PCOS Challenge E-ZINE

APRIL 2014 | VOLUME 1 | ISSUE 4

PCOS AND NATURAL FAMILY PLANNING

MINORITY HEALTH MONTH

INFERTILITY AWARENESS STORIES

NEW GENE DISCOVERY IN PCOS

FEATURED RADIO SHOWS, VIDEOS, RECIPES & MORE!

Could You Have Polycystic Ovary Syndrome?

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LETTER FROM THE EXECUTIVE DIRECTOR

This month is National Minority Health Month, and National Infertility Awareness Week is observed April 20 - 26, 2014.

National Minority Health Month

April is National Minority Health Month, and this year's theme is Prevention is Power: Taking Action for Health Equity. This encourages us all that much of our health is in our hands. There are steps that we can all take to live healthier lives. The food we eat, how much we move our bodies, whether we smoke and use drugs or alcohol all play a role in our health. People of color die younger and more frequently suffer from preventible diseases due to less access to quality health care, language and cultural barriers and socioeconomic influences. Regardless of skin color, language spoken or home address, everyone deserves to live life the healthiest way possible. Delivering health care and disease prevention options to everyone will not only allow everyone the opportunity to live healthier, but it also lessens the economic strain caused by disease treatment. Prevention is power. Being proactive is the key to better health.

Infertility Awareness Week

Infertility is as a disease of the reproductive system that affects 10% of the population. One third of infertility cases are attributed to male infertility, another third to female factors and 10% a combination of both male and female, and 20% is unexplained. Polycystic ovary syndrome is the most common cause of female infertility.

In this issue of the PCOS Challenge e-zine, we will bring you stories from some women who face infertility and wanted to share their stories.

In good health,

Sasha Ottey

Executive Director
PCOS Challenge, Inc.
501(c)(3) Public Charity

FEATURED ARTICLE

WHAT IS POLYCYSTIC OVARY SYNDROME?

By Shahab Minassian, M.D.

The changes are gradual but no less frustrating. Weight gain, excessive hair growth, acne and a steadily worsening irregularity of menstrual periods begin to surface. Fertility, once thought to be a natural process, is impaired. After its formal reports in the medical literature and for decades in modern times, the diagnosis, treatment and health risks of Polycystic Ovarian Syndrome (PCOS) have afflicted patients and perplexed their physicians. However recent advances in the knowledge of this common syndrome, especially in the area of insulin resistance, have helped everyone involved to better understand the problems PCOS causes and turn to newer, more effective treatments to combat them. It is hoped that this will serve as an overview to our readers and offer them hope that was not available until recently.

Women have most likely been affected by PCOS as a disease for a very long time. However, it wasn't until a French physician reported the appearance of polycystic ovaries in the mid 1800's that brought it to the attention of the medical community. Gradually more reports surfaced including surgical recommendations for treatment, most notably the "wedge resection", in which wedge-shaped portions of the ovaries were removed. In 1935 Stein and Leventhal, two gynecologists from Chicago, described the symptoms of PCOS (immediately named the Stein-Leventhal Syndrome), and noticed that they disappeared, at least for a while, after the wedge resections were done. These patients were for the most part overweight, infertile, hirsute and had a lack of periods. Since those reports many if not most physicians, until recently, have thought of PCOS in this way. There are, however, a significant number of patients who are not overweight, or may have one or a few of these symptoms. In 1990, an NIH consensus conference defined PCOS as the finding of elevated androgens and impaired (irregular) ovulation when the hormonal diseases of congenital adrenal hyperplasia (an inherited enzyme disorder), elevated prolactin, thyroid disease and Cushing's syndrome were excluded.

Later on, in 2003, a conference of specialists in the field held in Rotterdam, Netherlands proposed a modification of the definition. They supported the finding of polycystic ovaries during ultrasounds as part of the criteria to diagnose PCOS. They also proposed that PCOS can be diagnosed even if a woman has regular periods. This definition is accepted by many PCOS specialists worldwide, as is the NIH definition. Needless to say there is a great worldwide controversy going on about the definition of PCOS.

Somehow along the way, I started to forgot to advocate for myself but thankfully I eventually remembered the valuable gift you gave me and I will never forget again. Today I am a woman's health advocate because of you. I help other women educate themselves about their own health. I want to be for other women what you have been for me – a supportive friend who guides women to become their own health advocate. You've inspired me to help other women feel empowered.

Not all patients have all of the symptoms of PCOS. Hirsutism (90%), menstrual irregularities (90%) and infertility (75%) are the most common. Polycystic ovaries can be seen on ultrasound in many (84%). Excessive weight is commonly seen but not exclusive (50%). Insulin resistance is a rather newly found problem (up to 70% of PCOS patients have proven insulin resistance, but many more – if not all - probably have it as well). Insulin resistance can be so serious in some patients that Type 2 (adult-type) diabetes has been found in up to 7% of PCOS patients.

Article continued on page 3...

WHAT IS POLYCYSTIC OVARY SYNDROME?

...Article continued from page 2.

How common is PCOS? Much work has been and continues to be done in this area. The answer may depend on many factors, including how it's diagnosed or who is being diagnosed. If ultrasound is the only way used, over 20% of all women have polycystic ovaries. If only irregular periods are used about 10% have PCOS. Ethnicity plays a major role. For example, Caucasians and African-American women have a 4% incidence, but certain Native American groups have an over 20% incidence. Greek women (9%) and perhaps certain Latino groups have a higher incidence. There is emerging evidence that PCOS maybe transmitted in some families themselves through genetics. These facts lead many researchers to suggest that PCOS may be an inherited problem in some women. Insulin resistance appears to be inherited too. Can this be a partial answer?

In an effort to confirm a PCOS diagnosis, and to locate a possible source of the problem, doctors will turn to physical exams, laboratory tests and imaging tests. Women with PCOS and excessive weight tend to have more fat tissue at the waist and upper body. In addition to the usual weight and height measurements, the waist-hip ratio and body-mass index are then excellent tools to evaluate excessive weight. Common blood tests include androgen levels (testosterone, DHEA-sulfate, 17-hydroxyprogesterone, androstenedione for example). Many women have increased LH (luteinizing hormone) levels compared to FSH (follicle-stimulating hormone), resulting in an elevated LH to FSH ratio. However the elevated LH to FSH ratio is not a definitive way to diagnose PCOS. Vaginal ultrasound is an increasingly popular test. The ovaries are seen to have a polycystic appearance, a bit enlarged and with collections of small follicle cysts lining the outer edge, just under the surface. This finding is called the "pearl necklace", "string of pearls" or "necklace" sign. Ultrasound alone, however, is not a definitive way to diagnose PCOS.

The current opinion of many PCOS researchers is that it is a syndrome with more than one cause. Two have been most often proposed: (1) insulin resistance and (2) some type of abnormality in the way the ovary produces hormones (androgens and estrogens). Insulin resistance is strongly linked to PCOS. In this problem the cells of the body cannot process insulin, to keep the blood sugar normal, very efficiently. Excessive weight further aggravates the insulin resistance. The body will compensate by making more insulin. The excessive insulin stimulates the ovary to make androgens. Additionally, it's difficult to lose weight when insulin levels are elevated, further compounding the problem.

At least one third of patients with PCOS can have insulin resistance. In the second case, some researchers have proposed that a gene defect may force the ovary into making the excessive androgens. Either way, the androgens will cause follicles, normally trying to mature and ovulate, to stop growing. The follicles collect in the ovary (making it appear polycystic), and eventually degenerate. The androgens also may create excessive hair and/or acne.

Shahab S. Minassian, M.D. is the former Co-Director of the nationally recognized Center for Polycystic Ovarian Syndrome at Drexel, he is an acknowledged PCOS expert with special expertise in the relationship between infertility and PCOS. He is a founding member and the first Chair of the Androgen Excess (PCOS) Special Interest Group of the American Society for Reproductive Medicine. He has won numerous teaching and clinical awards in this field, and has published numerous research article and abstracts.

Dr. Shahab Minassian joined the IVF-Fertility Division of Women's Clinic, Ltd. in Reading, PA. in September 2007. Dr. Minassian is one of only 900 board-certified infertility specialists in the U.S.

Dr. Minassian is Section Chief for Fertility and Reproductive Endocrinology at The Reading Hospital and Medical Center and is certified by the American Board of Obstetrics and Gynecology as a Reproductive Endocrinologist. He has over 25 years of experience in the field and has treated thousands of patients for infertility.

www.infertilitypa.com

One area that is much less studied, but may be important, is the effect of stress on PCOS. There have been some older and more recent reports that PCOS patients score higher on anxiety or other psychological testing. Adding stress reduction techniques seems to help with PCOS treatments.

READ PART TWO OF ARTICLE

PCOS Challenge

The Support System to Help Women Beat PCOS

National Volunteer Week April 6-12

Want to volunteer with PCOS Challenge?
Click here to apply.

Infertility Awareness Stories

PART I WITH ALISA G.

How has PCOS affected your fertility?
Because of PCOS I have long and irregular cycles. Also because of PCOS I do not ovulate every cycle. Both of these by themselves makes trying to conceive a challenge, but together it makes it very hard to know when to even try to conceive.

Was there ever a time when you felt like giving up?
More then once! Every time my cycles went longer then 40 days it made me depressed and made me feel like having another baby was just not going to happen for us. There were so many times when I was tired of taking ovulation tests and check my temperature every morning.

When you or your partner became frustrated with not getting pregnant, how did you handle that frustration?
My husband was my rock through all of this. He always told me that we were doing everything that we could and that we just needed to relax. When things got stressful or I had one of my breakdowns, which happened often, we would do something just for the two of us. We would go out to eat or relax and watch a movie. Anything that would keep our minds off the TTC for that time period. And when things got too stressful, we took a break.

Did you chart, track or have a game plan to conceive?
Yes, all of my cycles were charted. I tracked my BBT (Basal Body Temp) everyday, I tracked my cervical mucus and cervical position, and we used ovulation tests as well. Since my cycles were very long and irregular it was hard to know when or if I was even ovulating. Ovulation tests helped give us a little bit of a clue as to what was going on, but false positives happened many times during my cycle. The more I used ovulation tests the more I began to understand my cycle and how my body worked. We made sure that during our peak days we did the deed so that if I did ovulate we had a chance during that cycle.

Article continued on page 6...

MORE ABOUT ALISHA:

I am an English tutor and have the great privilege of working from home. I have been married to my sweet and loving husband for 10 years.

Age: 29 years old

How long trying to conceive:
We were TTC for 15 months this time around. We were TTC for 4 years prior to that with no success, we took a break for a year and a half and then started TTC again.

Previous losses?
I had 2 early losses before carrying our son to full term. This time TTC we have not had any losses.

Other children: We have one son who is 8 years old.

Infertility Awareness Stories

PART II WITH LYNN R.

Tell us about when you found out that you had conceived. How did you feel?
This cycle was a bit odd. Because we needed a small break I decided that I wasn't going to temp every morning. Because of that I was relying only on ovulation tests to give us our windows to try. Shortly after our window came of when I "might" be ovulating I ended up getting sick and needing to stay in the hospital for 2 nights. When I came home I was still a little under the weather but feeling better. The next day after I came home I was starting to feel a little worse again, but I figured it was just because of being sick. The next morning I woke up with the strongest urge to test. And the test was positive. I was beyond happy, but worried at the same time because of the time I spent in the hospital. But the doctors and my morning sickness all convinced me that things should be just fine.

What advice do you have for others with PCOS who are trying to conceive?
Never lose hope. TTC is a hard journey and TTC with PCOS is even harder. But it is possible and that little bit of hope is all you need to keep going some days. Everyone is going to tell you to just relax and it will happen, and although that's not always the case there is some value there. Stress can cause PCOS symptoms to flare up and make TTC even harder, so finding ways to de-stress your life can make a difference. Also talk to your doctors, they may not always know everything, but they may just have an idea that you haven't thought about or tried yet. And don't forget the power of a healthy diet and exercise. Your body is going to be home to your baby for 40 weeks, you want your body to be the best home you can give your child, to give him or her the best shot at life. So treat your body well.

How has PCOS affected your fertility?
Because of PCOS, I don't ovulate, so I don't have a monthly period. I have to medically induce menstration with progesterone. I have taken clomid many times to try and induce ovulation. I am now trying Femera. If that doesn't work then we will move on to injectables for ovulation induction or even IUI.

Was there a time when you were excited about trying to conceive?
I was very excited to try and conceive. The most precious gift is a child!

Was there ever a time when you felt like giving up?
My husband and I wanted to give up plenty of times over the last 4 years. But each cycle we gave it another shot. We did decide to give up in October 2013. After a few months, we are now trying again. I think we just needed a break.

When you or your partner became frustrated with not getting pregnant, how did you handle that frustration?
My husband and I had plenty of times of frustration. Seeing that negative pregnancy test every cycle isn't easy.

During our 4 years of trying we have welcomed 2 nephews and a niece into the world, with one more niece due to arrive this month. Every time someone announced they were pregnant we would become angry, sad, and just defeated. We would talk about how unfair it is and sometimes cry. I think talking, crying or even screaming it out is what really kept us going.

Do you chart, track or have a game plan to conceive?
I track and chart my temp everyday. I mark down the drugs I'm taking, every cramp, everything!

What advice do you have for others with PCOS who are trying to conceive?
Get checked out. Ultrasound, HSG, bloodwork. If your doctor won't do that, find a a new doctor! There is never a reason for your doctor to say no! If you and your significant other are feeling trouble in your relationship, take a break. But don't give up! Never give up!

MORE ABOUT LYNN:

Age: 33 years old

Married to Eric since 2003.

Trying to conceive for four years.

One previous miscarriage in January 2013. No other children.

Eric and I strongly desire to have a family and started a fundraiser to raise money for a monitored cycle.

You can see my full story at
www.gofundme.com/operation-baby

We are still trying our best to achieve our dream anyway we know how!

Infertility Awareness Stories

PART III WITH KEISHA HEIL

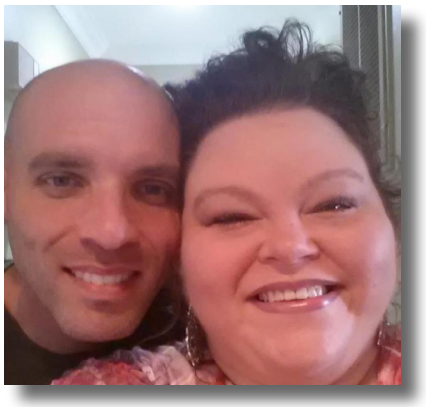
How has PCOS affected your fertility?
I do not ovulate and I also have irregular cycles and both are needed to conceive a child. I was told by few doctors that ovulation shots would help me a lot, and that I should look into IVF.

Was there ever a time that you felt like giving up?
Over the last 16 years of my infertility struggle, I never really felt like giving up, but I was always wondering why God couldn't just "fix me" as I felt like a piece of glass, trying to mingle itself back together.
I have my doubts at times, and I have my fear that my dream of becoming a mother, will never happen. I have my hidden tears quite often, but I never will give up on my hope or my desire to be a mom. That is, at times, all you have to hold onto.

How did you decided adoption was an option for you?
My husband was adopted, so we always knew that was an option for us once we were financially capable of doing so. In our eyes, being parents has little to do with biology, but rather the love you hold inside your heart for any child that God has chose for you. Blood doesn't create a family, the love within your hearts is what connects you.

Tell us about your adoption process?
At the moment, we are still saving money in hopes to be able to adopt a child who is in need of a home and family. Right now, all we can do is pray that God has this option for our future.

What advice do you have for others with PCOS who are trying to conceive?
To never give up. No matter how many obstacles that seem to come your way. God has a plan. Never let your fears conquer your dreams. The desire inside your heart is there for a reason.



I want to be that one person, that you possibly think of when saying, "Because of her, I never gave up." Never give up on a dream that you feel, without a doubt, is your purpose, your calling on Earth. Blessings to you all.

My husband and I do have a fundraiser site that we hope to be able to get some help to guide us closer to our dream of becoming parents. We are open to adoption or IVF. As I stated before, blood doesn't make you family, the love does.

Here is the link to our page:
http://www.gofundme.com/lovingachild

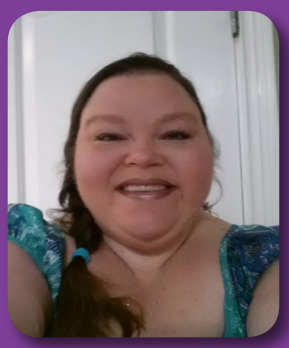
MORE ABOUT KEISHA

Age: 36

We have been trying for nearly 16 years.

Previous losses - 1

We have no children.



MINORITY HEALTH

While there are some genetic factors that play a role in disease, our environment, lifestyle and access to healthcare have a strong influence on health outcomes. Minorities have less access to quality, preventive health care, and the cultural and language barriers also worsen health disparities.

Women of color experience negative reproductive health outcomes at greater rates. One major factor that influences this is lack of access to quality health care. If women do not have access to health care, then they are more prone to suffer from illnesses such as pregnancy-related diseases, sexually-transmitted infections, and detect cancer at later stages.

Heart disease is a vicious killer of most people in the United States, and people of color are especially at risk for strokes and heart disease. Learn more from the fact sheet from the Centers for Disease Control and Prevention here:

http://www.cdc.gov/dhdsp/data_statistics/fact_sheets/fs_heart_disease.htm

Preventative measures such as getting more exercise or moving more every day, eating a healthy diet, taking care of your oral health, not smoking, and not doing drugs or alcohol can help with preventing many diseases. Also, finding programs in your state or city that give you access to health care can help. You can no longer be denied health insurance coverage due to pre-existing conditions, so obtaining private insurance if your employer doesn't cover health care is much more accessible.

Get yearly physicals, gynecologic and dental exams. These can help you to keep track of your health, prevent disease and find abnormalities such as cancers and heart disease at earlier stages. Being proactive about your health care is the only way to ensure that you live the healthiest life possible. Everyone deserves the opportunity to live the healthiest life possible.

Reference:
http://minorityhealth.hhs.gov/nmhm14/blog/

PCOS CHALLENGE RADIO

Diabetes Prevention Advice from Celebrity Chef Charles Mattocks

CLICK HERE TO LISTEN NOW

Celebrity Chef and Worldwide Diabetes Advocate Charles Mattocks joins the PCOS Challenge radio show to discuss the PCOS-Diabetes connection. Listen to the show for healthy cooking and lifestyle strategies to help prevent and manage diabetes in women with PCOS.

Chef Charles has been a featured guest on *Dr. Oz*, *The Today Show*, *Good Morning America*, *Martha Stewart Radio* and many other top media outlets.

VOLUNTEER

WE NEED YOU

YOU'RE BRILLIANT PASSIONATE CREATIVE AMAZING!

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 sales and fundraising, graphic design, publicity, volunteer management, and event planning and management.

VOLUNTEER WITH PCOS CHALLENGE

CLICK HERE

PCOS CHALLENGE RADIO

PCOS & PREGNANCY THROUGH NATURAL FAMILY PLANNING

CLICK HERE TO LISTEN NOW

Melinda and Jana Heen, her FertilityCare Practitioner, discuss how Melinda was able to get pregnant with natural family planning despite PCOS and very irregular cycles.

Melinda has PCOS. She also had very irregular cycles. When she got married to her husband, who is Catholic, she got introduced to Natural Family Planning. How did a woman with PCOS and very irregular cycles get pregnant with NFP?

Jana and her husband have used the Creighton Model FertilityCare System in their marriage of 13 years. They have 4 children and are now due to have their 5th. In 2004, Jana was asked by her local priest to consider becoming a Practitioner for the Creighton Model system.

She accepted the offer and went to Omaha, NE to begin her education with the Pope Paul VI Institute and Creighton University. She finished the practitioner program in the spring of 2006. Jana has been teaching the Creighton Model of the Diocese of Bismarck for nearly 8 years. She has worked with a variety of couples with various fertility situations. An increasing number of her clients are coming to her due to issues with infertility and a good number of them have been diagnosed with PCOS.

PCOS & INFERTILITY AWARENESS

CLICK HERE TO LISTEN NOW

Dr. Shahab Minassian answer your questions about PCOS and infertility.

Dr. Minassian is former Co-Director of the nationally recognized Center for Polycystic Ovarian Syndrome at Drexel and a founding member of the Androgen Excess and PCOS Society.

He joins the *PCOS Challenge* radio for infertility awareness week to answer your questions about PCOS and infertility.

PCOS TOP 10 DO'S & DON'TS

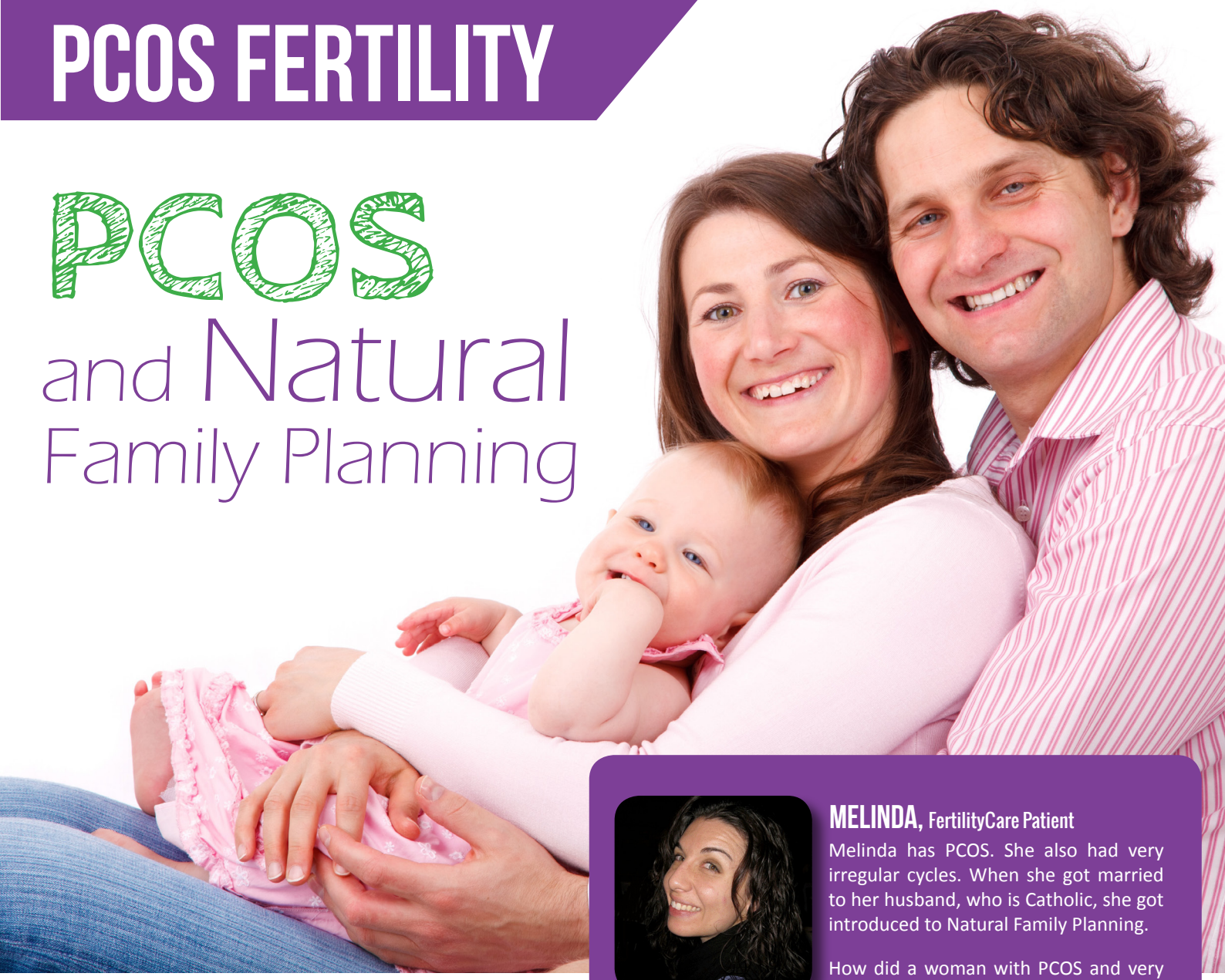
CLICK HERE TO LISTEN NOW

Dr. Rebecca Harwin discusses the "Top 10 Do's and Don'ts for Women with PCOS."

Dr. Rebecca Harwin is a chiropractor and nutritionist in Australia. She is author of *Conquer Your PCOS Naturally*.

She joins the *PCOS Challenge* radio show to discuss the "Top 10 Ten Dos and Don'ts" for women with PCOS. Dr. Rebecca understands how tough PCOS can be, having previously suffered with the syndrome herself.

PCOS and Natural Family Planning



Polycystic ovary syndrome, or PCOS, one of the leading causes of infertility and a main reason some women don't ovulate regularly. Fertility is a concern for most who have been diagnosed with PCOS. Many women with PCOS are trying to get pregnant naturally.

Jana Heen has been teaching the Creighton Model Fertility Care™ System at the Diocese of Bismark for over 10 years. An increasing number of her clients are having issues with infertility, and many of them have been diagnosed with PCOS. One is Melinda, who, despite PCOS and very irregular cycles, was able to get pregnant with natural family planning (NFP) or fertility care.

Natural Family Planning (NFP) is an umbrella term for methods used to achieve or avoid pregnancy. The Catholic church does not stand behind contraceptives, and teaches natural family planning to married couples. The belief is that fertility is not a disease to be treated, but something to be worked with more naturally. Using the Creighton model, a woman observes and charts the cervical mucus and uses the signs to determine fertile and infertile times as well as detect abnormalities in the menstrual cycle.

MELINDA, FertilityCare Patient

Melinda has PCOS. She also had very irregular cycles. When she got married to her husband, who is Catholic, she got introduced to Natural Family Planning.

How did a woman with PCOS and very irregular cycles get pregnant with NFP?

Listen to the *PCOS Challenge* radio show on to hear Melinda's story.

JANA HEEN, FertilityCare Practitioner
Creighton Model FertilityCare System

Jana and her husband have used the Creighton Model FertilityCare System in their marriage of 13 years. They have 4 children and are now due to have their 5th. In 2004, Jana was asked by her local priest to consider becoming a Practitioner for the Creighton Model system. She accepted the offer and went to Omaha, NE to begin her education with the Pope Paul VI Institute and Creighton University. She finished the practitioner program in the spring of 2006.

Jana has been teaching the Creighton Model of the Diocese of Bismarck for nearly 8 years. She has worked with a variety of couples with various fertility situations. An increasing number of her clients are coming to her due to issues with infertility and a good number of them have been diagnosed with PCOS.

PCOS AND NATURAL FAMILY PLANNING

NaProTECHNOLOGY (natural procreative technology) uses the information obtained through the charts from the Creighton model to address abnormalities, infertility and underlying disease.

Individualized Method

Women are taught to observe and chart the symptoms that occur during their cycles. Some women don't know that those symptoms of the body are signs of fertility (such as temperature changes, cervical mucus, abdominal pain around the time of ovulation, etc.).
Although the Catholic Church promotes natural fertility care and family planning, it is not a religious method, but rather a method that works for anyone, using signs from her body to determine fertile times.

Working as a Couple

Male factor infertility is also taken into consideration, and semen analysis should be done. Melinda describes the natural family planning process as a unique way to work together as a couple and strengthen the marital bond.

Become Informed

Jana encourages people to research different NFP options available. A good place to start can be the website NaProTechnology.com. NFP is a great way to get to know yourself better and is very individualized, because what works for other women may not work for you. If you need help, try to reach the NFP practitioners in your area.

Melinda is proof that this method can work if you are willing to learn and be patient with your body. She has PCOS, didn't have regular cycles and sometimes wasn't ovulating at all. However, even with her 80 day cycle, her and her husband used cues from her body to conceive their healthy child.

FEATURED VIDEO

PCOS AND FERTILITY

PCOS and Fertility – Reproductive Endocrinologist Dr. Nancy Durso speaks to the women about PCOS and fertility. The women also begin phase two of their workout routines with PCOS Challenge Fitness Coach Josef Brandenburg to help with insulin resistance related to PCOS.

Farewell Dear Ava

AN ACCOUNT OF HOW ONE LIFE CAN AFFECT MANY

by Sonya Satveit

I will never forget the first time we spoke – it was after my first miscarriage. It had been weeks since my D&C and I was still sad but was moving along with life as expected. For me, the fact that I'd only been pregnant for 10 weeks didn't lessen my sadness – I'd already made plans with my baby and had hopes and dreams for his or her future. Somehow it felt like no one else really understood. I woke up one morning immobilized with the grief of losing my baby. I only stopped crying long enough to call in sick to work that day and later call the health unit nurse who told me you had started a support group for women who'd lost a baby. When you called me back that day, I heard the voice of an angel. You cried with me and helped me get through that day and many other days that were to come. You were the first person to acknowledge that I was already a mom. You were the first person to understand that even though I'd had a first term miscarriage, I felt the loss of my baby and was entitled to my grief. I suddenly didn't feel so alone. You introduced me to other wonderful women who'd also lost babies and we helped each other get through our grief and our next pregnancies.

When I got pregnant again I called you with with every little twinge and worry, you were so patient and supportive. When I had another miscarriage you were there for me so I didn't have to go through it alone. You helped me come to the decision to avoid the same horrible D&C experience I'd had the first time. I allowed my miscarriage to happen naturally and you were there for me every step of the way.

You weren't there just for me – you supported all of us that you brought together with your kindness, generosity and understanding. Oh how many of us grieving moms did you help? I don't even know the number but I know you were there for every us who lost babies and you were there throughout our successful pregnancies too.

Besides being the most supportive person in my life at that time, you taught me something that changed my life. You taught me to be my own health advocate. You set an example for me as I watched you successfully advocate for yourself after you lost your precious twins and then go on to have a beautiful baby boy! You taught me to do my own research about my miscarriages (which was a feat in 1998 with very little information on the internet). You encouraged me to figure out what tests and treatments I wanted and to walk into my doctor and tell him what I wanted. So I did just that. I walked into my ob/gyn's office and told him I wanted him to prescribe me progesterone because I believed I was losing my babies due to insufficient progesterone production. He told me it was a "placebo effect" and recommended we simply try a third pregnancy to see what would happen. Thanks to you I stood my ground! It was powerful and it worked – he wrote me the prescription. My first baby was born in January 2000 because of you! I almost named my baby Ava, I wish I had. Because of you, I have never had another miscarriage and I went on to have three beautiful children!

Somehow along the way, I started to forgot to advocate for myself but thankfully I eventually remembered the valuable gift you gave me and I will never forget again. Today I am a woman's health advocate because of you. I help other women educate themselves about their own health. I want to be for other women what you have been for me – a supportive friend who guides women to become their own health advocate. You've inspired me to help other women feel empowered.

(Continued from page 13)

Farewell Dear Ava

AN ACCOUNT OF HOW ONE LIFE CAN AFFECT MANY

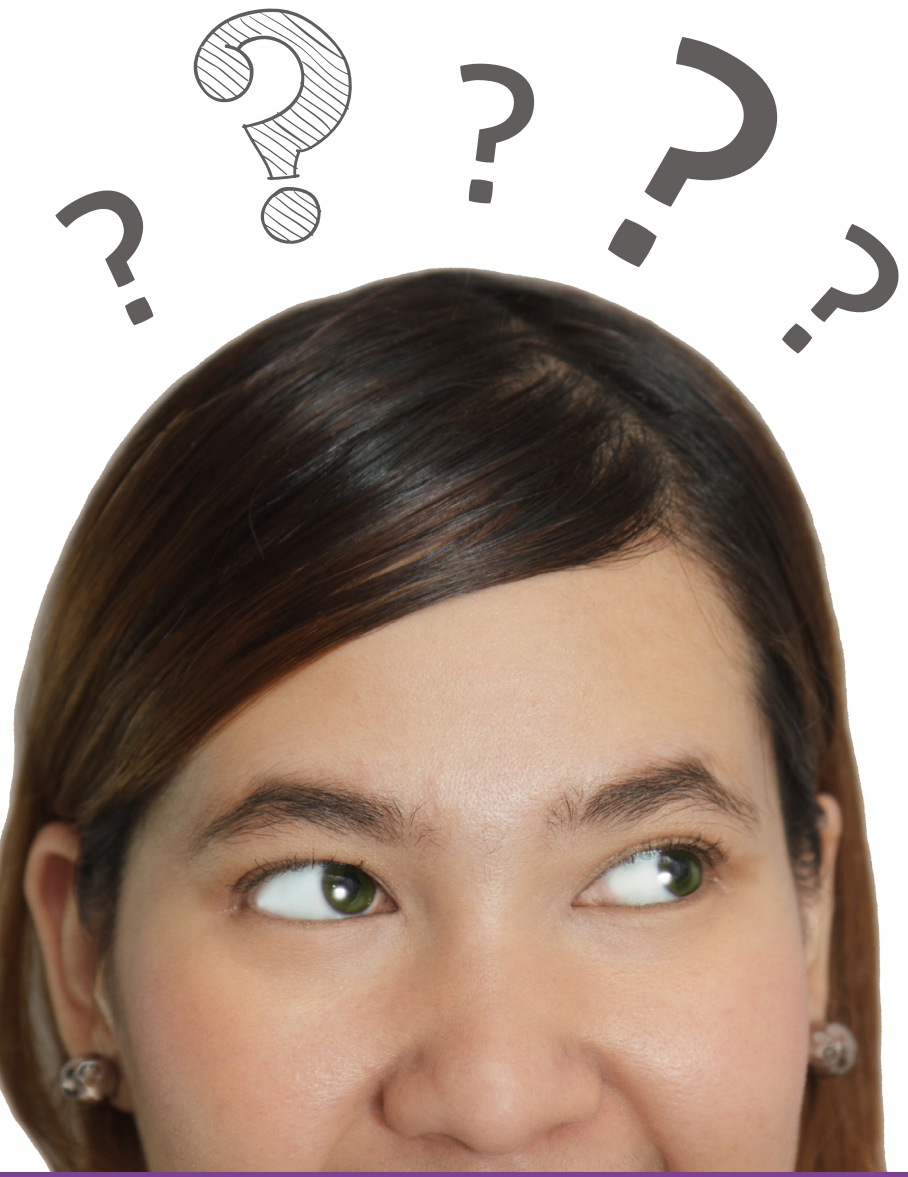
By Sonya Satveit

We lost touch when I moved all over this vast country so I didn't know you were sick. I was going to ask you to contribute articles about things like incompetent cervixes and supporting moms who've lost babies and advocating for your own health. I am sad that I never got a chance to help you like you helped me. I'm sad I never got the chance to tell you about what I'm doing today because of you. The impact of a single person on tyour life can be profound and for me that person has been you.

I'm sad I never got the chance to tell you about what I'm doing today because of you. The impact of a single person on your life can be profound and for me that person has been you.
Instead of you sharing your story on my site I am sharing with the world the story of one of the most amazing women I have ever had the privilege of knowing – my dear friend Ava – your legacy lives on. Thank you for the most wonderful gift.

Rest in Peace dear friend.

MAKE A DIFFERENCE



Why DONATE to PCOS CHALLENGE?

You Can Help Change
The Future for
Women with PCOS

Your gift will help PCOS Challenge, Inc. raise public awareness about Polycystic Ovarian Syndrome (PCOS) and related conditions as well as provide critical education and support resources to women with PCOS and the medical community. Our programs help women overcome their struggles with infertility, weight gain, anxiety and depression and reduce their risk for life-threatening related diseases.

DONATE NOW

VOLUNTEER **BE INFORMED** **ADVOCATE**

Obesity & Still Birth Risk

"Stillbirth risk escalated more sharply near the end of pregnancy for women with higher BMIs. Compared with normal weight women, having a BMI of 50 kg/m2 or higher was associated with a 5.7 times greater risk for stillbirth at 39 weeks' gestation and a 13.6 times greater risk at 41 weeks' gestation"

Obesity has long been proven to have a negative effect on health. The excess body fat may lead to reduced life expectancy and increased health problems such as heart disease, diabetes and certain types of cancer. Obesity is determined if the Body Mass Index or BMI exceeds 30 kg/m2 (You can measure your BMI by getting your weight in kilograms divided by the square of your height in meters, or use an online BMI calculator).

BMI results are further classified by level:

- Under weight, BMI less than 18.50
- Normal weight, BMI around 18.50-24.99
- Overweight, BMI 25.00-29.99
- Obese, BMI 30.0-39.99
- Extreme obesity, BMI ≥ 40.0

A recent study published in the American Journal of Obstetrics and Gynecology also concluded that nearly 1 in 4 stillbirths may be linked to maternal obesity. According to the large population study, the risk of stillbirth goes higher as the gestational stage (pregnancy stage or term) progresses and as the obesity level increases. The hazard ratio shows how often a particular event happens in one group, as compared to how it would happen in another group, and in this case, as compared with normal weight women.

The hazard ratio is as follows:

BMI Classification	Stillbirth Risk Hazard Ratio
Overweight: BMI 25.0 -29.9	1.36
Class 1: BMI 30.0 - 34.9	1.71
Class 2: BMI 35.0 - 39.9	2.00
Class 3: BMI equal or more than 40	2.48
BMI above 50	3.16

The study identified 2,88,482 singleton births (no twins or multiple babies born at the same time included in the statistics), including 9,030 stillbirths. Based on the records, the risk of stillbirth increases nearly by 25% among obese women between gestational weeks 37 and 42, also as the BMI increased so did the risk for stillbirth. This escalates further near the end of pregnancy for women with higher BMIs.

As compared with normal weight women, a BMI of 50 kg/m2 or more than class 3 obesity would have a 5.7 greater risk for stillbirth at 39 weeks and 13.6 times greater risk than normal at 41 weeks gestation.

The authors of the study also emphasized that perinatal (fetal) deaths also begin to increase at 41 weeks for most women, but this increased to 39 weeks for women with BMIs of 50 kg/m2 or higher. This pattern is caused by an earlier fetal growth speed and the insufficient blood flow to the placenta during pregnancy (also known as utero-placental insufficiency) among obese pregnant women.

The results of this study further supports the current practice of delivering babies at 41 weeks. Also the stillbirth risk with increasing BMI happens more during the early and late term gestation periods. This further encourages fetal surveillance or monitoring among obese pregnant women. The conclusion is that maternal obesity is a risk factor to fetal health and increases the chance of stillbirth.

Resources:

Hackethal, V. Maternal Obesity May Account for 25% of Late Stillbirth. Mar 27, 2014. http://www.medscape.com/viewarticle/822711

Yao R, Ananth CV, Park BY, et al. Obesity and the risk of stillbirth: a population-based cohort study. Am J Obstet Gynecol 2014;210.

Hazard Ratio, Wikipedia. http://en.wikipedia.org/wiki/Hazard_ratio

NEW GENE DISCOVERY IN PCOS

PCOS is one of the most common disorders affecting women in their reproductive age (approximately 12 to 45 years old), with symptoms such as insulin resistance, hirsutism, acne, irregular menstruation, obesity, and depression. If not managed, PCOS can lead to life threatening illnesses such as cardiovascular diseases and diabetes that persist, and possibly worsen beyond reproductive years.

One of the main problems with PCOS is hormone imbalance which causes the ovaries to release more androgens than normal. These high levels affect the development and release of eggs during ovulation, causing anovulation (a condition where an egg is not released from the ovaries), irregular menstrual periods, and amenorrhea (the absence of a menstrual period in a woman in her reproductive age). All of these lead to ovulation-related infertility issues.

Unfortunately there is still limited information about what causes this disease and most studies have concluded that genetics may be a factor and women with PCOS are more likely to have a mother or sister with the same condition.

Recently, researchers from Penn State College of Medicine and Virginia Commonwealth University School of Medicine have found a genetic anomaly that causes an increase of androgen production in the theca cells, the cells that line the follicles in the ovaries. Theca cells have been previously shown to cause excess androgens in women with PCOS.

This study found an increase in the variant gene, DENND1A.V2, in the theca cells of women with PCOS, and found that the mRNA for DENND1A.V2 protein was higher in the urine samples of women with PCOS.

Based on their observations, they found that this gene may be involved in the increased production of androgens in women with PCOS. They also observed that blocking this DENND1A.V2 gene reverted the theca cells to normal production of androgen.

This exciting news could lead to the development of better diagnostic tests for PCOS and this may also one day lead to better medicinal intervention to reverse or neutralize the effects of this gene.

Although this is one of the first published studies, both universities have the common goal of moving these important findings from the lab to the clinic and community.

More information about the study can be found:

http://www.healthcanal.com/female-reproductive/49280-researchers-identify-a-gene-that-causes-excessive-androgen-production-in-polycystic-ovary-syndrome.html

http://nih.gov/news/health/apr2014/nichd-15.htm

IS BEING OVERWEIGHT THE NEW NORMAL?

Doctors are expressing concern about the perceived risk (or lack of perceived risk) for gynecologic cancers and other chronic illnesses in overweight and obese women.

In a special issue is of the journal Gynecologic Oncology titled "Obesity Crisis in Cancer Care: Gynecologic Cancer Prevention, Treatment and Survivorship in Obese Women in the United States," writers highlight some challenges surrounding obesity and gynecologic cancers. In the United States, the majority of women are overweight.

A daunting 72% of American women have a BMI greater than or equal to 25 kg/m2. As the obesity epidemic increases, some doctors believe that a large part of the population have accepted obesity to be the norm and that people are no longer as alarmed about being overweight or obese as they once were.

Another group who studied women who went for bariatric surgery concluded that even though many of them were in fact obese and had high rates of menstrual dysfunction, they often did not perceive themselves to be at risk for uterine cancer. Also, many did not identify themselves as overweight or obese.

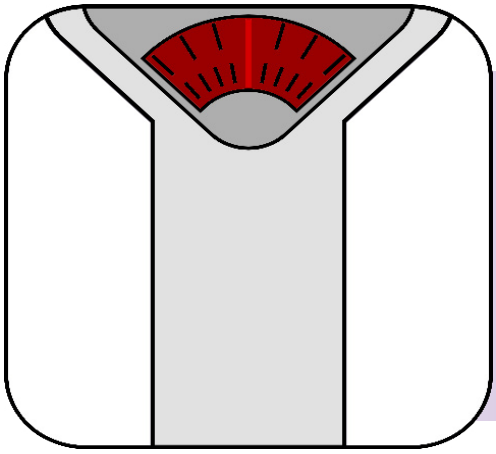
The challenge here, as perceived by these physicians is that obesity is now being viewed as the norm in the US. This failure to identify oneself as being overweight or obese will also result in the inability to recognize risks for many health and quality of life issues including gynecologic cancers that are caused by or exacerbated by obesity.

The hope is that the United States as a nation will put more effort into health care concerning obese women including improving prevention, symptom management and cancer care.

What do you think?
Are you overweight or obese?
Do you consider obesity to be a serious health risk?
Have you suffered health issues related to being overweight?

Reference:

1. Modesitt S, Walker J. Obesity Crisis in Cancer Care: Gynecologic Cancer Prevention, Treatment and Survivorship in Obese Women in the United States. Gynecologic Oncology 133 (2014) 1-3.
2. Henretta MS, et al. Perceptions of obesity and cancer risk in female bariatric surgery candidates: Highlighting the need for physician action for unsuspectingly obese and high risk patients. Gynecologic Oncology 133 (2014) 73–7.



FEATURED RECIPE

FAST AND EASY!

LOW-GLYCEMIC LENTIL SOUP

Recipe and photograph provided courtesy of www.healthysmartsmd.com

INGREDIENTS

ONION
CARROTS
CELERY
OLIVE OIL
LENTILS
BAY LEAF
SALT
PEPPER

DIRECTIONS

Perfect and easy idea to warm up- cook a pot of PCOS friendly lentil soup in less than 30 minutes.

1. Sauté chopped onion, carrots, celery in some olive oil in a big soup pot for a few minutes
2. Add 1 cup lentils
3. 1 quart of stock, and a bay leaf.
4. Bring to boil and then simmer on low for about 20 min.
5. Add salt and pepper to taste.

Save leftovers for a low-glycemic lunch tomorrow!

VIEW MORE PCOS FRIENDLY RECIPES

PCOS Challenge

The Support System to Help Women Beat PCOS

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