

I've Been Diagnosed with PCOS, Now What?

A Guide to Thriving with Polycystic Ovary Syndrome

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Introduction

My previous book *How to Build a Strong PCOS Practice, Treating One Beautiful Woman at a Time* was written for healthcare providers. This, my second book, is for people affected by PCOS, whether you personally have PCOS or a friend or loved one does.

A common condition affecting approximately 10 percent of women, PCOS is complex, but it doesn't have to be complicated. If you learn all you can about it and get the right treatment and support, then you will live a happier, healthier life.

The PCOS treatment helps you to lose weight, decrease insulin levels, balance hormones, improve fertility, regulate cycles, and decrease the risk of long-term health complications. A combination of exercise, healthy eating, medication, and/or supplements may be used to treat the condition.

Maybe you were motivated to seek treatment for PCOS because of a specific problem like weight gain, dark hair growth, or difficulty getting pregnant. As you initiate treatment, you will find more benefits to your health and well-being than you ever expected.

In the short run, you will feel better because you will have fewer PCOS symptoms (fatigue, sugar cravings, dark hair growth, acne, mood swings, bleeding irregularities, weight gain, and so on). Your long-term health will also benefit because you will decrease your odds of developing diabetes, high blood pressure, heart disease, and other health complications.

I hope this guide will inspire you to do everything you can to proactively treat PCOS. When you treat PCOS you will feel and look better and people will ask you what you are doing. Take the opportunity to educate others about PCOS and be an advocate within your own family and community. You will likely have many opportunities to share your knowledge and your personal success story. Just remember, PCOS is manageable with the right treatment and support!

Best Wishes,

Lisa A. Borunda Conner, FNP-BC

Disclaimer: The information contained in this book is for educational purposes only. Please consult with a healthcare provider before starting or stopping any treatment.

Chapter 1: What is PCOS/Why is it Important to Treat

What is PCOS

Polycystic Ovary Syndrome (PCOS) is a common hormonal disorder that affects approximately 10 percent of reproductive age women—around 5 million women in the United States.

A polycystic ovary has multiple small “cysts,” which are actually small follicles that stopped developing due to a hormonal imbalance. When a follicle develops but does not reach full maturity (and fails to release an egg) the remnant of the follicle may remain along the edge of the ovary. Women who have PCOS secrete higher than normal amounts of male hormones (mainly testosterone), but polycystic ovaries are a symptom of a hormonal imbalance not the cause.

Although PCOS is a common cause of infertility, it also has the potential to affect multiple systems of the body and can increase a woman’s risk for emotional and physical health problems.

As if dealing with the symptoms of PCOS wasn’t enough, PCOS also increases a woman’s risk for diseases such as type 2 diabetes and heart disease. That’s why treating PCOS is so important.

Many women suffer with the symptoms of PCOS for years without ever receiving a diagnosis. The fact that you have received a diagnosis and are starting treatment is positive! Many women see multiple specialists for symptoms of PCOS, and far too often the pieces aren’t pulled together to make the diagnosis and PCOS is missed or misdiagnosed.

Passed down genetically, PCOS requires only one parent to be a carrier for the child to inherit the predisposing gene, and each pregnancy has a 50 percent chance of carrying the abnormal gene. However, not all people who inherit the gene will develop PCOS. Men may be carriers of PCOS. They may have no symptoms or have symptoms such as early baldness and excessive hair growth. They are more likely to gain weight in their abdomen and are at higher risk for insulin resistance, type 2 diabetes, and heart problems.

PCOS was first recognized in 1935 as Stein-Leventhal syndrome (named after the two American physicians who discovered the relationship between multiple follicles on the ovaries and irregular menstrual cycles). However, the first PCOS textbook was not written until 1984 by an expert named Walter Futterweit, M.D. Furthermore, the link between insulin resistance and PCOS was not discovered until the 1990s. The medication Metformin, which is commonly used to treat insulin resistance in type 2 diabetes and PCOS, has only been on the market in the United States since 1995. We are learning more about PCOS all the time.

Identifying PCOS

As previously mentioned, identifying PCOS remains a major challenge and most women see several health care providers before receiving a diagnosis. They often seek treatment from multiple specialists for the symptoms of PCOS. For example, a woman may seek treatment from a dermatologist for acne and a gynecologist for irregular cycles. Seeing multiple specialists can fragment care, and although each specialist manages the symptoms specific to his or her area of expertise, PCOS can be easily missed.

I have seen patients who have been told they have elevated testosterone and insulin resistance and are being treated for both, but they have never heard of PCOS. I think it's important to call it what it is so people can learn about the intricacies of PCOS and treat the whole syndrome.

Note: If a woman starts on birth control for irregular cycles without having a proper work-up, she may be led to believe that birth control cured her irregular cycles. Additionally, she may have no idea that she may have a condition that could affect her weight, fertility, and significantly increase her risk for type 2 diabetes, heart disease, and other long-term health problems. Up to 80 percent of women with irregular cycles have PCOS.

Myths about PCOS

The following myths have persisted for decades about this condition:

- ❖ You are too thin to have PCOS. (Fact: only 60 to 70 percent of women with PCOS are overweight.)
- ❖ You do not have PCOS because you have had children. (Fact: many women with PCOS ovulate intermittently and conceive spontaneously; many others conceive with the help of assisted reproduction.)
- ❖ If you eat less and exercise more, you'll lose weight. (Fact: that is true for many but not all women with PCOS. Sometimes it has a whole lot more to do with **what** they eat. Insulin resistance can make weight loss difficult. Ask for a referral to a dietician for help with personalized meal planning for insulin resistance/PCOS).
- ❖ You do not have PCOS because your testosterone level is normal. (Fact: many women do not have elevated circulating androgens such as testosterone. Clinical evidence of androgen excess such as dark hair growth on the face and body also meets the criteria for PCOS.)
- ❖ You must have polycystic appearing ovaries, on ultrasound, to have PCOS. (Fact: only 75 percent of women with PCOS will have polycystic ovaries.)
- ❖ If you cycle regularly you do not have PCOS. (Fact: some women with PCOS have regular cycles. Many others do not understand that cycles of fewer than 21 days or more than 35 days apart are not considered regular).

Importance of Diagnosing and Treating PCOS

Let me emphasize why it is so important to diagnose and properly treat PCOS. PCOS can greatly affect a person's quality of life and significantly increase the risk for other conditions.

According to the US Department of Health and Human Services, Office on Women's Health, more than 50 percent of women with PCOS will have impaired glucose tolerance (pre-diabetes) or type 2 diabetes before the age of 40. They also have a 4 to 7 times greater risk of heart attack than their same-aged peers without PCOS.

In addition, they may suffer from one or many of the additional symptoms and conditions associated with PCOS, such as:

- ❖ obesity
- ❖ premenstrual syndrome (PMS)

- ❖ depression
- ❖ anxiety
- ❖ acne
- ❖ abnormal dark hair growth on face and body
- ❖ male pattern baldness
- ❖ sleep apnea
- ❖ thyroid problems
- ❖ non-alcoholic fatty liver disease (NAFLD)
- ❖ recurrent miscarriage
- ❖ infertility
- ❖ endometrial hyperplasia or pre-cancer
- ❖ cancer of the uterus
- ❖ elevated cholesterol and triglycerides
- ❖ high blood pressure.

Chapter 2: Diagnosing PCOS

Diagnostic Criteria

There are three different criteria for diagnosing PCOS (see Appendix B). They vary slightly and require either two or three of the following:

1. Irregular cycles
2. Signs of elevated androgens (such as high testosterone or dark hair growth)
3. Polycystic ovaries.

History and Physical for Diagnosis

A detailed history is important to diagnosing PCOS. Many conditions occur throughout a woman's life that can tip off doctors about this condition. Let's look at some of these possible conditions in a woman's health history.

One common condition is irregular or absent menstrual periods. These usually begin in the teen years, but frequently people with PCOS have started birth control as teens, and the diagnosis of PCOS is not made until they try to conceive in their twenties or later. Often cycles are 35 days or more apart. Some women skip months, while others have continuous spotting or more than one period a month.

These irregular cycles can become a problem later in life. Some women report regular cycles and no difficulty conceiving their first child or two and then things change: cycles become irregular, they stop ovulating, and their infertility work-up leads to a PCOS diagnosis.

Two conditions that could signal PCOS relate to clinical (physical) symptoms of androgen excess: male pattern hair growth (dark hair growth on the face and body) and acne. For androgens to have an effect on the skin they must bind with a skin androgen receptor and have adequate enzyme converting capacity. The numbers of androgen receptors vary among different ethnic groups. There may be little evidence of androgen excess despite high serum levels in individuals with few or no skin androgen receptors.

Many women don't know that it's abnormal to have dark hair growth on their bodies (especially face or low abdomen), and their healthcare providers may not notice dark hair if it has been waxed off or shaved. It's important to report dark hair growth to your healthcare provider because it can be a sign of PCOS.

Similarly, biochemical androgen excess includes elevated serum levels of androgens such as testosterone. Birth control pills will affect hormones levels, so they should not be checked until you have been off birth control for at least 4-6 weeks.

Ultrasound

A transvaginal ultrasound is an important diagnostic tool for PCOS. Polycystic ovaries on ultrasound are only present in about 75 percent of women with PCOS. The finding of 12 or more small follicles, in either ovary, meets the diagnostic criteria for polycystic ovaries (see Figure 2.1.). The follicles, usually located along the edge of the ovary, are often described as "a string of pearls." Follicular development stops prematurely so the follicles

are usually between 4 to 8 millimeters in size. PCOS ovaries are typically enlarged; sometimes they are up to three times the normal size, which can lead to pelvic pain.

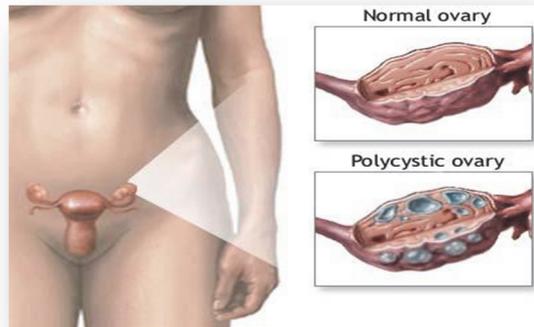


Figure 2.1. Normal versus polycystic ovary

Laboratory Tests

There is no consensus about which laboratory tests should be performed to diagnose PCOS. Tests may confirm PCOS and rule out other problems that may cause similar symptoms. Commonly the baseline tests include a TSH, total testosterone, DHEA-S, fasting glucose, fasting blood insulin, 17OH progesterone, and prolactin. Let's look at the rationale for each test:

- ❖ **TSH:** Thyroid problems can cause cycle irregularities and contribute to infertility. Testing the thyroid will rule out thyroid related causes for irregular cycles. Hypothyroidism (low thyroid) is a common problem and more common among women with PCOS.
- ❖ **Total Testosterone:** It should be less than 50 in women. Elevated testosterone (or clinical symptoms of androgen excess such as dark hair growth) meets one of the two diagnostic criteria for PCOS.
- ❖ **DHEA-S:** This is an androgen that is converted to testosterone. Elevated levels can be due to adrenal problems that can mimic PCOS. Slight elevations can be seen in PCOS.
- ❖ **Fasting blood glucose:** This helps screen for impaired fasting glucose (pre-diabetes) or diabetes. The impaired fasting glucose range is from 100 to 126. The diagnosis of diabetes is made with two or more fasting glucose levels over 126.
- ❖ **Fasting insulin:** This is used to screen for insulin resistance. The fasting insulin should be less than 10. To calculate a glucose-to-insulin ratio, divide the fasting glucose by the fasting insulin; a value of 4.5 or less may be suggestive of insulin resistance (for example a blood glucose of 80 divided by a fasting insulin of 20 = 4). Insulin levels may be helpful but are not always reliable and not necessary for diagnosing insulin resistance.
- ❖ **17OHProgesterone:** This test helps to rule out congenital adrenal hyperplasia (CAH) as CAH symptoms can mimic PCOS symptoms. The levels can also be elevated during pregnancy and while using fertility medication such as Clomid.