

PCOS*Challenge*

JAN - MAR 2018 | VOLUME 3 | ISSUE 1

**WHAT NO ONE
TELLS YOU ABOUT
INFERTILITY**

**HISTORIC YEAR FOR
PCOS ADVOCACY**

**“I WOULD
RATHER BE
ALIVE
WITH PCOS
THAN DEAD
WITHOUT IT”**

**PCOS
ADOPTION
STORY**



**HOW TO TALK TO YOUR PARTNER ABOUT
PCOS-RELATED MENTAL HEALTH ISSUES**

CONTENTS



3 **Letter from the Executive Director**

4 **I Would Rather Be Alive with PCOS Than Dead without It**
By Audrey Holsclaw

8 **How to Talk to Your Significant Other About PCOS-Related Mental Health Issues**
By Gretchen Kubacky, PsyD

12 **Multiple Disorders in One Body**
By Felice Gersh, MD

18 **Heart Disease and PCOS**
By Catherine Koutroumpis, RN, CWOCN

22 **PCOS and Breastfeeding Featuring Lisa Marasco, MA, IBLCC**
By Renetta DuBose

25 **PCOS Diva/PCOS Challenge Confidence Grant**

26 **Historic Year for PCOS Advocacy: U.S. Senate Passes PCOS Resolution**

30 **Understanding the Scope of PCOS from the Patient Support Nonprofit Perspective**
By Sasha Ottey, MHA, MT (ASCP)

34 **PCOS Challenge 2017 Highlights**

48 **Thank You to Our 2017 Supporters**

58 **The Things No One Tells You About Infertility**
By Jennifer "Jay" Palumbo

60 **My PCOS Adoption Story**
By Dina Stonberg

64 **Remembering a Pioneer: PCOS Dietitian Monika Woolsey**
By Gretchen Kubacky, PsyD

66 **An Integrative Approach to Wellness and Fertility in Women with PCOS**
By Maureen Kelly, MD

70 **Mark Perloe, MD Receives Ricardo Azziz/PCOS Challenge Advocacy Leadership Award**

71 **The Three Worst Diets for PCOS**
Featuring Julie Duffy Dillon, MS, RD, NCC, LDN, CEDRD

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LETTER FROM THE EXECUTIVE DIRECTOR

In 2017, PCOS Challenge:

The National Polycystic Ovary Syndrome Association worked with our advisors, advocates, partners and members on Capitol Hill to put polycystic ovary syndrome on the national agenda in the U.S. Congress in an effort to recognize the seriousness of the syndrome and officially

designate September as PCOS Awareness Month. Members of Congress introduced two historic resolutions - H.Res.495, and S.Res.336 which passed in the U.S. Senate on December 21, 2017. This year, we will continue to provide a platform for you to reach out to your legislators about the need for PCOS to be treated as a public health priority.

PCOS Challenge partners with some of the world's leading researchers and healthcare providers in the field to provide education to those affected by PCOS and healthcare providers. Be sure to [sign up to our mailing list](#) for notifications about 2018 PCOS awareness and advocacy events, including the PCOS Awareness Weekend, PCOS Advocacy Day, and other upcoming 2018 events.

In 2018, international PCOS advancements include the first PCOS study in Sub-Saharan Africa that will commence thanks to a collaboration between Prof. Richard Adanu at the University of Ghana and Dr. Ricardo Azziz at the State University of New York. PCOS Challenge was also invited to India for international PCOS educational activities this February, and the International Guidelines on PCOS updates will be released mid-2018. We advocate for a patient-centered approach to PCOS research and care, one where our voices are included and respected as patients work together with researchers, healthcare providers and legislators for a better future and a cure for PCOS.

In good health,

Sasha Ottey

Executive Director

PCOS Challenge:

The National Polycystic Ovary Syndrome Association



I WOULD RATHER BE ALIVE WITH PCOS THAN DEAD WITHOUT IT – AUDREY HOLSCLAW

There was always something wrong with me. My parents, without medical degrees and with their own hang ups, named it being fat. In their minds, being fat had nothing to do with whether or not my ovaries were functioning properly. In high school, I nursed the bleakness of what I wrongly thought was teenage angst with food, drugs, and alcohol. I was on my period more often than not and in crippling pain, and my goal in life became numbness. With the poor coping mechanisms of substance abuse and eating disorders, I kept a 4.0 GPA and graduated near the top of my class.

By college, my world could only exist as black and white. I was either drunk, high, and numb or not. Food filled the hole through the middle of me, but it didn't make my period stop and it certainly didn't manage the anger, anxiety, and depression



that were my everyday uncomfortable. Cannabis, carbohydrates, and liquor made being alive, if one could even call it that, tolerable. But it really wasn't more than just trying to breathe. The eating disorder morphed into a committee in my brain that judged everything I did on an unreasonable scale with goals that could never be met and progress that could never be seen. It made the mood swings more violent, the anxiety became rage, and, like a white girl during autumn at Starbucks, I lost my ability to "even."

When I met my husband, long before Taylor Swift's song "Blank Space," he called me "a nightmare dressed like a daydream." I was out of my mind. I was at the gym with a personal trainer three hours a day, six days a week and putting on two pounds a week. I would fill my car with Taco Bell and cry while I ate in the parking lot. We fought constantly, and my husband knew something was terribly wrong with me, but every doctor simply said, "Well, if you lost a little weight..." The emotional abuse I directed at my husband very nearly ended our marriage. He was afraid to tell me something was really, really wrong with me.

We had been married a year when I stopped going to the doctor. Then, my period lasted 121 days, and my husband's hemophobia-induced nausea prevented any intimacy, so I went back to the doctor. My gynecologist said I had PCOS along with metabolic disorder. Being crazy had a name, but it offered no path to navigate towards health. I was sent packing with birth control and a generalized, "You'll never have kids." We were devastated. Our dreamy white picket fence morphed into an insurmountable, barbed wire-topped wall. Suicide seemed preferable to the failure of divorce and being a morbidly obese hermit with no family or friends to speak of, but my husband and I started looking for help outside of ourselves. We found PCOS Challenge. We were no longer alone.

I found a sliver of light in a terrible darkness by way of a therapist introducing me to Eating Dis-

orders Anonymous, the authors Geneen Roth and Thich Naht Hanh, and a skill set that made being angry, sad, or even exuberantly happy manageable. She also recommended I get on antidepressants because brain chemistry being out of whack seemed obvious to her. We worked adamantly on my learning to be comfortable with being uncomfortable, and with the help of those skills, self-care, and new brain chemistry, I got okay with being a human, being married to a fellow human, and became the best version of me

And here, on the other side of 2008, after completing the *PCOS Challenge* television show, after having two kids, after building a better marriage with my husband, after working with numerous doctors and therapist, and after Crossfit, I like being alive. I'm impressed with what my body has accomplished. I'm proud of overcoming substance abuse and using my experiences of miscarriage, depression, anxiety, and PCOS to help others. I would rather be alive with PCOS than dead without it.

Audrey Holsclaw was born in Grand Rapids, MI, in 1983. She received a bachelor of arts in English from West Virginia University in 2006. In 2007, she married Aaron Holsclaw. After working in the IT industry after graduation, she gave Aaron two children, Delilah, who is three years old, and Margot, who recently celebrated her first birthday. She currently resides in Canonsburg, PA, where she is an attentive wife, patient mother and a sarcastic friend.

[View the Care For Your Mind Post to read Dr. Gretchen's notes and advice for Audrey and others facing similar challenges.](#)

10 FOR 10

ARE YOU UP FOR THE CHALLENGE?

ZubiaLive wants women, girls, parents, partners, friends, healthcare professionals - everyone impacted by polycystic ovary syndrome to share their PCOS story.

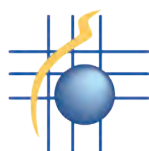
YOUR STORY MATTERS

THE PCOS 10-FOR-10

We are seeking 100 people to share their PCOS story at ZubiaLive to help spread awareness. By sharing your PCOS story on ZubiaLive, you can earn a \$10 Amazon eGift card and \$10 will also be donated to PCOS Challenge: The National Polycystic Ovary Syndrome Association.



zubiaLIVE



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Here are the steps:

1. Share your 5-10 minute story on video at ZubiaLive.
View details at ZubiaLive.net/pcos.
2. CCRM donates \$10 to PCOS Challenge.
3. ZubiaLive sends you a \$10 gift card.*

***This offer is currently for the first 100 people who share their PCOS stories before January 31st.**

SHARE YOUR STORY

HOW TO TALK TO YOUR SIGNIFICANT OTHER ABOUT PCOS-RELATED MENTAL HEALTH ISSUES



By Gretchen Kubacky, PsyD

Women with PCOS have a much higher rate of mental health issues than women who don't have PCOS. These include depression, anxiety, bipolar disorder, mood swings, suicidal thoughts and eating disorders. And the truth

is, as difficult as it is to be alone, it's also hard to be in a relationship when you have not only the physical issues of PCOS, but also the mental health issues. Learning how to live well with PCOS-related mental health issues is always a work in progress.

HERE ARE SOME TIPS TO HELP YOU AND YOUR SIGNIFICANT OTHER (SO) BETTER MANAGE MENTAL HEALTH ISSUES

OPEN THE LINES OF COMMUNICATION

Having a chronic illness like PCOS is hard. Mental health issues are hard too. Combined, they need a lot of time, attention, self-care and patience. If you are dealing with a mental health issue, it's critically important to talk to your SO regularly about what you're experiencing. Make time once a day for a brief check in, or once a week for a deeper dive. Be candid about what's affecting you, and what kind of support you need. If you don't want advice, ask your SO to just listen. But do also make it a dialogue; your SO needs support too.

LEARN ABOUT THE MENTAL HEALTH ISSUES TOGETHER

Mental health is everyone's business, and inescapably part of a relationship. So make the challenge of care/self-care a couples challenge. It's important to not only include your SO in awareness of the issues, but also to invite them to join you in learning the details of your condition, and how best to help manage it. You don't need to take your SO to therapy with you, but perhaps including him or her in an occasional session, going to your psychiatrist, or going to a meeting of the Depression and Bipolar Support Alliance would be really helpful for both of you. Learning more, and seeing the experience through other people's eyes, can really help build compassion.

DON'T LET MENTAL HEALTH ISSUES DOMINATE THE RELATIONSHIP

Mental health issues can sometimes feel like they are taking over your relationship. However, as important as mental health issues are, make efforts to ensure that they do not dominate the relationship. Relationships in which one person is "the sick one" and the other becomes a caregiver/de facto parent can quickly lose romance, equality and sexuality. Unbalanced relationships give rise to anger, resentment and frustration too. Give the mental health issues the time and attention they deserve, and then focus on something else.

DON'T EXPECT YOUR PARTNER TO MEET ALL YOUR NEEDS

No one is perfect, including your SO. Hopefully, he or she meets most of your needs, but it's important to understand that your SO can't meet all of your mental health needs. If you're dealing with a mental health disorder, you also need professional support (psychiatrists, therapists, nutritionists, etc.) and perhaps peer support, like from an online support group, or a local chapter of a relevant mental health association.

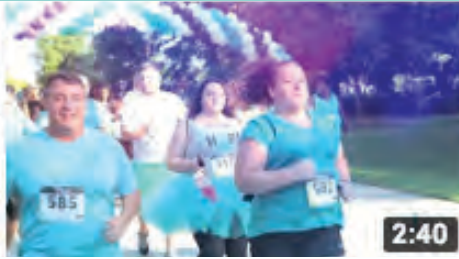
With this perspective in mind, consistent time and attention, and a little understanding, your mental health issues can become integrated into your relationship in a healthier way.



MORE ABOUT GRETCHEN KUBACKY, PsyD

Dr. Gretchen Kubacky, "The PCOS Psychologist," is a health psychologist in private practice in Los Angeles, California, an inCyst Certified PCOS Educator, and the founder of PCOS Wellness. Her goal is to dramatically improve the life and health of every PCOS patient. Dr. Gretchen offers insight, advice, education, and practical approaches on how to deal with the depression, mood swings, irritability, anxiety, sleep and eating issues, frustration, and lack of motivation that plague so many PCOS patients. She is also a member of the PCOS Challenge Health Advisory Board, and a frequent writer and speaker on PCOS and related topics.

PCOSWellness.com



Thank you!

1 Million

You VIEWS

We are excited to announce that the PCOS Challenge YouTube channel has hit one million video views. Subscribe to our YouTube channel and check out highlights from the PCOS Challenge television show and the 2017 PCOS Awareness Symposium and Bolt for PCOS 5K Run/Walk.

PCOS Challenge has more PCOS education, awareness and advocacy video content coming soon.

[YouTube.com/pcoschallenge](https://www.youtube.com/pcoschallenge)

SUBSCRIBE

CARE FOR YOUR MIND SERIES

ON PCOS AND MENTAL HEALTH

PCOS Challenge has partnered with the Depression and Bipolar Support Alliance for the Care for Your Mind series in January 2018. This series of articles will be completely dedicated to PCOS and Mental Health. Follow the series at careforyourmind.org.

POST 1 (Jan 9):

Interview with a PCOS Psychologist – Awareness post describing the link between PCOS and mental health.

POST 2 (JAN 16):

"I would rather be alive with PCOS than dead without it" – Audrey Holsclaw's personal story about her struggles with body image, substance abuse, eating disorders and PCOS.

POST 4 (JAN 30):

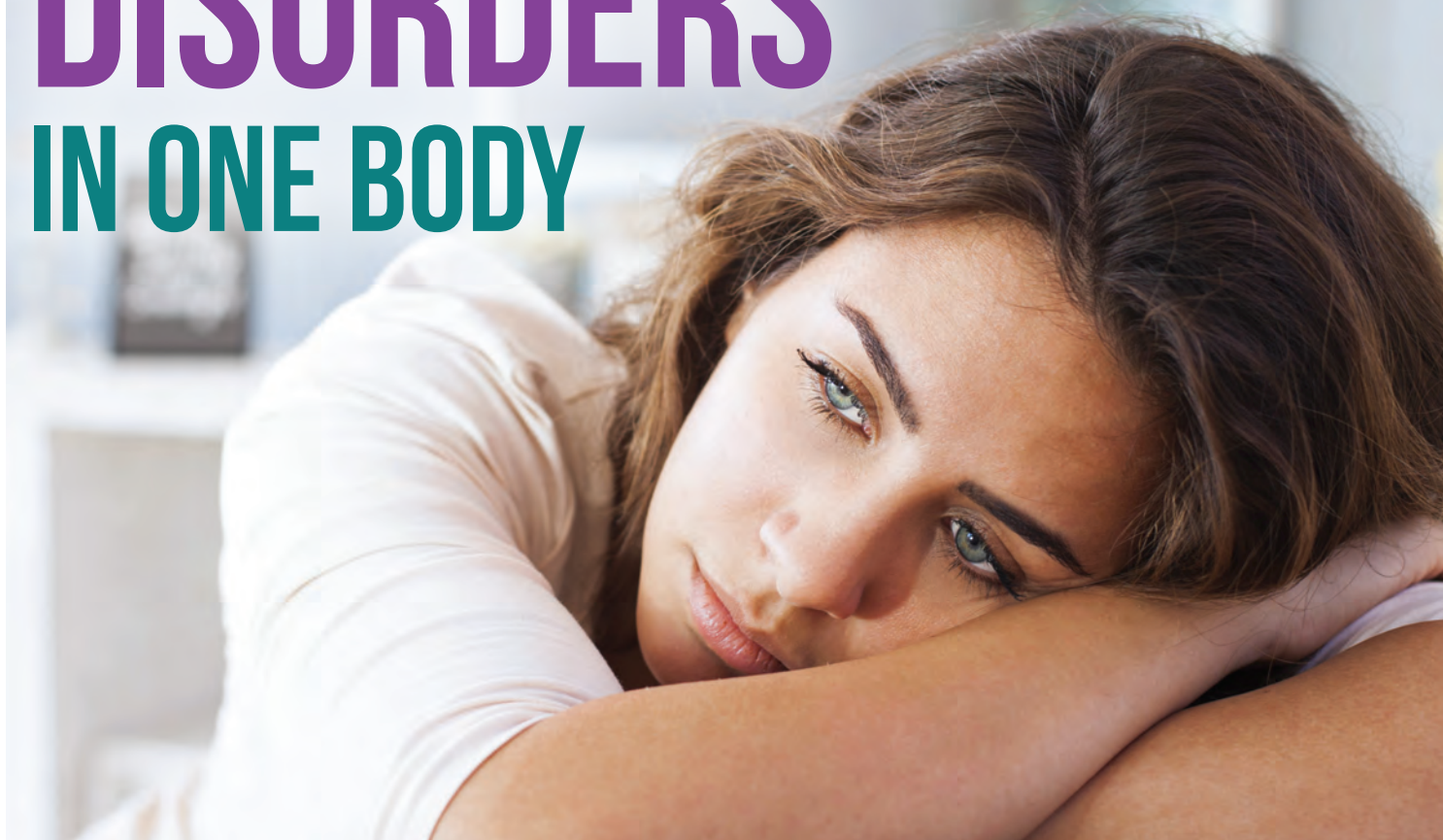
State of research on PCOS and Mental Health.
Are there any successes to report in getting funding or in outcomes? What needs to be done?
Is there anything readers can and should be doing to support research?

POST 3 (JAN 23):

PCOS Advocacy – Why Polycystic Ovary Syndrome Needs to Be A Public Health Priority – OpEd from the Experts



MULTIPLE DISORDERS IN ONE BODY



By Felice Gersh, MD

Women with PCOS exhibit a very high degree of medical complexity, including dysfunctions of key metabolic and immune mechanisms, affecting a wide range of organ systems. Such dysfunctions can manifest as multiple disorders in one body! Identifying the root causes and common conditions that weave their way through these multiple disorders will facilitate finding a unifying remedy, and eventually a cure, for PCOS and its related conditions.

By understanding how foundational dysfunctions develop and then lead to a myriad of manifestations, we can take those crucial first steps. Conditions found at higher rates in PCOS women than in the general population are autoimmune thyroid disease (Hashimoto's Thyroiditis), endometriosis, uterine fibroids (leiomyomata), adenomyosis (uterine lining glands within the muscle of the uterus), and several cancers.

Are women with PCOS simply unlucky to have so many medical maladies

in one body, or is there a common theme to explain this? Once you delve beneath the surface, you come to recognize that all of these conditions have similar underlying mechanisms. Uniting all of them are the following: an abnormally functioning immune system, marked by chronic inflammation with elevations of inflammatory signaling agents called inflammatory cytokines, early age exposures to environmental toxicants (chemical endocrine disruptors), nutritional deficiencies, and gut microbiome abnormalities (dysbiosis). The ultimate unifying and underlying cause for all of these maladies in PCOS women is a foundational hormonal problem: a major dysfunction of estrogen and its receptors, including its production and metabolic degradation. Estrogen is the master hormone, essential for metabolic health, and this requires a properly regulated immune system. Sadly, PCOS women do not have proper metabolic or immune health.

Let's begin with a quick overview of the conditions mentioned above. Endometriosis involves a severe localized inflammation in the pelvis, with high levels of inflammatory cytokines within the intra-abdominal (peritoneal) fluid. Interestingly, most menstruating women have some uterine contents flow backwards with each menses, with fluids and tissue passing through and out the fallopian tubes. The body's immune system normally dissolves and gobbles up that tissue, but in women with endometriosis, this process malfunctions, and little holes in the lining of the pelvis (the peritoneum) are created, allowing living cells from the uterine lining to implant and thrive.

This process is controlled by a system of enzymes, called matrix metalloproteinases (which remodel tissue) along with immune cells of the body. These cells and processes are under the control of estrogen, which in PCOS women is not functioning correctly. One type of these immune cells – the mast cell, which is also controlled by estrogen – accumulates within the pelvis of women with endome-

triosis, releasing massive quantities of inflammatory cytokines and chemokines (signaling agents which call other inflammatory white blood cells to the scene). This creates and sustains localized inflammation, promoting local estrogen production, and further stimulating growth of the ectopic endometrial cells.

In the case of uterine fibroids, malfunctioning matrix metalloproteinases and abnormal local production of estrogen and progesterone cause the muscle cells of the uterus to grow abnormally, creating muscle tumors – fibroids (leiomyomata). Likewise, adenomyosis involves the dysfunction of both the matrix metalloproteinases and of estrogen, resulting in the invasion of the endometrial (lining) cells into the muscle of the uterus.

Hashimoto's thyroiditis, an autoimmune disease, also involves dysfunction of the immune system, gut dysbiosis, and impaired gut permeability (leaky gut), all related to abnormal estrogen function. Lastly, cancer, the ultimate immune dysfunction, involves uncontrolled inflammation and estrogen malfunction or deficiency. Not surprisingly, the incidence of many cancers is substantially higher in women with estrogen dysfunctions - PCOS, adenomyosis, fibroids, and endometriosis - compared with the rest of the female population.

And what connects PCOS with those other conditions? What is the root cause of PCOS? We now understand that it involves chronic inflammation, gut dysbiosis, and leaky gut; and that estrogen malfunction is at the root of those problems. The cause for this estrogen malfunction involves exposures to endocrine disrupting chemicals at critical points of development – in utero, during infancy, and at puberty, in genetically susceptible women. This inflammatory state is exacerbated by continued chemical exposures and the consumption of the inflammatory Standard American Diet.

Despite all of this, there is substantial reason for hope. A fiber rich diet, stress control, exercise,

Continued on page 14...



....Continued from page 13.

timed eating and periodic fasting, along with the judicious use of bioidentical hormones, can ameliorate these problems.



MORE ABOUT FELICE GERSH, MD

Dr. Gersh is Medical Director of Integrative Medical Group of Irvine. She is one of only a small number of fellowship trained integrative gynecologists in the U.S. Dr. Gersh has developed comprehensive programs to treat PCOS, fibroids, endometriosis, menstrual disorders, vaginitis, bladder disorders, pelvic pain, vulvodynia and vulvar diseases, infertility and menopause. She integrates natural and holistic medicine with state of the art functional and allopathic medical treatments to help women maintain and regain their health. Dr. Gersh has a B.A. from Princeton University and a Medical Degree from the University of Southern California School of Medicine where she graduated in the top 5% of her class and as the #1 woman graduate.

IntegrativeMGI.com

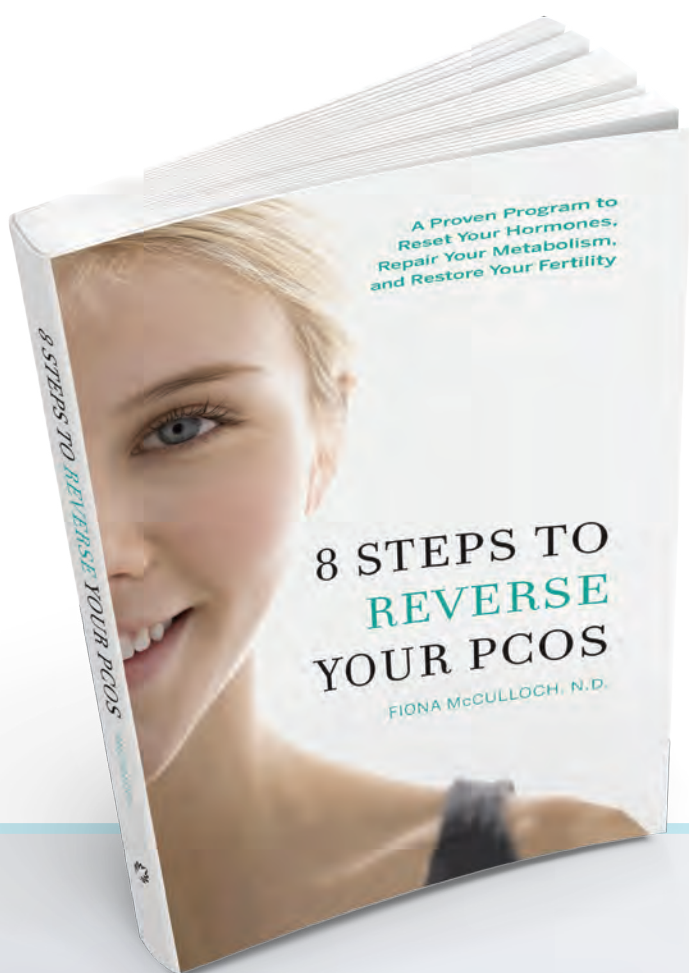
REFERENCES:

- Nielsen NM et al. Hum Reprod. 2011; 26(6):1555-9
- Smarr MM et al. Fertil Steril. 2016 Jul 15. Soo15-0282(16)61389-4
- Khoufache et al. Minerva Endocrinol. 2012; 37(1):75-92
- Burney et al. Fert and Steril. 2012; 98(3):511-19
- Konno et al. Human Cell. 2003; 16(3):144-49
- Cuevas et al. Reprod Sci.2012; 19(8):851-62
- Theoharides. Exp Dermatol. 2017
- Nat Rev Immunol. 2010
- Hart, David. 2015. Intern J of Inflamm. 2012; 452095
- Urb et al. PLOS Pathog. 2012; 8(4)
- Abraham et al. Nat Rev Immunol. 2010; 10(6):440-52
- Menzies et al. Hum Reprod Update. 2011; 17:383-96
- Binda et al. Exp Opin on Ther Targets. 2017; 21(1):67-75
- Vliagoftis et al. Immunol Rev. 2005; 206:190-203
- Qiao et al. Blood. 2006; 107:610-18
- Plos Pathog.2012; 8(4):e1002619
- Alvarez et al. Neuroscience. 2014; 258:111-120
- Hart, David. 2015. Intern J of Inflamm. 2012; 452095
- Bulun et al. Sme Repr Med 2004; 22(1):45
- Sharpe-Timms et al. Ann NY Acad Sci.2002; 955:147-56
- Smarr MM et al. Fertil Steril. 2016 Jul 15. Soo15-0282(16)61389-4
- Bayoglu et al. Eur J Ob Gyn Reprod Biol. 2015; 184:1-6
- Ozcan et al. Gynecol Endocrinol. 2015; 31(3):219-24
- Yavuz et al. J Cancer Res Ther. 2014; 10(2):324-9
- Cao et al. Evid Based Complement Alternat Med. 2014; 781684
- Wang et al. Angiogenesis. 2013; 16(1):59-69
- Ricci et al. Hum Reprod. 2013; 28(1):178-88
- Xu et al. Fertil Steril. 2011; 96(4):1021-8
- Jackson et al. Hum Reprod. 2005; 20:2014-20
- Halpam et al. Rev Assoc Med Bras 2015; 61(6):519-23
- Agostinis et al. Mediators Inflamm. 2015; 918089
- Mojzis J et al. Pharmacol Res 2008. 57(4):259-65
- Maia et al. Int J of Women's Health;2012; 4:61-65
- Kim KA et al. PLOS one. 2012; 7(10):47713
- Heard ME et al. Endocrinology. 2016 Jul; 157(7):2870-82

8 STEPS TO REVERSE YOUR PCOS

A Proven Program to Reset Your Hormones, Repair Your Metabolism, and Restore Your Fertility

In this new encyclopedic handbook for women with PCOS, Dr. Fiona McCulloch dives deep into the science underlying the mysteries of the condition, offering the newest research and discoveries and a detailed array of treatment options. 8 Steps to Reverse your PCOS gives you the knowledge to take charge of your PCOS-related health concerns addressing hair loss, acne, hirsutism, irregular menstrual cycles, weight gain, and infertility.



Dr. McCulloch introduces the key health factors that must be addressed to reverse PCOS. Through quizzes, symptom checklists, and lab tests, she'll guide you in identifying which of the factors are present and what you can do to treat them. You'll have a clear path to health with the help of this unique, step-by-step natural medicine system to heal your PCOS.

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INTERNATIONAL EVENTS



February 13, 2018

Ahmedabad, India

Safal Fertility Foundation:

The role of the patient in improving outcomes in PCOS

Interactive panel on PCOS

February 18, 2018

Kochi, India

International Conference on PCOS

Hotel Airlink Castle and GIFT IVF Center

Medical and Patient Conference on PCOS

February 27-28, 2018

Kochi, India

Cycle for PCOS

2018 INTERNATIONAL CONFERENCE ON PCOS

Learn from Leading Experts on Polycystic Ovary Syndrome

FEBRUARY 18, 2018

CONDUCTED BY



Dr. Anita Mani



LOCATION

GIFT IVF CENTRE, KOCHI INDIA

Held in beautiful Kochi, ranked as one of India's best tourist destinations

Conference Highlights

- First Indian medical conference bringing together clinicians, researchers, women with polycystic ovary syndrome and their supporters for a day of sharing insights and the latest updates about PCOS
- Training for patients and physicians on PCOS treatment and management lead by renowned international PCOS researchers, clinicians and specialists

Presentations will cover:

- PCOS Nutrition, Exercise and Lifestyle Management
- Improving Fertility in Women with PCOS
- Preventing Cardiovascular Disease, Diabetes and Other Complications in Women with PCOS
- Creating a PCOS Treatment Plan
- Integrative Care Approaches to PCOS
- Managing the Psychological Impacts of PCOS
- Hair and Skin Treatment Options for Women with PCOS
- PCOS in Adolescents: Early Diagnosis and Intervention
- And More!

Includes Live Yoga, Zumba and Fitness Classes



RIDE IN TEAL & NATURE SPORTS

For Polycystic Ovarian Syndrome Awareness (PCOS)



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*Includes T-Shirt, Breakfast, Lunch, Jungle Safari, Tent Rental & Dinner
*Bring your own Cycle, Helmet, Visibility Lights, Sleeping Bag, Insulation Mat or Blankets & Head Light.



FOR MORE INFORMATION, VISIT PCOSCHALLENGE.ORG/INDIA



By Catherine Koutroumpis, RN, CWOCN

HEART DISEASE AND PCOS

According to the Centers for Disease Control, the risk of heart attack is four to seven times higher for women with PCOS compared to women the same age who do not have PCOS. Many PCOS symptoms are independently connected to heart disease. Women with PCOS have multiple of these symptoms which can increase heart disease risk. Heart disease does not happen overnight, therefore prevention must begin early. As a nurse, many patients have shared what they wished they would have done

differently. Let their experiences motivate you to take preventative action now for a more quality filled life later.

Heart failure is a general term, referring to when the heart is not pumping as it should. You probably are most familiar with high blood pressure, clogged arteries, or heart muscle damage. A future with heart disease may include medication to lower blood pressure, sometimes four or more times a day! Your heart may enlarge, beat faster or weaker

due to strain. You may be placed on medication to counteract this fatigue. You may have to wear a nasal cannula and carry an oxygen tank to enrich what blood is making it around your system, as the quality and quantity of blood flow has changed. You may need blood thinners in the event of a heart attack. Tight, uncomfortable swollen legs occur from fluid back up and frequently lead to wounds and infection. You may grow breathless due to fluid back-up into the lungs, and have frequent urination due to some of the medications needed. On and on quality of life decreases gradually, and the effects of heart disease accumulate greatly.

This may feel like such a downer, but the good news is much of this is preventable! Start now and make it a habit. The biggest PCOS culprits leading to heart disease are diabetes, insulin resistance and obesity. Also, anything else that may interfere with treating these culprits can be a challenge, such as depression, sedentary life, or sleep apnea. For the best overall success, be sure to treat these as well.

Be proactive. Personal responsibility is vital in monitoring blood glucose, ensuring your HbA1c is within normal range (that is less than 7 for diabetics), and seeing your doctor or endocrinologist when recommended or a concern pops up. Blood glucose problems are rarely a one-and-done kind of problem, so keep on top of it.

Eat mindfully. If you do not have the first clue how to eat, find a registered dietician or a diabetes educator to get the skinny on eating for balanced glucose and nutritional intake. Drop the complexity and unrealistic expectations of fad diets. Lifestyle change! The same rules have been supported for decades; eat lean proteins, fruits, veggies, and complex grains. Avoid alcohol, sugar, refined carbs and processed foods for the most part; enjoy them only in moderation. Drop that sugary drink! No sodas, energy drinks or other liquid sugars.

Get moving! Exercise not only helps you lose weight, but it also helps all the processes in your body work better: glucose regulation, blood pressure, metabolism, hormones (think endorphins!),



MORE ABOUT CATHERINE KOUTROUMPIS, RN

Catherine Koutroumpis is a Wound Ostomy Continence Nurse Specialist at Iredell Health Systems in Statesville, NC. She holds two bachelor degrees (Biology and Nursing from Gettysburg College and Marymount University respectively). Catherine was a recipient of the US Nurse Corps Loan Repayment program and has also mentored countless new graduate nurses. She was a clinical nurse and nurse manager at the area's largest certified Comprehensive Stroke Center in Washington, DC, as well as a WOCN Specialist. Catherine has been a researcher in multiple process improvement and EBP projects, including creation of system wide policies to guide consistent levels of care. She presented at the Mid-Atlantic Regional WOCN Memorial conference on Negative Pressure Wound Therapy. She hopes to bring her variegated experiences and knowledge to other healthcare professionals and patients so they may live the highest quality life as possible.

improved sleep and decreased anxiety. Get the juices flowing! 10 minutes a day is a great start, add more as you go with an eventual 30 minute per day goal. Three 10 minute sessions a day still equals 30 minutes. No need to max out at the gym either. Walking is a seriously underrated exercise. Fast enough that you cannot sing, but you could talk with a workout partner. No excuses. Excuses do not prevent disease.

In the end, heart disease, or any disease for that matter, may still happen thanks to genetics. However, there are many modifiable risk factors that can be addressed with a few daily habit changes. By being proactive, you can greatly improve your chances for a more healthful future.

DOWNLOAD PCOS CHALLENGE



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 Medisafe

Never forget to take your meds and supplements again with our “must have” free app.

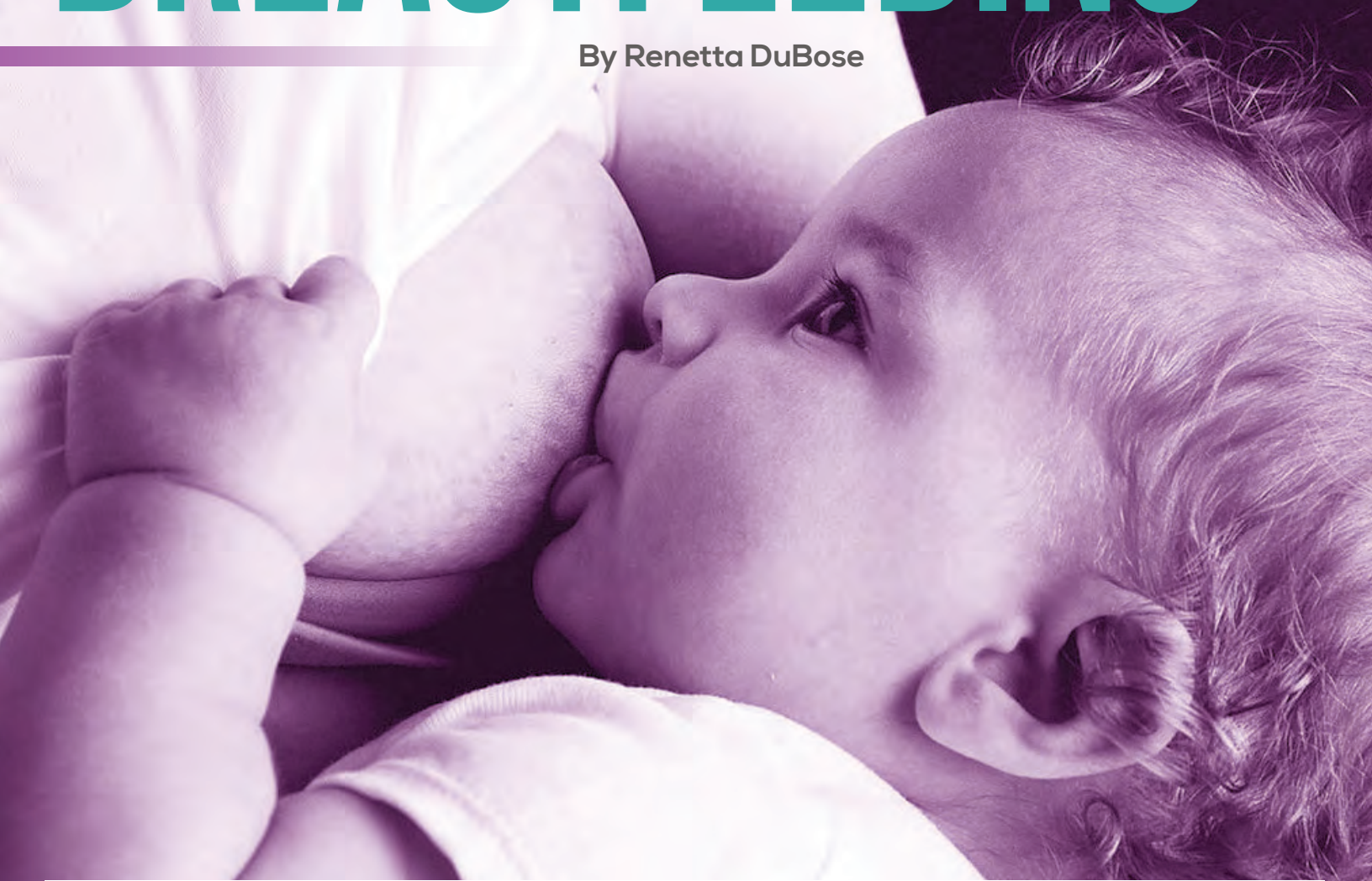
- Free to PCOS Challenge members!
- PCOS Challenge updates and info in-app
- Easily handles complex dosing schedules and refill reminders
- Ability to track 20+ measurements with full reports
- Can be used anonymously - no email or any personal info required
- Ability to invite a Medfriend to get a notification if you've missed meds
- Ability to manage unlimited family members or friends in your account; Even track pet meds!
- GoodRx Coupons
- Automatically Import Meds (CVS, Walgreens)
- Personalized Med info - pharmacist videos
- Ability to keep all your appointments in one place, with reminders
- Replace paper journaling - now available in-app diary
- Works with iPhone, Android Phones, Apple Watch, Android wearables
- 100% HIPAA compliant and ISO 27001 Secure

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PCOS & BREASTFEEDING

By Renetta DuBose



Do you plan to breastfeed or bottle feed? That's the question new moms and soon to be new moms hear from medical staff as their new bundle of joy arrives. For some women, it's a decision that is made during the early term of the pregnancy. For others, the

decision is made after a lactation consultant talks with a new mother post-partum. No matter how light or heavy the decision, choosing to breastfeed is an important health decision for both baby and mother, especially for a mother living with polycystic ovary syndrome.

The 2016 Breastfeeding Report Card issued by the Centers for Disease Control show an increase in women who breastfeed annually. While the American Academy of Pediatrics recommends women breastfeed exclusively for the first six months and through the first year with complementary foods, that's not happening. More than 80 percent of babies are initially being breastfed at birth, according to the CDC's report card. That number decreased to a little more than half or 50 percent by six months and drops to one third or around 30 percent by 12 months.

Lactation Consultant Lisa Marasco says a mother's breast milk is part of the baby's immune system, helping to protect him or her from the environment and ultimately reducing visits to the doctor. The act of a baby connecting to his or her mother's breast also helps to develop the child's face, oral health and develop the child's airway, according to Marasco, who works with WIC in Santa Barbara County Public Health Department Nutrition Services. It helps mom too Marasco says. Breastfeeding is part of the reproductive cycle and women who take part in it have a lower incidence of premenopausal breast cancer and lower rates of osteoporosis.

Marasco says women with PCOS can be impacted by the breastfeeding process and it begins with pregnancy. During that process the metabolism changes. She says breastfeeding resets the metabolism. Marasco says when women, especially those with PCOS, don't breastfeed and allow their metabolism to reset, it can become a problem where women are stuck in the weight accumulation stage.

It's not all bad news. Marasco says just because a woman has PCOS does not mean she cannot make enough milk. The focus though is on hormones. The possible hormonal imbalances that go with PCOS raise the risk of lactation issues. Insulin resistance and high androgens are the factors to consider. High testosterone treatments were used a long time ago to dry up women who did not want to breastfeed, she says. Some women with PCOS

tend to have high testosterone levels, which can impair milk production. Additionally, Marasco says research shows women with metabolic issues, insulin resistance, diabetes, and gestational diabetes can have problems with lactation. Women with PCOS and hypothyroidism can have issues with milk production too. As a lactation consultant, Marasco conducts risk assessments, looking into several factors. Those include insulin resistance, hyperandrogenism, and breast development, such as the appearance of the breast, hypothyroidism, and estrogen.

Obesity is a risk factor for low milk production as well. Women who have high BMI and express difficulties breastfeeding may have blunted prolactin response every time the baby is put to the breast. A baby's suckling should stimulate the prolactin surge and give the mother a spike in breast milk production. Prolactin levels drop after the baby stops suckling. However, sometimes when a woman is heavier and she struggles with breastfeeding, her prolactin surge response to suckling is not as high or strong, resulting in a faster drop in baseline prolactin than is normal. Baseline serum prolactin is normally high at birth then begins to drop, according to Marasco. More frequent and strong breastfeeding is going to keep the baseline higher for longer. She adds, "Weak suckling or weak pituitary response to suckling does not stimulate prolactin well, resulting in the baseline dropping faster than it should, and lactation may not be 'robust.'"

A 2016 published article on obesity, polycystic ovary syndrome and breastfeeding states that women with PCOS breastfed for a shorter amount of time compared to women who did not have PCOS.

There is a lot of research being done on Metformin as a possible therapy for lactation, but Marasco says that's still in the works. Herbs such as chasteberry help balance out hormones, but Marasco says PCOS patients may want to work with a naturopathic doctor or lactation consultant proficient in PCOS.

Continued on page 24...



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She adds that if you are concerned about milk production, you should monitor if the baby is swallowing, putting out the right amount of diapers, and check stool changes. New mothers can detect whether a baby is swallowing properly by listening for a subtle “kuh” sound along with a low jaw drop. Babies will also have a 1-1-1 suck-swallow-breathe pattern for one to several minutes according to Marasco. As for stool changes, it should transition from brown to green in about three to four days. By day five, it should have a yellow color. Mothers should get help right away if stool changes are not going through this process.

So what options do mothers have who experience problems with breastfeeding? Marasco says it is not all or nothing. Mothers with difficulty latching have the option of exclusively pumping. She adds, “If milk production is very low, some mothers will offer a bottle first, then ‘finish at the breast.’ Other mothers may choose to supplement at the breast with an at-breast supplementing system that can be made or purchased. The important thing is for your baby to be fed well.” As a positive, according to the Australian Breastfeeding Association, many mothers with PCOS breastfeed successfully.



MORE ABOUT LISA MARASCO, MA, IBLCC

Lisa Marasco has been working with breastfeeding mothers for over 30 years and has been Internationally Board Certified since 1993. She holds a Master's degree in Human Development with specialization in Lactation Consulting and was designated a Fellow of ILCA in 2009. Lisa is co-author of *The Breastfeeding Mother's Guide to Making More Milk*, a contributing author to the *Core Curriculum for Lactation Consultants*, and a new *Cochrane Collaborative* author. She is employed by WIC of Santa Barbara County while she continues to research, write and speak. In addition, Lisa is an Associate Area Professional Liaison for La Leche League of So. Calif/Nevada, and serves on the Breastfeeding Coalition of Santa Barbara County.

lowmilksupply.org

PCOS Confidence GRANT

PCOS *Diva*®



Through an endowment from PCOS Diva, PCOS Challenge provides grants for women and girls with PCOS struggling with hair and skin issues related to the condition. The grants are awarded in amounts up to \$500 per individual to assist with the costs associated with dermatology treatments, laser hair removal or electrolysis.

Learn more at PCOSChallenge.org/confidence



APPLICATIONS ACCEPTED STARTING FEBRUARY 20, 2018

The PCOS Diva/PCOS Challenge Confidence Grant was created to help women and girls struggling with hair and skin issues related to polycystic ovary syndrome. The grants are awarded in amounts up to \$500 per individual to assist with the costs associated with dermatology treatments, laser hair removal or electrolysis. Payments are made directly to the provider performing the treatments.

The only restrictions for applying are:

- Applicant **MUST** have a diagnosis of polycystic ovary syndrome from a physician.
- Applicant **MUST** be a legal permanent US resident.
- Applicant **MUST** be at least 18 years of age or application must be completed by a parent or legal guardian if prospective grant recipient is less than 18 years of age.

LEARN MORE



HISTORIC YEAR FOR PCOS ADVOCACY

U.S. SENATE PASSES RESOLUTION RECOGNIZING SERIOUSNESS OF PCOS

On December 21, 2017 the U.S. Senate passed by unanimous consent S.Res.336, a resolution recognizing the seriousness of polycystic ovary syndrome (PCOS) and expressing support for the designation of the month of September 2018 as "Polycystic Ovary Syndrome Awareness Month." This historic and bipartisan resolution represents the first time there has been a central focus on PCOS in the U.S. Senate.

PCOS Challenge: The National Polycystic Ovary Syndrome Association worked with U.S. Senators Elizabeth Warren (D-MA), David Perdue (R-GA) and five other leaders in the U.S. Senate to introduce S.Res.336 and U.S. Congressman David Scott (D-GA-13) and 20 other leaders in the U.S. House of Representatives to introduce H.Res.495. The resolutions encourage states, territories and localities to support the goals and ideals of PCOS Awareness Month which are to: increase awareness of, and education about, the disorder among the general public, women, girls and healthcare professionals; improve diagnosis and treatment of the disorder; and to improve quality of life and outcomes for women and girls with PCOS. The resolutions also recognize the need for further research, improved treatment and care options, and for a cure for PCOS as well as acknowledge the struggles affecting all women and girls afflicted with PCOS residing within the United States. H.Res.495 is currently the leading Health resolution in the 115th Congress with 67 cosponsors.

U.S. Congressman David Scott (D-GA-13) says, "It's an honor to work with PCOS Challenge in sponsoring this historic PCOS Awareness resolution in the U.S. House of Representatives and to be a champion for women and girls with polycystic ovary syndrome. I have always been an advocate in the area of health, and particularly women's health. PCOS is a serious issue that affects hundreds of thousands of women in Georgia and millions across the country. I commend the original 20 cosponsors for their leadership and hope that others in the House will join us in this bipartisan effort by cosponsoring and supporting this important resolution. There needs to be an increased focus on PCOS. The women and families impacted by the disorder need help. This is our opportunity to make a difference, so we should act now!"

"We are extremely pleased at the introduction of these resolutions and that the U.S. Senate passed S.Res.336," says Sasha Ottey, Executive Director of PCOS Challenge. "It is an important first step to improving outcomes for millions of women and girls affected by PCOS across the country. As the world's largest polycystic ovary syndrome patient advocacy organization, PCOS Challenge sees the broad adverse impact that the lack of awareness about PCOS is having on quality of care, research and health outcomes. Many women go decades exhibiting clear signs and symptoms of PCOS without a diagnosis or receiving adequate care, which impacts their quality of life and puts them at



CHANGING THE FUTURE
FOR WOMEN AND GIRLS WITH
PCOS



**Sasha Ottey, Founder and Executive Director
PCOS Challenge: The National Polycystic Ovary Syndrome Association**

risk for other serious conditions including cardiovascular disease, diabetes and endometrial cancer. PCOS affects an estimated 10-15 percent of women (more than 20 percent in some countries). Despite being the most common endocrine (hormone) disorder in women, PCOS is one of the most underserved areas of health. There are significant gaps regarding PCOS education, treatment options, research and research funding.

A number of leaders in Congress have expressed interest in working on subsequent legislation around PCOS. We are excited to work with them to address these critical healthcare gaps and improve outcomes for women and girls battling the disorder. We are proud of the PCOS Challenge community of advocates who wrote, called and met with their legislators."

Continued on page 28...

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U.S. Senator Elizabeth Warren (D-MA) says, "Polycystic ovary syndrome is a health issue that affects millions of women in the United States. I am encouraged by my bipartisan work with Senator Perdue to raise awareness for the syndrome and will continue to push for the investments in biomedical research and the improvements to our healthcare system necessary to solve the challenges posed by PCOS."

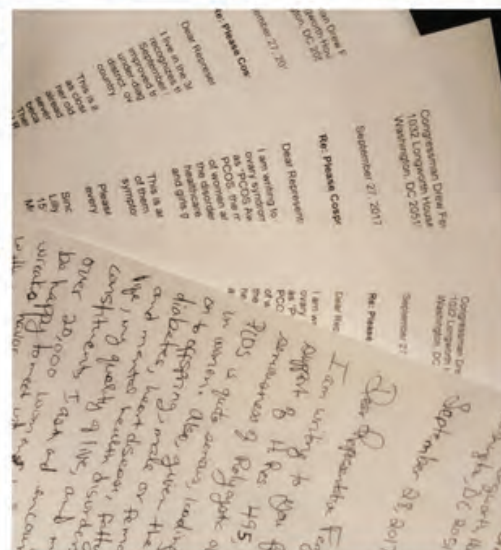
"Polycystic ovary syndrome affects more than 200,000 women in the state of Georgia and can lead to other serious conditions such as diabetes and heart disease. Raising awareness for this

syndrome is the first step in preventing further health risks. I am proud to be part of this effort in the Senate to bring greater awareness to the need for improved care and more research," says U.S. Senator David Perdue (R-GA).

The PCOS resolutions were supported by a coalition of over 70 national and international health organizations.

[View List of Supporting Organizations and Congressional Cosponsors](#)

Check to see if your Representative or Senator supported H.Res.495 or S.Res.336.



GEORGIA

Representative "Able" Mable Thomas (District 56) presented PCOS Challenge with a proclamation from the Georgia House of Representatives recognizing the seriousness of polycystic ovary syndrome and designating September as PCOS Awareness Month.



OTHER STATES LEADING THE WAY

VIRGINIA

On February 14, 2017, The House of Delegates and Senate passed House Joint Resolution 823 designating September, in 2017 and in each succeeding year, as PCOS Awareness Month in Virginia.

PENNSYLVANIA

On June 28, 2017, The General Assembly of Pennsylvania adopted House Resolution PA - HR380 designating the month of September 2017 as PCOS Awareness Month in Pennsylvania.

UNDERSTANDING THE SCOPE OF PCOS

FROM THE PATIENT SUPPORT NONPROFIT PERSPECTIVE



By Sasha Ottey, MHA, MT (ASCP)

Founder and Executive Director

PCOS Challenge: The National Polycystic Ovary Syndrome Association

When speaking about polycystic ovary syndrome (PCOS) to the general public, I am often met with confused looks from those who have never heard of PCOS before or wide-eyed stares that are mixed with relief and elation that someone else understands what they are experiencing; a feeling of not being so alone. Founding and running PCOS Challenge: The National Polycystic Ovary Syndrome Association, has been an eye opening experience into the true state of women's health.

The lack of prioritization that is given to PCOS is appalling, especially when you consider some of the research and statistics. PCOS is the most common endocrine disorder in women, the most common cause of female anovulatory infertility, and one of the most common human disorders. Women with PCOS constitute the largest group of women at risk for type 2 diabetes and cardiovascular disease. Fifty percent of women with the condition will develop type 2 diabetes before age 40. They are at four to seven times higher risk of heart attacks, three times greater risk for endometrial cancer and twice as likely to be hospitalized. One research study found suicide attempts to be seven times more common in women with PCOS. Polycystic ovary syndrome is a major problem that not enough people are paying attention to or taking seriously.

After my own diagnosis with PCOS, I saw immediate signals that my then health care collective (my gynecologist, endocrinologist, insurance company and others) was either not willing or able to provide me with the resources necessary to fully manage PCOS and to prevent some of the aforementioned diseases. After a bit of research, it became clear that I was not alone and millions of women with PCOS urgently needed more support and better care.

REFERENCES

Magnotti M et al. Med Clin North Am. 2007 Nov; 91(6):1151-68

PCOS and Diabetes, Heart Disease, Stroke. Retrieved from cdc.gov/diabetes/library/spotlights/pcos.html

Can PCOS Lead to Cancer? Retrieved from nichd.nih.gov/health/topics/PCOS/conditioninfo/Pages/cancer.aspx

Hart R et al. J Clin Endocrinol Metab. 2015 Mar;100(3):911-9. doi: 10.1210/jc.2014-3886. Epub 2014 Dec 22

Månsson M et al. 2008 Sep;33(8):1132-8. doi: 10.1016/j.psychen.2008.06.003. Epub 2008 Jul 30

Brakta S et al. J Clin Endocrinol Metab. 2017 Dec 1;102(12):4421-4427. doi: 10.1210/jc.2017-01415.

March WA et al. Hum Reprod. 2010 Feb;25(2):544-51. doi: 10.1093/humrep/dep399. Epub 2009 Nov 12.

SYSTEMIC PROBLEMS IN HEALTHCARE REGARDING PCOS

For too long, the calls for help by millions of women and girls affected by PCOS have gone unanswered. The system is broken for those with PCOS and it is leading to major health problems that could be prevented if identified and addressed early. Fifty to 70 percent of women and girls are going undiagnosed or misdiagnosed. Many doctors are missing the diagnosis and it is leaving patients to struggle without appropriate care. Our organization is seeing far too many women who were never diagnosed with PCOS until their 40s and 50s, or who were never told about the associated health risks, and are now battling diabetes, heart disease and cancer. There are serious and systemic problems in health care regarding PCOS diagnosis, treatment and support. These problems are compounded by the fact that PCOS support and awareness organizations are severely and

disproportionately underfunded, receiving less than 0.1 percent of the funding that other major health conditions receive. The lack of funding extends into PCOS research, stifling advancements and the number of young investigators entering the field. Moreover, there is a general lack of awareness and education about the condition, particularly among those who are responsible for protecting public health, making funding decisions and those who are in a position to influence health care policy. There is an urgent need to address PCOS to help improve and save lives. It is time that we make PCOS a public health priority!

To address this major health care epidemic, we have started educating our government agencies and need everyone who is in a position to help to get involved.

HOW PATIENTS CAN HELP

Historically, there has been limited support from PCOS patients for PCOS nonprofit organizations, which is one of the reasons most PCOS support organizations cease to operate. All PCOS nonprofits worldwide are run by dedicated volunteers due to the lack of funding. This is why it is vital for those affected by PCOS to be the biggest supporters of PCOS nonprofit organizations in order to send a clear message about the importance of this cause.

PCOS symptoms and diagnosis have been a source of shame or embarrassment for women, causing many to hide it even from their loved ones. However, over the last five to ten years, there has been a shifting tide when it comes to PCOS patient advocacy. More patients are willing to talk about the condition, volunteer with nonprofits and donate. Women and their supporters are recognizing the urgent need for advocating for support for PCOS awareness, education and

research, especially as their daughters, sisters, nieces and other family members get diagnosed, or as they recognize the link between PCOS and other conditions that persist or worsen beyond reproductive years. Most advocates recognize that this cause is much bigger than their individual experiences and are concerned about future generations. While the number of active and vocal advocates is still small relative to other conditions, it is trending upward. We were pleased that so many of our members, healthcare providers and other supporters took part in our advocacy efforts on Capitol Hill. To continue to drive change, PCOS Challenge needs more patients to become sustainer donors, to be present at awareness and educational events, to hold awareness sessions at their companies and to get their companies engaged in the fight against PCOS, as well as to get involved with legislative advocacy efforts.

Continued on page 32...

HOW GOVERNMENT AGENCIES CAN HELP

Currently, PCOS research receives less than 0.1% of the NIH research budget. Most funding comes from the National Institutes of Child Health and Development (NICHD). While we are grateful for the NICHD's support of PCOS, other institutes, most of which have much larger budgets, such as the National Cancer Institute; National Heart, Lung and Blood Institute (NHLBI); National Institute of General Medical Sciences; National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK); National Institute of Neurological Disorders and Stroke; and National Institute of Mental Health should all be funding more PCOS research. Many of the country's top PCOS researchers have told us that their grant applications are not being reviewed by some of the institutes, resulting in them missing out on funding opportunities for

critical research. This is also discouraging to young investigators who will opt to go into other areas of research if their PCOS studies continue to not get funded. Many funding sources see the name polycystic ovary syndrome and treat it as only a female reproductive issue; however, there is no dispute about the heterogeneity of PCOS. Based on decades of research, PCOS is understood to be a genetic, metabolic and endocrine disorder that can lead to cancer, diabetes, heart disease and many of the leading killers of women. PCOS research urgently needs greater support from other institutes such as the NIDDK, NHLBI and NCI. PCOS should be viewed not only as a fertility issue, but also as a major problem that the entire NIH and other government funding agencies should work together to solve.

HOW FOUNDATIONS CAN HELP

When it comes to foundations, there are few to no grants specifically for PCOS as with other major health conditions. Moreover, when PCOS organizations try to apply for grants around conditions related to PCOS, such as diabetes and cardiovascular disease, they are often not seriously considered by foundations funding those areas, or in some cases even allowed to apply. Many of the initial application screeners have very narrow guidelines and don't have the latitude or understanding to make the connections between PCOS and other conditions even when those connections are clearly made in the application by well documented research. The lack of funding for PCOS creates a vicious cycle of not enough awareness leading to very limited funding, which makes it difficult to create more awareness. It is time that nonprofit organizations seeking grant funding for PCOS have the option for grants that are earmarked for PCOS.

HOW INDUSTRY CAN HELP

With a growing workforce of women, PCOS likely affects up to 15% of a company's employees. It affects even more if you count the husbands, partners and fathers who have connections to women and girls with PCOS. It is important that corporations begin to look beyond the areas that they have traditionally funded, which often already receive hundreds of millions of dollars or more a year in support, to areas like PCOS where there support can have much greater visibility and impact. By supporting PCOS nonprofit organizations, they have an opportunity to really move the needle.



HOW COMMUNITY GROUPS CAN HELP

Community organizations can assist by hosting health fairs and information sessions. Since so many doctors are missing the diagnosis and are not offering the treatment that patients need, it is important that more families begin to recognize the signs and symptoms of PCOS in order to become the first line of defense against the condition and its progression to life-threatening diseases.

It is abundantly clear that there are major systemic problems around polycystic ovary syndrome diagnosis, treatment, care and funding. PCOS Challenge is working hard to address these problems, but we need the help and support of patients, government, industry, foundations and community organizations. Together we will positively change the future for women and girls with PCOS.

HOW HEALTHCARE PROVIDERS CAN HELP

When PCOS Challenge first presented the idea of our PCOS Awareness Symposium to one of the leaders of a major scientific organization, we were asked: “Why would doctors want to learn from a patient group?” Through our PCOS Awareness Symposia, we now educate over 1,000 patients and health care providers each year, but it is not enough. With 50-70 percent of women with PCOS going undiagnosed or misdiagnosed, it is time that more health care providers realize that they can and should learn from patients, their experiences and their needs. It is also time that more health systems support our programs. When we do our PCOS Awareness Symposia, 77 percent learn things about PCOS that their doctors never told them and 83% learn things that will change the way they

manage PCOS. Additionally, we have surveyed over 45,000 women and it is clear that there are major education and practice gaps related to diagnosis; nutrition, obesity and weight management counseling; cardiometabolic risk education and disease management; fertility management and reproductive health; hair and skin treatment; mental health; and integrative care. It is also important that more health care providers work together to provide integrative care to patients. The silo approach is not working and it is exposing patients to major health risks. We are grateful for those providers and organizations who support us, who are compassionate and knowledgeable and work with their PCOS patients to improve their health and quality of life.

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PCOS CHALLENGE 2017 HIGHLIGHTS



PCOS Challenge Presented the First Congressional Briefing on Polycystic Ovary Syndrome September 27, 2017



U.S. Congressman David Scott (GA-13)



Sasha Ottey, MHA, MT (ASCP)
PCOS Challenge



Anuja Dokras, MD, PhD
PENN PCOS Center



Katherine Sherif, MD
Jefferson Women's Primary Care



Ricardo Azziz, MD, MPH, MBA
The State University of New York

FIRST EVER U.S. CONGRESSIONAL BRIEFING ON POLYCYSTIC OVARY SYNDROME

On September 27, 2017, PCOS Challenge: The National Polycystic Ovary Syndrome Association conducted the first congressional briefing on PCOS for members of the U.S. Congress, health staffers and policy representatives from other major health organizations. The honorary co-hosts for the PCOS briefing were U.S. Congressmen David Scott (D-GA-13) and Roger Marshall, M.D. (R-KS-1). Featured Speakers included Anuja Dokras, MD, PhD Director of PENN Polycystic Ovary Syndrome Center; Ricardo Azziz, MD, MPH, MBA, Chief Officer of Academic Health and Hospital Affairs at State University of New York (SUNY); Katherine Sherif, MD, Director, of Jefferson Women's Primary Care; Sasha Ottey, MHA, MT (ASCP), Executive Director of PCOS Challenge; and PCOS advocates Ashley Levinson, Hannah Tabeling, Tina Howlett and Donna Fossum.

PCOS ADVOCATES SPEAK OUT



Ashley Levinson



Tina Howlett



Hannah Tabelaing



Deborah Bernick



Donna Fossum





Sasha Ottey
Executive Director
PCOS Challenge, Inc.



Rep. "Able" Mable Thomas (D)
District 56



ADVOCACY DAY FOR UTERINE HEALTH

By Danielle DeUrso

Polycystic ovary syndrome (PCOS) and uterine fibroids are two of the most pervasive women's health issues, yet many people have never heard of either condition. Both conditions are underfunded, underdiagnosed and underserved. PCOS Challenge and The White Dress Project are two of the leading organizations raising awareness around these important issues through education and advocacy to help make women's uterine health a priority.

On March 20, 2017, representatives from PCOS Challenge and The White Dress Project united at

the Georgia State Capitol to make a case for the importance of proper treatment, awareness and education for women's uterine health. Dressed in teal and white, women—from a variety of backgrounds—came together to support one another and share their stories as advocates. "Incredible things happen when women work together," said Sasha Ottey, Founder and Executive Director of PCOS Challenge, in a rousing speech at the Advocacy Day. "Any society where women's health and women's rights are not treated as a priority will not thrive. Working together unifies our voices and increases our strength. Together, we can move the



Shelby Eckard
PCOS Advocate



Rep. Erica Thomas (D)
District 39



Laura Colbert
Georgians for a
Healthy Future



AT THE GEORGIA STATE CAPITOL

needle in improving health outcomes and quality of care for women.”

Georgia State Representative “Able” Mable Thomas (D), District 56, echoed this sentiment: “Women’s health should be a priority. It is imperative that advocates speak out about important issues such as PCOS, fibroids and maternal-fetal health. By working with our Representatives and community organizations like PCOS Challenge and The White Dress Project, we can raise greater awareness and effect positive change.”

When many women are first diagnosed with PCOS

or uterine fibroids, they often feel isolated. Additionally, many healthcare providers are undereducated about both conditions and are unable to give patients the adequate care and support they need. “When I was diagnosed with PCOS, I didn’t know how common it was or even one other person who had it. I felt completely alone,” PCOS Challenge member Shelby Eckard said. “If there was more awareness, there would be far more support, education and resources.” Through the collaborative partnership formed by PCOS Challenge and The White Dress Project to advocate for uterine health, women don’t have to feel alone anymore.

PCOS CHALLENGE 2017 HIGHLIGHTS



Tanika Gray Valbrun
Executive Director, The White Dress Project



Gabrielle Gaston, another PCOS Challenge member, also attended the Advocacy Day to help spread awareness about PCOS. Gabrielle said, “It is important to educate people so that when they hear the letters PCOS, they are not confused and do not mistake it for other conditions or a sexually transmitted infection. It is also important for them to know that PCOS is very common.” Gabrielle stressed the importance of person-to-person advocacy to help spread awareness. “It can be difficult to tell if a woman has PCOS just from looking at her, and you never know who you may help by sharing your story.”

Shelby Eckard said one of the most impactful aspects of the Advocacy Day for her was raising awareness and showing women that they have support: “It’s important to help other women when they get diagnosed because they’ll feel empow-

ered by knowing they’re not alone. When people feel empowered, they are more inspired to take action, which can lead to advocacy and change.”

Legislators have the power to enable significant change and multiply impact through laws, regulations and funding decisions. “This Advocacy Day shows our legislators that we are our own health advocates,” Tanika Gray, Founder and Executive Director of The White Dress Project, reflected. “We need to make sure that the people who are making decisions for funding and bills for healthcare know how important these issues are.” Both PCOS and fibroids have tremendous effects on women’s health and quality of life, but if government representatives are not made aware, women’s health will not be elevated to a priority. It’s up to women to spread awareness and serve as advocates for themselves and for other women.

U.S. CAPITOL, WASHINGTON, D.C.



On May 18th, 2017, PCOS Challenge supported RESOLVE's Advocacy Day on Capitol Hill in Washington, D.C. to advocate for resources and support of those building their families through adoption and assisted reproductive technology. The event was held in partnership with the American Society for Reproductive Medicine (ASRM). The day brought together hundreds of leaders and advocates to talk to Members of Congress about legislation impacting the infertility community.





PRECISION

ON JUNE 11-13, 2017,

the second annual Personalized Medicine Summit was held at the University of British Columbia in Vancouver, Canada. The event brought together healthcare leaders from around the world to help design a roadmap to assist government, the public and healthcare providers in implementing personalized precision medicine as a means to provide more efficient and effective healthcare. PCOS Challenge Executive Director Sasha Ottey presented on Engaging the Patient Stakeholder in Personalized Medicine. The Summit was hosted by the Personalized Medicine Initiative and the Life Sciences Institute at the University of British Columbia.



MEDICINE SUMMIT: TRANSFORMING THE PRACTICE OF MEDICINE



INTERNATIONAL EVIDENCE-BASED GUIDELINE ON PCOS MEETING



PCOS Challenge is a part of the important international initiative to develop an updated international evidence-based guideline in PCOS. Some of you may have responded to surveys as a part of this process. We advocate for the patient voice to be included and respected in processes that affect us, our health and our future.

The international PCOS initiative includes the update and expansion of the Evidence-Based Guideline for the Assessment and Management of PCOS, published in 2011. The Australian

Centre for Research Excellence in PCOS, in partnership with the European Society of Human Reproduction and Embryology and the American Society for Reproductive Medicine and in collaboration with other international Societies, will update and expand the guideline and adapt it to international settings. The guideline which is being developed in collaboration with more than 30 international societies and internationally recognized researchers, clinicians and patient groups, is proposed to be the primary international evidence-based guideline in PCOS and is slated to be released in mid-2018.

CONGRESSMAN DAVID SCOTT'S 13TH ANNUAL HEALTH FAIR



PCOS Challenge participated in Congressman David Scott's 13th Annual Health Fair, which was attended by thousands of Georgians. The health fair provided nearly 15,000 healthcare screenings, consultations, referrals and informational materials from Georgia's leading community organizations and medical professionals – all free of charge. As one of the event's featured speakers, Sasha Ottey spoke about PCOS and the associated health risks.





ANOTHER HISTORIC YEAR FOR PCOS AWARENESS, EDUCATION AND ADVOCACY

Answering the call of the U.S. Congress to increase awareness of, and education about, polycystic ovary syndrome among the general public, women, girls and healthcare professionals, PCOS Challenge: The National Polycystic Ovary Syndrome Association, Omega Phi Alpha National Service Sorority, healthcare leaders and patient advocates gathered in Atlanta on September 16-17th for PCOS Awareness Weekend, the largest event dedicated to patient and healthcare-provider education as well as raising awareness and funds to help fight polycys-

tic ovary syndrome. The weekend's events included the fifth annual PCOS Awareness Symposium in Atlanta and the ninth annual Bolt for PCOS 5K Run/Walk presented by PCOS Challenge and hosted by Omega Phi Alpha National Service Sorority.

The PCOS Challenge events were attended by hundreds of people throughout the U.S. and various parts of the world. The events were also mentioned by hundreds of media outlets including ABC, NBC, CBS and FOX affiliates across the country.

Over the last five years, PCOS Challenge's PCOS Awareness Symposia have raised the profile of PCOS and directly impacted the lives of thousands of women and girls who have been struggling with PCOS for years and have been unable to get the help and support they need. The PCOS Awareness Symposia have also been an invaluable resource for healthcare providers to improve their ability to recognize, diagnose, treat and improve outcomes for their patients with PCOS.

CHANGING THE FUTURE FOR WOMEN & GIRLS WITH POLYCYSTIC OVARY SYNDROME



MAKING A DIFFERENCE

"We are grateful to the many members of Congress and state governments who now recognize the seriousness of PCOS and to Omega Phi Alpha for hosting PCOS Awareness Weekend," says Sasha Ottey, Executive Director of PCOS Challenge. "For too long, the calls for help by millions of women and girls affected by PCOS have gone unanswered. PCOS is leading to major health problems that could be prevented if identified and addressed early. 50 to 70 percent of women and girls with PCOS are going undiagnosed or misdiagnosed. Our organization is seeing far too many women who

were never diagnosed with PCOS until their 40s and 50s, or who were never told about the associated health risks, and are now battling diabetes, heart disease and cancer. There are serious and systemic problems in healthcare regarding PCOS diagnosis, treatment and support. There is an urgent need to address PCOS to help improve and save lives. It is time that we make PCOS a public-health priority!"

Ashley Brady, President of Omega Phi Alpha at Nu Chapter (Georgia Tech), says, "We are extremely honored as a sisterhood to do

our part in supporting women with PCOS by partnering with PCOS Challenge and hosting the PCOS Awareness Weekend here at Georgia Tech. The sisters of Omega Phi Alpha started the Bolt for PCOS 5K Run/Walk to raise awareness for a cause that resides close to us. We have alumni and current sisters who struggle with PCOS, and we have made it a priority to raise awareness for the condition. The Bolt 5K event was created to spread awareness and to raise funds to help in the fight against PCOS. Through our passion for service, we are fortunate to be able to help others affected by the disorder."

PCOS CHALLENGE 2017 HIGHLIGHTS

EDUCATING PATIENTS AND HEALTHCARE PROFESSIONALS



Angela Grassi, RD
PCOS Nutrition Center



Ricardo Azziz, MD, MPH, MBA
The State University of New York



Fiona McCulloch, ND
White Lotus Naturopathic Clinic



Martha McKittrick, RD, CDE
Martha McKittrick Nutrition



Jim Toner, MD, PhD
Atlanta Center for Reproductive Medicine



Maria Horstmann, CPT, IRC
Be Fab – Be You



Katherine Sherif, MD
Jefferson Women's Primary Care



Mary Spivey-Just, CPE
American Electrology Association

PCOS AWARENESS SYMPOSIUM - ATLANTA HOST ORGANIZATION:

OMEGA PHI ALPHA
NATIONAL SERVICE SORORITY



On September 16, 2017, PCOS Challenge held its fifth annual PCOS Awareness Symposium in Atlanta, Georgia which was attended by hundreds of patients and healthcare professionals. Attendees traveled from over 30 states and all over the world to attend the event. Registered nurses, physicians, dietitians, electrologists and medical students all came to show their support and to gain valuable knowledge from some of the field's top researchers and clinicians in an effort to improve outcomes and quality of care for women and girls with PCOS.



[VIEW HIGHLIGHT VIDEO](#)



Renetta DuBose



Shelby Eckard



Nichole Domineck



BENEFITS FOR PATIENTS

For patients, the PCOS Awareness Symposium helps women and girls affected by the condition become proactive about their health and discover strategies and resources to help overcome their symptoms and reduce their risk for life-threatening related diseases.

BENEFITS FOR HEALTHCARE PROVIDERS

For healthcare providers, the PCOS Awareness Symposium helps to improve competence in the field of PCOS and address seven identified education and practice gaps.

AWARDS AND HONORS

Renetta DuBose and Shelby Eckard (PCOS Support Girl) were honored with the PCOS Challenge Community Leader Award for their outstanding work in PCOS awareness and advocacy.

Nichole Domineck was also honored with the PCOS Challenge Exceptional Volunteer Award in appreciation of her dedicated and outstanding service to PCOS Challenge.





BOLT FOR PCOS 5K/RUN WALK

HOST ORGANIZATION:

OMEGA PHI ALPHA

NATIONAL SERVICE SORORITY



The Bolt for PCOS 5K Run/Walk was the second major event during PCOS Awareness Weekend 2017 in Atlanta. The Bolt for PCOS 5K event is hosted by Omega Phi Alpha National Service SorORITY and benefits PCOS Challenge. It is the largest event in the U.S. dedicated to raising awareness and funds to help fight polycystic ovary syndrome. During the Bolt for PCOS event, Omega Phi Alpha and PCOS Challenge raised over \$37,000. Proceeds from the Bolt for PCOS event go toward PCOS education and support programs, health screenings, grants, research efforts and increasing awareness and public support for those with the condition.



[VIEW HIGHLIGHT VIDEO](#)



THANK YOU TO ALL OUR SUPPORTERS

We are grateful to Omega Phi Alpha National Service Sorority and all our event sponsors, presenters, donors and volunteers for your national leadership on PCOS and commitment to women's health. There are people and organizations that talk about change and there are those who really move the needle when it comes to PCOS awareness, education, support and research. You all are true champions for women and girls with PCOS. Thank you!"

— SASHA OTTEY, EXECUTIVE DIRECTOR
PCOS CHALLENGE

THANK YOU FOR YOUR SUPPORT

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The Vanguard Group
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PCOS DIVA / PCOS CHALLENGE CONFIDENCE GRANT DONORS AND MATCHING CONTRIBUTORS

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American Electrology Association

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J. Christopher Scott
Kerstin Smith
Tyasia Stratford
Christine M. Trefethen
Tyronza Daigle Walker
Rasheen Whidbee



TOP VOLUNTEERING ORGANIZATIONS

Omega Phi Alpha National Service Sorority
Spelman College
Emory

TOP BOLT FOR PCOS 5K RUN/WALK TEAMS (MOST FUNDS RAISED)

PCOS Challengers
PCOS Positivity
The Barons
Nichole's PCOS Fighters
The Cysters & The Mysters
Tough Pearls Wear Teal
PCOS Divas
Team Amanda
Wellness Warriors
Women of Teal

TOP BOLT FOR PCOS 5K RUN/WALK TEAMS (MOST PARTICIPANTS)

PCOS Support Gurls And Guys
Omega Phi Alpha GT
Kappa Epsilon Fraternity
Firebirds
Wayward Cysters
Nichole's PCOS Fighters

TOP BOLT FOR PCOS 5K FUNDRAISERS

Shelby Eckard (PCOS Support Girl)
Sasha Ottey
William Patterson
Renetta DuBose
PCOS Nutrition Center LLC
Ashley Levinson (PCOS Gurl)
Virginia Silvestro
Stefania Cattaneo
Christine Cirella
Maria Horstmann

TOP VIRTUAL RUN/WALK FUNDRAISERS

Vicky T. Davis
Amanda Ramos
Genna Zunde
Jessica Pursino
Sarah Prohaska

OTHER TOP FUNDRAISERS

Tom Toale
Clareblend
Christina Ohler/Soul Cyster Creations
Contessa Clark
Christine's Thrifty Finds

SPECIAL ACKNOWLEDGMENT

Nichole Domineck
Shelby Eckard
Renetta Dubose, WJBF Television
Mark Perloe, MD
Endocrine Society



THE HUGE IMPACT OF YOUR SUPPORT



SUPPORT PROGRAMS

PROVIDES ANSWERS, RESOURCES AND ONGOING SUPPORT

- Helps fund online and offline support programs that over 40,000 women and girls depend on to help overcome their symptoms and reduce their risk for life-threatening related diseases.



LIVE EDUCATION

ADDRESSES GAPS RELATED TO CARE AND TREATMENT

- Helps provide vital live educational programs for over 1,000 patients and healthcare professionals across the U.S. each year. These programs address seven identified education and healthcare practice gaps adversely impacting millions of women and girls with PCOS.



HEALTH SCREENINGS

HELPS SAVE LIVES

- Women with PCOS constitute the largest group of women at risk for type 2 diabetes and cardiovascular disease. Your support helps provide health screenings to identify and reduce PCOS patients' risk of type 2 diabetes, cardiovascular disease and stroke.



GRANTS & RESEARCH

IMPROVES ACCESS, CARE AND QUALITY OF LIFE

- Helps PCOS Challenge provide grants for women and girls with PCOS in medical and financial need to assist with the costs of services not covered by insurance such as nutrition counseling, fertility treatments and hair and skin treatments.
- PCOS Challenge is partnered with many of the leading PCOS research centers globally. Your support helps with recruiting and important research efforts.

SMALL DONATIONS MAKE A BIG DIFFERENCE.

YOUR SUPPORT CAN
POSITIVELY IMPACT THE
LIVES OF MILLIONS OF
WOMEN WITH PCOS.

**HOPE
FOR
PCOS**



BECOME A HOPE FOR PCOS MONTHLY DONOR

For as little as \$5 or \$10 a month, you can make a difference in the fight against polycystic ovary syndrome by supporting PCOS awareness, education, advocacy and research efforts. As a HOPE for PCOS monthly donor, you provide much needed financial support to programs that women with PCOS depend on to help overcome their symptoms and reduce their risk for life-threatening related diseases including cancer, diabetes and cardiovascular disease.

Monthly donations of all sizes are welcome and greatly appreciated!

PCOS Challenge, Inc. is a 501(c)(3) public charity.

Donations are tax deductible to the fullest extent permitted by law.

Give Today at PCOSChallenge.org/pcos-donate



WE HAVE ANOTHER AM



DON'T MISS PCOS EVENT

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**THE BIGGEST
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NOTIFICATION LIST



100 NEW TEAM CAPTAINS

2018 PCOS CHALLENGE



TEAMS NEEDED FOR THE 5K RUN/WALK EVENTS

HELP END PCOS

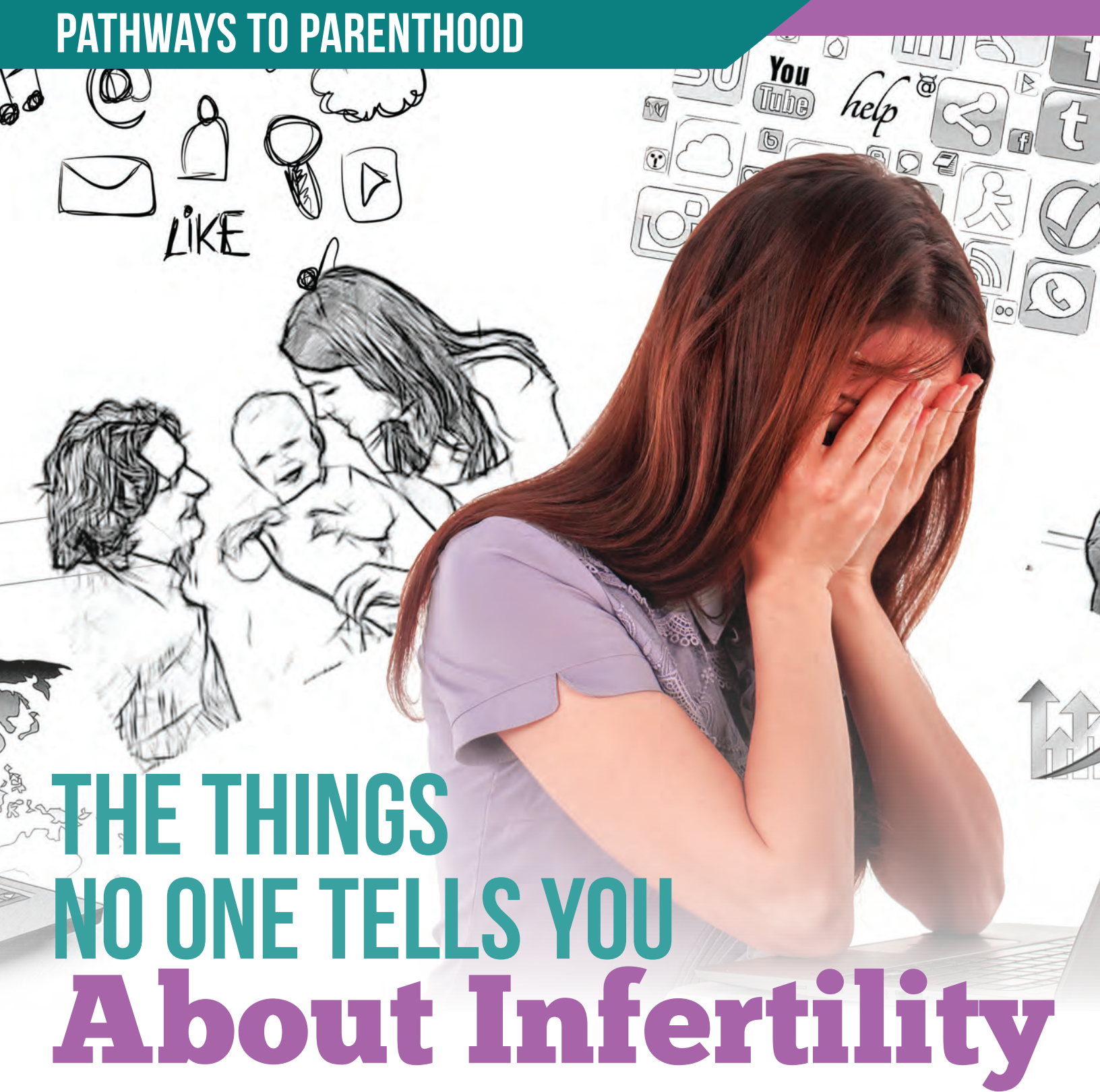
The PCOS Challenge 5K Run/Walk events are the largest events in the country dedicated to raising awareness and funds to help fight polycystic ovary syndrome (PCOS).

You are invited to take a leadership role in the fight against PCOS by becoming a Team Captain for the 2018 PCOS Challenge Run/Walk events. We need your help to end PCOS!

***SIGN UP TO BE A
TEAM CAPTAIN***

**YOU MAY SERVE AS A
TEAM CAPTAIN FROM ANY LOCATION**





THE THINGS NO ONE TELLS YOU About Infertility

By Jennifer "Jay" Palumbo

While there are many valuable resources online about the infertility journey, there are still some random little tidbits that I didn't know "then" that I certainly know now. Here are a few:

IT'S OK NOT TO ALWAYS BE RAINBOWS, SUNSHINE AND KITTENS.

Yes, you know the infertility journey sucks, but what it's worth stating outright that if you need to

RSVP a polite, “No thanks” to that baby shower, you’re not a bad person. If you have an unkind thought about a pregnant woman, you’re not an evil, horrible person. You will have the occasional “not nice” thoughts, and that is OK. It doesn’t mean you’re a bad person. It just means you’re human and it’s quite alright to not always be Suzy Sunshine.

THAT YOU WILL BECOME A DIFFERENT VERSION OF YOURSELF FOR A WHILE.

On the note above, in addition to being the occasional understandable poop pants; infertility, hormones, fertility treatment and feeling like a failure altered who I was for a good period of time. I’ve heard several relate to the very end of Moana (spoiler alert!) when the viewer finds out the “Lava Monster”, Te Ka, was actually the beautiful Te Fiti the whole time. It was only when her “heart was returned” did she go back to her usual self. And boy, that was me. That doesn’t mean you must have children to have your heart returned. It just means that no matter how your journey resolves (IVF, adoption, surrogacy, child-free, etc.), you may realize how much infertility affected who you were. Again though, that’s OK. Be forgiving of yourself while you muddle through it all.

THE WEIRDEST THINGS MAY “TRIGGER” YOU.

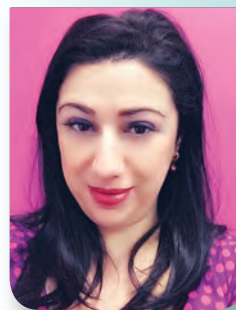
Being in a fertility clinic waiting room and having someone come in with a baby is a clear and obvious trigger. What surprised me though was the “not so obvious” moments that reminded me of how much infertility issues suck. Television and movie plot lines, pregnancy test commercials, greeting card stores, baby diaper aisles, music, social media, balloons, strollers, going outside, walking down a street, etc. All have triggers about pregnancy, babies and so forth. You just never know what may affect you. One thing that helped me tremendously was watching RuPaul’s Drag Race. No pregnancies, the commercials were either about pet food or exercise products and who doesn’t want to look at fierce Drag Queens instead of negative pregnancy tests?

THAT STATISTICALLY, THE FIRST IVF ISN'T ALWAYS SUCCESSFUL.

Now before you smack me in the face with a “Duh!”, I genuinely didn’t know this when I was about to do my first IVF. I naively assumed when you do IVF, you get pregnant. I found out much later that according to a recent study, for all women, the odds of having a baby on the first IVF attempt was 29.5 percent and the chance of having a baby jumped up to 65 percent by the sixth attempt. Lord knows I couldn’t afford six IVFs but knowing this, as much as no one wants to hear this when they are about to do their first IVF, would have been a comfort when it didn’t work. It would have felt less like a failure and more like an accurate statistic.

THAT IT’S NOT ALL THAT BAD.

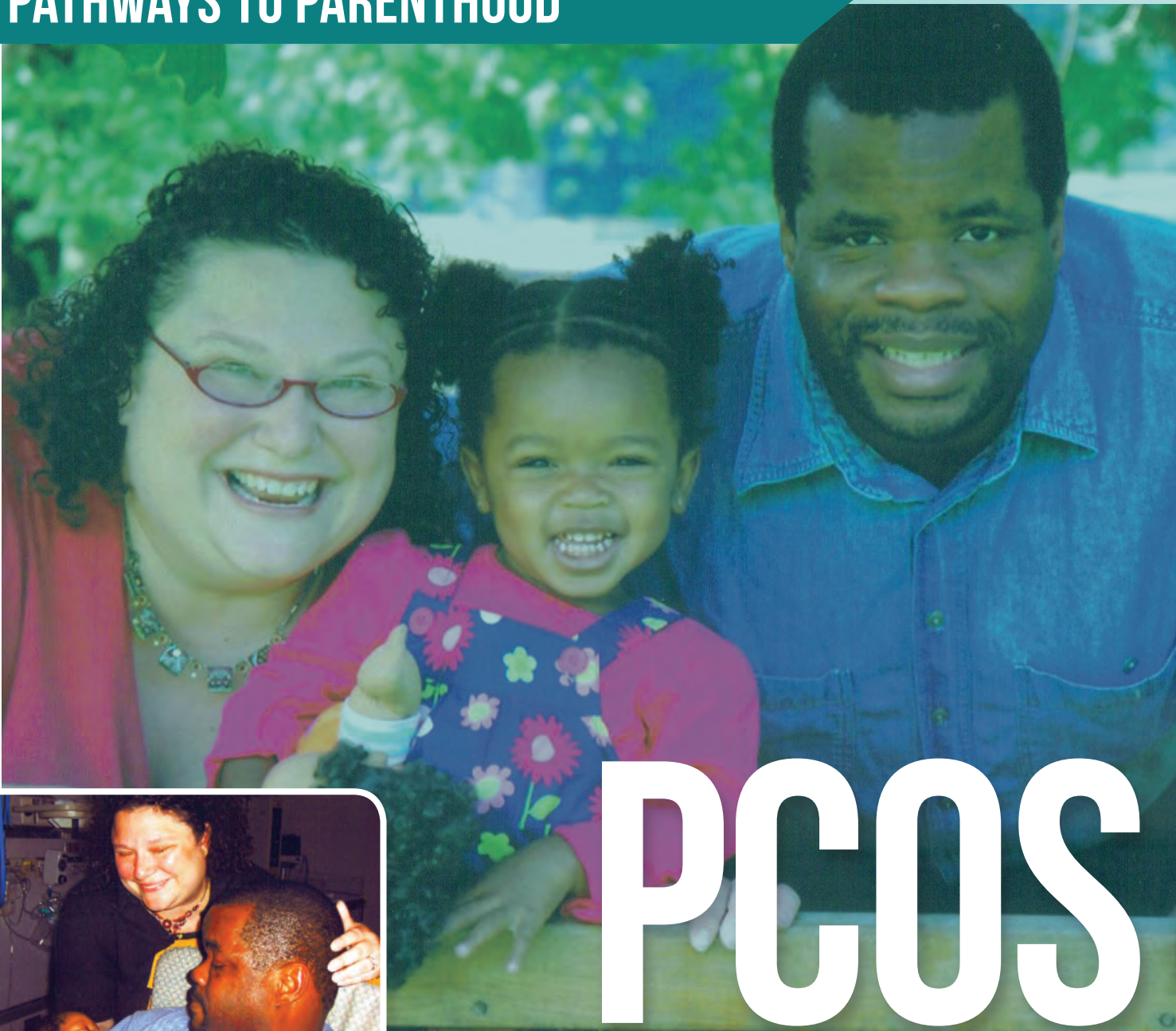
That may sound insane, but when we were first told about doing IVF, I felt like it was the end of the world and really, it’s not. I mean, it’s not as enjoyable as getting a massage or conceiving through sex (which is way more fun than IVF), but in the end, it’s good to know that the technology exists to help those who need it.



MORE ABOUT JAY PALUMBO

Jennifer “Jay” Palumbo is a freelance writer, public speaker, infertility/women’s rights advocate, former stand-up comic, author of the blog *The 2 Week Wait*, and proud IVF Mom. Jay was the recipient of the 2017 RESOLVE: The National Infertility Association Blog of Hope Award. You can follow her on Twitter at @jennpal(which is non-uterus related) or @the2weekwait (which features fertility-related fun).

the2weekwait.blogspot.com



PCOS AND ADOPTION

By Dina Stonberg

I never thought about my fertility until we could not conceive. We started fertility treatment with a specialist who was familiar with PCOS. I have never dreaded getting my period as much as I did those months we did Intrauterine Insemination (IUI). It was simply heartbreaking. Every month when I got my period I experienced

a disappointment like I had never felt. So many emotions but ultimately one step further from our ultimate goal of parenthood. I really wanted to be a mom and, when it came right down to it, having a biological connection was not very important to me. It was our fertility doctor who started the adoption discussion with me – around month eight after



our sixth unsuccessful IUI. I thought about it a bit and was sold on the idea. My husband was a different story. Though he was very supportive through the fertility treatment process, he really had the “fun” part. I was the one enduring all the painful procedures, taking all the meds, etc. After a couple of very intense talks, we decided together that we just really wanted to be parents regardless of the child’s biological connection to us. I am so grateful for such a strong, supportive partner.

After completing our home visit, it was time for the wait. We waited and waited and waited. We waited far less than many but far longer than we were expecting as the only interracial couple (black/white) in our cohort. We submitted our paperwork in the end of June and had three near misses (three situations where we were picked by birth parents who ultimately made other plans for their babies including parenting, familial adoption and foster care until they got their life together). These were heartbreaking experiences but our agency kept telling us that our baby had not been born yet. That is the most frustrating thing to hear, but now I get it.

On September 8th, I was at my desk at 9:00 AM on the day our social worker was going out on medical leave. Our social worker called and asked if I could get my husband on the phone in a conference call. Once we were all on the phone together she told us about a baby girl that was born. All of the consents had been signed (initial consents – final consents take six months in New Jersey) and could we get to the hospital to visit her around 4:00 PM. I think I said “yes,” but I do not remember. The whole thing was surreal. We met our baby girl that night. It was magical. You forget that she did not come out of your body. You forget everything. All you see is this beautiful baby.

Eight years later, we are raising a feisty, sassy, Jewish, African American girl whom everybody says looks exactly like my husband and talks just like me. It is a miracle. She is a miracle. Our miracle. I didn’t understand what the agency people meant, but now I know.



Want to chat more about PCOS and adoption?

Connect with me through
my website and we can talk further:
www.dinastoberg.com

There is so much uncertainty about fertility: Will it work? What will it do to my body? How will it affect my PCOS? Each month is a rollercoaster. Will I get my period? Won't I? Am I pregnant or is it regular PCOS?

What I can tell you about adoption is this: There is always a baby at the end. You will forget that you are not biologically related. They are no less your child than if he or she grew inside you. You will not love him or her any less than a biological child. There is a lot of misinformation out there about domestic adoption – please know there is a whole community of people out there for whom adoption is a dream come true.

VOLUNTEER



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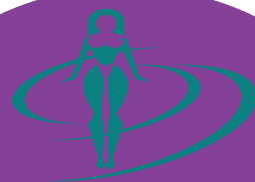
TOGETHER WE CAN CHANGE THE FUTURE FOR WOMEN WITH PCOS



PCOS Challenge needs your leadership, skills, talent and passion to continue our mission and advocate on behalf of women with PCOS.

We have both “virtual” volunteer opportunities and opportunities in the Atlanta metro area. Virtual positions are open to individuals nationally and can be done online, by phone or email. Some of

the areas where we need immediate volunteers include fundraising, graphic design, publicity, volunteer management, and event planning and management.



**VOLUNTEER WITH
PCOS CHALLENGE**

CLICK HERE

In Loving Memory of

*Ashley
Halverson Walker*



Ashley Halverson WALKER MEMORIAL

Karyn Halverson reached out to PCOS Challenge to share the news about Ashley Walker, her daughter who passed away on September 30, 2017. Ashley Coral Walker (Halverson) was 23 years old and died from complications of an unknown illness. Ashley fought so hard and was surrounded by love and her family at the time of her passing. At the time of her passing, Ashley and her husband Jonny had recently moved to Atlanta, Georgia to start their newest adventure together. Ashley's greatest joys were to be with her husband, her dog, her parents, her brother and sister, and Jonny's family. Ashley was never shy about telling those she loved that she "loved them so much". She never left any doubt about how she felt. Ashley's amazing sense of humor, beautiful voice, and kind heart will be missed by all who know and love her. Ashley is survived by her husband Jonathan Walker, Scott and Karyn Halverson her parents, Joshua Halverson (brother), Taylor Halverson (sister), Sheldon and Cindy Walker (mother and father-in-law) and brothers- and sisters-in-law, Bryce, Spencer, Jeremy, Joshua, Braden, Ashley and Emily Walker, and her dog Zero.

Ashley's family wanted to honor Ashley through charity work that was important to her and her family. They chose to set up a memorial fund through PCOS Challenge to support our work and mission to improve the lives of those affected by polycystic ovary syndrome.

PCOS Challenge honors Ashley Walker, a cyster who departed this earth much too soon. We will continue our mission with girls and women like Ashely in our hearts - those who know all too well the importance of making PCOS a public health priority.

Rest peacefully, Ashley

REMEMBERING A PIONEER PCOS DIETITIAN MONIKA WOOLSEY



By Gretchen Kubacky PsyD

Monika Woolsey, a pioneering PCOS advocate and dietitian, passed away unexpectedly on September 26, 2017 after a brief illness. Her contributions to the PCOS community are remarkable for the way in which they influenced the professional development of other PCOS healthcare professionals.

Monika was a friend, a colleague, and a mentor to me in the world of PCOS. I first met her nearly

a decade ago, when she gave a presentation entitled “PCOS: The Perfect Endocrine Storm” at St. John’s Hospital in Santa Monica, California. It was the most comprehensive, thoughtful, and hopeful perspective I had seen on PCOS to that point, and I found it highly inspirational.

Monika had a BS in Nutrition from Cornell University, and MS in Kinesiology from the University of Colorado Boulder. This educational background, combined with her experience working

in eating disorder treatment centers, led to the realization that PCOS was an overlooked and undertreated disorder. Monika strongly believed that women with PCOS could improve their health primarily through lifestyle modifications. She had the empowering belief that women with PCOS are “not broken, and do not need to be fixed.”

She founded the non-profit inCyst Institute for Hormone Health, and advocated fiercely for the care and needs of PCOS patients. For many years, she published a daily blog that featured nutrition, exercise and information about the latest PCOS research, medical treatments, supplementation and mental health information for women with PCOS. Monika's blogs were noted for their deep scientific research and support, and strong point of view. She believed that every good choice moves you forward, and in a 2011 Maxim Hygiene blog post, Monika noted that “Every woman with PCOS who makes even the smallest choice to do something positive for her own health each day is a fierce woman.”

Sasha Ottey, Executive Director of PCOS Challenge, said “She was well-respected in the PCOS community as one of the most dependable 'go to' experts in the space. PCOS Challenge is proud to have partnered with Monika on the creation of its first digital education series, which featured Monika discussing “Nutri-

tion Essentials for Polycystic Ovary Syndrome.” Monika was also a nutritional consultant for the *PCOS Challenge* television show.

Over the years, Monika had many projects and passions, always circling around healthy food, hunger relief, local produce, and community involvement. Monika was passionate about making vegetables a central part of one's diet. To that end, she founded Hip Veggies, a Phoenix based organization that promoted consumption of fresh, local, farmers' market produce through the production of colorful canvas shopping bags, development and dissemination of recipes, and special events.

Monika's long career in professional dietetics included stints at Remuda Ranch Center for Eating Disorders, developing an inpatient PCOS program at Green Mountain at Fox Run, and, most recently, serving as nutritional consultant for the Milwaukee Brewers baseball team at their Phoenix training facility. She was bilingual in English and Spanish, and prided herself on her depth of knowledge of various cultures and their food traditions.

Monika lived in Phoenix, Arizona, where she was a popular member of the community. She is survived by her parents, who are tending to her beloved “Kitty Girl.” A memorial service for friends and colleagues was held on Saturday, October 28, 2017.



MORE ABOUT GRETCHEN KUBACKY, PsyD

Dr. Gretchen Kubacki, “The PCOS Psychologist,” is a health psychologist in private practice in Los Angeles, California, an inCyst Certified PCOS Educator, and the founder of PCOS Wellness. Her goal is to dramatically improve the life and health of every PCOS patient. Dr. Gretchen offers insight, advice, education, and practical approaches on how to deal with the depression, mood swings, irritability, anxiety, sleep and eating issues, frustration, and lack of motivation that plague so many PCOS patients. She is also a member of the PCOS Challenge Health Advisory Board, and a frequent writer and speaker on PCOS and related topics.

PCOSWellness.com



AN INTEGRATIVE APPROACH TO WELLNESS AND FERTILITY IN WOMEN WITH PCOS

By Maureen Kelly, MD

PCOS is a whole body endocrine syndrome. The root causes of PCOS lie in hormonal interactions that occur in multiple places throughout the body. Conventional medical treatment, however, typically attempts to suppress symptoms rather than address the root causes of those symptoms. An integrative approach to whole body wellness is critical to breaking the cycle of complex interactions that cause the difficult symptoms of PCOS and reduces the risk of complications from PCOS such as diabetes and heart disease.

In recent years, it has become increasingly evident that an integrative approach to wellness and

fertility has brought astounding results for women with PCOS. Adding complementary therapies into the mix such as nutrition counseling, acupuncture, psychological counseling and stress-reducing activities like yoga and meditation has played a key role for many women in shifting the tide to hormonal balance and overall wellness.

First, let's take a look at nutrition. Diet is one of the primary lifestyle contributors that can either greatly limit or exacerbate PCOS. Why is this the case? Sugar and refined carbohydrates cause unhealthy spikes in insulin levels. This aggravates PCOS because insulin stimulates certain receptors in the ovaries, leading to symptoms such as acne,



irregular menstrual cycles, weight gain and excess hair growth. Moreover, insulin-lowering and hormone-blocking drugs don't always have long-term success when other underlying factors such as a person's daily food intake are not addressed.

Other adjustments in overall diet and nutrition, not just sugar and carbohydrate intake, help manage PCOS symptoms. Eating at certain time intervals throughout the day and making sure you have enough protein in your diet can stabilize insulin and testosterone levels. As these changes occur, symptoms such as acne, irregular menstrual cycles, weight gain and excess hair growth become less problematic or even disappear entirely. Making ongoing dietary changes such as these can be daunting. Seeking the advice of a dietitian or nutrition coach experienced in treating PCOS can be beneficial for many patients.

Another complementary therapy to conventional treatment is acupuncture. Those who have never experienced acupuncture may wonder how it works. In the case of a PCOS patient, small needles are placed along acupuncture meridians, or energy pathways, which are related to the reproductive system. These needles stimulate organs, lessen stress and anxiety, increase blood flow and balance



MORE ABOUT MAUREEN KELLY, MD

Maureen Kelly, MD is a leading Reproductive Endocrinologist and has been treating women with PCOS in the Philadelphia area for over 20 years. Dr. Kelly is a longtime advocate for a holistic approach to treating PCOS. She is Medical Director of Society Hill Reproductive Medicine, a medical practice she founded specializing in women's endocrine, fertility, and gynecologic health. She also founded The Wellnest, a wellness center which offers therapies such as nutrition counseling, therapy and acupuncture and which has unique expertise in supporting women with PCOS. Dr. Kelly is an attending physician and surgeon at Pennsylvania Hospital and Thomas Jefferson University. She has garnered numerous honors, including Vitals Patients' Choice Award and Most Compassionate Doctor Award.

TheWellne.st

hormone levels. As a result periods are regulated, fertility is increased and hormones are balanced.

Women with PCOS have a daily struggle. There is a link between androgen excess, insulin resistance and anxiety and depression. To make matters worse, symptoms such as weight gain and excess hair growth can lead to body image issues, further contributing to anxiety and depression. Anxiety leads to elevated cortisol, a stress hormone associated with spikes in insulin and other health issues as well. It can be a vicious cycle. A combination of private counseling, support groups, stress-reducing activities such as yoga and meditation, and nutritional support have lead many women to a dramatically improved state of health and wellbeing along with increased fertility. An integrative, whole body approach is a must when treating PCOS.

THIS YEAR, DONATE YOUR BIRTHDAY!

YOU CAN MAKE A BIG DIFFERENCE IN THE FIGHT AGAINST PCOS WITH A FACEBOOK FUNDRAISER

Raising awareness and funds for PCOS Challenge has never been **easier or more fun!**



GO TO YOUR FACEBOOK PAGE



CLICK ON FUNDRAISERS



CLICK ON RAISE MONEY



SEARCH FOR PCOS CHALLENGE



INVITE FAMILY & FRIENDS TO DONATE



Ask your family and friends to celebrate your birthday or another special event by making a **donation to PCOS Challenge** in your honor. Whether it's \$10 or \$100, their heartfelt gift will help provide a brighter future for women and girls by supporting critical PCOS programs.



MARK PERLOE, MD RECEIVES RICARDO AZZIZ/PCOS CHALLENGE ADVOCACY LEADERSHIP AWARD



Dr. Mark Perloe was honored with the 2017 Ricardo Azziz PCOS Challenge Advocacy Leadership Award at the fifth annual PCOS Awareness Symposium in Atlanta, Georgia. The award recognizes individuals who have demonstrated extraordinary dedication to awareness, advocacy and public policy efforts that expand access to resources and support for women and girls with polycystic ovary syndrome, one of the most neglected areas of health.

Sasha Ottey, Executive Director of PCOS Challenge: The National Polycystic Ovary Syndrome Association says, "Dr. Perloe is one of the country's leading physician-advocates for women and girls with PCOS and a shining example for other health-care providers. He has been our champion and a true supporter since PCOS Challenge expand-

ed to the Atlanta area. Dr. Perloe was instrumental in the advent of the PCOS Awareness Symposium and was our first partner and sponsor of the event. He is a genuine PCOS advocate with vast knowledge about the disorder and the complex challenges that women with PCOS face. He dedicates much of his time to increasing PCOS awareness. We are pleased to present Dr. Perloe with this award and are excited about his continued commitment to work with us on legislative and community advocacy efforts to improve the lives of those with PCOS."

Dr. Perloe remarks, "I've had the distinct privilege of working with women and girls with PCOS throughout my career, as well as many people and organizations who have worked equally hard or harder to raise awareness within the community. I am deeply honored to receive this recognition and share this award with all of the men and women who advocate on behalf of those with PCOS. I look forward to continuing our efforts on behalf of those affected by PCOS to help them achieve a better quality of life and, for many, to help them conceive."

ABOUT DR. MARK PERLOE

Dr. Perloe is a reproductive endocrinologist with over 30 years of experience performing in vitro fertilization (IVF) and treating conditions related to infertility including PCOS. He has served as principal investigator in numerous reproductive health research studies including innovative IVF treatments, ovulation induction, and PCOS. Dr. Perloe is the co-author of *Miracle Babies and Other Happy Endings for Couples with Fertility Problems*. Most recently, Georgia Reproductive Specialists (GRS), the practice which Dr. Perloe founded, joined forces with Shady Grove Fertility (SGF) to form Shady Grove Fertility Atlanta. To learn more about Dr. Perloe, visit IVF.com.

ABOUT THE AWARD

PCOS Challenge named the advocacy leadership award in honor of Dr. Ricardo Azziz, an international authority on polycystic ovary syndrome and one of the country's most impactful advocates for the PCOS patient community. For the past 25 years, Dr. Azziz has developed an internationally recognized research program which has been continuously funded by the National Institutes of Health, generated over 500 peer-reviewed articles, book chapters and reviews; over 300 abstracts and presentations at national meetings; and nine texts. Dr. Azziz has made major contributions to the field through his research and clinical work as well as his support and advocacy for PCOS patients. Dr. Azziz has been instrumental in enabling events like PCOS Challenge's Awareness Symposia to happen across the country. PCOS Challenge recognizes the significance of Dr. Azziz's contributions to the PCOS movement with this award. Learn more about Dr. Azziz at RicardoAzziz.com.

THE 3 WORST DIETS FOR PCOS

Featuring
Julie Duffy Dillon
MS, RD, NCC, LDN, CEDRD

Julie Duffy Dillon is a registered dietitian trained in mental health counseling. She helps women with PCOS and eating disorders work toward Food Peace and feel more at home in the skin they are in. Julie produces and hosts the popular weekly podcast, Love Food which helps women with a complicated relationship with food rewrite their fate. Learn more at PCOSandFoodPeace.com.



Julie Dillon believes diet culture is bad for PCOS and eating disorders.

VIEW VIDEO

Try the NEDA Eating Disorders Screening Tool



National Eating Disorders Association

Research has found an increased prevalence of eating disorders in women with PCOS.¹

Get Started

¹ Curr Pharm Des. 2017 Dec 4. doi: 10.2174/1381612824666171204151209

nationaleatingdisorders.org/screening-tool



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