Unleash The Power Of Your Patient Voice Transcript

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Introduction and Ashley's PCOS advocacy journey

Hi. Welcome to this episode of PCOS Summit. I'm your host, Dr. Felice Gersh. I'm here today and so thrilled to welcome my dear friend Ashley Levinson, who is an incredible advocate for patients with PCOS.

Her journey is amazing. I'm going to let her share that with you. But what I can tell you is, for over 20 years, she has been advocating from the patient point of view for PCOS education and research and all kinds of amazing things.

So Ashley, welcome and please share some of your journey and you'll help all the listeners out there today to do what they can do to advocate for themselves, their family, their friends and so forth.

Thank you so much for having me here today. I'm really excited to be a part of this. I have been part of the PCOS community for close to 25 years now.

Like most patients, I started out not being able to get pregnant and gaining weight and getting adult acne and had a lot of different symptoms that no one could connect together.

Eventually, I did find a doctor who diagnosed me with PCOS, but they didn't know much about the condition or how to treat it. And through the frustration that continued to build over not getting pregnant, not being able to lose weight, and no one knowing about the condition it kind of birthed my my advocacy because no one was listening to me.

So I felt we needed more resources and better ways to connect patients and providers. So throughout the years, I have worked with multiple organizations that deal with polycystic ovary syndrome and women's health, and I have started campaigns on social media such as for PCOS, the Lemon Paste Challenge, and have worked with PCOS Challenge, the National Polycystic Ovary Syndrome Association to advance advocacy for patients with Congress, with organizations like the National Institutes of Health, the FDA.

So behind the scenes, I've been doing a lot of things to help raise the profile for PCOS. Which is amazing. Maybe you can go back a couple of steps and just explain to people who don't really know what does it mean to be an advocate advocacy for a medical condition and why does a medical condition need an advocate?

Sure. So basically the way I define advocacy is basically sharing your story, which would be your patient experience with the condition, how it has affected you with symptoms, your daily life with getting care so you share that information with the public so they get a better understanding of the condition.

On the other side of that, you also reaching out to providers to help them get more educated about the things that you're going through. Some providers who specialize in PCOS are very good at recognizing the symptoms and the diagnosis and the treatment.

However, there are a lot of providers who still don't know much about the condition. Being an advocate means sharing that experience, sharing education and bridging the gap between patients and providers.

And lastly, you want to raise the profile of the condition.

What PCOS advocacy means and why it matters

So for me personally, I use social media as a tool to engage audiences, whether it be the public patients or, again, providers. Through doing different campaigns that focus on different parts of the condition, on different aspects of the condition.

So bottom line, it's sharing your story and your patient experience and then learning how to take that and build a movement with it. Well, I know in terms of some of the like lesser talked about issues relating to PCOS like we were talking about before we came on that.

So much relating to PCOS is about just weight gain and the fertility issues which are not insignificant issues whatsoever, but it's so much more so. Maybe you could tell us a little bit about some of these other areas that you have sort of educated on and and some of the campaigns that you've participated on and some of which I've been with you and worked with you because you recruited me, which was fantastic. Yes.

So the biggest campaign that I have built and worked on is called the Heart for PCOS campaign, and it focuses on the metabolic issues of PCOS and the consequences that can occur.

If we don't look at PCOS as a full body condition and that it goes beyond reproductive years, that goes beyond infertility and goes beyond weight loss.

A lot of people don't realize that PCOS is significant in cardiovascular health. So if our insulin is high, our androgens are high, it can put us at higher risk for cardiovascular disease, seven times greater risk for heart attack, four times greater risk for stroke.

So there are these aspects that we have to really pay attention to because they impact our health long term. We can't just ignore women's health prior to them trying to have a child or after they have a child because PCOS is lifelong.

And that's pretty much the lesson that I've taught in that the PCOS is lifelong and that we have to manage our health with this condition throughout the lifespan so we don't find ourselves having cardiovascular disease later in life.

Well, that is so critically important. And you know that that's an area that I have always emphasized as well. And you mentioned issues with providers.

So, you know, which now is a broad group of people, you know, not just physicians. And what can and what would you help the patient, you know, from the patient's perspective as an advocate, to help the patient to present their issues and to be heard more and to educate as well their providers about this condition that they're seeking help for.

So what what about the provider and what's the interrelationship there between the patient and the provider? And what can advocacy do to help build that relationship to be stronger and more beneficial to the patient?

Right. So I come from a place where I believe that health care providers and patients really need to be partners with PCOS care. And it's because there are a lot of nuances that come with care for PCOS.

It is individualized because PCOS, PCOS was. Let's go back a minute. PCOS is considered a syndrome because it's a combination of symptoms that you could have or may not have.

It depends on the individual. So therefore the care has to be individualized. So first and foremost, you need a partner or a provider that is going to listen to you and that you're able to listen to.

There has to be trust there. If a provider is not well versed but is willing to learn about PCOS, tell them what you know.

Heart for PCOS and lifelong metabolic risk

Tell them about your patient experience because that's how they learn what's going on with the patient and what their needs may be. There are a lot of pamphlets.

There is a lot of information that's provided online through researchers. Take some of the studies into your providers. Point them to organizations like PCOS Challenge that are doing the work to advance education advocacy.

They have provide resources. They have conferences, follow people like Dr. Felice Gersh who are always educating others about PCOS and the metabolic consequences and the long term consequences.

So there are a lot of resources out there and I think it's just redirecting some of these providers when you address them about your condition. Well, that's all well said.

And so important because it's so frustrating when patients go in and they're not heard or they're they're really just minimized. That's how they feel about it.

And maybe from your perspective, because you are coming from the patient's side, I would love to hear more about your journey. I know you were even on a television show about about PCOS and maybe you could go back to the beginning because I think people can really learn and and just help themselves to know what path they wanted take by hearing other people's stories.

And, you know, that's what you deal with all the time is all the stories of women with PCOS. So maybe you could share your personal story, if that's okay with you.

Absolutely. So my diagnosis came all the way back in 1999 where there was even less known and less talked about with PCOS than now. And when I started, it was out of a desire to become a mother.

I went off the birth control pills and within a three month period of time I had all of these overwhelming symptoms hit me. I had weight gain. I had put on close to 100 pounds I started having adult acne, dark skin patches, which are called Acanthosis Nigricans I started seeing skin tags.

I wasn't getting a period and when I would take a pregnancy test, I wasn't pregnant. So there was a lot going on and I didn't understand it. And I went to my general practitioner and I said, Listen, all these things are going on. Is there something seriously wrong with me?

Do I have some sort of condition? And I was accused pretty much of stress eating and worrying too much about getting pregnant and probably eating when I shouldn't eat because I'm trying to compensate for not getting pregnant.

So there was a lot of blame placed on me for what was going on and I didn't know what was going on. So I started reaching out to different doctors, to different specialists.

I probably saw, I would say probably five doctors over a two year period before someone actually diagnosed me with PCOS. And it was interesting because the doctor who did diagnosed me finally had just finished his residency and just went into practice.

And I remember walking into his office and I said, you know, I've seen a lot of different doctors. I have all this stuff going off me, weight gain, acne, blah, blah, blah, my hair seems like it's falling out.

I don't know what's going on. And his eyes got real wide and he ran out of the room. And I'm sitting there saying to myself, Oh my God, do I have a tropical disease?

What's going on with me? I don't know. And he came back with a textbook, and I think this is what defined things for me. He opened up the textbook and he said, Here, look at this right here.

And I looked down and there were four letters that were going to define the rest of my life and my choice to become an advocate. PCOS And he said to me, I don't know much about the condition, but I'm willing to work with you and I'm willing to learn with you.

So at that point, he didn't really know much about lifestyle management and overall care for PCOS. So he said to me, Do you want to get pregnant? And I said, Yeah, I want to get pregnant.

So he sent me to a reproductive endocrinologist and the goal was to get me pregnant, which I was fortunate enough to get pregnant. And that was pretty much it.

I mean, it was just getting pregnant and dealing with that.

Building patient-provider partnerships

And then after I had PCOS, I started using a doctor who was a at the time one of the top PCOS experts in my area and decided I was going to get healthy with PCOS.

And I did. I started losing weight, I started getting medications and I started understanding about the condition because she was so heavily involved with PCOS research and bringing awareness to the condition she asked me at one of the appointments, Would you please share your story with people?

And I'm like, Yeah, sure, I'll share my story. I didn't realize that it was actually on Discovery Health Mystery Diagnosis, that she was competing to share my story.

So I went on national international television and shared my story. And within a very short period of time of it airing, I had all of a sudden thousands of people sending me emails and contacting me online and saying, you know, I had the same symptoms.

I didn't know what it was. I told them my doctor about and they told me it was PCOS. And it was at that point that I realized by sharing my story that I could make change happen and I could help people understand my condition and not go through what I had to go through to get where I am today.

Well, your story is amazing and it's also in many ways typical. That's the thing. And it's still typical. And look how many years have come and gone. I know they had a study published quite a few just a few years ago that talked about that the typical woman with PCOS may see 11 providers before she gets a label.

I mean, it's just getting a label, a name for what she is experiencing and that's not even treating her. That's just giving right people. So it is amazing.

But I think one of the things that really resonated with me was your persistence. You didn't just accept this label of blame. They gave you the blame game label, right?

It's like your fault, which is so prevalent in the PCOS community. Is it so that women feel like somehow they're responsible completely for all the different problems they're experiencing?

How did you feel when they said, It's your fault, Ashley, you're doing this to yourself? I mean, how does that affect your self-esteem or, you know, just your view of the world and yourself in it?

Well, I think I'm a rare breed in the sense, like, I know for a lot of people, it can trigger a lot of emotions of depression, of sadness. But in me, it triggered anger because I know myself and I knew I wasn't doing things to harm myself.

I wouldn't be seeking out medical care, you know, if I didn't care about myself and, you know, just being told that I'm not eating right and I'm not exercising, which was the farthest thing from the truth.

I said, you know, I can't allow this to happen. And for people to misrepresent this condition and the patients that have it because PCOS does not discriminate.

There are patients of every size, every color that have maybe one symptom and some maybe have 50 symptoms.

And we can't judge people for having these symptoms or having feelings about having a condition.

We need to validate their experience and use that to help understand what they're going through and how to treat that. Well, absolutely. And I know that, you know, you do work quite a bit with PCOS Challenge.

Can you talk about some of the advocacy that you've done in relationship with their organization and also some of what you're doing on social media and the different forms of social media?

So that, you know, maybe you'll inspire other social media mavens out there to want to get involved or just for people to know what's out there and what you're doing.

Absolutely. So PCOS Challenge is an incredible organization that was created by Sasha and William Patterson and they are pretty much patient run, patient led.

The patients are extremely involved in all of the activities and all of the planning. And what they have done is giving patients a voice with national medical organizations, with Congress.

They started, I guess it would be about six years ago, PCOS, Advocacy Day and once a year. Usually in March we go and we talk to members of Congress, of the House of Representatives and the Senate, and we tell them why it's important for them to recognize PCOS nationally for September's PCOS Awareness Month that we asked them why.

We asked them to help with funding research and to introduce different legislation that would help patients receive care with PCOS.

Ashleyu2019s diagnosis story and early struggles

So that's really important and that's a really easy way that if you really wanted to dove into advocacy, you could get involved because you sign up. They give you a mentor, they give you all the information that you need to train yourself and train with others.

So you know what you're going to say to these legislators, which is very easy. I know it can sound intimidating, but it's very easy to do. And they are really excited when their constituents come in and share their stories with them.

So that's one way. PCOS Challenge also gets involved with the National Institutes of Health, where they had a panel on PCOS across the lifespan where they talked about cardiovascular health and metabolic health and kind of move it in the direction of the condition.

In November, they are going to be meeting with the FDA because there are no specific drugs for PCOS. So we want the FDA to look at some of the drugs that are being used off label about research to create a drug specific for PCOS.

And that's going to be a really big patient event. So they're encouraging everyone who is a patient to come down to this meeting, to support this meeting and, you know, to to speak about their patient experiences.

So it's really great because they they've also married patients and providers like you. That's, you know, one of the ways that I learned about you and we started working together on things.

So they do vital work and it's important that people get out there and share their stories with them. Now, as far as social media is concerned, a lot of people ask me, well, how do I start?

You know, how do I become an advocate online? And it's very simple. You just share your story and you keep sharing your story, and maybe one day one person will listen to your story.

The next day may be five or six, but if you can change just one perspective or support one person, then it's worth it.

And you are an advocate. If you're doing that, you don't have to have years of experience or educate action or connections to become an advocate.

Because I didn't have any of that. I just decided that enough was enough and use my voice for change and everybody has the ability to do that. And you you took on a new name, right?

A little bit of a different persona. Tell us how you chose your name, what it is. And, you know, just how you've used that name to help promote and advocate for PCOS.

Well, my name online or my persona is PCOS Girl, but it's with a you instead of eyes. So it's PCOS. Gee, you are out because I had to be a little fancy and that really helped me online with people being able to identify that I was educating about PCOS and I was a patient that had PCOS.

So it's become my online name and people probably know me online as PCOS girl than they do Ashley Levinson. Like if you say Ashley episode, they're going to be like, Who's that?

But if you say PCOS girl, people know that that's me because I built that brand over the years. Which is great. That's exactly how I first got to know you as that.

And then I put that that's who you are, right? So which is great. Now, you've been doing this for over 20 years, as you said. So what are some of the changes you've seen?

I mean, what are what's the progress? Where do you see things now versus 20 so years ago in terms of education, knowledge and just sort of advancement in all sorts of ways for women suffering from PCOS.

Believe it or not. And I know for people especially that are just getting diagnosed and learning about the condition, there's a lot more awareness about PCOS than there ever had been before.

It was almost like being shoved in the back of a closet and nobody really talked about it. And the patients that have it were ashamed to share their story stories because it was considered a fat girl's condition or, you know, a condition where people don't take care of themselves.

So you didn't want to talk about it much. But with a lot of the movements for body acceptance, for self awareness, people are speaking up more. So there's been a lot more awareness.

A lot of the medical organizations are starting to realize that PCOS impacts patients in significant ways and have started to pay more attention to that.

And in doing that, there has been a lot more research that's being done. Not enough, I will say that, but there's more research that's being done for the past six years.

We we have a connection with government and government agencies to help advance this research and funding and awareness of the condition. So we've come a very long way.

We still have a little ways to go to get over that goal line. But I feel really positive about the changes that I've seen lately. And, you know, it was like going from the dark ages into the light.

So I think we're in that period of time where we're starting to see the light at the end of the tunnel and together and with people again sharing their voices and experiences.

I think we're going to get there. Yes. And I totally agree. There's been so much more awareness of the condition known as PCOS. In fact, one of the things that's talked about is recognizing the different manifestations and metabolic consequences.

There's this whole like little movement about changing the name of it. And I was wondering, from a patient

advocacy point of view, is that helpful? Is it harmful?

What do you think about that whole discussion of changing the name of PCOS to something totally different?

Finding a voice through sharing her story

To tell you honestly, I don't think the name matters at all. And even as a patient, I don't care what you call it. What I care about is the definition of the condition and what people do with that definition.

As far as research, as far as education, as far as treatment. So I think people need to stop thinking about investing way too much money to change something that people are extremely familiar with the name PCOS and they need to invest that money in again, more research, better care, better treatments, better resources and tools for patients because that's what they need.

They don't need another name change in going through, you know, medical professionals and people that are getting diagnosed, being confused about, wait a minute, I thought this was PCOS.

This is something new that I have. I just think it it harms the the movement and it also harms organizations that have been branded or, you know, social media creators that have been branded under PCOS.

You know, it's sending us back a few steps. And I don't think we have the time to do that. I 100% agree. I think that this is an academic pursuit of people who are not thinking of advocacy the way we are or what it means for organizations or names.

And it is a diversion. It is a waste of time. And there are so many medical conditions that do not express what the medical condition actually is in the name.

And and PCOS actually is in the vast majority of cases involving the ovaries and the little cysts that form. And so it's not irrelevant. I mean, there are names that of diseases and conditions that are names of a person who actually was the first one maybe to write it up or a name like diabetes, which in itself, what is that telling you about blood sugar regulation?

So I 100% I think that advocating to keep the name the same and then to work on things that actually change lives, which this will not, is really important.

And, you know, that is, I think, just a false waste of time and a pursuit that gets you nowhere. So I'm so glad we 100% agree on keep the name PCOS what it is and then work, you know, with changing how it's treated, getting better treatments, better understanding research and so on.

That's where time and money should be spent. So 100%, we're definitely on the same page in everything and that as well. Yes, absolutely. And in terms of like these other manifestations, I was hoping you could just tell us a little bit more about the work that you've done involving cardiovascular awareness and the fact that so many physicians are still not really aware of the metabolic consequences, the cardiovascular issues.

And you've done so much in that arena, and I think you've been involved as well with the American Heart Association. So maybe you could go a little bit more into because that is amazing, incredibly important area of advocacy that you've been involved with.

Yeah. And you know, again, that patient experiences birth movements. I have a family history of cardiovascular disease and quite a few years ago, probably about 11 years ago, I had a little bit of a scare.

I was having heart palpitations and we started talking about, well, I could be having this. And a lot of it came down to my hormones were just all over the place.

My weight was up and down and a lot of it, the doctor said, could put me at risk. They said he said that, you know,

if I didn't change things around, I could become a diabetic and that I could potentially have complications with cardiovascular disease.

And I really sat down and thought about it and it hit me. Yeah, you're right. And you know what? All along my health care providers have never discussed this with me.

PCOS Challenge, Congress, and FDA advocacy

It was always take this pill with no explanation or you want to get pregnant, great. This is what we have to do to get you pregnant. And then there wasn't really much conversation beyond that.

So with PCOS, because there are so many metabolic connections that can create these risks, I felt that it was time that we started talking about ways people can manage their PCOS throughout the lifespan.

Because one of the things that drives me crazy, I don't know about your police is a lot of articles and websites refer to PCOS as a condition of reproductive women between age 14 and 33 or something, but it doesn't talk about what happens after those years, and that's when we really have to start paying attention to the metabolic issues because just because you have a child or maybe you've had a hysterectomy or something else doesn't mean that you get rid of PCOS.

Menopause does not does not cure PCOS, but a lot of patients are told this. So they think after those reproductive years, they don't have to worry about anything and take care of their health.

Not realizing that not taking care of things is exposing them to these dangers. Well, I think that you have just hit on such an important point, because for years I would go to some of these conferences that were put on predominantly by academics, and they would actually say things like, once a woman with PCOS hits menopause, there's no difference in outcomes.

They're there same as every other group of women who enter menopause. And of course, that made no sense to me, knowing that by age 40, women with PCOS have like a seven fold higher risk of developing diabetes.

How could those risk evaporate when they hit age 50, ten years later, approximately? And and it made no sense whatsoever. And now, of course, we have published peer reviewed articles saying exactly that, that, of course, women with PCOS during the reproductive years have a higher risk of all the cardiometabolic events, like the bad things that can happen, like like you mentioned heart attacks, strokes and so on when they become older.

And although some of the symptoms may dissipate, like the elevated androgens may dissipate, and you're not having periods. So you can't say you have irregular cycles because you're in menopause like other women who are in menopause.

But the metabolic consequences have already accelerated the cardiovascular risk event, you know, kind of profile. So it is so important. I'm so happy you're advocating for education and for patient awareness that their risk doesn't disappear when they hit age 50.

In fact, it may even accelerate. It's just that it manifests in different ways so that things change as you age and the manifestations of PCOS can change as you age, but they don't go away.

You're not cured by menopause. You know, some of the symptoms, like I said, will obviously go away and blend with the general population because nobody's having periods.

But the underlying cardio metabolic risks actually increase. So this is such an incredible area and hopefully we'll work together to educate the population of patients and the providers because most of them are still very unaware.

In fact, it's not even a common question. And it's supposed to be like when a woman is in her early fifties and they meet a new doctor and they're given a history intake form where they're asked questions about their medical past,

often issues of Did you have irregular cycles?

Did you have fertility problems? You know, all those really critical issues that actually extend into risk factors in menopause are not even asked. So, you know, for all the patients out there who are older, you know, because maybe if you're not older now, you will be older soon enough.

But it happens, you know, make sure your provider is aware because you're advocating for yourself to improve your medical care and the quality of your life is really everything that you're doing.

Social media advocacy and the PCOS Gurl brand

And, you know, it's so wonderful. And I applaud you a thousand fold, Ashley, for everything that you have been doing and that you're still doing. And this has to take up so much of your time and it's all volunteer.

It's wonderful and we should all, you know, stand up and give you, you know, a grounding, you know, applause here. And I certainly do. And for everyone out there who says, you know, I really want to be an advocate, you know, I want to also learn from myself, you know, so it's a a dual kind of a thing.

How can they, like, take the next steps? Like how do they find you online and the different like are you on Instagram or Twitter or Facebook or, you know, are there events that are coming up that maybe you're promoting or that you're creating that they would want to know about and so on? Yes.

So I am on social media, on Instagram, Twitter and Facebook as PCOS Gurl, PCOS G U R L also you can always reach out to me in that way if you're interested in sharing your story, your voice, or have an idea and you need a little support in getting that started, please reach out to me.

That's what I do is helping patients get involved and be heard again. One of the best things that you can do for advocacy is sharing a story. Put up a post online about, you know, maybe you've changed something in your lifestyle.

You started a new nutrition plan or a new exercise regimen. Share that, share your journey and tell people why you're doing it.

PCOS across the lifespan and menopause risks

And a lot of times people would be like, Hey, oh, I didn't realize that you had this condition and tell me more about it or, you know, I want to learn or, you know what I noticed I have a lot of those same symptoms so that that's how it starts, just sharing your story and you know, I tell people all the time, if you post about having PCOS tag me and I'll share it on my timeline and before you know it, you'll be on your way to being an advocate as far again is getting more involved.

Join organizations like PCOS Challenge which are volunteer run, volunteer led with patients. So get involved because they do PCOS Advocacy Day, they do programs throughout the year with like the FDA and the NIH to help patients with PCOS share their story with these different agencies.

So that's another way to advocate and advocate excuse me and become strong at being an advocate. Well, I hope everyone will take the first steps and actually become involved.

And it's really fun. You know, I've been to several of these events and the advocacy day in Washington, D. C., and it really is a fun experience and educational and connecting with other women.

Meeting your congressional representatives and their their staffs is can be very, very fun as well. So I hope everyone will become an advocate or at least get educated as the recipient of your advocacy.

Right. So thank you so much for joining me on my PCOS series here. It's really been fabulous to reconnect with

you.

How to get involved and closing remarks

It's been too long and I hope everyone will see that they have the power to make change, just as you did. You did you you grabbed the moment and you look look what you've done over 20 plus years.

So thank you so much for joining me. And I look forward to many more wonderful adventures together in the world of PCOS. Ashley Thank you so much. Felice And yes, I think you you phrased that correctly, we do have many more adventures and people have much more to learn, so I'm in it as long as you're in it.

And thank you so much for being that friend, that partner and that mentor to me. Thank you again. And more to come because we are just beginning our advocacy.

After 20 something years, we are rolling power safely. So take care and I'll see you soon. Ashley.