PCOS Challenge
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Are doctors missing the PCOS diagnosis in lean women?

Preventing diabetes in women with PCOS

Tips for a healthy waistline with PCOS

Infertility awareness

Surviving multiple miscarriages

PCOS and eating disorders

National sleep awareness month
Contents

3 Letter from the Executive Director

4 Infertility Awareness: Surviving Multiple Miscarriages
By Christina Ohler

6 Polycystic Ovary Syndrome: An Overview
By Desireé McCarthy Keith, MD, MPH, FACOG

8 Dieting + PCOS = Eating Disorders for Many
By Julie Duffy Dillon, MS, RD, NCC, LDN, CEDRD

10 Electrolysis: How it Helps Hirsute Women with PCOS
By Mary Spivey-Just, CPE

12 PCOS Diva/PCOS Challenge Confidence Grant

13 Advocacy Day at the Georgia State Capitol

14 PCOS and the Battle of the Bulge: Tips for a Healthy Waistline
By Maria Horstmann, MBA, CPT, PNL1, IRC

18 Ask the PCOS Expert (Q&A) - PCOS and Sleep Disorders
Featuring David Ehrmann, MD

24 Opinion Editorial: Are We Missing the PCOS Diagnosis in Lean Women?
By Ricardo Azziz, MD, MBA, MPH

26 I Have PCOS and Prediabetes, Now What?
By Hillary Wright, MEd, RD, LDN

28 2017 PCOS Challenge Events

30 Cyster Corner: How to Keep Your Happiness
Featuring Keshena Patterson

32 PCOS Challenge Mobile App Powered by Medisafe

34 Featured PCOS Challenge Radio Shows

35 PCOS Friendly Recipe of the Month
Welcome to the second issue of the new PCOS Challenge magazine. In the following pages, we celebrate the strength and diversity of women and girls with polycystic ovary syndrome. You will read interesting perspectives from both prominent PCOS experts and women with PCOS.

In this issue, we recognize some of the national health observances and awareness initiatives for March and April which are relevant to those of us living with PCOS. Some of these observances include Electrolysis Awareness; Infertility Awareness; Sleep Awareness; Endometriosis Awareness and National Nutrition Month.

Join Us as an Advocate for PCOS Awareness and Change
This year, PCOS Challenge will be expanding its legislative advocacy efforts as part of our mission to help raise awareness and increase public support for those living with polycystic ovary syndrome. On March 20th, we will join The White Dress Project at the Georgia State Capitol to “make a case for uterine health.” If you are in Atlanta, please join us!

For PCOS Awareness month in September, PCOS Challenge will bring together hundreds of women from all over the United States and throughout the world for the PCOS Awareness Weekend. This weekend is where we will all come together in unison to spread awareness about polycystic ovary syndrome, walk or run the Bolt for PCOS 5K, attend the PCOS Awareness Symposium and join initiatives to promote PCOS research and healthcare. We encourage you to sign up as a volunteer or team leader.

Thank you for supporting PCOS Challenge and our vision to make PCOS a public health priority!

In good health,

Sasha Ottey
Executive Director
PCOS Challenge, Inc.
After years of living on hope and leaving it in God’s hands, my husband and I found out we were having a baby. We never believed it would be our reality because doctors told us I was unable to get pregnant. But we soon realized that not even PCOS exempts you from getting pregnant. It was a surreal moment.

We’ve always seen ourselves as a strong couple whose faith is the heart of our foundation. In spite of this, nothing prepared us for the journey through PCOS, infertility and multiple losses. But we developed the strength and endurance necessary; and are better because of it. Of course, we’re not without scars. We are blemished and fractured, but stronger because of it all.

Like most couples, we discussed having children. Originally, we planned to wait but quickly changed our minds. Thus we began the journey of growing our family of two to three. A year later, our dreams were shattered. I was diagnosed with PCOS, four letters that completely and irrevocably altered our lives. Yes, our lives. Many people forget PCOS alters their spouses’ lives too.

My husband and I have gone through a lot during our 15-year marriage: being told that PCOS meant I had cancer, to learning that the doctor misinformed us, to being told I could never conceive. I was prescribed various drugs due to PCOS. I felt like a lab rat, having tests done weekly. Eventually, a doctor said new studies show PCOS didn’t necessarily mean you couldn’t have children, so we tried Clomid for a year with no success. We spoke to five fertility doctors who only offered IVF as an option. My PCOS spun out of control, so I fought back by joining a gym and placing second in a weight-loss challenge.

My husband came home mid tour from military service and I became pregnant. He left to finish his tour and a few weeks later, we lost our baby. Grieving was especially difficult because we were separated...
from one another. And because we grieve differently, we had to figure out how to do so as a couple and as individuals. Later that year, we lost our second child. I became depressed, and my PCOS worsened. Eventually, I focused on my health and got pregnant again. Unfortunately, I miscarried a third time. I was confused and tired of feeling like a lab rat.

After some time, we discovered a fertility clinic which offered less invasive fertility treatments. Surprisingly, on our first visit, we found out I had ovulated. We hoped this meant I didn’t need to pursue treatments, but alas we lost our fourth child. I continued treatments of pills, injections and trigger shots; then realized my body couldn’t tolerate injections as the dosage increased. My trigger shot was canceled, so my husband and I had to accept that IVF or further treatment weren’t an option. We found out later, I was pregnant again even without the trigger shot, but alas we lost our fifth child.

We’ve grappled with impatience, resentment, jealousy, confusion and depression. We’ve thought, why us? Was this a punishment? We asked questions we knew would never be answered. Eventually we asked, why not us?

Ultimately, we found the silver linings to PCOS: (1) discovering who I am today, (2) developing connections with so many beautiful souls and (3) starting my company Soul Cyster Creations, which has been a core part of navigating through this journey. Soul Cyster Creations has allowed me to find my niche in the world of creating meaningful jewelry pieces and has allowed me to give back to others struggling with PCOS, infertility, losses and military life. Concentrating on the positives has helped us face our losses, infertility and everyday life in general. This new way of thinking has become automatic. The past couple of years, my husband and I have discovered a beauty and happiness we never imagined. Becoming parents was rewarding. We claim our rights as parents to our five children. We know that parenthood is not defined by the number of children you’re able to raise. We honor their memory and no longer see them as losses.

My husband and I have come to realize that without suffering our losses, we wouldn’t be the couple we are today. At first, the losses were a burden on our relationship. But soon, we discovered a strength and love for one another we could never have fathomed had this not been our journey. We’ve helped and comforted many through PCOS and loss by sharing our story.

MORE ABOUT THE OHLERS

Matthew and Christina met at a job orientation and soon became high school sweethearts. Their first official date was prom. For Matthew it was love at first sight; he knew he would marry her. Christina was smitten the moment Matthew helped his mom put on her coat. Soon after they went on their first date: prom. A few years later, Matthew proposed to Christina at their church. They were married there in 2002. Christina is owner of Soul Cyster Creations where she uses her creativity to give back to causes near and dear to their hearts.

SoulCysterCreations.com
Polycystic ovary syndrome (PCOS) is a hormone disorder that affects six to 12 percent of women of all ethnicities. It is very likely that you or someone you know have been affected by PCOS. Typical features of PCOS include 1) high testosterone levels or male hormone effects 2) irregular or absent menstrual cycles and 3) ovaries that contain multiple small cysts. A woman is considered to have PCOS if she has two out of these three features. PCOS can cause diabetes, infertility and unpleasant skin changes like acne and facial hair growth.

With PCOS, a woman’s ovaries are filled with tiny egg-containing cysts called follicles. Normally, one follicle fully develops each month, and ovulation is the release of an egg from the follicle. For women with PCOS, even though there are many follicles in the ovary, ovulations do not occur regularly. When ovulations don’t occur, then menstrual
cycles will be irregular or not come at all. Skipped or unpredictable menstrual cycles is the most common symptom of PCOS, and is also a common cause of infertility. Fertility medicines like Clomid or Letrozole can help women with PCOS ovulate and have a better chance of getting pregnant. In vitro fertilization (IVF) is also an effective fertility treatment for women with PCOS.

Whether a woman with PCOS is trying to get pregnant or not, she should have a menstrual cycle at least every two to three months. Every month, the lining of the uterus thickens in preparation for pregnancy. A menstrual cycle is the shedding of this lining. If a woman does not have a menstrual cycle every month, the uterine lining continues to build up and can become very thick. For some women, this thickened lining can develop into pre-cancer of the uterus. To prevent the development of pre-cancer of the uterus, women with PCOS should take birth control pills or progesterone hormones to bring on a period. If a woman has gone for many months without a menstrual cycle, she may be advised to have a biopsy of her uterine lining to check for precancerous cells.

PCOS has major metabolic implications for a woman’s health as well. Many women with PCOS are overweight or obese and having PCOS increases a woman’s chance of developing pre-diabetes or insulin resistance. We always recommend weight loss for overweight women with PCOS and all women with PCOS should focus on maintaining a healthy weight. Regardless of weight, women with PCOS should be tested for diabetes and started on insulin-lowering medications if they are at risk.

PCOS is a common cause of infertility that affects women of all ethnicities. It may increase a woman’s risk of developing diabetes or even cancer of the uterus. The condition is easy to diagnose with simple blood tests, an ultrasound and a physical exam. If a woman has any of the typical PCOS symptoms (acne, facial hair, weight gain or irregular periods), she should see a specialist for testing and treatment of any related conditions.

MORE ABOUT DR. DESIREÉ MCCARTHY-KEITH

Dr. McCarthy-Keith is board certified in both obstetrics and gynecology and reproductive endocrinology and infertility. She is a fellow of the American Congress of Obstetrics and Gynecology, a member of the American Society for Reproductive Medicine and was honored by Black Health Magazine as one of Atlanta’s most influential African American doctors. She is honored to serve as Adjunct Clinical Assistant Professor of obstetrics and gynecology at Morehouse School of Medicine and was recognized by Who’s Who in Black Atlanta in 2011, 2012, 2014, 2015 and 2016.

Dr. McCarthy-Keith earned her medical degree from the University of North Carolina at Chapel Hill and also a Master of Public Health in maternal and child health from the University of North Carolina. She completed her obstetrics and gynecology residency training at Duke University Medical Center and a fellowship in Reproductive Endocrinology and Infertility at the National Institutes of Health in Bethesda, Maryland. During her fellowship, Dr. McCarthy-Keith’s research focused on the molecular mechanisms of uterine fibroid regulation and reproductive health disparities. She has special interests in male and female infertility, polycystic ovary syndrome, uterine fibroids and in vitro fertilization.
Women with PCOS are at very high risk for developing an eating disorder. One of the main reasons comes from the frequent recommendation to focus primarily on weight loss to treat the condition. Not only do diets not work, they are the greatest predictor for weight gain and eating disorders. Instead, I encourage women with PCOS to focus on respecting their bodies without pursuing weight loss. This focus prevents eating disorders and promotes long-term health.

It can be tough to respect a body that feels abnormal due to symptoms such as facial hair, abnormal periods, male pattern baldness or rapid weight gain. High insulin levels will make it darn near impossible to walk past a plate of brownies without eating them all. Having PCOS also often includes more depression and anxiety.

But fighting your body will not make it healthier. Punishing your body with painful diet fixes will only make you feel worse emotionally and physically in the long run.

Often times women with PCOS have to torture their bodies with diets and over exercise just to see a scale budge. This is not ok. We are giving that hunk of metal too much power! Why must someone in a bigger body do the same things we refer to as an eating disorder in a smaller person? Why must one torture herself in the name of health? You shouldn’t. Over-exercising or under-eating are still eating disorder behaviors even if you live in a fat body. They are not healthy or justifiable. They can still be deadly.

So how does one with PCOS experience good health and respect her body?

She responds compassionately to what her body is saying.

When your cravings feel out of control or you feel fatigued to the core, use this as a message that your body needs you to change course. This may mean eating breakfast, getting more sleep or changing medication. It also may mean that focusing on that scale isn’t helping things. Instead, focus on healthy behaviors. Starting with healthy sleeping and eating habits can increase your energy and give you a boost to become more physically active. Another good place to start is getting into a routine consistently taking medication and supplements as directed by your doctor and dietitian. Doing all of these will help you work with your body to feel more energized, empowered and at home in your own skin.
Your body may not be the one you wish you had yet it holds your soul. It deserves your respect as you walk this earth. Coming together and not fighting will help you dance together toward health and happiness.

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.

JulieDillonRD.com

PCOS CHALLENGE RECOGNIZES

March
National Endometriosis Awareness Month
National Kidney Month
National Nutrition Month
Sleep Awareness Month
Women’s History Month

April
Electrolysis Awareness Month
National Minority Health Month
National Public Health Week (April 3-9)
Week of National Infertility Awareness (April 23-29)
World Health Day (April 7)
Electrolysis was discovered by Dr. Charles E. Michel, an ophthalmologist, more than 130 years ago; and in the 21st century it remains the only proven method of permanent hair removal approved by the FDA. In today’s industry, with the use of innovative technology and state of the art equipment, the process and treatment has tremendously improved to better serve in eradicating unwanted hair.

The original modalities used in electrolysis treatments have evolved over the years. The galvanic (true electrolysis) modality causes a chemical decomposition of the hair follicle cells; the thermolysis (high frequency, shortwave) modality destroys the hair growing cells with heat; and the blend modality combines galvanic and high frequency to disable and destroy regenerative growth in the hair follicle. The blend method is said to be more effective and the regrowth rate is lower.

When seeking treatment, prospective clients are given detailed counsel during their initial visit with an electrologist. A modality is chosen based on a thorough consultation and a discussion of treatment to ensure every hair growth cycle is captured and all the hairs in that cycle are destroyed as quickly as possible. A series of treatments are needed to see effectiveness and good results.

Electrolysis is a very personable service; and the confidentiality of each client is highly respected. It is a trust that is dear to the heart of electrologists.

We now know that excessive hair growth, known as hirsutism, can range from fine vellus hair, to dark coarse hair on the face and body. Deep, coarse hairs cannot always be eliminated with one
treatment; thus breaking down the hair growth cell may require additional treatments. This may be true because hairs are cyclical and have different cycles of growth. Many of which are not visible on the surface of the skin at the same time. The follicle produces the hair from the blood supply, and discards it eventually through shedding. The process of growth, rest and replacement are known as the hair growth cycle. The growth cycle is repeated until the hair ceases to be formed or is permanently removed.

Curly hair is more prone to become ingrown and may cause raised bumps on the skin. Coarse hair may become stuck under the skin. Attempting to manage these problems with temporary methods may cause scarring and skin discoloration. An electrologist can assist in alleviating these problems.

It is important to remember that excessive hair growth took, in most cases, many years to develop. Likewise, one should not expect to see immediate results in their hair reduction rate.

ELECTROLYSIS IS HELPFUL FOR HIRSUTE WOMEN WITH PCOS FOR THE FOLLOWING REASONS:

- Removes hair safely and permanently
- Works on all skin tones and types of hair
- Increases self-esteem
- Offers treatments that are individualized, comfortable and effective
- Transforms lives by eliminating the need to use temporary hair removal methods
- Ensures the best care from a well-trained, hair removal professional

No matter what the specific problem area, age, hair or skin tone, the solution is electrolysis. It is not an overnight process, but a permanent one. Electrolysis is the gold standard for permanent hair removal and patience is of utmost importance in the treatment of hirsutism.

Mary Spivey-Just is an electrologist in Charleston, South Carolina and delegate for the American Electrology Association (AEA), the largest international professional membership organization for practitioners of electrolysis (permanent hair removal). She is a member of the AEA Advertising and Publications Committee. Mary is a 2015 AEA Gold Probe Recipient. Mary graduated from the Electrology Institute of New England in Tewksbury, Massachusetts and holds a Bachelors of Science degree in Accounting from the University of South Carolina. Mary has transitioned from corporate accounting to become a proud and productive electrologist. Working with PCOS clients on a regular basis has allowed her to hear their stories, discuss their desires and perform treatments to assist them in eradicating unwanted hair. She endeavors to empower clients with information to make informed decisions. Mary’s motto is Educate, Educate and Educate.
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 of up to $500 per individual to assist with the costs of treatments and options for addressing hair and skin issues related to PCOS, including dermatology treatments, laser hair removal, electrolysis, androgenetic alopecia solutions and others.

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.

SPRING GRANT DEADLINE
MAY 1, 2017
APPLY NOW
PCOS Challenge Joins The White Dress Project For a Day of Advocacy, Education and Legislation at The Georgia State Capitol

NOW IS THE TIME TO LEARN. DISCUSS. GALVANIZE.

We need your voice to make a case for uterine health.

YOUR VOICE, YOUR STORY, YOUR HEALTH!

Join Us
Monday
March 20, 2017
2:00-4:00 PM
Georgia State Capitol South Wing
206 Washington St SW
Atlanta, GA 30334

Join the social media conversation
@pcoschallenge
#happyperiod
#womenshealth #fibroids #pcos #pcosadvocacy

Space is Limited - RSVP at PCOSChallenge.org/advocacy
PCOS AND THE BATTLE OF THE BULGE

TIPS FOR A HEALTHY WAISTLINE

By Maria Horstmann, MBA, CPT, PNL1, IRC
It’s you against you! You are tired of being tired and fighting the battle of the bulge. Abdominal adiposity, or “belly fat,” is an issue for many women with polycystic ovary syndrome regardless of body type. Scientific studies suggest that abdominal adiposity and resulting insulin resistance, both components of metabolic syndrome, contribute to ovarian dysfunction and hormone irregularities.

If you’ve been discouraged, let’s change that feeling! 
**CHOOSE to shift your MINDSET:**
1. Take deep breaths
2. Open your heart to knowledge
3. Apply new strategies
4. Implement changes
5. Get support

Sedentarism wins no battle! Along with adequate nutrition, supplementation, sleep and stress management, exercise must be at the forefront of the battle.

**GLUCOSE, INSULIN, FAT AND ENERGY**

Insulin is a fat storage hormone and essential to survival. It brings glucose from bloodstream into cells for energy production. Energy you need for:
- Gland and organ function
- Mental clarity and focus
- Cellular growth and repair
- Success and fun

Insulin resistance (IR) in PCOS is believed to be developed through two mechanisms: increased insulin production and insulin binding defects in peripheral insulin receptors. When receptors on the cell surface are not binding to insulin effectively, chaos is happening.

IR is also associated with adiponectin, a hormone that regulates lipid and glucose levels. Women with PCOS are found to have lower adiponectin levels than women without PCOS, which puts them at high risk for elevated cholesterol levels, obesity and cardiovascular diseases. As the insulin level increases, the internal inflammation also increases. This causes changes in fat deposits where fat is stored by the body instead of being burned.

Maria Horstmann is a Health and Insulin Resistance Coach, a Personal Trainer, and a Corporate Wellness Consultant. She left the corporate world to start Be Fab – Be You LLC to follow her passion to empower others to get their lives back by identifying what is on their way while taking sustainable and holistic health steps.

Maria spent most of her life compromising her health until she realized her ticket to reaching full potential in life was a “healthy lifestyle.” She turned her lifestyle 180°; overcame pre-diabetes and chronic digestive and gastrointestinal.

Maria creates personalized experiences and programs for single clients, families, groups, and organizations. Her custom programs, including a Insulin Resistance and Blood Sugar Program, help people struggling with PCOS, weight, fatigue, brain fog, blood sugar and hormonal imbalances, digestion, depression, and more.

Visit BeFabBeYou.com to learn more about Maria’s journey, services and credentials.

Continued on page 16...
When you MOVE YOUR BODY consistently, you can improve symptoms of PCOS, insulin sensitivity and your waistline. You can also balance hormones and lower risk of metabolic and chronic diseases.

Exercise: The Best Free Prescription Yet!

Meet GLUT4 — a glucose transporter that regulates muscle glucose uptake, improves insulin action and glucose disposal, and enhances glycogen storage. What is fantastic is that exercise is the most potent stimulus to increase the expression of GLUT4.

While embracing daily activity is indispensable, you benefit the most when you engage in anaerobic exercise such as weightlifting, bursts and tabatas. These activities burn the energy in the form of glucose in your blood and thereby inhibit insulin production. You build lean muscles accelerating fat burning — the body burns fat from fat deposits to supply the lacking energy. Pretty sweet!

Whether you are just beginning or kicking it up a notch, try these simple and effective fat burners and energy boosters:

**BURST EXERCISES**
- Go all-out for 30-60 seconds. Rest equally. Repeat 1-2 more times.
- Try ball squat toss, high knees, sprinting, jumping rope, running in place, jumping jacks and squats.

**THE TABATA METHOD**
- Do a 4-minute workout: 8 rounds of 20 seconds at maximum effort with 10 seconds rest.
- Also try lunges, push-ups, pull-ups, planks, crunches, dumbbell presses, rows, flies and squats.

**BEGINNER LEVEL**
- Do 3 bursts daily: waking, afternoon, 1-hour before bed.
- Tabata 1 x per week.
- Walk/jog daily: 3 x 10 minutes.

**INTERMEDIATE/ADVANCED LEVELS**
- Increase intensity by adjusting length, frequency, speed and weight.
- Do 30 minutes of strength training 3 x per week:
  - Take breaks of less than 30 seconds.
  - Fatigue the muscles.
- Add bursts to any routine.

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**MOVE YOUR BODY AND HAVE FUN!**

- Think long-term. Stay positive.
- Be patient and kind to yourself.
- Get accountability. Be consistent.
- You got this. You deserve it!
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.
SLEEP

How do you know if you are not sleeping properly?

Patients often don't know. Some of the signs would be daytime somnolence or fatigue during the day-time that's disproportionate to their activity level. Waking up in the morning with headaches, is another sign of disruptive sleep.

How essential is getting a good night's rest in terms of avoiding a sleep disorder, and is there a specific number of hours that a person should sleep?

There isn't really a one-size-fits-all recommendation, but generally individuals should try to get six to eight hours of sleep per night, the minimum would be six. It's not only the duration of sleep, but it's the quality of that sleep that impacts the effects of normal sleep and the repercussions of abnormal sleep.

What do you mean by quality of sleep?

I'm referring to the medical quality of sleep. Sleep disruption, sleep disordered breathing, restless leg syndrome and obstructive sleep apnea. All of these things can have a major impact on the quality of sleep. Also, there are people who do shift work. They should be aware that shift work can have an impact on the quality of their sleep. People who are sleep deprived for whatever reason tend to have increased levels of hunger and appetite and they tend to gravitate toward less healthy food choices. Sleep disruption or sleep shortening can have an impact on health as well.

SLEEP DISORDERS

What is a sleep disorder?

There are many different types of sleep disorders. The one that is pertinent to PCOS is obstructive sleep apnea. Overweight and obese individuals are more likely to have this disorder. With obstructive sleep apnea, during sleep there are episodic periods where breathing ceases for a short interval of time. The oxygen level in the blood drifts down and that sends a signal to the brain to take in a breath. It usually lasts several seconds, and it's not unusual to have about three to four of those types of events per hour of sleep. But, with obstructive sleep apnea what typically happens is that the airway closes and it's usually for a longer period of time with a more profound decrease in oxygen level in the blood. The individual takes in a deep breath and that's what the snoring actually is. What happens when this gets repeated throughout the night is that sleep is decreased, not in a conscious awakening way but through what we
call micro arousals as measured in a sleep study. Micro arousals occur when an individual is sort of awake on electroencephalogram (EEG), but not consciously awake. Instead of getting the restorative type of sleep, they get sleep disruption and that causes all of the issues that I mentioned earlier, among them being morning headaches, daytime somnolence, and what’s even more important is that it’s now known to be associated with an increased risk for diabetes and obesity. Even though obesity can make this worse, the syndrome of sleep apnea can also make obesity worse.

**SLEEP DISORDERS AND PCOS**

What PCOS-related symptoms have you identified that can lead to a sleep disorder?

It turns out that there is an astounding number of women with PCOS who have sleep apnea. At least half of women with PCOS seem to have the disorder. Just by virtue of having PCOS there is a higher risk. Women who are overweight or obese are at even greater risk. There are questionnaires that can be used to assess the risk, but simple questions like the ones I have mentioned relating to daytime somnolence, morning headaches and snoring can suggest that the disorder is present. The definitive test for sleep apnea is a polysomnogram, which is a sleep study that’s done overnight during sleep.

How does insulin resistance play a role in sleep disorders with women with PCOS?

A lot of women with PCOS also have insulin resistance. The direction of causality is more in the direction of the sleep disorder exacerbating the insulin resistance. If you take an individual with no sleep disorder who doesn’t have PCOS, who is lean and otherwise healthy, do an intervention that recapitulates what is seen in any form of sleep apnea over an interval of time, their insulin resistance gets worse. There are many reasons thought to underlie that phenomenon. A lot of them relate to other hormones that get secreted because of the disruption in sleep, but it’s really that sleep apnea exacerbates or induces insulin resistance rather than the other way around.

If a woman gets her PCOS under control, will it help her sleep disorder?

The treatment of PCOS really varies depending on the stage of life of the individual. Let’s say, for instance, we have a 28-year-old woman who is diagnosed with PCOS and starts an oral contraceptive as a form of treatment. That in general will not affect or improve sleep apnea, if it’s present. There are some reasons to think that it could, and there may be a very modest effect of hormonal treatment of estrogen and progesterone on sleep

Continued on page 20...
quality. However, the main factor in PCOS that is modifiable and that would improve sleep apnea would be a reduction in body weight, which is also the most difficult thing to achieve in PCOS or probably in any population.

Talk about the significance of sleep apnea for women with PCOS.

Sleep apnea is one of the key factors in women with PCOS that has an impact on their sense of well-being and their cardio-metabolic health. Sleep apnea has implications for both cardiac function, risk of sudden death and risk of heart disease, as well as metabolic abnormalities, primarily insulin resistance and increased risk for diabetes. Because about half of women with PCOS have sleep apnea, it’s recommended that when there is any suspicion of the presence of sleep apnea in women with PCOS that they should be tested by having a sleep study and then treated appropriately if they do have sleep apnea. It’s far more common than people realize.

FOOD AND EXERCISE

Do foods and exercise impact sleep quality?

Exercise and nutrition in general do have an effect on sleep. Obvious things like caffeinated beverages should be avoided. Some people recommend not working out close to the time of sleep because it may make sleep more difficult. However, that’s not true for all individuals. Some individuals actually get better sleep when they exercise in the evening. Lifestyle changes can have an impact as well.

SLEEP AND HORMONES

What is the relationship between hormone interference and poor sleep hygiene?

Most people thought going into this area of research that the excess testosterone that women with PCOS have was going to be the culprit hormone causing sleep apnea. Testosterone for many reasons would seem the logical hormone on which to focus. Men have higher risk of sleep apnea than do women and one of the major hormonal differences between men and women is the testosterone level, which is higher in men. Women with PCOS have testosterone levels that are higher than women without PCOS, but certainly not as high as men. However, testosterone does not appear to be the culprit hormone. In all of the studies that we’ve done, and others have done, testosterone levels do not seem to have a major impact or really any impact on the risk of sleep apnea or the severity of sleep apnea. There may be a role for progesterone. Women with PCOS tend to be progesterone deficient because they don’t ovulate regularly, if at all. When they don’t ovulate, their progesterone levels are low and progesterone is something that does have an impact on sleep more central than mechanical. It doesn’t
affect airway dynamics as much as it does central perception of sleep.

**RISKS**

Does obstructive sleep apnea present any risks that are dangerous to women with PCOS?

Sleep apnea is potentially risky because of the low oxygen levels and there is a risk of heart disease and even sudden cardiac death. I don’t want to overplay that in young women with PCOS, but there are definitely medical sequelae of the components of obstructive sleep apnea that have major implications for overall health in people who have the disorder.

**RESULTS**

Can sleep apnea be reversed?

There are things that can treat sleep apnea. I don’t know that I would say reverse it. The mainstay of treatment is continuous positive airway pressure or CPAP. Therapy is applied using a mask-like device that delivers positive pressure so that the airway doesn’t collapse during sleep. It’s very effective if it’s worn properly and if it’s worn for a sufficient number of hours during sleep. One issue with this treatment is that it is sometimes very uncomfortable for patients, and some people just don’t tolerate it very well. The next issue is body weight reduction. It is a major way to reduce either the severity or presence of sleep apnea. Now, there are some oral appliances that are being used to help protect closure of the airway during sleep so that the apnea events are less likely to occur. There is no sort of magic bullet for the treatment of sleep apnea. However, weight reduction is the one that is probably the best but also sometimes the most difficult for patients to achieve.

Is there one particular treatment or preventative method you do stress among your patients for preventing sleep apnea?

The safest and the best thing for health would be to reduce body weight. That’s really where our patients’ lifestyle can make a great impact on the presence and severity of sleep apnea. Now, the women who have it and are just modestly overweight or who are not overweight are less likely to have sleep apnea, but if they do, they can reduce it by weight loss.

Are there any other common types of sleep disorders other than obstructive sleep apnea that are associated with PCOS?

Over 90 percent of sleep disorders in PCOS are related to sleep apnea. The rest are relatively uncommon and probably not frequent enough to comment upon. There are rare cases of other things that are not seemingly directly related to sleep apnea.
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Use your spare change and the new Coin Up app to help fund PCOS research, health screenings, grants, education and support programs.

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3. Round up the change from your transactions to support PCOS Challenge and help end PCOS.

Challenge.org/coinup
Today we know that PCOS is the single most common endocrine, metabolic and reproductive disorder of the human female, affecting anywhere between 1 in 12 to 1 in 7 women worldwide, depending on definition. But it was not always so. In fact, even Dr. Irving F. Stein, he of the famed Stein-Leventhal Syndrome, felt it was a rare disorder going so far as to state in his 1958 review that the syndrome “... plays but a small part in the overall picture of female sterility ...” In fact, less than 20 years ago we simply did not know how common PCOS was. When our team decided in 1994 to assess for the first time the prevalence of PCOS in a medically unbiased population, we were not expecting to find the high percentage that we eventually found. We were certainly not expecting our estimates to be confirmed so fast in similar studies conducted around the world.

Three of Stein and Leventhal’s seven patients in their original 1935 report were obese (43 percent if you are keeping count). Subsequent observations suggested that many, even the majority of women with PCOS, were overweight or obese. This is unfortunate because it’s not true.

How can this be the case? Let’s look at the evidence. Firstly, we know from quality of life studies that women with PCOS tend to go see physicians or seek care primarily for complaints of excess male-like hair growth (called hirsutism), male-like balding (i.e., androgenic alopecia) and obesity. So to try and understand the true appearance of
PCOS, our team compared the presentation (the phenotype) of women with PCOS seen in doctor’s offices (the clinical setting) with those detected in our medically unbiased populational studies (the unselected setting). We found that patients with PCOS in the clinical setting were more hirsute, more androgenic and more obese than PCOS women observed in unselected settings. In fact, PCOS women detected in the general population (the unselected setting) have similar or only slightly more obesity than women without PCOS. Overall, in our studies in the United States, approximately 45 percent of women with PCOS detected in the unselected setting are of normal or low weight. The proportion of women with PCOS who are normal weight is even higher in countries with lower obesity rates than the United States (which is almost all of them). In fact, the proportion of women with PCOS who are obese has been increasing steadily as the rate of obesity in our country has also increased. This indicates that women with PCOS are not immune to the ravages of our obesity prone lifestyle.

So what does this mean for you? All women with PCOS should adopt a healthy lifestyle. If you have PCOS and are overweight or obese, then the first level of treatment should be to embrace an effective diet, low in starches and simple sugars, and a rigorous exercise program, preferably under professional guidance. This lifestyle program should be accompanied by the necessary hormonal treatment to ensure suppression of your excess hair growth and protection of your uterine lining (i.e., endometrium) as needed.

If you are not obese or overweight, it does not mean you do not have PCOS. If you think you have PCOS, for example because your cycles are irregular and/or you have excess male-like hair growth, then you should see a knowledgeable physician.

Finally, just because you are obese does not mean you have PCOS. PCOS itself is not a strong cause of obesity. So if you are obese, please see a physician to be evaluated and then start a rigorous lifestyle modification program. It can save your life.

Ricardo Azziz is an internationally recognized physician, scientist and executive who currently serves as Chief Officer of Academic Health and Hospital Affairs at the State University of New York (SUNY), the largest university system in the nation. Dr. Azziz's biomedical research focuses on the study of reproductive endocrinology and androgen excess disorders. He has published over 500 original peer-reviewed articles, book chapters, and reviews, and is consistently ranked one of America’s Top Doctors. He has received, among other recognitions, the 2000 President's Achievement Award of the Society for Gynecologic Investigation, and was an elected member of the Association of American Physicians. He previously served as Deputy Director of the Clinical & Translational Sciences Institute and Assistant Dean for Clinical and Translational Sciences at UCLA; and Director of the Center for Androgen-Related Disorders at Cedars-Sinai Medical Center, Los Angeles. He is the founder and serves as Senior Executive Director of the Androgen Excess & PCOS Society. Among other advisory capacities, he served on multiple NIH committees, chaired the US FDA Advisory Board on Reproductive Health Drugs, and served on the oversight committee for the California Institute for Regenerative Medicine. Dr. Azziz previously also served as president of Georgia Health Sciences University and then founding president of Georgia Regents University, one of Georgia’s four comprehensive research-level universities. Dr. Azziz also served as founding CEO of the Georgia Regents Health System, the state’s only public academic health center.
As a nutritionist for a fertility clinic, I frequently counsel women trying to manage PCOS while also dealing with the stress of infertility treatment. As glucose testing is a common part of that process, I’m often the first person to address the fact that they may now also have prediabetes, a state that precedes diabetes where blood sugar levels are starting to rise but not yet to the level of diabetes. What both PCOS and prediabetes have in common is insulin resistance, a condition which in its most advanced form causes type 2 diabetes, a disease now considered epidemic in our population. Insulin is a hormone produced by the pancreas, its main job being to “unlock” cells to move glucose (blood sugar) out of the blood and into the cells after eating. In insulin resistance, the cells become numb to the action of insulin, forcing the pancreas to work harder to make more to get the job done.
According to the Centers for Disease Control (CDC), about 86 million individuals in the United States have prediabetes. That's on top of the 29 million Americans who are already diabetic, eight million of whom don't yet know they have it. It's estimated that one of every three people born in 2000 in the United States will develop diabetes in his or her lifetime, and that 50 percent of women with PCOS will be prediabetic or diabetic by age 40. The lifetime risk of developing diabetes is even greater for ethnic minorities, where two of every five African-Americans and Hispanics (one of every two Hispanic females) will develop the disease. Fortunately, if addressed early on, prediabetes can often be reversed before it progresses to full blown diabetes.

**NEXT STEPS**

If you're diagnosed with prediabetes, in many instances it can be reversed with the same strategies used to manage PCOS – increasing your intake of whole fruits, vegetables, whole grains and legumes; curbing carbohydrate portions; limiting intake of sweets and processed grains; eating a bit more lean protein (including plant proteins) and healthy fats (olive or canola oil, nuts, seeds, avocado and fatty fish); and regular physical activity, including both cardio and strengthening exercises. Most importantly, if you are overweight, losing as little as seven percent of your weight may normalize blood glucose, significantly reducing your risk of developing diabetes.

**HOW DO I KNOW IF I HAVE PREDIABETES?**

Just as prediabetes precedes diabetes, generally for a period of years prior to prediabetes the person is already insulin resistant but their pancreas is youthful enough to compensate for it by working harder. As the pancreas gets tuckered out, blood glucose levels rise, leading to prediabetes, and often eventually diabetes.

The easiest test for prediabetes is a fasting glucose, where blood is drawn after a ten-hour fast. The results are as follows:

- 99 mg/dl – Normal
- 100–125 mg/dl – Prediabetes
- 126 mg/dl or higher – Diabetes

Increasingly, another screening test called a hemoglobin A1C is also being used (normal is below 5.7, prediabetes if 5.7 to 6.4, diabetes is 6.5 or higher), but some research suggests the best test for prediabetes in women with PCOS is an oral glucose tolerance test (OGTT). This involves at least an eight hour fast followed by blood glucose testing immediately before and two hours after drinking 75 grams of glucose. The results suggest the following:

- 139 and below – Normal
- 140 to 199 – Prediabetes
- 200 and above – Diabetes

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1Assessment of glucose metabolism in PCOS: HbA1c or FG compared with OGTT as a screening method Lerchbaum et al, Hum Reprod. 2013 Sep;28(9):2537-44.
UPCOMING

2017

PCOS EVENTS

ATTEND THE BIGGEST
PCOS EVENTS OF THE YEAR

PCOS AWARENESS SYMPOSIUM
GEORGIA TECH - ATLANTA, GA
Saturday, September 16, 2017*

BOLT FOR PCOS 5K RUN/WALK
GEORGIA TECH - ATLANTA, GA
Sunday, September 17, 2017*

BOLT FOR PCOS VIRTUAL WALK
WORLDWIDE
Sunday, September 17, 2017*

*Dates are tentative and subject to change.

VISIT PCOSCHALLENGE.ORG FOR DETAILS
PCOS is a lifelong battle, but that hasn’t stopped Keshena Patterson from keeping her happiness. At age ten, she knew that some things about her were “just kind of off,” however, it would be another eight years before she received a diagnosis. After a myriad of tests, including blood sugar, thyroid and an ultrasound, her doctor called to confirm Keshena’s PCOS diagnosis. After receiving the news at age 18, Keshena said, “I didn’t really feel like it impacted my life.” She had already been taking birth control pills, so adding Metformin and Spironolactone, as well as attempting to diet and exercise, wasn’t much of a change for her.

As Keshena learned more about the disorder, she discovered that everything that had previously been off with her all stemmed from PCOS. From depression and dandruff to irregular periods, hair growing in strange places and self-consciousness, everything that led to her doctor’s visit at age 18 could be traced back to PCOS. She recalled it being a “confusing time for a couple of years after being diagnosed,” and likened the emotional and physical changes she experienced to a circus.

It wasn’t until a few years after her diagnosis that Keshena decided to take PCOS into her own hands and become her own healthcare advocate,
something she recommends to any newly diagnosed cystyer. Through research, Keshena discovered that dropping Metformin, eating whatever she wants in moderation, taking vitamins, meditating, having a good relationship with higher powers as well as family and friends, and exercising all help her to manage PCOS symptoms.

Her favorite form of exercise is walking, but she also loves to lift weights and do CrossFit and Zumba. She hopes to run a marathon one day and travel more. The Houston-based radiology technician has already been to exciting places including Jamaica and Nicaragua. She loves to watch reality television and stay up to date on the latest technology products.

Another hobby that helps Keshena manage her PCOS is writing. She highly recommends keeping a journal and stresses that “whatever you put in your journal, whether it’s good times, bad times or sad times, it’s all necessary.” Keshena started writing about her PCOS so much that she decided to write a book. There are many books out there about PCOS, but Keshena never saw one written by someone who had been through the PCOS journey like she had. Keshena hopes that her book will help other cysters cope with PCOS by providing another perspective, and also by serving as an information resource. Her book is called *I Kept My Smile: From a Girl to a Woman with PCOS*, and the title underscores her secret to managing the condition.

“Sometimes, there’s nothing you can do about the condition you have,” Keshena says. “You could diet, you could exercise, you could take all of the pills in the world, but it’s not going to change the fact that you still have it. If I can’t change having PCOS, I might as well smile.”
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RADIO SHOWS AND VIDEOS

RADIO SHOW

ENDOMETRIOSIS AWARENESS – Mary Lou Ballweg
Mary Lou Ballweg, founder, President and Executive Director of the Endometriosis Association speaks about endometriosis and the importance of advocating for your health.
PCOS.tv/endometriosis-awareness

RADIO SHOW

ELECTROLYSIS AWARENESS – Lara Iskander, LE, CPE
Lara Iskander, a woman with PCOS and a licensed and certified electrologist, discusses hair removal options for women with PCOS.
PCOS.tv/pcos-hair-removal-options

VIDEO

INFERTILITY AWARENESS VIDEO – Beth Heller
Beth Heller, Co-founder of Pulling Down the Moon, shares her personal story about dealing with infertility.
PCOS.tv/pcos-infertility-awareness
ONE POT MEXICAN QUINOA

By Mae Reilly, RD   Adapted from Annie's Eats

INGREDIENTS
- 1 Tablespoon olive oil
- 3 cloves garlic, minced
- 3 jalapeños, seeded and finely chopped
- 1 and ¼ cups vegetable broth
- 1 (14.5 oz) can diced tomatoes, with juices
- 1 cup uncooked quinoa
- 1 can or 1 and ½ cups black beans, drained and rinsed
- 1 cup frozen corn
- ½ teaspoon salt
- 1 teaspoon chili powder
- ½ teaspoon cumin
- cup fresh cilantro, chopped
- 1 quarter of a lime, juiced
- Toppings as desired:
  - Shredded cheese
  - Avocado, cubed
  - Green onions, sliced

INSTRUCTIONS
1. Heat olive oil over medium-high heat in a Dutch oven or medium saucepan.
2. Add garlic and jalapeños to the pan and sauté until fragrant; about 2-3 minutes.
3. Stir in the vegetable broth, diced tomatoes, quinoa, black beans, and frozen corn.
4. Add salt, chili powder, and cumin. Bring to a boil. Reduce heat to medium-low and simmer for 30-35 minutes, or until the liquid is fully absorbed.
5. Stir in the cilantro and lime juice. Serve with desired toppings such as shredded cheese, avocado and green onions.

NUTRITION INFORMATION
(not including cheese or avocado garnish)

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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.

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• 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
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• PCOS Challenge is partnered with many of the leading PCOS research centers globally. Your support helps with recruiting and important research efforts.
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40,000
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