their a rider, on their insurance on their health insurance.

So I had no health insurance, age 21 and my OBGYN, they had diagnosed me. She was kind enough to use me as like a paper study, a medical study for her.

And she was able to discount my, my, you know, my medical bills at that point. But I was admitted into the E. R. because my cysts ruptured on my ovaries and the pain was just astronomical.

And at that point, it was like, I can't be the only one that's going through this. I just can't be at the time, really. The only that was there was a couple of PCOS kind of advocacy groups out there, but really where you would get a lot of your information was Craigslist chats.

So I went out to Craigslist chats and did a search for PCOS in my area and found a couple other women that were also dealing with PCOS. And they they too were saying, we just can't be the only ones.

And how is it that I'm the only one suffering this and nobody's talking about it? It was at that point that I'm so I'm very close to my family. And I started making because they were asking me like, what happened in the hospital?

What's going on with your health and how how are things going with you? So I started making teal handmade bracelets because I had found out the official color of PCOS was teal.

So I started making handmade bracelets and started giving them out to family and friends and hopes that they as cause. You know, I would tell them I'm dealing with PCOS and they'd be like, What?

What, what's that like? And I would explain to them and then and hopes that they would be able to explain it to others. And it'd be a conversational piece that they would be wearing these teal bracelets and someone would be like, Hey, what's that mean?

And they would be able to then further, further, further the advocacy in that aspect. At that time, Instagram started became becoming live and a big thing.

And I had a cousin that had purchased for me like arms full of the teal bracelets. Right. And also at the time, Wonder Woman was starting to become a big thing as well.

And so my cousin posted on her Instagram, you know, The Wonder Woman pose with all of her teal bracelets and talking about how like PCOS, what PCOS was and that if anybody needed any information, they could come to me.

And next thing I knew, I had people from all over the world contacting me about PCOS and where they could get a

bracelet. And it was at that point that PCOS Awareness Association was born and it was like, okay, this is something that's going to happen.

We're going to run with it and we're going to keep going. And to this day, like, I have never been more blessed in the reach that we have and the people that we touch and that the hope that we bring other people all over the world.

I often say any time that we put on an event, you know, the stress of the events and whatnot, I, I'll say during the event, I'm never doing this again.

Like can't do this, can't handle this. And then there's always that one moment during the event that somebody comes up to me and they are so appreciative of what's going on that that reignites the passion and the drive in me to keep going and continuing on with another event and another event and another event.

So I just love that our reach and the people that we help and the people that I've met along the way, such as yourself. Dr. Gersh It's just amazing, you know, we do an event that we call PCOS Con and it's a bi annual event, so it's happening in 2023 and then it'll happen again in 2025.

Building PCOS Awareness Association

And it's something that we started off being a whole we started like right before the pandemic had happened and it started being a whole weekend event in one location.

And then the pandemic happened and we went totally virtual for the, the, the next PCOS kind of event. And then this year to 2023 is the first year that we were back in person and we've decided to break it down into three different events in three different locations.

So we're doing first events in New York. Second event is in Houston, Texas. And then third event is in Los Angeles, California. So we're super excited to keep keep going with that process.

And hopefully in 2025, we'll be able to do more, more locations and spread across the U. S. that much more. At PCOS Awareness Association, we base ourselves on a couple of pillars and those pillars being providing information, providing support for those who are suffering from PCOS and those that are wanting to support those suffering from PCOS, along with providing resources.

One of the biggest things that we do is we don't reinvent the wheel. So if we know that there's another organization out there that is, you know, dedicated to something that has to do with a symptom of PCOS, we will partner with them to be able to provide that resource and service.

Case in point, we partner with the crisis text line because we know that a lot of women with PCOS deal with depression and anxiety and it can get to be a lot.

So we partner with them and if you text PCOS to 741741, you will get a dedicated support person that'll help you through any sort of crisis issue that you're dealing with when it comes to PCOS, whether it's feeling, you know, completely at a loss or feeling, we've even had cases of, you know, suicide.

So we want to be able to support women as much as possible. The other pillar that we we handle at PCOS Awareness Association is that we help fund the research of PCOS, and the research is being handled by Lujan Labs of Cornell University.

When I was searching for a lab to support, it just so happens that Lujan Labs was one of the only labs that was researching the cause of PCOS. A lot of the other research labs they're researching, whether it be infertility or obesity, and nobody was really talking about like, okay, what is PCOS and where is it coming from and why is it happening?

Lujan Labs happened to be the only laboratory that was actually, you know, diving into that question. And I think they're actually going to be having some answers here in the next couple of years on like what what PCOS really is.

So those are like our our main pillars, but of course, like we are here for any anybody that has PCOS and anybody that is supporting anybody with PCOS.

We have a program that we call Man of Steel and it was actually started by my father. He was struggling with the fact of like, how do I talk to Megan about this woman issue and what do I say and how do I deal with it?

And he really finds it important that we are talking to whether it's fathers talking to daughters, fathers supporting daughters, fathers supporting, you know, or husbands supporting wives, brothers supporting sisters, uncles supporting nieces, you know, whatever it is that we are getting that male support as well.

We come up with all sorts of different ways that we can support women with PCOS in different aspects. So it's really, really about like the gist of PCOS Awareness Association.

Wow, that is quite a phenomenal pathway that you took. It's almost like you fell into this by chance, you know, that you were doing one thing and then it sort of exploded into something so much grander and so like incredible in terms of its impact, like you said, global impact.

And I'd like to dissect a few of the different things that really impacted me through your amazing story. And the first one, which you actually sort of came back to there just a few moments ago, was the mental health aspects, which seem to be a big contributor to your suffering with PCOS and yet so poorly talked about.

And, and that is, you know, the depression, the anxiety and how that is, you know, both a cause and an exacerbating of PCOS. Right. So in terms of yourself, how did you ultimately deal with your mental health challenges?

Because this is a very well known there are books and articles written about the mental health issues in women with PCOS, and it can stem from the hormonal imbalances as well.

As you mentioned, the self-esteem issues like when you are overweight and you do everything you can and you're given these ridiculous little statements by the physicians, like just lose weight, like you could just do it, you know, like I can will it?

And it will just happen when we know there are massive metabolic alterations that are happening in the body that promote the storage and deposition of fat, that have nothing to do with willpower or any of that sort of thing.

And so in terms of like helping, because I'm sure there are many women out there listening to this interview are saying, you know, no one's even talking about my mental health, my anxiety, my moods, my depression.

And here I'm looking at this beautiful Meghan and she has dealt with this. So maybe going back, you know, and talking a little bit about how you did deal with that huge issue that involves so many women with PCOS.

Yeah, right. Right. Well, first, let me just tell you a story about trying to lose weight. So again, going back to ages nine through 16, I remember at one point Weight Watchers.

So back in the day, again, dating myself.

Mental health, self-care, and exercise

Back in the day, we the way Weight Watchers used to work is that you you signed up and every week you would go into an actual physical location and you would be weighed, and then you would sit in like a meeting that talked about all the the yays and the, you know, congratulation guess you lost £5 or you get a little star, that type of thing.

So my mom signed us up for Weight Watchers and of course, being age like 1011. I wasn't making food, my mom was making my meals and sending them to school with me and, you know, making sure I had my meals set for the days and and nights and whatnot.

I just remember this one time going in to that weekly session. And my mom, because she was doing it with me, my mom for the week had lost something like £2.

Megan had lost £2.2, eating the same exact thing my mom was eating and doing the same exact exercises. My mom was doing. So it was very hurtful. Like, it was, it was hot.

It was horrible, like feeling right. Everybody in the room is getting the star because they lost two plus pounds and Meghan didn't lose anything. So it was that's that's that definitely feeds into the Depression, right?

And can make you feel a certain way about yourself. So I think for myself, one of the things that I definitely do, I'm intentional about the way that I think in the way that I speak to myself.

I try not to, you know, put put down hours on myself daily. And I also try not to look at other people and other people's like paths and roadways through through life because that's theirs.

That's not mine. So I think that social media can be a it can be hurtful, right? Like you're looking at people's lives through what they want you to see and what they want, what they're posting.

So what they want you to see. And that's one of the things like, I won't even lie. My family, my extended family, they sometimes complain to my parents because of the things that I post on my personal social media page, because they're like, That was a little too honest and a little too open.

But you know what? I have to be? Because if if I'm not who who is who's going to be honest and open about the fact that I'm dealing with anxiety or depression or I've even been diagnosed with PTSD.

Right. Like certain things in my life that have happened. So I think just being honest and open with yourself and honest and open with others is key in helping to heal and helping to be intentional in the way that you think about yourself.

Also, another big thing that I did was therapy. Don't knock it because it's it's amazing. It can help you. I can give you different stepping stones to get to where you need to be and to feel better about yourself and then also, you know, when it comes to the weight loss, they always say lose 20% or whatever and get active.

That was one of the things that I really needed to do. After the age of 21, I realized that, you know, I bought a Fitbit and I realized that I wasn't getting any steps.

My my job my day job is I'm stationary at a desk all day. So I wasn't getting anywhere near 5000 steps a day, let alone 10,000 steps a day. So I was being very intentional in that as well after I got the Fitbit.

So it was like, okay, let's get up, let's go walking, let's do this, let's do that. And I think that even today I, you know, I work out with a personal trainer twice a week and I'm just active not because I want to lose any weight, but just because of my mood is that much better after I, you know, those endorphins get go start going through my body and I start feeling better about myself.

So those are like the key, key points that I'd have to say. Well, I love that. And we always try to focus on health, right? Because so many people who try to lose weight with or without PCOS, they do it through starvation, which is hopeless.

I mean, how many times do you have to reinvent the wheel? That doesn't work, right? Because we know that no one can starve themselves. Well, I mean, what one in a million that will stay on a starvation diet for life?

Because that's what you'd have to do. Because as soon as you start re feeding, you gain the weight back and more and more hard to have not be malnourished.

You're on a starvation diet because how do you get all the nutrients in on that kind of a crazy diet and then your hair falls out? That even adds insult to injury, right?

So we do not advocate for that. We advocate for to what you said, you know, focus on health, the things that you can control. And when they've actually I'm not against using antidepressants, but when they've actually compared antidepressants to exercise, which work better for depression, it just turned out that in most cases, exercise actually worked better with you, discovered yourself that, you know, therapy, exercise as and when needed, of course, medications.

So those are all really important. And another thing that resonated with me about your story was your real desire to have a community, to have others who were going through what you were going through that you could actually connect with and you had to go to Craigslist.

I know one has to do that any more because there are people like you who have created a community. So I thought maybe you could share with our viewers, listeners like the community that you have created and how they can utilize PCOS Awareness Association to get connected with people who have the same similarities in terms of what they're suffering and their journeys and sharing stories so that they can both commiserate but do much more than that.

Learn from each other and build support to actually grow together in this journey. Yeah, absolutely. And I have to say, when we first started PCOS Awareness Association and we were on Facebook, just Facebook by itself and people would send in questions, you know, private message questions all the time.

And what I would do is I would take their names out of it and take any identifiable information out of the questions. And I would repost it onto the Facebook page as like a PCOS question, and people would literally start answering or providing advice or letting others know like This is what I did for this and here's how I handled it.

And I think that that is super helpful, not in the sense of medical, you know, guidance or whatnot, but in the sense of the community drive that you're talking about and feeling like, oh, okay, this question's out here and I'm not the only one that's dealing with this now.

I know that it's not just me. And then also on top of that, you know, women with PCOS, my PCOS symptoms could look very different than somebody else's PCOS symptoms.

And so one of the biggest things that we also drive a PCOS awareness association is that what works for one may or may not work for another.

Community support and resource partnerships

So we try and provide all of the options of all of the different resources, such as, you know, the hair growth on the face. We have a partnership with Milan Laser and we also promote electronic assets, right?

Like we want to give you all of the options and let's leave it in your hands to have that power to be able to say, okay, well, this works for me and this one doesn't.

But I think that that choice and that decision, because prior it was like, I don't have any options. What am I doing? Like, how do I how do I get rid of this?

So that's one of the biggest things. And so now we are not just on Facebook, we are on Instagram, Twitter, LinkedIn, Pinterest. I can't even think of anywhere else.

But, you know, all the places that's on social media that we could be, we're thinking about Tik Tok, but I don't know,

getting me on a Tik Tok video is probably not the best idea.

Well, that is so wonderful to know that you're really out there and you're providing both the community and the resources that women who don't know where to turn in and sometimes their own health care providers don't know where to turn.

I mean, because, you know, one of the things that you mentioned was linking people like me, health care providers who want to participate in the whole community of PCOS with awareness, education, global mobilization, in fact, and all the research and so on.

So for there are health care providers out there as well who are listening in, right. They think are, you know, probably out there among our audience right now.

It could be a third could be actually health care professionals, but they can also help. Right? They can work with these. Yes, please. We we absolutely love our health care professional, you know, partners.

We started the way Dr. Gershon I met, actually, was I think it was around maybe the second year that that PCOS Awareness Association was around. I partnered with a organization called OMICS that put on like medical professional conferences.

And so in my mind, it was a need to get the PCOS medical professionals in a room. And we got to talk about we are talking about this. So they had I think that first session was in Seattle, Washington.

And I want to say there was about 30 or 40 medical professionals. And it was it was such an informative bunch that, like, I learned things that I could never even imagine and fathom.

And as years went on, it turned into, Well, I think we need something that combines both the professional roles with the patients, because the patients want to hear this too, even though they may not talk, fully understand everything that's being said.

They they want to hear this, too. And not only that, but medical professionals such as yourself, you guys were telling me that you wanted to hear the patient side of things.

So bringing that into a PCOS kind of that was like it was having that whole weekend long event was amazing. I know I loved being part of it and I'm looking forward to being part of the Los Angeles PCOS con that you're going to be putting on.

And you know, we're talking now and we're ahead of that. But when this actually goes live, it will be in the past. So maybe you can talk because this is going to happen again.

It's going to be bigger and grander. Okay. So that for all of you who maybe missed it, but we're going to get this out on social media. So, you know, hopefully in hindsight, you'll say I did get there, right?

You're right. But, you know, in case you didn't, maybe you could just talk about what is happening will be happening and then that it will be in the past tense when this plays out.

But what is being planned and then this will happen again in the future. And then how they can still, even if they missed it, you know, how they can access some of this information and, you know, that may still be available or archived in somewhere.

Absolutely. So with our first PCOS con and then our PCOS con that we had to go virtual, we realized a couple of things. One, we needed to get more global where with the locations.

So that's why we've decided to do three locations this year. And then two when it came down to now is being in three locations this year. Like how much money is always involved, right?

How much can we do in each location and still be beneficial to those that attend? And one of the things that I said to the team was, okay, so we're not flying and we're not flying medical professionals out to any of these locations.

We need medical professionals in each location because that will be beneficial to the women that are actually coming. Right. Look, if they're coming if they're attending the L. A.

one L. A. location, PCOS con, they're going to want to see L. A located medical professionals because then they could be like, okay, well, I'm going to go to them in a week and make an appointment.

So we have what we're trying to focus on a couple of different aspects in each location for L. A., I believe we have Dr. Kirk. She's coming, and then I believe we have a mental health medical provider.

And then we have a couple other specialists that are also coming to L. A. and then the same in each and each of the other locations as well. We also have we are bringing us along one person that is traveling to each of the locations with us.

And we found that this topic in particular was huge at the very first PCOS con and it's PCOS and sexual health. That's something that we really don't talk about as a as a group of women.

Right? Like we don't talk about our sex lives, but we all know that PCOS is affecting our sex lives. So she's actually going to come to all of the locations on her own, her own bill.

PCOS Con events and future plans

And she's she's amazing. She's a kind of a sex therapist. So she's going to be joining us on all of the locations. So we're excited about that in the future.

We really want to do more than three locations and we don't want to have it barebones because this year it'll be kind of bare bones. We're testing the waters to see how it's going to work.

So my vision for the future is that each location will be a weekend. It would be literally, you know, you can come on Fridays, Mingle Network, Saturday, start off a whole full day of different speakers and then Sunday the same right.

Look, I really like the way our first PCOS con went. We threw in some fun activities such as yoga in the morning and I think the next day we had Whitney Way thore who's the actress on my big fat Fabulous Life.

She came out and did a whole workout session, dance session one morning. So just, you know, just a very chill vibe. I don't want it. I never wanted PCOS kind of feel like it's uptight and that nobody can relate to each other or speak to each other.

Just kind of like, like, remember camp when you were, when you were younger and how you went to camp and you were very much like you made new friends and you went home and you, you know, wrote the letters afterwards.

That's the type of things that I want to feel out of coming out of PCOS. So yeah, I'm excited about what the future of PCOS Council will look like. Well, I know that in the ones that I've been a part of in the past, that everyone was just themselves, you know, there was so much fun and friendships were made and you had really interesting, you know, people who came and brought their products and so on.

So there was like that educational part as far as like, well, what kind of supplements or other devices and so on. So it was a wonderful blend and everyone just had so much fun.

So I can't wait for the one that's coming up in L. A. and and I'm so excited that this is going to be ongoing. And like I said, bigger and grander, because this is evolving just like we all are on our endless journeys that hopefully are going to go on and on and we're going to keep evolving and getting better at managing PCOS and our lives in general.

And so too with PCOS, right. It's just getting, you know, like it's like multiplying, right? It's it's very prolific now in terms of all the cities that you're going to be dealing with and so on.

And you know, I thought I want I know that when you had submitted some information, you talked about a book that you had written a preface for. So I thought maybe you could just touch on that because, you know, that's another interesting area that you've now written a preface.

And tell us a little bit about that and the book perhaps. Yeah. So I, I believe I did yours as well. I do know it. You definitely are in my book. Yes.

Right, right. So I had PCOS Diet Book, which is not really a diet. It's written by Tara Spencer and she's done a couple of PCOS books, but it, it, it's named again, it's named PCOS Diet Book But really it's just a bunch of recipes that she's put together that are really fact based, guided on like what a woman with PCOS should have in their diet.

And it's I actually follow a couple of the recipes in there. Not really a cook. So having the recipes around are great. So I, yeah, I would definitely go out to Amazon and find the PCOS diet book and then of course, Dr. Gersh's SOS PCOS book was amazing as well.

Like, I still talk about the first PCOS con, like the things that Dr. Gersh was saying and how it man I, you know, there's certain things that you think about PCOS and then somebody will say something and it clicks like, Oh, that makes so much sense, right?

And Dr. Gersh definitely does that in her speeches as well as her book. So I definitely say go out and get those. Oh, well, thank you. And we just love I just love all the things that you're doing for advocacy and your own journey, which has been a struggle, but with so many, so many successes.

And when I hear about your family, like what your dad has done and how your family has supported you, I think it's so important. Like you said, the honesty that that is was another thing that really resonated with me, how you were honest.

You're always honest and open and you try to be about, oh, my gosh, you talked about what you were going through with your family and how your mom was there for you and took you to multiple doctors for several years before you finally got a diagnosis at still a very young age.

Books, family support, and closing remarks

And so, I mean, for everyone out there, if your family is supportive, I mean, just thank them every day because that's one thing. And if you just happen to have a family that doesn't understand, you know, that's where maybe somebody that's professional can come in and help them to understand, you know, what you're going through.

Because it's not always obvious to family members like what you're going through if they haven't gone through it themselves. And this is new to them. So not only that, but I think for a lot of people, if it's not physically in front of them, if it's something that's internal, right, they can't see it, therefore it doesn't really like they don't understand it.

But if it's something that's physical, like if you're walking around with a broken arm, somebody is going to be like, Oh, let me help you. Right. But since PCOS is more internal, it's yeah, nobody like you have to be honest about it and let people know that you need the help.

And because support is so important and that to me is one of the huge things that PCOS Awareness Association can provide for people even if they don't have like you like this amazing supportive family you can have like they so the family you create, right?

Right. One that you why you didn't get born into but the family that you create through networking, through associations like like yours that can help them to find people they can associate with and understand.

They don't have to have the identical symptoms, but they're part of this same community of women striving to be healthier and happier and find answers and and you're there helping to provide them every day.

So can you, like, share? Like, how can they find your organization? And, you know, how can they, like, watch you and see what's going on on these different social media platforms?

Absolutely. So we are definitely our website, which is www.pcosaa.org But we are also on Facebook, which is Facebook.com/PCOSAwarenessAssociation. And then our other handles on Instagram and Twitter are going to be PCOSAA.

You can also find us on LinkedIn and I believe that one is PCOS Awareness Association. Well, that gives them so many options to choose from and hopefully they'll try them all and go down the road to one of the many PCOS cons that will be coming coming in the future to hopefully a city near you.

I'll be seeing you. Well, I'm not sure if you'll be in LA, but. Well, you will be. I'm going to see pretty soon. Yes. And we will always stay connected because that's what we do right.

And thank you so much for joining me on this episode and continued success and joy in all you do. Megan. Thank you so much. Dr. Gersh, same to you.