Advocate For PCOS: A Global Perspective Transcript

(Transcripts are generated by AI and may contain errors)

Introduction and Sasha Otteyu2019s PCOS journey

Welcome to this episode of the PCOS SOS Summit. I'm your host, Dr. Felice Gersh. With me for this really special episode is a long time associate and friend and fellow advocate for PCOS women globally.

Sasha Ottey, she is the founder and executive director of a global organization that advocates and supports women with PCOS. PCOS Challenge the National Polycystic Ovary Syndrome Association.

So welcome, Sasha. Thank you so much for joining me. This is so special, especially as when we're recording this, we're right on the cusp of PCOS Awareness Month.

But first, I would love everyone to know something about you, your journey, and how you came to be the founder of this amazing nonprofit organization.

Thank you so much, Dr. Gersh, for having me on this special event. As you mentioned, my name is Sasha Ottey. I am founder and executive director of PCOS Challenge, the National Polycystic Ovary Syndrome Association.

I founded the Organized session after my own diagnosis with PCOS. I went to see an OB-GYN after I had missed some periods, and I knew that wasn't normal.

I was working at a as a microbiologist at the time. And what what really was the defining moment for me was I left the office after having been told no worry about not having your periods.

Plenty of women would love not having their periods and come back to see me. When you want to get pregnant, I. I only got a little pamphlet that I read within 5 minutes and that was it.

I felt so unsupported and I felt like it was up to me to figure out what this was and how what it was for me and how to treat it. So that became the defining moment for me where I decided I had to do something.

After researching and finding out that there were millions of other women and girls and other people who have PCOS and felt the same, they got the same sort of dismissal or that's how it felt to me when I went worried about my periods and my doctor told me not to worry about not having my periods.

So most people felt dismissed and without adequate information, without evidence based information, because the research was almost was not there. And then subsequently finding out that PCOS had an awareness problem.

PCOS has an underfunding problem of research and which leads to the lack of knowledge and the lack of treatment options. And so that's what PCOS challenge set out to do, was to provide evidence based information to PCOS patients and their supporters and also healthcare providers, and then also advocate on behalf of the millions of people with PCOS, women and girls all around the world who have PCOS and felt so alone and unsupported.

Well, I bet everyone out there, or the vast majority are saying, wow, I had that same experience because I can't say that I had that same experience. And it's so fabulous.

Is that you you created this organization. So tell us a little bit about what does advocacy mean when you talk about the nitty gritty, like what do you do to create this awareness, to help to fund research and to educate providers?

Building PCOS Challenge and early advocacy

So tell us a little bit about the inner workings of your organization and how you go about actually accomplishing these really critically important goals.

Well, Dr. Gersh, back in 2017 or before that, we had to investigate. Why was this so underfunded? Why was there were there the lack of resources for PCOS?

And so we had to understand how research was funded. And that's when we found out that PCOS gets almost at least back then the funding was abysmal. It was less than 0.1% of the NIH budget and that for a disorder that's this prevalent more than 10% of women have PCOS.

It was it was astounding that the the there wasn't the investment in research that was necessary to fully understand this disorder. And so we also then searched for bills that mentioned PCOS.

Was there any policy surrounding PCOS? Any legislation? And there was none. There were none. So that's what we set out to do. We wanted to, one, increase PCOS awareness, PCOS funding for research and then also for education for health care providers, because we know that the majority of so 50% or more of PCOS patients go undiagnosed.

So there's an issue with health care providers being able to identify PCOS, diagnose it and treat. So we went to Congress, we built a platform where patients could advocate and bring their lived experiences, their stories about how it impacts them, bring it to their representatives and their senators.

And so that the government was now aware of this disorder that was so pervasive and that was so impactful because PCOS impacts not just your reproductive health, which is an important aspect, but it impacts your metabolic health, your mental health, maternal health, infant health.

And it's so and it even impacts your academic life, your career. Right. So PCOS spans multiple areas of life and but yet there was this lack of awareness in the government, which is who funds PCOS research.

So we had to strategize. So there is this awareness issue. We needed the government to be aware to prioritize PCOS because our organization's vision is, or at least our short term vision is, that PCOS becomes a public health priority, is treated as a public health priority.

And so we had to tackle the awareness issue first. How we did this was PCOS was September was a red already being I guess celebrated as PCOS Awareness Month within the patient community.

But it wasn't listed on any government websites. Nobody knew that this was happening besides some of some patients. So we one of the first things we set out to do was that to have September officially designated as PCOS Awareness Month, because if the government doesn't know, you know, their their awareness calendar, that kind of mentioned other or focus on other disorders throughout the year.

So February is heart month. October is breast cancer awareness month. And so September being PCOS Awareness Month was a really important first step in raising the profile of PCOS.

So we got the we got PCOS patients. We built this platform for patients to share their stories. We had got a resolution drafted and supported within the US Congress and the Senate.

Senators all unanimously supported September to become PCOS Awareness Month. And this was step one in our advocacy strategy that really, really propelled PCOS advocacy to where it is nowadays, where all around the world, organizations, people, all stakeholders use September as kind of a way to to magnify what PCOS is and raise awareness and educate the general public and others about about what PCOS is and how it impacts people.

So this this was an important first step in advocacy and in the resolution, we, the government, now wants all states to recognize September as PCOS Awareness Month, recognize the seriousness of PCOS and the impact that it has on and on citizens or everyone who lives in the US.

And also for there to be increased education, awareness and research into PCOS. And so this is a long term strategy of ours where we use the powerful voices of those who live with PCOS and who are impacted by PCOS

and and use them to create the change that we need.

Well, I know it's been very, very helpful, even recruiting a few celebrities to come out from the corners in the shadows and say, you know what, I've been dealing with PCOS.

I think that's that's always helpful. And I know that as part of PCOS awareness, you've had a color maybe you could talk a little bit about the color that goes along with PCOS awareness and and how that has been beneficial.

And police, I see you have a colored feel, a teal lab, teal flower pot.

Awareness Month, teal, and insurance barriers

It stands out this color was was being used to signify that this is PCOS awareness. So this this is happening before we we I formed the organization but the majority of people didn't know.

Right. So as a part of the awareness, the awareness campaign, we use teal as the color of PCOS awareness. And so now you'll see all throughout PCOS Awareness Month, anytime there are people speaking about PCOS, they'll wear the color teal or teal ribbons.

We've had events with hundreds of patients doing walks in teal tutus or going to our PCOS awareness symposium all dressed into this. This creates kind of a source of unity for the PCOS community where we just like other causes and other disorders.

A color is used to signify and unify the mission. And so yes, teal is the color of PCOS awareness. You will see PCOS supporters and patients wearing the color teal teal T-shirts, teal ribbons all throughout the month and throughout the year signify that this is a serious condition that requires a support, requires attention, and requires us working together to find ultimately find a cure.

Well, it happens to have always been one of my favorite colors. So that worked out really well. And it's such an interesting thing to think about the intersection between politics and medicine, although it sort of became more awareness in a lot of people's minds when we had COVID, that suddenly there was this intersection and that you utilized it to really forward the cause of women.

With PCOS. And what about like insurance? I know it's been so frustrating for so many women that things like hirsutism and alopecia and even acne are sometimes deemed, Oh, they're frivolous or cosmetic.

So have you been working on that front at all and making any headway? Yeah, this is a really important piece. I even I when I got diagnosed with PCOS, my doctor didn't put PCOS, she didn't use the ICD code for PCOS.

She was something else. And this is because there was there's a reimbursement issue for physicians. This is still a huge thing where PCOS really isn't as well recognized.

There was a recent study that showed that healthcare organizations and they the PCOS diagnosis was far underdiagnosed. PCOS was much more underdiagnosed in medical records than we even realized.

So even compared to the the general 10% or even 4 to 20%, depending on where you are. And so there is an issue where PCOS isn't being diagnosed and insurance companies aren't taking it seriously enough.

They're not or the majority of them aren't. Right. They don't quite recognize that PCOS connects to skin issues, that PCOS connects to mental health issues, that connects to pregnancy issues.

And and so this is this has been a part of our awareness where we've been reaching out to insurance companies. We've been this is a part of our long term strategy to get PCOS more recognized, but then also for insurance to understand the connection between PCOS and other disorders.

Hirsutism is not just a cosmetic disorder. Up to 70% of PCOS patients have hirsutism. This is a medical issue, not simply a cosmetic issue. There are other disorders or other instances where Hirsutism management will be covered by insurance.

But PCOS isn't. It's the leading leading cause of hirsutism in in women. So this is another area where not only was is there a lack of awareness, but it's a lack of prioritization, right?

There's that issue in women's health where our pain isn't prioritized or isn't even acknowledged. In some cases, our PCOS impacts quality of life, it impacts health, impacts mental health, and insurance companies should be treating it accordingly.

So, yes, this is a huge part of our plan. And Felicia, I have to tell you that this once we did start to unravel some of the issues behind PCOS as it became a bigger and bigger mountain, every time we understood why, why this wasn't happening, why there was the lack of reimbursement for doctors.

And so this but the tides are changing. The government, not only our government, other governments are now starting to recognize that PCOS is an issue.

And that's that's due to advocacy. That's due to, to, to patients being frustrated at and and asking for change. And so we had to do it in a really strategic and organized way.

We have every year we have PCOS Advocacy Day where we get PCOS mentioned in and bills and in appropriations request and we even figured out that PCOS wasn't listed on the in the NIH as lists of diseases.

And so how could we understand a disorder and, and understand how it's impacting people if if this isn't listed as a priority on the world's largest funder of biomedical research through the NIH?

And so we advocated for PCOS to be listed and it just recently did make its way onto the list of diseases and conditions that the NIH studies, but also now that Congress can can get more information about how it's being funded, how much funding is going into PCOS research.

So we can really understand and have more transparency around that. Yeah. So we, we, we understand it's really important. And PCOS spans so many parts of medicine that it, it really didn't have a home.

It was viewed as mostly as a reproductive disorder, which is one of our the biggest issues that we had as an organization is that reproductive disorders are not taken as seriously as they should, unfortunately, because, of course, that's a part of health.

But PCOS is a metabolic disorder, PCOS is a cardio metabolic disorder, and PCOS is a hyper androgen ism disorder. And so there are multiple areas of health where PCOS belongs.

And so we need all funders in multiple areas to treat PCOS as the syndrome that it is and understand that that each of these pieces are as and are as important a piece of the puzzle to to unravel and understand in in moving the understanding of PCOS forward.

Absolutely. And what you've accomplished is amazing just to imagine that the the NIH, you know, the government didn't really even have a habit as it listed, you know, is amazing.

And as you mentioned, PCOS spans the whole gamut of organs, systems, basically. It could involve just about anything and it does. So how about advocacy involving other will say you know, cousins of, you know, medical organizations like the American Heart Association or Diabetes Associations or, you know, some certain things with dermatological Society.

So are you trying to link in some fashion with existing medical organizations for them to educate their own groups and both patients and the physicians that are associated with those organizations about how PCOS fits into it?

Yeah. Felice, we've been connecting all of the dots and so we have built multiple relationships with multiple organizations and we've been doing this for quite some time.

At first there was resistance, even from the ones that made the most sense, right? This didn't.

Research funding, NIH recognition, and patient-centered treatment

And this is why we had to chip away at the awareness issue. But now there's a lot more people are organizations are reaching out to us organizations and even state public health departments.

Everyone's been much more open to meeting with us. We meet with a lot of public health organizations, so we do a lot of advocacy not just within the government, but also organizations, the organization as well.

And so we're a part of a consortium that that investigates and raise awareness around maternal health, around heart health, around metabolic health, mental health.

So you name it, we've we our one of our goals and one of our the way we work is connecting the dots around PCOS. And yeah, it's, it's the more the awareness grows and the more governments become interested or having to or are having to respond to Congress requests around PCOS.

You know, and this is based on our advocacy and the advocacy of the people who come to our advocacy days. Right. And, and Felice, you've you've been a part of PCOS Advocacy Day.

You've been on Capitol Hill with us and educated your your Congress people and your representatives. And there's nothing like that feeling when you know you're doing something, you're using your lived experiences.

Right? You're live, you're using your and in your case, it's both your professional experience and your lived experience to educate your legislators about why this should be a priority.

It's it's it's really important. And one of the things that's happening is that there's now become there's now been more interest or growing interest around trying to solve PCOS and trying to treat PCOS.

So in over almost 90 years, there hadn't been any PCOS, any FDA approved medications or treatments for PCOS. And now there there's interest and now there's a pipeline of companies that want to treat PCOS.

And one of the things that we want to, to we want to ensure that happens is that the PCOS patients and our priorities are at the core of what's done because there have been other issues where there have been treatments for treatments for the condition.

And once these these treatments came out, the patient, the patients kind of rebelled or the patients weren't involved in or they didn't feel like they were involved in in in any decision around their treatment.

So this is it's really important that anything that happens within the PCOS space includes and prioritize and partners with patients and listens to our experiences, listen to our priorities, which is why we're leading the the patient focused drug development meeting, where the FDA will listen to patients and their lived experiences and and listen to what they what they want for treatments, listen to their priorities.

And so this is happening this year in November. And it's a really important meeting, the only one of its kind. And why is this important? Not because if their treatments that are going to be happening for for PCOS patients, the PCOS patients need to be the ones who are kind of directing and directing any kind of innovations around around PCOS management.

So the PCOS patients should be at the core of anything that's done for the patients. That seems so basic and yet it's not being done in most cases. So that is fantastic that you're that you're moving it in that direction.

My goodness. Who's, who's supposed to benefit the big pharma or the patient, you know, hopefully it could be both, but the patient definitely has to be in the equation.

And, you know, we in in our, you know, compatriots in this field keep using the term PCOS polycystic ovary syndrome. I know there's a group out there.

We know these people and they want to change the name. So I have to have you chime in on what you think about this and how is this supposed to actually help women who are dealing with this problem?

I'll just say I'll start with. Okay. Yes, I agree. The name does not fully describe Encompass what PCOS is that that kind of goes without saying. Yes, not everyone has polycystic ovary is PCOS is not a reproductive disorder for everyone.

Yes, I agree with that. That's probably about the only thing that I agree with them about. Right. Because if you looked at the history of PCOS and the name the names been PCOS has had three names.

Stein Leventhal syndrome. He's polycystic ovary disease and now polycystic ovary syndrome. So we had three times to get it right. Right. And now at this point where yes, PCOS, not everyone has polycystic ovaries.

There's still not the understanding of PCOS that's required to ensure that the name will never need changing again. Right? So if you change it to reproductive anything that kind of isolates some people, you cannot name this disorder for in to features because as we mentioned before, PCOS spans multiple organ systems, spans multiple areas of health.

And so renaming a condition when you still don't have a full understanding of what it is, it only it's it's a waste of time. It's a waste of money. It will be an expensive undertaking.

It will take years and so much confusion. There will be so much confusion between the time when the name is changed. But importantly, and this is from our perspective, we have been involved in efforts to change the name before where we voted against it because we were asking for we are asking for an impact assessment.

How is changing the name going to impact a patient in Bangalore, India? In Montego Bay, Jamaica, in in Colombia? And how how is changing the name in South Carolina, United States?

How is that going to impact patients around the world? What does changing the name of a disorder using features of the disorder that there is infighting about.

So a gynecologist versus an endocrinologist will want to treat different aspects of PCOS. They'll view PCOS through different lenses. And the thing is, we as patients said we did not want this, but the group that's that's that wants to change.

It keeps saying that patients are asking for this. So which patients are asking for this? So we know they're the one group that's asking for this. But why ignore the other patients who are not asking for it?

Because we're telling them that this will have a detrimental impact on advocacy, on the work that we've done. This will create confusion. This will create confusion within not not only this will set us back.

And there are other patients and many patients and organizations that feel the same way, and doctors and other health care providers, so many that we've spoken to, think this is a terrible idea.

This is a terrible idea because it's too late.

Why the PCOS name should not change

It is too late for you to change the name. There's so much advocacy and awareness around PCOS now that why

would you want to so create confusion and set us back years in advocacy.

Well I echo and put 25 exclamation point because talk about like the the antithesis of advocacy just when you're trying to bring awareness to a certain condition that has a certain label, a name, and then you want to change it so that it'll just be even more confusing.

And if someone goes to PubMed, you know, or Google Scholar and they want to do research, what are they going to use as their buzzwords? How are they going to find research on a topic or or like find you if they keep changing the name, it's pointless.

And like you said, total waste of time, energy and misdirected in in every which way. And there are so many diseases that have names that have nothing to do with all the symptomatology or etiology, like diabetes or Alzheimer's.

I mean, Hashimoto's, it has people's names, you know, so what is even going on in these people's minds? And these are some of the like people who are the most prolific in doing research.

So it's like really weird. I agree. So I'm with you and everyone out there who's hearing this, you know, do whatever you can do to say to anyone who will listen.

Do not change the name. That is not where the energy should be directed. Directed at what all the things that you're doing, bringing awareness, therapeutics, research, all of that.

And you mentioned like Bangalore, you know, so you're a global organizer zation. How do you reach people around the world? And we know this is a worldwide epidemic.

So what's going on in the world and how do you intersect with that group out there, the world? Felice One of the things that we do and we do well, we we started world peace S. O. S., the 1st of September to to kick off the month World Peace S. O. S.

And the reasoning behind this is that PCOS is a global issue. PCOS impacts people everywhere in the world. And, and these people have different resources based on where they are, right?

We all have. But one of the connecting threads is the story. Most of us, whether you're in Kenya, Jamaica, UK, anywhere, most of us have the same story.

We were told, come back to see me when you want to get pregnant or or something similar. And so this is one of the things that we we decided with world PCOS that is is connecting with others around the globe.

Other organizations help support other organizations in their efforts around the around the globe. And so that's what we've done. We, we we're just we're we're doing a study in Trinidad.

We're working with someone in Trinidad and Tobago, Jamaica. We have partners in India, France all over the world because this does I mean, this is a really vast mission.

And it's it like we said, it spans so many areas of help. But I think what we need to empower patients all over the globe. We need to empower organizations all over the globe.

So whatever we can do to help some an organization in Kenya or what they can do to help us, you know, with strategies for for advocacy, we do. And so that's how we connect. That's how we we help each other and support each other because it's a global issue.

Patients from all around the globe feel the same. They they feel isolated there. There are issues that may that someone in and Kenya or Nigeria may have that if we can help if we can help with any education, any support advocating helping with advocating, we've we signed letters to governments.

We've done a lot. And we believe in in supporting each other and listening and respecting to people and their unique experiences. Because we do know that we while the symptoms may be similar and our experiences can be different in some respects.

And so and that's based on whatever constraints we may have, where we are and around the globe. So we work in partnership with organizations. And so that's what we are.

We're going to continue to build on view this as a global issue and help to empower people all around the globe and feel more empowered because the empowered patients are the ones who drive this forward and are the ones who create change.

And we see it all the time. People feel so much more empowered when they can use their stories, when they have their organizations that are having an impact in their communities.

So yeah, anyone, any organization around the globe, we welcome partnerships as long as we have similar missions and similar intentions. Right? Those are the only people who we we can we we work with because we're not we have a vision, we have a mission and we will continue to to work along those those lines.

But yes, we do not want to be distracted by by noise. So organizations that have the mission the priority that the goal that PCOS is treated as a public health priority.

Yes, let's work together and let's use our voices together to to amplify our message and create the change that we need. Ensure that PCOS is treated as a global priority.

And I can see this happening. I can feel it. You know, patients are more empowered. This year, our our theme for the month of September for PCOS Awareness Month is the Empowered Patient and all the things we can do together when empowered patients work together just like you and I are doing today.

Felice Well, your mission and your advocacy is just solid gold. It's so amazing and how that light bulb went on in your head that day and look where it has led around the world, because I think that's really important that women around the world are dealing with PCOS and it's like, we're all part of this.

Every single one of you out there who has PCOS, you have sisters all over the globe and so many out there hearing this message want to become an advocate and want to be part of this mission.

You know, just as when I learned about your organization, it's like I'm in.

Global advocacy and how to get involved

So everyone out there who says I'm in, how can I work with you and your organization to better the lives of women in the U. S., in my state, but also around the world?

So what's their next step to work as an advocate with you? Reach out to us. pcoschallenge.org if you're if you wanted to find out this is after PCOS awareness month however PCOSAwarenessMonth.org, pcoschallenge.org.

Those are websites you can reach out to us. You know we those are really busy months so if it takes a while for us to get back to you yet don't don't mind and continue reaching out because one of the things that is common across all organizations, all patient organizations is that we are mostly volunteer run because the funding for PCOS, for PCOS research, for PCOS support, PCOS, anything around PCOS, the funding just has not been there and that's what we're continuing to work to ensure that PCOS is a priority, ensure that or organizations can be built in and grown around this around this mission.

And so yeah, I think patients organizations reach out to us and other organizations that want to support our mission. It's really important that that if you're a stakeholder, if you're a company, that believes in the mission, that PCOS should be a public health priority.

Reach out to us. Reach out to us at pcoschallenge.org. and hopefully we can have a positive impact together. Well, I think it's so important, right, to emphasize that you are a nonprofit organization and that you would definitely welcome donations of both time money companies that can work in some kind of joint fashion for the good, for the overall good of their women employees and so on, I'm sure many of whom have PCOS.

So that's really important because without organization, missions like yours, all that you've accomplished would not have come to pass. I mean, that's really so vital to understand that you are really the interface between all of us women with PCOS and all the powers out there that control the research dollars, the insurance coding and and all of the things that go into helping to do the research and, and the support systems that you're like the public health issues involving PCOS.

So I thank you from the bottom of my heart for all that you have done and a lot of self-sacrifice. I know that. And hours and hours of work nonstop has gone into creating this advocacy organization.

So I can't thank you enough for joining me for the summit, for spreading the word. And, you know, just keep it up. I can like whatever we can do to support.

You were here. Dr. Felice, thank you so much for all the time and efforts we've traveled around the world together. We've educated people in distant parts of the world together.

We've we've done a lot of this advocacy and education together. And so it requires we you know, we want more people to be like you, to listen to the patients.

Right. Listen. And you're patient with PCOS, but you also have patients with their own unique needs. And you listen to them and and you show up to advocate for them.

And that's that's that's going above and beyond. And we welcome more physicians like you, more health care providers, and there are plenty of them out there.

But we welcome more people like you to join our efforts to reach out to us and and just work together for the greater good for PCOS patients everywhere.

So thank you. Thank you for having me at the summit and thank you for continuing to spread your knowledge and and actually now providing this platform for others to do the same.

So thank you so much for having me. Well, this is a mutual admiration, and I can't tell you how much I look forward to continuing our journey together for advocacy for Women with PCOS.

Thank you so much. Thank you.