PCOS & Menstrual Cycle - A PCOS Community Q&A Session

PCOS is an enigmatic disease with the most common symptoms being irregular menstrual cycles and ovulation leading to infertility in many cases. We created a PCOS Tracker, a free app for women to track their PCOS symptoms, and as it completes one year, it is now helping more than 18,000 women stay aware of their condition. We are having a Q&A session with PCOS expert Dr. Carolyn Alexander of Southern California Reproductive Center and reproductive endocrinologist Dr Aimee Eyvazzadeh of Egg Whisperer Enterprises to discuss questions related to irregular periods, periods pain and associated infertility. We will be joined by a community of patients and well known PCOS advocates to guide the discussion. The panel will also discuss the most common questions asked by women tracking their PCOS symptoms.

1. How to get rid of monthly pain?
2. I have had irregular periods for the last 5 years, periods getting delayed by more than 3-4 weeks. What can I do?
3. I want to conceive? How do I do that with PCOS?
4. How can I overcome PCOS without using pills?
5. Is intermittent fasting a good idea to help with PCOS?
6. Can you suggest how to cure my PCOS?

Please RSVP to join us and clarify your queries on PCOS or just listen to the discussion. You can also post your questions below.

Full Transcript:

Shweta Mishra: Hello everyone. I'm Shweta Mishra, your host and I welcome you all this evening to this PCOS Community Q&A session. We have gathered here today to help address some very basic questions related to menstrual cycle in women dealing with Polycystic Ovary Syndrome on occasion of the one year completion of the TrialX PCOS tracker. We launched this tracker last year and the driving force behind this is a mix of personal story, advocacy, opportunity and motivation and over the last year the response of the app has been overwhelming. And it has been downloaded more than 19 thousand times now by women who are either diagnosed with PCOS or who just think they may have PCOS, to track their symptoms and to understand their condition better. Every week we're having nearly 400 participants joining us and this response just confirms how troubled women of all ages are with this enigmatic cluster of symptoms that is PCOS and that they're looking for solutions. We have received quite a few questions from these women and girls using the PCOS tracker as well as the women from larger PCOS community and to help answer these and many other questions we have our eminent guests and experts, Dr. Carolyn Alexander from Southern California Reproductive Center and Dr. Aimee from Egg Whisperer Enterprises. Dr. Alexander has conducted extensive research on PCOS, specializes in the treatment of patients facing diagnosis of PCOS and infertility and has been a dedicated Physician for over 17 years now. Dr. Aimee on the panel is a Harvard-educated, board certified specialist in reproductive endocrinology, and infertility, is one of America's most renowned fertility doctors' famously known as the Egg Whisperer. Dr. Alexander, Dr. Aimee welcome to the panel, and thanks for finding time to educate us today.

Dr. Carolyn Alexander: Thank you.

Dr. Aimee Eyvazzadeh: Thank you.

Shweta Mishra: On the patient panel, we have well-known Patient Advocates. Ashley Levinson, Michelle Schwarz, Lisa Rosenthal. Ashley, Lisa, Michelle, welcome to the session and thank you for finding time to join us today. We are also joined by women from the PCOS struggle Community as well as the larger PCOS community. They can either ask their questions, participate anonymously or just listen in to the talk. Dr. Alexander, Dr. Aimee I will start will Michelle now. Michelle over to you, you can ask your questions.

Michelle Schwarz: Thank you so much for having me today. I'm an epidemiologist and also a patient advocate. I would like to know, so I heard that 35 to 45, this time the PCOS sweeps back when the menstrual cycle cannot find its groove and tends to normal out. My question is around perimenopause, which is also the time frame 40 to 50 when women start to experience perimenopause. So, I was wondering if you could tell us what women with PCOS can expect, what kind of symptoms might they have with perimenopause. How can they tell the difference between what is perimenopause and what is PCOS?

Dr. Aimee Eyvazzadeh: So. we're really lucky. We have a lot of blood tests that we can now do that can guide a woman to answer that question. And I always tell people get your levels checked and especially if you have PCOS. So, part of an annual exam, I think for women who have PCOS is to get your blood pressure checked, look at your lipid levels. Ask your doctor if you need any other test for example looking at your cardiovascular health, and then there's the test called the AMH test-Anti-Mullerian Hormone and this is something that a woman who is curious about where she's at with perimenopause can do over time. And if you have PCOS certainly you can't rely on having irregular cycles as a sign. We know the definition of menopause is basically having absence of periods over a 12-month period of time and women with PCOS can sometimes see that. And if you're a patient of mine or Dr. Alexander's we will certainly tell you what we need to do to make sure you're not at higher risk for things like for example uterine cancer and that's another thing is making sure that you've had an ultrasound done on a regular basis. That would be my strategy that I would recommend for women having PCOS who are over 45, for example who are really looking to optimize their health. But we know that women with PCOS are at higher risk, especially in the perimenopausal time frame are at higher risk of having more complications from metabolic syndrome, right? So, we got to watch out for that. So, I think an easy test to do is just your AMH level and make sure that if you are seeing a provider that's not educated on PCOS, there are really easy summary articles you can print them out, bring them into your doctor that show what PCOS patients are at risk for during perimenopause and they make sure they just check all the boxes. You keep everything in a binder, keep your Labs, track them over time, that way you can be your own best Advocate if you have PCOS, especially around perimenopause.

Michelle Schwarz: Thank you so much.

Shweta Mishra: All right. Thank you, Michelle. Dr. Aimee I'll just move on to Stephanie's question. She has sent in some questions. She's a 31 year old woman and she's been struggling with missing irregular and heavy and painful periods since the age of 15 now and she was formally diagnosed with PCOS in 2018 at the age of 30 and she wants to conceive now and found out that she has tubule issues. So, IVF is her only option now and she wants to ask why do Cycles vary from month to month with PCOS? And how can I best regulate them? And what is the best way to try and figure out a relation when the Cycles are 33 to 50 days? Dr. Alexander, if you can please answer this question.

Dr. Carolyn Alexander: Sure. I think that's a really important question. In terms of the periods, the reason the periods get further apart is ovulation occurs later in the cycle from when you started your cycle. And the mystery about PCOS is that proper ovulation doesn't necessarily occur at a synchronously timed point. I think a lot of that has to do with a proper diet and exercise as well as if you have insulin resistance or hemoglobin A1c level that's higher. Thinking about taking metformin because sometimes metformin can help make the ovulations a little better. In terms of intimacy and timing in unprotected intercourse when you're trying to get pregnant, I tend to encourage people at least twice a week if not three times a week. Because the sperm can live in the fallopian tube and it can stay there longer. So, if someone ovulates day 18 and they had only been trying day 10 to 13, then they would have missed their ovulation window for unprotected intercourse. But if your fallopian tubes are closed then the only other option is in vitro fertilization

and that can be done where the eggs are grown, where the follicles are recruited with medication and being very cognizant to avoid hyperstimulation syndrome, which I know Dr. Aimee and I have always work really hard to avoid that issue and then the eggs are obtained with the thin needle through in vitro fertilization fertilized and can either be placed in a frozen embryo. Because with PCOS, there's evidence that an embryo that's placed fresh, there may be more high blood pressure and preeclampsia issues with pregnancy and preterm labor, than if you freeze the embryos and place them at the subsequent period or a month or two later when that lining got a chance to shed. I hope that answers the questions that you asked.

Shweta Mishra: All right. Thank you. Dr. Aimee, I'm kind of going to pool two questions here sent in by two different folks. But on the same lines, the person asked that she has been dealing with PCOS for 20 years now and has been trying to get pregnant but she notices that she only gets her periods on pills and she needs your advice on how to proceed further if she wants to get pregnant? And the other one was how can PCOS impact IVF success? So, you can answer that.

Dr. Aimee Eyvazzadeh: Okay, cool. Well, I'll start with how can PCOS affect IVF success and there's so many myths about PCOS and one of them is you have a lot of eggs. They're all really bad, they've just been sitting there for a really long time and they're going to come out and they're going to be rotten. But that's actually totally not true. I consider my PCOS patients super fertile. I believe that all the eggs are going to come out good. Certainly, there are some scenarios where you will learn that you might have less mature eggs than what you expected. Because if let's say you have a follicle count of 40 you might end up with 40 eggs, but let's say 10 might be mature and the way I frame that is it takes 40 eggs to get the ten mature out from that patient. So, that's kind of how PCOS can affect IVF. You might get a lot of follicles not as many mature as the eggs you get out and the one tip that I have for women going through IVF who have PCOS is try and balance your hormones up front, see a nutritionist, personal trainer. Get all your hormones balanced first because then your cycle will be optimized and then you'll be certainly very well prepared for a pregnancy. For example make sure your vitamin D is normal, your lipids are normal, A1C is normal and there's so many different ways of doing that and there isn't a one-size-fits-all approach and I'm not a BMI calculator and I don't like pressure women to reach a certain BMI before they start. I use the hormone levels to make sure that they're balanced and use that as the green light for me to say you're ready for IVF. And then the other question about not getting a period unless you're on pills to induce one and still wanting to get pregnant. Well, if you're okay using pills like Femara, for example. Femara is an ovulation induction drug that can stimulate the release of one egg and hopefully it's just one. Sometimes it can be more than one but that's a strategy that we used. You've heard of drugs like Femara, Clomid, those are two medications that we can use to help women who have PCOS ovulate and they're usually very well tolerated, have the low side effect profile. But I do recommend that you do that with the help of a doctor who can also monitor your ovaries and look at your follicles and give you the information you need like how many eggs are you ovulating, when are you going to ovulate and is this really working for you. Because sometimes these medications, the dose that you start off with don't always work if you have PCOS the first time.

Shweta Mishra: Okay, thank you for that answer, Dr. Aimee. Dr. Alexander, the next one is for you. The patient says I was diagnosed at 14 years of age and I recovered from PCOS after treatment with medicines. I feel like my disease is back again because I've been trying to conceive for the last 18 months now. Could you please suggest what to do? Dr. Alexander it would be great if you can comment on how we medically decide for a patient that her PCOS is treated?

Dr. Carolyn Alexander: Yeah, I think like Dr. Aimee mentioned, once the metabolic function is better with PCOS and that does tend to happen as we get older, closer to perimenopause there still tends to be more regular cycles and some women have it a pregnancy that can occur after they have been struggling for years and that you'll hear that at 40 someone got pregnant and they had been trying for so long. And it can be because suddenly the system ovulates at a better timing. In terms of this situation where you've been trying for 18 months, it's really important to get an ultrasound to see if you've really been ovulating and know luteal phase progesterone level, to see if the progesterone rose in the luteal phase which is after ovulation, to see if the actual ovulations been happening because sometimes we have been trying but perhaps the egg isn't actually popping out to ovulate and that can be the reason you haven't conceived. It can be remedied

with Femara or Clomid which are tablets that you take Day 3-7 of your cycle depending on what your doctor recommends and that can optimize ovulation. It can sometimes cause two eggs to ovulate but traditionally it usually helps us ovulate one egg. In addition if it's been that long it's important to talk to your doctor about checking a semen analysis because about a third of the time even though we think it's us with PCOS, and it's not ovulating and those kinds of things, we are surprised to find out that it actually could be a sperm issue too. And so, it's important to check a semen analysis and then like the fallopian tube test which is called the HSG or Hysterosalpingogram can be encouraged too because it also potentially can flush the tubes. So, theoretically it could actually help you see through everything clear. And so that occasionally can also be therapeutic to help the sperm and egg combine and make the pregnancy successfully and it's important to check that your thyroids are at a normal level, your prolactin that you don't need a medicine to lower those hormone levels if they're off grid in that your vitamin D levels normal.

Shweta Mishra: Okay. All right. Thank you. Thank you for that answer, Dr. Alexander. At this point I would like to invite Deborah. Please ask your question to Dr. Aimee.

Deborah: Yes. So, my question was can birth control help treat PCOS and should all women take it and what are the side effects if they do?

Dr. Aimee Eyvazzadeh: Great question Deborah. I mean I use birth control pills a lot for a number of reasons. I call them fertility planning pills. I tell women when you take it, especially if you're trying to get pregnant, I don't want you to think that I'm trying to prevent pregnancy for you. I'm just trying to put a pause on things so I can manage your symptoms of PCOS. And as soon as everything is under control, then we can stop the birth control pills and move forward with our plan. So that's one way that I use them as fertility planning pills, and I wish that the birth control pill company out there would hear this and then maybe formulate a new pack with a different name. How sometimes you have drugs like Wellbutrin and Zyban, they're the exact same drug, but they're news for totally different things because it's so confusing that women who sometimes have PCOS, especially when you're trying to get pregnant to be told that they should take a birth control pill and it's like ….wait am I in the right place, am I with the right doctor, why are you doing this? So, birth control pills can also help lower testosterone levels and depending on what a woman's goals are and how higher testosterone levels sometimes I use it and I monitor levels. I've said this before get your levels checked, I check a baseline testosterone put you on birth control pills if that's acceptable you to take and then maybe a month later or two months later, we see where your testosterone levels are and then we decide if we should maybe stop them and see if at this point you might start having regular and more 'normal cycles.' The other thing about birth control pills, I'm very sensitive about how they change our brain chemistry. Some women are very sensitive to how they change our brain chemistry and they become depressed on birth control pills. So, if I have a patient who has PCOS and already is dealing with some symptoms of depression, I definitely don't want her to take birth control pills. But it can help manage cycles, it can decrease testosterone and with that comes less hirsutism that hair growth in some women and acne as well. That can be a treatment not all women should take it there certainly are so many other options that you can look into, but it is a tool in our toolbox that we use for patients with PCOS.

Deborah: Okay. Thank you.

Shweta Mishra: I'll move on to Ashley now. Ashley, could you please introduce yourself briefly and go on to ask your questions?

Ashley Levinson: Yes. Hi everybody, I'm Ashley Levinson. Most of you know me on social media as PCOS girl. I have been a PCOS Patient Advocate and educator for over 21 years now and I'm thrilled to be here. Dr. Aimee, I have a question for you first. If only 20% of women present with cystic ovaries, is using a diagnostic tool like ultrasound a good tool to use?

Dr. Aimee Eyvazzadeh: My answer is yes. I find the pelvic exam for example, to be extremely barbaric. Right, so we don't have cameras at the end of our fingers and yet sometimes women go in for their pelvic ultrasound their pap smears and they go through a pelvic exam and then find out years later that they have

other pathology like a fiber that's been growing there this whole time and the thing is you probably know this as much as I do sometimes women are given this diagnosis of PCOS just based on their physical appearance. You go into the doctor, maybe you're just a little bit curvier, you report irregular cycles. They just label as PCOS send you on your way and then no ultrasound. But the reality is if they had done a little bit more digging they would have done an ultrasound and if they didn't see polycystic ovaries and they saw a low egg count, you might be dealing with the condition called Decreased Ovarian Reserve and it's heartbreaking for me when people are incorrectly diagnosed with PCOS, when they really have Decreased Ovarian Reserve and by the time they get to me, sometimes it can be too late. So, that's one very important reason to look and the other is to look at the lining, look at the uterus and see if the lining is thickened especially if you're having irregular cycles. So, I think those are very important reasons to still do an ultrasound. But I don't rely on the ultrasound, how to make the diagnosis but it's definitely part of the full clinical picture and something that women should ask. Ultrasound, please.

Ashley Levinson: Thank you. Dr. Alexander, if a woman or girl has a prolonged history of irregular menstrual cycles, how likely is it that it could be PCOS?

Dr. Carolyn Alexander: I always think of it other than PCOS, for issues it still can be a prolactin issue which is from the pituitary gland, a thyroid issue and like Dr. Aimee said it can be a low egg reserve. So, if the FSH starts to creep up which implies that the egg supply is lower that can also be a culprit too and as well as metabolic issues such as insulin resistance and not be PCOS. But at the same time whenever there are irregular periods, our mind always thinks of Polycystic Ovary Syndrome as an issue. So, I think it's a really good question, but it's important to check all the other hormones that could be the causal factor as well. In LA, we see every month there's at least a couple patients were told yes you have PCOS and then lo and behold they actually have non-classical adrenal hyperplasia. And that's to me a very different situation because there are times where a baby can be born with ambiguous genitalia as the partner also carries a classical adrenal hyperplasia gene. And so that can be very alarming, and we see that every once in a while. And so, and here we are very careful to check the 17 hydroxy progesterone to make sure it is PCOS and not necessarily a non-classical adrenal hyperplasia kind of an issue.

Ashley Levinson: And the second part of the question is if a person with PCOS goes for long period of time without the period, does that put them at risk for other conditions or more serious consequences?

Dr. Carolyn Alexander: I think in younger PCOS patients, we do sometimes catch pre-cancer inside the uterus which is like hyperplasia and it can have atypia like atypical cells in there, it's very rare, but it has happened in these 15 years that I've been doing this here. Sometimes we catch real adenocarcinoma or cancer inside and that tends to happen, and people say years and years of no period and they didn't take progesterone to shed the lining or a birth control pill necessarily. So, it is a vital sign, I call it the fifth vital sign that we should be getting our periods. Obviously if someone has a Mirena IUD, they're not going to get their period or if they're taking continuous birth control pills because they have really bad cramps and they need to be on birth control pills for that kind of regulation you're not going to get your period. But taking no birth control and no progesterone and not getting your period is not really advisable and it's good to get a checkup with your doctor and talk it out.

Ashley Levinson: Thank you.

Shweta Mishra: Thank you Ashley. Now, I guess I will ask Hanmah's questions now. She was supposed to join the call, but due to unforeseen circumstances she could not. Hanmah is a student and she's studying business and has a very hectic schedule through the day and very less free time and for her peace of mind she writes poems and short stories. She is only 16 years old and was diagnosed with PCOS almost a year back and she says that I'm tired of all the treatments I have to go through whenever I start my healthy routine I get tired in a month. She wants to know why this happens. She says I've started cycling and exercising since the last three weeks and I've been doing yoga, on and off and still there are no results I have seen. Will I ever be cured? That's the question, Dr. Alexander, if you can answer.

Dr. Carolyn Alexander: Sure. I think it's a really good question. I know it's super frustrating. At Cedars, we did a lot of research to understand why PCOS even happens and it wasn't one gene that you carry. That's like a yes or no, it's from both our parents and there are certain genes that just turn on or off from environmental things or nutritional changes those things. So, you have a little bit of control of your system like you're doing with the yoga and cycling and eating a clean Diet. You are young, you're only 16. So, I always think of these when we were younger you have to have a day that you be free on your nutrition and be normal with your friends. But the other rest of the days of the week, you should be more consistent with frequent small meals and avoiding white carbohydrates and those kinds of things. In terms of cure, I definitely have seen that after having a healthy baby, there's people who call and say, oh my God, you did tell me that that might happen, but my periods back to normal and I'm regular again and the hair is kind of a little better. And so, we do sometimes see that nature after a pregnancy kind of likes clears the system, but I don't have like there's no perfect cure like you're saying. I think it's just accepted what our circumstances are. It's very empowering now that women know what they have because in the past like for me, I was always overweight since I was 16 and people just said, oh it's just you're overeating, and I actually wasn't eating badly. I was actually eating healthy, but it's just interesting to think we were just blamed that yeah, you're just overweight because of whatever you're doing, but it was really my metabolic function that I didn't have an understanding of it till now, kind of a thing. But anyway, those are my thoughts.

Shweta Mishra: Right. Thank you. The other question that she has I guess Dr. Aimee you can take is on the psychological side of PCOS. She says people keep asking me about my acne, weight gain, and I'm tired of these questions and my mind keeps repeating these questions deep inside and what to do?

Dr. Aimee Eyvazzadeh: Well, I mean a long line of what. Dr. Alexander just said it comes from our parents. So, if you're 16 years old you would just tell them can you ask my mom. So that's one way of dealing with it, the second way of dealing with it. You just turn it back around at them and be like, isn't it funny that you think that that's an okay question to ask me or you just say look if I was a boy, would you be asking me the same thing? I don't see people asking my brother this or boys this. That's kind of rude. So, I feel like you should get up for yourself and turn it around and be like God, how would you feel if someone kept asking you that. I don't think it would feel really good. So that's kind of what I would equip you at 16 with to like turn around and just try and make it something funny and if they persist literally tell your mother and have your mother call them and tell them to stop especially if they're adults because they should know better.

Shweta Mishra: All right, that's right. Thank you. That's great, Dr. Aimee. I guess now I'll move on to Lisa. Lisa, go ahead. Please introduce yourself a bit and then go ahead and ask your question.

Lisa Rosenthal: I am thrilled to be here getting all this incredibly good information. My name is Lisa Rosenthal and I'm patient advocate at Reproductive Medicine Associates of Connecticut and have been here for 12 years. I've been an advocate for 30 years and went through six and half years of infertility myself with guess what undiagnosed PCOS, right never diagnosed went to some of the top clinics. I had a little bit of this a little bit of that. It was a long time ago, obviously, but as one of the leading causes infertility, PCOS is always of course on my radar. So, thank you for having me. So, Dr. Aimee, one of the questions I got when I asked some of our patients was, I'm determined to manage my insulin resistance with diet and exercise. Is this really possible with PCOS, or do I have to be on medication?

Dr. Aimee Eyvazzadeh: So, you know all too well that so many women go years, decades of their life before they get a diagnosis and they're sometimes given a diagnosis of let's say 20 and then they are told you don't really need to worry about it until you're ready to have a baby. And by then testostrones go through the roof and now you're dealing with something that's going to take longer to manage. And so, it really kind of depends where you're at, what's going on with your hormone levels. I have patients, they meet me and they're like ready to go. Like they want to jump start and so I do find that giving them some tools like birth control pills Spironolactone, Metformin, I call it my PCOS Special Sauce. So, to speak of supplements and you don't necessarily have to try all of them at once. You can try one set for see how you do, try another just kind of see how your body reacts but I think that patients who have high testosterone it affects your mood and affects your appetite, affects your metabolism. And you may not be seeing the same results that you

would if you may be tried it with a Metformin for example, and then continue to do all the right things that you're definitely doing. So that's what I tell my patients is that you don't necessarily have to be on medication. We can certainly focus on eating right or meeting with a nutritionist for example, but sometimes just that little boost of drugs can sometimes help you. See the results quickly and then you'll feel very encouraged because it's very discouraging not to see the results that you want, I hear all the time. So that's kind of how I guide my patients on this question.

Lisa Rosenthal: Okay, thank you for the answer. If I were going to follow that up, I would ask about so many patients seem to have a lot of trouble with Metformin, but I'll go on to my next question. So, Dr. Alexander nice to see you and meet you. How genetic is PCOS? Let's say I have daughters. Is there something I can do while I'm pregnant and as soon as she's born to help her avoid PCOS? Are there genetic markers, can pregenetic testing help me pick an embryo that won't have as high likelihood for PCOS? I know it's a big question.

Dr. Carolyn Alexander: Yeah, that's a big question. It is when we did do cross analysis of all the different genes, it was associated with the were like 20 or more hot spots of genes. So, there isn't a pre-implantation genetic diagnosis. One thing I've noticed over the years is that there's a high family predisposition of diabetes. So, a lot of the family history will have diabetes in the family. So, Grandma, Grandpa and the aunts have diabetes and so I think teaching our kids proper like what to crave like cucumbers and celery versus candy, chips and things like that. So, I think the Pediatric population does look at early breast development and early underarm hair as it is a smoke signal and maybe that might be one of the clues that there's a higher level of hormones popping up at a younger age. I think that's an opportunity to talk to those girls with the nutritionist and work as a multidisciplinary approach to her and I think it is under-recognized but like the psychological aspect that maybe there might be a hormonal imbalance like they might have. They have undergone genetic changes in pregnancy and some women who really don't eat very much food and those kids get genes that turn on that may cause more PCOS, but it's hard to blame. I don't like looking back and try to blame our moms or whatever it is. I think there is a specific genetic mutation that we know of but I think there's clues that we can get and if we have a family history of diabetes, it's important to think about it for our girls and the boys too, because they could have metabolic syndrome. There were some long-term studies that we had done looking at the boys of moms with PCOS and they also sometimes have a propensity for obesity and metabolic syndrome as they age. So, it's important to check them too. That's my thought.

Lisa Rosenthal: Well, thank you. I know it was a lot and of course speaks to the fact that we need more money for more research and all of that. So, also for Dr. Alexander one of the things that I hear from patients all the time is how could I be on birth control when I'm trying to get pregnant? So, the question from this one patient was I've been diagnosed with PCOS and I'm on birth control, but what's going to happen when I want to get pregnant. If I'll have to be off birth control and I'm afraid of how bad the symptoms of PCOS will be.

Dr. Carolyn Alexander: Yeah, I think that's a really good question. I always get asked like when is the perfect time to stop the pill when I'm thinking at a try. Let's say it's December, during the summer I tend to say like, Dr. Aimee mentioned is like your testosterone and your metabolic tests are normal, right, in that six weeks after we stop the pill. So, you really want to give it a full try to get pregnant. Once you stop on control pills, there may be an older thought that we used to do is say take three months off the pill and then start trying. But now if we see from my side of it, I always say start trying right away when you stop it. Because it seems that when people stop the pills, they get pregnant pretty easily. That's what I thought and I was really worried that I'm in my late 30's and I'm like oh no I must have an infertility examination from a doctor and then it just sort of like landed out with the Metformin timing and I had stopped Spironolactone six weeks in advance because it's not allowed in pregnancy. So, we try to stop it a little bit more advanced but at least it helps regulate your hormones. But I definitely understand how challenging that is and frustrating when you're on the pill, but you like want to be pregnant.

Lisa Rosenthal: Thank you again. Very thoughtful, very informative answers.

Shweta Mishra: All right. Thank you, Lisa. Thank you, Dr. Alexander. I guess I'll move on to some questions send in via the PCOS tracker and the larger community. This one is for you, Dr. Aimee. The person says I've had irregular periods for the last five years and period is getting delayed by more than three to four weeks and I really have good amount of pain when they do come. So, what do I do? What can you suggest?

Dr. Aimee Eyvazzadeh: I think the most important thing is to see a doctor, get an ultrasound done, take a look at your uterus, see if there's a fibroid, see if there's endometriosis. I mean you can have PCOS endometriosis and fibroid. So, I think that's really important as far as what to do about the pain, I think that identifying the cause and then you can actually treat the pain with birth control pills which is one way to do it with someone who's not trying to get pregnant. Because that can decrease the amount of menstrual flow. If there's any endometriosis it can prevent the progression of endometriosis as well. And then get your hormone levels checked like your testosterone and all the things we've talked about like AMH as well. And then the other thing that might help is looking at your body size and how you're eating that might be something you need to focus on as well because if let's say, you lose let's say 10% of your body weight. There is a potential for having less menstrual pain with your periods when they come and that might help regulate your periods as well. So that's those are the kinds of things that I would think of in a case like this.

Shweta Mishra: The next questions are those mostly on the lines of diet and weight related to intermittent fasting basically and the person is asking Dr. Aimee, Dr. Alexander. Both of you can chime in here. Can I lose weight on PCOS and the person says she lost her periods when she was intermittently fasting and then went on a 1200 calorie diet and I was nearly underweight then, now I have gained back all the weight and plus more. So, with regular periods, but I am too chubby, and I want to lose weight. Is it possible with intermittent fasting?

Dr. Aimee Eyvazzadeh: Dr. Alexander, what do you think about intermittent fasting? Are you a fan?

Dr. Carolyn Alexander: I know. I feel like Hypothalamus Pituitary___ things. It is in starvation mode. I know from certain body types that 8 p.m. to 7 a.m. or 8 p.m. to 8 a.m. is like the best time to not really eat anything may be decaf for tea if you really need something but that I have seen people say they had a dramatic improvement but there are a whole lot people who say that 16 hours out of the whole day they eat randomly like _____ food. I'm not an expert on it, I'm not sure because I don't know if I can do really that. I think it might be worth trying to see if it works for you but becoming overly hungry this doesn't sound like any fun to me. The term I would think of immediately is called hangry when you're hungry and angry and then all of a sudden you just make maybe some poor choices with food options that you have so I'm not a big fan of intermittent fasting and my patients. But I totally agree with what Dr. Alexander just said.

Shweta Mishra: Okay, the next question asks how to lose belly fat with PCOS. I was diagnosed in 2018 and lost weight after that got regular periods for two years. Recently since April, they are back to irregular again. I eat food and work out regularly. What do I do? So basically, it's about belly fat.

Dr. Carolyn Alexander: Yeah, I mean even though many medications are the answer but, in my experience, if they take Metformin even a tablet per day, I have seen people especially the tummy roll that is above your belly button. I see a lot of people with that..where Metformin seems to help. There's some evidence about Myo-inositol to which is not like medication but like a supplement. But it's the tummy I have seen that the Metformin helps and obviously exercise is critical, but it sounds like the person is exercising already. I always believe people when they say I'm exercising so much in calorie restriction, but my tummy is bloating. Sometimes it can be an underlying thyroid issue too or probiotics can help but we learn now with newer studies about probiotics that not taking a probiotic every single day is actually better. So, taking it like twice a week or three times a week may be more realistic for the GI tract then to do every day probiotics.

Shweta Mishra: Okay. Thank you. Dr. Alexander for that answer. The other one is about bloating and PCOS. And I think I've got quite a few questions and I pulled it all together about this. And the person asks will PCOS cause bloating I get a lot and it hurts. How can I avoid bloating too much? Should milk be avoided.

Dr. Aimee Eyvazzadeh: I mean what I would say is I have patients that they feel like they're getting their period all the time but it doesn't come and I think sometimes as you're lining thickens, your uterus swells and contracts and you can feel cramps and it can feel like a form of bloating. So, certainly trying to regulate your period and focusing on that can sometimes help with that bloating and then it could also be something else. So, there are so many other things that can cause bloating, not just PCOS. It would be important to also see a Specialist to make sure you are not missing another diagnosis.

Shweta Mishra: Okay. Thank you. The other question is, that's a far-fetched question. I guess everybody's trying to find an answer for that. But the person is asking can you suggest how to cure my PCOS? So, actually Dr. Aimee, Dr. Alexander, what does research say so far? How far are we in finding a cure based on whatever we have seen in these recent years in research?

Dr. Aimee Eyvazzadeh: Yeah, I think. There's no magic here. It's a chronic LH elevation from your pituitary that starts before puberty. So, like even before we start to get breast development and underarm hair, there's this chronic LH elevation is just beating on the system that makes the ovaries evolved in its pathophysiology in the way the functioning of the Ovaries. I think the challenge is that it's not like we can catch that before it starts to happen. I think early intervention is just recognizing the symptoms in early puberty. I think the other like flip side is there are some people who pop up with just really bad insulin resistance, but they're having regular periods. So, I think it's a really mixed group of women and there isn't necessarily one big cure. I wish there was, but I just can't think of it. I think that the important thing is just keeping your own, protecting yourself and keeping track that your uterus is protected from pre-cancer, you are protected from Type 2 Diabetes by exercise, diet and in potentially if needed a medicine and when you're trying to get pregnant talk to a Doctor, like one of us or whoever your OB/GYN and then empower yourself with information.

Shweta Mishra: Ashley, you wanted to ask a follow-up question?

Ashley Levinson: Yes, I'm interested to find out from your perspectives from both of you. Is insulin always affective with PCOS. I have some women and girls who say I'm not insulin resistant, but then I hear that there's always some sort of issue with insulin, whether you are insulin resistant or not. So, does that play a factor? And is that something that we should be looking at more PCOS with diagnosis and treatment?

Dr. Carolyn Alexander: Yeah, I mean for my standpoint it is like when I was trained, we checked fasting and phones on everybody no matter what your body size was. So it is part of my diagnostic tool set, that I do for patients and it's not something that I see elevated and everybody but it can also help me guide treatment and I use it as a benchmark to check it in the beginning and then follow up and make sure that it has come down before we initiate treatment to help someone get pregnant for example. So that's how I would answer that. And it seems that in Los Angeles the thin PCOS patients are the ones who call me and say they got gestational diabetes in pregnancy and I always find that interesting because their hemoglobin A1C and their insulins are normal, but it's the thin PCOS patients that I tend to see this like anecdotal clinical thing where they have a higher propensity gestational diabetes in pregnancy. So, I don't know and then that has a ramification for lifelong increased risk of type 2 diabetes when you get older, so I think there's is probably some underlying, interesting phenomenon of insulin, but we just don't always can't always detect it.

Ashley Levinson: Thank you.

Shweta Mishra: Right. Lisa, you have a question.

Lisa Rosenthal: Yeah, it's sort of relating to a PCOS cure. Could you explain why it's called a syndrome and not a disease. A lot of people you say disease and then it's sort of corrected. But what makes this a syndrome rather than a disease.

Dr. Aimee Eyvazzadeh: I mean the way I think about it is because there are so many symptoms associated with it and not everyone has all the symptoms and so that's why I think of it as a syndrome and maybe if we

thought about it as a disease people would get early diagnosis and treatment from a young age and see a specialist rather than syndrome sounds like kind of soft and there's so many different things that are involved and sometimes that can be a little bit confusing. Well, that's why I think it comes through.

Dr. Carolyn Alexander: Yeah, I agree.

Lisa Rosenthal: Is there any possibility that PCOS is sort of this big umbrella diagnosis or is it really just as complex, complicated and multifaceted as it seems to be?

Dr. Aimee Eyvazzadeh: I think it is exactly as it seems to be. It isn't the same thing for every single person and for some people it could mean having a really hard time getting pregnant and not responding to fertility pills. For other people, it could mean just be with fertility pills and they get pregnant every single time. So, that's why everyone should be treated like an individual and I actually have renamed PCOS and I'll tell you I've renamed it, 'HOPE syndrome'. This is just a very simple way for people to know exactly what it means so the H is High androgens or high testosterone. The O is lots of follicles on the ovaries. The P is irregular periods and the E is eating and exercise, right. So, that's what makes it HOPE syndrome and it's not about being infertile or having rotten eggs or having a hard time getting pregnant. It's literally about these things and if you know what it is from the very beginning than you address each of those things and then voila. You're not seeing me at the age of 40 and finding out that you have the diagnosis for the first time.

Shweta Mishra: I must tell everybody that you're fabulous at making abbreviations. The other question that just came on Instagram is, how do I know if I have adrenal type PCOS? Dr. Alexander you want to take it?

Dr. Carolyn Alexander: I'm sure yeah, I see a lot of Asian women having very high DHEA-S and they'll sometimes get cystic acne on their back and when we were looking at the genetics of all this it was interesting because in different ethnic groups there were different genes that turned on but the adrenal type of PCOS is a little interesting because birth control pills doesn't lower that male hormone. So, some of the patients will say their mood and feeling that they just feel hormonally off, it still stays even when they've taken birth control pills, which is supposed to lower the internal testosterone level. So, adrenal PCOS can be kind of from the DHEA-S being high, but that's different than adrenal hyperplasia, which I don't know if that's the question. But congenital adrenal hyperplasia is a genetic specific mutation and that is a high 17 hydroxy progesterone and that's important to do when you're not on birth control pills during the first week of your period. And if that level is over 200 that can be a warning signal and it's not actually really even PCOS and that's a different ballgame.

Shweta Mishra: I see Cam has posted one question here and she asks how to do you get tested for PCOS?

Dr. Aimee Eyvazzadeh: Yeah, I mean if you think of my HOPE syndrome, I mean, that's basically how you check your testosterone levels, get your ovaries checked, get an AMH level done, talk to a doctor and the diagnosis is not that mysterious and it shouldn't be. And so, if someone is not able to give you a clear diagnosis, it's a good idea to get a second opinion. There is good medical endocrinologist in our area that do pride themselves in being PCOS experts as well. So if you're not getting the help from an OB-GYN and sometimes unfortunately reproductive endocrinologist not Dr. Alexander and I, sometimes they say things like well, we won't really help you unless you're trying to get pregnant and I do PCOS management for people who are not interested in getting pregnant in my practice. So, if you're not getting the help that you need reach out to one of us either Dr. Alexander where I and we're will guide you to find someone that can help you.

Shweta Mishra: Thank you. So what age is a minimum age to get tested for PCOS, Dr. Alexander.

Dr. Carolyn Alexander: There isn't any specific age. I work closely with our Pediatric Group near us. Typically, it pops up around 16, but I think if younger girls are having issues, it's important to talk to your doctor. I'm very hesitant to start young girls on birth control pills, so I'm very more natural for them till they get a little bit older. Unless they need contraception, which is a different discussion. But there's not a

specific age to diagnose it as just a discussion.

Shweta Mishra: All right. Thank you. I guess another question is, is it safe to take Metformin and Spironolactone to treat PCOS. I've heard Spironolactone could cause harmful birth defects.

Dr. Aimee Eyvazzadeh: I mean, I love Spironolactone and I think it's a great tool. I take it myself hence the clear skin right now and if I don't take it for like two weeks all of a sudden, my cystic acne comes back and I get really annoyed that I didn't refill my prescription. And so, my style is there's a certain amount of time for patients who are trying to get pregnant that I had in them on it. And then I have them stop it. For example, when they start their ovulation induction medications or when they start cycling to try and get pregnant. So, it is safe to take with Metformin. However, if you're trying to get pregnant, obviously we don't recommend it, and we don't want you to take it if you're trying.

Shweta Mishra: Ashley, you have any final questions? You can you please unmute.

Ashley Levinson: Yes, I do have one final question. Lifestyle management is often brought up that's really kind of the Pinnacle as far as the PCOS treatment. So, what can we do to live a healthier lifestyle with PCOS? What steps should we be taking?

Dr. Aimee Eyvazzadeh: I'll start. I'm very passionate about this and I feel like you need a team and believe it or not. I have a mnemonic for that. I mean it really is like Dr. Alexander said multidisciplinary approach and you can't take someone who's been living with this for 40 years and just say go find a trainer and find a nutritionist. It's not as easy as that. I mean I do think involving a therapist, a physical trainer definitely so team is therapy. Eating, exercise recommendations, acupuncture even can help. Believe it or not I've had some great results with acupuncture with my PCOS patients, especially those who are not responding to fertility drugs. I've seen them help my patients with their magic that they do for me and the last thing is meditation and mindfulness. So, I think that you especially now in this pandemic you have to create your own mind body team and create your own mind body stature in your home and figure out all those things that you need so that you can keep moving, eat right and you're really getting the very best advice for yourself. And if you don't like the advice you're getting like find someone else, find a group, go to your social media pages, reach the social media pages and try to build a group of people that are in the same boat as you are and so you can all give each other really great advice.

Ashley Levinson: Thank you. So that's also one of the key, support is so vital right new now, especially people don't feel like they're getting the same care as they normally would because we're in the middle of the pandemic and especially with the mental health aspect with PCOS with the anxiety and the depression being so prevalent. I think it's important that people are able to connect online and find support. So, thank you so much for everything and for doing this and Dr. Alexander, thank you as well.

Shweta Mishra: Lisa, would you like to ask some final questions.

Lisa Rosenthal: Well, Ashley really posted a beautiful question. I have a final question. I guess, endocrinologist don't necessarily want to be handling this, pediatricians aren't necessarily handling this that's what we've found on the east coast and reproductive endocrinologist, don't necessarily want to be handling this. So, I guess piggybacking on what you just Dr. Aimee, how do you find somebody aside and certainly coming to Ashley or she does amazing work. So, I think we put out some good information to but how do you find somebody who's really qualified so that you're not wasting your time because right now it's not easy to see doctors. It's easy to do tell out but that's my question. How do you find somebody who's really good and that you can trust?

Dr. Aimee Eyvazzadeh: So, there is an app. It's POLLIE and I'm sure you guys know about it. So that's a telemedicine platform I believe that will match you with someone that will suit your needs related to PCOS. So, that's one way of doing it. So, everyone that is on that app. is basically a PCOS expert in whatever field that they are in and there are doctors on there that can help patients who are not getting the help that they

need and so I think that's one way of doing it. And our country is so large and I think sometimes people are afraid to care outside of their state but getting a second opinion consult through telemedicine platform, I think is definitely suitable and there are enough PCOS experts out there that I think that women can get the help that they need right now. And it's like I said, and if you if you aren't able to find that person, I know who those people are, and I can help connect.

Lisa Rosenthal: All right, thank you. Thank you.

Shweta Mishra: Alright, thank you so much everybody. I think we answered quite a lot of questions. Dr. Alexander has dropped but I think she will be back again. But I will conclude the talk now. We are already at the end of the hour. So, folks we were listening to Dr. Aimee and Dr. Alexander who answered questions related to everyday lives of women dealing with PCOS. We heard the panel guide us through some very basic questions and help us understand how we can deal with PCOS better. We hope we were able to touch upon quite a few of the many doubts that we women dealing with PCOS have and hope that a discussion was helpful to those who are newly diagnosed as well. Dr. Alexander, Dr. Aimee thank you very much for your time and all the information that you shared with us today. Michelle, Stephanie, Ashley, Lisa, Deborah and Lorraine. Thank you for joining the panel and each one you of in the audience. Thanks for your participation and your insightful questions that brought out a very informative discussion today.

I request everyone to check out the PCOS tracker that has now been downloaded more than 19 thousand times and I would appreciate each and every feedback on that. That will help us make the tracker helpful for women as well as help Advance PCOS research. So, we are looking to collaborate with research teams working on PCOS or women's health so that we can put the anonymous contributions that we have on our app from citizen scientists to constructive use, to help in PCOS research. So, if anyone is interested, please write to me at my shweta@trialx.com and this talk will be available on Curetalks platform, and the link will be shared with everyone. So, please visit our website for details on upcoming talks. Until next time we meet, wish you all well. Thank you and have a great day.