

# **Project PCOS**

## **better diagnosis, treatment and awareness for Polycystic Ovary Syndrome**

### **Mission statement**

Project PCOS. envisions PCOS being recognized as a significant public health concern, with any stigmas associated with the syndrome being removed. Founder Ashley Tabeling along with the PCOS Community will continue to be a vocal proponents in the media, advocacy coalitions, and educational forums, both online and within the PCOS and health related communities. People with PCOS, their families, supporters, the medical community and the general public will all be active participants in this effort.

### **History**

Founder Mrs. Tabeling, has served the PCOS community for over six years. She started out as the founder of PCOS Pals, an online support group for women and girls with PCOS and moderated the PCOS Chat series and boards under Tracy Morris, the first infertility leader at about.com.

Realizing there was a strong need for women and girls with PCOS to be able to connect one on one , Mrs. Tabeling joined The Polycystic Ovarian Syndrome Association as a chapter coordinator. Mrs. Tabeling served in various capacities for PCOSA from 1999-2004 including chapter of manager services, director of development and executive director.

Mrs. Tabeling currently serves as an advisory board member for PCOS Strategies and has been advocating for more PCOS Awareness through campaigns and appearances including; The Gloucester County Times, TLC and Discovery Health Channel, Woman's World Magazine, WCAU Philadelphia's 10! Morning show and most recently PCOS Today Magazine.

Mrs. Tabeling is currently working on an online petition which urges legislators to recognize the need for better diagnosis, treatment and awareness of PCOS and is preparing to launch Walk the Walk for PCOS, an international event to join together women and girls with PCOS and their supporters to raise awareness.

### **Location**

Ashley Tabeling is headquartered in Glassboro, NJ. She works with patients and doctors worldwide that are available for interviews, lectures and appearances. Further information can be obtained by visiting by e-mailing [ashleytabeling@yahoo.com](mailto:ashleytabeling@yahoo.com) or via phone 609-617-7499

## **A Quick Look at PCOS**

- Is also known as Stein-Leventhal Syndrome, Polycystic Ovary Disease (PCOD), Syndrome O or Syndrome X
- Is the leading causes of infertility in Women.
- PCOS is generally considered a syndrome rather than a disease (though it is sometimes called Polycystic Ovary Disease) because it manifests itself through a group of signs and symptoms that can occur in any combination, rather than having one known cause or presentation.
- There is no cure for PCOS. It is a condition that is managed through medications, diet and lifestyle changes, rather than cured.
- Is an endocrine disorder as opposed to a gynecological disorder
- At this time, there is no single definitive test for PCOS. This is because no exact cause of PCOS has been established yet. This is why there is a wide-range of opinion on how to diagnose and treat PCOS.
- Treatment of the symptoms of PCOS can help reduce risks of future health problems.
- PCOS is associated with increased risk for endometrial hyperplasia, endometrial cancer, insulin resistance, type II diabetes, high blood pressure, high cholesterol, and heart disease.
- Although up to 15 million women in the U.S. alone have PCOS, less than half know they have it!

# Symptoms Associated with Polycystic Ovary Syndrome

**Women with PCOS may have some of the following symptoms:**

- **Amenorrhea (no menstrual period), infrequent menses, and/or oligomenorrhea (irregular bleeding)** — Cycles are often greater than six weeks in length, with eight or fewer periods in a year. Irregular bleeding may include lengthy bleeding episodes, scant or heavy periods, or frequent spotting.
- **Oligo or anovulation (infrequent or absent ovulation)** — While women with PCOS produce follicles — which are fluid-filled sacs on the ovary that contain an egg — the follicles often do not mature and release as needed for ovulation. It is these immature follicles that create the cysts.
- **Hyperandrogenism** — Increased serum levels of male hormones. Specifically, testosterone, androstenedione, and dehydroepiandrosterone sulfate (DHEAS).
- **Infertility** — Infertility is the inability to get pregnant within six to 12 months of unprotected intercourse, depending on age. With PCOS, infertility is usually due to ovulatory dysfunction.
- **Cystic ovaries** — Classic PCOS ovaries have a "string of pearls" or "pearl necklace" appearance with many cysts (fluid-filled sacs). It is difficult to diagnose PCOS without the presence of some cysts or ovarian enlargement, but sometimes more subtle alterations may not have been recorded, or are not recognized as abnormal, by the ultrasonographer.
- **Enlarged ovaries** — Polycystic ovaries are usually 1.5 to 3 times larger than normal.
- **Chronic pelvic pain** — The exact cause of this pain isn't known, but it may be due to enlarged ovaries leading to pelvic crowding. It is considered chronic when it has been noted for greater than six months.
- **Obesity or weight gain** — Commonly a woman with PCOS will have what is called an apple figure where excess weight is concentrated heavily in the abdomen, similar to the way men often gain weight, with comparatively narrower arms and legs. The hip:waist ratio is smaller than on a pear-shaped woman — meaning there is less difference between hip and waist measurements. It should be noted that most, but not all, women with PCOS are overweight.
- **Insulin resistance, hyperinsulinemia, and diabetes** — Insulin resistance is a condition where the body's use of insulin is inefficient. It is usually accompanied by compensatory hyperinsulinemia — an over-production of insulin. Both conditions often occur with normal glucose levels, and may be a precursor to diabetes, in which glucose intolerance is further decreased and blood glucose levels may also be elevated.
- **Hypertension (high blood pressure)** — Blood pressure readings over 140/90.
- **Hirsutism (excess hair)** — Excess hair growth such as on the face, chest, abdomen, thumbs, or toes.
- **Alopecia (male-pattern baldness or thinning hair)** — The balding is more common on the top of the head than at the temples.
- **Acne/Oily Skin/Seborrhea** — Oil production is stimulated by overproduction of androgens. Seborrhea is dandruff — flaking skin on the scalp caused by excess oil.
- **Acanthosis nigricans (dark patches of skin, tan to dark brown/black)** — Most commonly on the back of the neck, but also but also in skin creases under arms, breasts, and between thighs, occasionally on the hands, elbows and knees. The darkened skin is usually velvety or rough to the touch.
- **Acrochordons (skin tags)** — Tiny flaps (tags) of skin that usually cause no symptoms unless irritated by rubbing.

# **Polycystic Ovary Syndrome (PCOS)**

## **Questions and Answers**

### **What is Polycystic Ovary Syndrome?**

Polycystic Ovary Syndrome (PCOS) is the most common hormonal problem in women. It is also a metabolic disorder that affects several body systems and can cause significant long-term health consequences. PCOS is often characterized by enlarged ovaries, with multiple small painless cysts or follicles that form in the ovary. Two other key features of PCOS are production of excess androgens (male sex hormones) and anovulation (the failure to ovulate properly), which makes PCOS the leading cause of infertility.

### **How many women are affected by PCOS?**

It is estimated that approximately five to ten percent of women may have PCOS, with some researchers suggesting that the number is as high as ten percent.

### **Is PCOS life-threatening?**

PCOS can be associated with a number of serious medical conditions. PCOS is frequently associated with decreased sensitivity to insulin (i.e., insulin resistance), which in turn may lead to an increased risk of adult on-set diabetes mellitus and cardiovascular disease. PCOS can also be associated with uterine and endometrial cancer. If left untreated, PCOS can lead to serious medical complications such as endometrial cancer and hysterectomy of the ovaries and uterus. PCOS affects the glucose levels of the body causing Insulin Resistance, a serious pre-diabetic condition. PCOS increases a woman's risk of heart attack and stroke because it increases cholesterol and blood pressure. PCOS is the leading cause of infertility in women. It causes Endometriosis, cysts, and early Ovarian failure.

### **What Causes PCOS?**

The susceptibility to PCOS is often inherited; however the precise cause is unknown.

### **How is PCOS diagnosed?**

While many physicians diagnose a woman with PCOS based on the symptoms listed above, confirmation of the diagnosis requires obtaining blood samples for a variety of hormones, including those produced by the ovaries, adrenal glands, pituitary gland and thyroid gland. A full physical examination and screening for cholesterol, triglyceride, glucose and insulin should also be part of a complete evaluation.

### **Is PCOS a gynecological or an endocrinological disorder?**

Since many of the symptoms involve a woman's reproductive system, PCOS is often mistaken for a gynecological disorder. It is, however, a disorder of the endocrine system, involving hormones and hormone production. Therefore a specialist in the endocrine system, such as a reproductive endocrinologist, should be consulted to confirm diagnosis.

### **Is there an overall treatment for PCOS?**

Unfortunately, at the present time doctors can only treat the individual symptoms of women with PCOS, rather than the entire syndrome. Once diagnosed, in most patients it can be managed effectively to help patients lead healthier and more satisfying lifestyles. In the meantime, research continues to determine the cause and look for new and better treatments for PCOS.

### **Are there other issues related to PCOS?**

There is often a stigma attached to many of the symptoms of PCOS, particularly facial and body hair, infertility and obesity. Some women may even suffer from depression as a result of the symptoms. Women with PCOS need emotional and social support to deal with the effects of this condition on their lives. Research has shown that a strong network of friends and family greatly enhances an individual's ability to cope with the distressing effects of the syndrome.

### **Why is public awareness of PCOS so critical?**

The symptoms of PCOS can vary significantly from one woman to the next, therefore a woman often does not realize she may have the syndrome. Public information and awareness about the symptoms and the serious nature of the disorder are crucial to identifying women in need of treatment.

In addition, for women to make informed decisions about their health management, the information upon which they base their decisions should be accurate, current, based upon well-performed research studies, and obtained from well-informed and well-trained physicians and other caregivers. This information must be easy for the general public to find and understand.

## **Quick facts and figures**

- There is no cure for PCOS, although it is treatable
- 70-90% of androgen excess is caused by PCOS
- It is the most common endocrine disturbance in women of reproductive age
- Patients who have PCOS are at higher risk for having insulin resistance, and for developing type II diabetes mellitus and possible cardiovascular disease.
- 4 in 10 cases of diabetes in pre-menopausal women can be linked to PCOS

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### **Polycystic Ovary Syndrome Carries a High Price Literally and Figuratively, So Why Is No One Talking About It?**

Polycystic ovary syndrome (PCOS) – the most common endocrine-related condition of reproductive-aged women, and a disease that causes male pattern balding in some women – affects nearly 4 million women in the U.S. and costs \$4.36 billion annually, according to a report released by The Endocrine Society. According to the Endocrine Society, screening for PCOS may reduce the overall economic burden associated with the condition. Following are highlights from the study:

- Costs from PCOS-associated diabetes = \$1.77 billion
- Costs from treating menstrual dysfunction/abnormal uterine bleeding associated with PCOS = \$1.35 billion
- Costs from treating hirsutism (excessive hair growth), a side effect of PCOS, = \$622 million. (Excess hair typically appears on the face and extremities, while hair on the head thins.)
- Costs from providing infertility care for PCOS patients = \$533 million

***These costs are compared to the costs of the initial evaluation of PCOS, which are estimated at \$93 million***

Source: <http://hairloss.about.com/b/a/256127.htm>

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### **PCOS Online Resources**

AACE - <http://www.aace.com/public/awareness/pcos/2005/>

AES - <http://www.androgenexcesssociety.org/>

PCOS Pals - <http://health.groups.yahoo.com/group/PCOS-Pals/>

PCOSA – <http://www.pcosupport.org>

Soul Cysters – <http://www.soulcysters.net>

# For Immediate Release

## Women with PCOS are finally speaking out!

**Author: Ashley Labeling**

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An online petition urging legislative leaders to recognize PCOS (Polycystic Ovary Syndrome) is now giving women, girls and supporters of better healthcare for PCOS a voice.

Up to 10% of women and girls worldwide have polycystic ovary syndrome (PCOS), a complex hormonal disorder for which there is no cure. If left untreated PCOS can be a precursor to many life threatening conditions including type II diabetes, hypertension, cardiovascular disease, stroke and kidney problems. This means PCOS contributes to some of the leading causes of death and disability in women today!

PCOS Awareness Advocate Ashley Labeling, after over six years of service to the PCOS Community is aggressively campaigning for more awareness, exposure and education for PCOS( Polycystic Ovary Syndrome ). For Ashley who was diagnosed with PCOS in 1999, PCOS Awareness has been played a key role in helping her learn to live and deal with Polycystic Ovary Syndrome and ultimately live a healthier life. Ashley says, "PCOS Awareness has to happen now to ensure women and girls do not have to go through another day, month or year of silent suffering and to ensure they are educated on how to live a healthier life with this syndrome."

What PCOS is, and what it does to women who have it, is complicated to explain as symptoms and severity of the syndrome can vary from person to person. Some of the classic symptoms are drastic weight gain, hair loss, depression, fatigue, thyroid problems, high cholesterol, panic attacks, headaches, dizzy spells, poor memory or muddled mind, sleeping disorders, constant thirst, extreme cravings, insulin resistance, cystic acne, cystic ovaries, menstrual cycles without ovulation, irregular cycles, severe mood swings, high testosterone levels, infertility problems, excess facial and body hair, not to mention a seven times greater risk than an average woman for four major health concerns affecting women in the United States today including heart disease, diabetes, endometrial cancer and stroke.

Now women who have spent their lives trying to come to terms with living with and understanding PCOS are asking for change, awareness and support with The PCOS Treatment and Awareness Petition which has recently been added to petitiononline.com

<http://www.petitiononline.com/pcosweb1/petition.html>

Women have not only been adding their signatures but, been expressing the reasons why more involvement from medical professionals insurance companies and the mainstream media are important. Women like Jean Murphy of New Hampshire address some of the many reasons why this petition is important. She states, "I run a support group for women with PCOS. I would like the House and Senate leaders to address the insurance companies so they will recognize and pay for not only treatment but complications of this syndrome. Diabetes, heart disease and cancer is costing the insurance company in unnecessary expenses if they would just pay for diagnosis and treatment of symptoms and also the costs of infertility caused by PCOS."

Because PCOS can cause some many physical and emotional complications, it is important for early detection, treatment and support. Chryis Wise of Georgia agrees, "I started showing signs at a very young age and went undiagnosed for many years. As a young girl, it was very hard when doctor after doctor kept telling me nothing was wrong!! Now, I know all the symptoms together equal pcos."

Thankfully this petition is not only raising awareness and gaining support, it is giving women, their families and supporters of PCOS awareness a voice, a strong voice that will hopefully incite, inspire and invoke change for better health, treatment and support of this syndrome.

## FOR IMMEDIATE RELEASE

### **PCOS – overcoming fears and barriers**

Sarah Yocheved Goldstein

New York

I found out I had PCOS when I was 24, a completely Orthodox Jewish woman. This is important, because it determines how I made some of my medical decisions. By now my weight was 230, after struggling with symptoms and misdiagnosis throughout my teens. Prior to my wedding in 2002 I had lost weight and had normal cycles. After my wedding, my cycles became very irregular and I went to my primary care physician to take a pregnancy test, which came back negative. He sent me to a Gynecologist, who very bluntly told me I have PCOS and there was little he could do for me. He sent me to a reproductive infertility specialist, who recommended that I have an HSG done to see if anything else was wrong, as at 19 I had gotten a case of Chlamydia. The test determined that my fallopian tubes were filled with fluid-filled scars, and I was told that IVF was my only option. By this point in my life I was 280, and was told if I did not lose at least 100 pounds this specialist would not help me in terms of IVF.

I went to a rabbi in my area who was known for his vast medical knowledge, and was advised to wait a year, to see if new treatment would develop. I was advised that I was still a newly wed- and to deal with this, after my husband and I were a stronger unit. I waited, as was advised and in Dec 2003, I started the course of treatment that would change my life. By this time I was 302 lbs, I had asthma that needed daily medications, my knees would give out on me, I had acne, excessive hair...and what I call the horrible hungers. As in I would wake in the middle of the night, screaming from pain and crying for cereal, crackers, anything to eat at all...just as long it was a carbohydrate and would make the pain go away. I would go out with my husband at the time and eat a huge meal in a restaurant, and sometimes right after leaving the restaurant I needed more food. Nothing would stop this, whether I ate salad or pasta, Nothing. I was terrified and furious all at once. I could not control what was happening to me. I went to a reproductive endocrinologist, who recommended Metformin, and after all the opinions of my primary care physician, the infertility specialist, and the reproductive endocrinologist, gastric bypass was given to me as an option. I was above and beyond as a candidate, and after securing blessings from my rabbis, I started that course of treatment.

In Aug of 2004, I had the surgery, a Roux en Y, which bypasses all but a thumb sized portion of the stomach and a large percentage of the intestine. I was told if I lost 75-90, considering I have PCOS and severe insulin resistance, the surgery would be a success. After leaving the hospital from the surgery 6 days later, I was down 20 lbs, and had my first period in years without the help of medications. I was told it was a fluke, a result of the shock that my body was feeling from the surgery. I did not believe that, and after speaking with my rabbi was told not to believe that either. Sure enough, 29 days later, I had a cycles again and this continued to be the pattern.

Finally when thing seemed to be on the right track, in September 2005, I did not get a real cycle and I panicked thinking the PCOS was coming back, after a year and a few months of losing weight, regular periods and hard work. I was told by the rabbi I went to for all my medical questions to take a pregnancy test! That was impossible, I thought due to my complications with my fallopian tubes and PCOS! I went to my primary care physician, had a blood test and was told I WAS pregnant!

So, why do I tell you all of this?

Because so many women with PCOS feel they will never conceive, that PCOS is a death sentence to a dream. It does not have to be! If I had been better educated, if my doctors earlier on had been educated, I might not have needed the surgery.

PCOS does not mean you can not conceive! It just makes your job a bit harder. I hope and pray daily that doctors will get more aggressive with treatment, ladies will educate themselves better, and insurance companies will give preventative treatment instead of waiting until a woman needs drastic measures to regain her life! It is my blessings that whoever helps in this, and any woman that educates herself and aggressively takes part in her care will experience some success, whether the return of her health and vitality, or the eventual birth of a child.

## **FOR IMMEDIATE RELEASE**

### **My PCOS Story Kimberly Saks Michigan**

My PCOS story began at an early age. I was always the first child in my class to develop—whether it be with regard to height, weight, shoe size, any immutable quality. I started wearing a bra at the age of 8 and got my first period at the age of 9. At the time, I never realized anything was different about me—just quicker. I was considered “overweight” from the age of 8 on. Doctors would try everything to get me to lose the extra pounds which, in hindsight, were probably not that detrimental. I was told that I was lazy by doctors, offered forms of speed to increase my metabolism and even told that if I didn’t lose weight that a doctor might, one day, have to stick a needle in my heart if I had a heart attack.

At the age of 12 I began having serious bouts of depression. I was originally sent to a social worker and placed on Zoloft. When that no longer worked, at the age of 14 I was switched to Paxil without much thought to side effects, and after self-mutilating episodes landed in the hospital. My medicine was changed to Prozac and I entered therapy with a new therapist after that time. I learned to control that part of the disease through medicine, activity and therapy.

After having steady and overly-predictable cycles for approximately seven years, at the age of 16 I had a stretch of 6 months without a period. A family doctor gave me a five-day dose of hormones to “jump-start” my period. That worked once, but when it didn’t work again I requested another doctor. A caring and intelligent young intern noticed the correlation of many of my medical conditions—the weight, the depression, and the break in my cycles. She diagnosed me with Polycystic Ovarian Syndrome (PCOS) right away and placed me on birth control pills to regulate my periods.

The birth control, though helpful for that one symptom, did not help regulate any other symptoms of the syndrome. When I was 20-21 I did research regarding PCOS and found a corollary condition—Insulin Resistance—which seemed to describe me perfectly. My family doctors told me that I was incorrect—that they did not test for such a disease and did not prescribe medicine for such a disease and sent me on my way. After again switching doctors, I was diagnosed with Insulin Resistance—with insulin levels twice as high as the normal person. Although the doctor I was seeing attempted to place me on insulin-controlling medication, the medication proved to be too harsh on my stomach and so I stopped taking it.

I am now 24 years old. Approximately one year ago, after reading a story regarding Type II diabetes and Insulin Resistance in the news, I decided it was time to take control of my health. I started to see an endocrinologist after my primary care physician refused to place me on a regular dose of proper medicine. I was given Metformin, an insulin controlling medication. I started on a low-carbohydrates diet, and began working out (a habit that I had for awhile, but because of the insulin resistance never led to genuine weight loss). I have lost approximately 50-plus pounds since then and continue on both the Metformin and birth control to help my symptoms. It is my hope to get to a healthy size in the next three years and within the next ten years, be able to start a family without many fertility complications.

# FOR IMMEDIATE RELEASE

## PCOS Then and Now Robin Brooks Radel Pennsylvania

I got my first period in the summer, at age 12. My Mom made such a big deal, I felt like I accomplished something. It was a special bonding moment for us both. Neither of us anticipated there would be anything unusual about me. But that first period might have been the only normal period I ever experienced. But even before that summer day, there were subtle indicators that something was different about me. When I was about 9, I had an unusual growth spurt. In fact, I went from a very small kid to an overweight kid, all in the space of a few months. By that summer I was 12, I was considered a 'pretty plus' size, and I had a couple of dark hairs growing on my chin.

I never had regular periods, in fact, it was rare that I had more than 2 or 3 a year, so by the time I turned 18, I knew something was wrong with me. I had a few other symptoms, I had this ugly brown line around my neck, and I now had enough dark hairs on my chin that I had to remove them. I also was significantly overweight. But I never put these symptoms together; I was most concerned about the lack of periods. The first doctor I saw was my Mother's OB/Gyn. Dr F was an older man when I met him, nearing retirement age, but still considered a very good physician, huge patient load and part of a large suburban practice. My experience with Dr F was humiliating, to say the least. I was instructed to disrobe and my Mother was not allowed to come into the room with me. Dr F was her doctor, so she never thought twice about this, and remained seated in the waiting room. Naked, covered only in a paper robe, the nurse asked me to jump up on the table, and place my feet in the stirrups. I waited, alone in that room for what seemed an eternity. When Dr F finally arrived, I was in tears and experiencing what I now know to be a panic attack. He did the exam, which I found very painful, and rough and he asked questions while he performed the exam. Eventually, he asked me why I was there, and I told him I hadn't had a period in about 18 months. Surprisingly, he told me that was no a big deal, that 'most girls would be thrilled not to have to deal with their period'. He leaned back in his chair, and rested his foot on the stirrup, while I was still lying there, vulnerable and exposed. "I think you are overreacting" he told me, but gave me a script for Triphasil.

I started triphasil the next day and took it for the next 3 years. I had regular periods but the other symptoms worsened. I still had the dark hairs and they were too numerous to pluck, and the brownish gray lines on my neck worsened, and in fact, I had similar skin discolorations on other parts of my body. I asked my family doctor about it, and he didn't know what it was, but he said, 'sometimes patients with obesity present with this on skin folds. Keep the area clean and it should help.' So I was fat and dirty, too.

At about 22, I went to a new doctor, for a regular check up and Dr. B wanted me off the birth control pills, as He felt they were unhealthy for me, as blood work showed higher triglycerides and she was concerned about my blood pressure. Once off the triphasil, it took less than 6 months to realize there was something seriously wrong with me. My periods were few and far between, and when I did have a 'normal' cycle, I would bleed for weeks at a time. But I just assumed it was because I was so grossly overweight. At this point, I was about 260 lbs, and I didn't understand why... I still lived at home and ate essentially what my parents ate, yet I gained and gained and even when I ate low fat, I still gained. The dark lines on my skin were even worse, and I was noticing that more and more hairs were growing on my chin. I was also dismayed to realize that my once very thick hair was getting more and more thin.

I went to a new ob/gyn at the request of my primary care doctor, as Dr B didn't know what was wrong with me, and it seemed to be a gynecological problem, anyway. Thus began the parade of doctors. Over the next 7 years, I saw 17 more doctors. I saw internists and Ob/GYNs and even a psychiatrist. They all said my problem was weight based. If I just ate less and exercised more, I would be all fixed. But I did eat less; I eat so little I worried my family. I had a high energy job (I ran a department store) and still I did not lose a pound. More and more hairs appeared where they were not supposed to be, and I was horrified to realize that my scalp showed through when I parted my hair. Over and over, I tried to find answers, but no one ever realized that all these seemingly unrelated symptoms were all Endocrine related. More than once a doctor wanted me to go back on Triphasil, but I was (and still am) convinced that this pill made all my symptoms flair up!

For a long time, I took a break from all doctors. I was just so tired of being told I was tired, or lazy or hysterical. Whatever was wrong with me was making life very difficult in so many areas and frustration was a way of life. Intimacy was out of the question, as I was morbidly overweight, and besides that the excess hair was horrifying to me, so I couldn't imagine a man's reaction to my 5 o'clock shadow.

In 2000, at age 30, I started to hear about this weight loss craze, this low carbohydrate idea. I read one of the books, and the idea of eating lots of bacon or steak at one sitting made me feel sort of ill, but I kept an open mind. I read several books, Protein Powers, Sugar Busters. Potatoes, not Prozac and finally, The Carbohydrate Addict's Diet. I liked the Carbohydrate Addicts Philosophy and I started to look for more research. I found an article in Women's Day Magazine, about a woman named Wendy. She was losing weight with this new diet, nicknamed CAD, and she had an interesting story. She told of a rapid weight gain, a velvety brown mark on her skin, hair loss on her head and excess hair everywhere else. Oh, and skipped periods, just like me. I felt as if I were floating; the idea of someone else like me was so foreign, so exciting and so validating! I wasn't crazy, this was a disease! It had a name! It was called Polycystic Ovarian Syndrome, or PCOS. I searched books and magazines and the internet until I was armed with enough information to take to a doctor. I took a recommendation from a friend and went to her family doctor, Dr. Karen Woods, MD.

Dr Woods did an exam, read my materials and told me, 'you seem like a classic case of PCOS'. We did lots of blood work, and I felt myself tearing up in her office. I told her, I was starting to believe all those doctors, 18 total, who told me it was all in my head, it was all because I was fat, and I was fat because I was lazy and undisciplined. I cried steadily the whole way, home, and we didn't even have blood tests results yet!

A few days later, blood work confirmed what we both suspected. It was PCOS, and I seemed to have Insulin Resistance as well. The next step was to find an endocrinologist that would confirm these findings and do an ultrasound for cysts. I found Dr Michael Birnbaum, in Jenkintown PA, and set up an appointment right away. The day I met with Dr Birnbaum, I was terrified, as my first pelvic exam always comes to mind. But I met with him fully clothed first, in his office. He set me at ease immediately, telling me he agreed with Dr Woods, and that his exam will most assuredly confirm her (and my!) diagnosis. It was a full pelvic exam, and it ended with a transvaginal ultrasound.

Afterward, quite a few vials of blood were drawn, and Dr. Birnbaum once again saw me in his office. We talked a bit about diet and exercise and keeping healthy overall, he told me my glucose was quiet high and that diabetes was a concern and then he prescribed Glucophage. Glucophage is an insulin sensitizing drug that seems to work well with PCOS patients, as insulin resistance seems to go hand and hand with the syndrome. I credit Dr Birnbaum and Dr Woods with changing my life. I joined several PCOS groups and educated myself as best I could. I had a disease, a syndrome, a collection of symptoms that meant something. It meant I was not crazy; my body was not operating correctly. It could not be cured, but it could be treated.

That was 6 years ago. Today I am happily married to Todd, who understands all about PCOS and is very supportive, and we working with Dr. Birnbaum on conceiving our first child. Unfortunately, I am now a Type II diabetic and I am trying very hard to control my blood sugar through diet, exercise and Glucophage. I often think that had one of those 18 doctors looked a bit harder, or listened or bit, or did some research, I might not have become diabetic. Sadly, it seems none of these respected physicians knew what to look for regarding PCOS and even misdiagnosed symptoms. The brown patches are called Acanthosis Nigricans and they are found frequently with insulin resistant patients. The hair loss and gain was due to excess testosterone, which is a key sign in PCOS. But none of these doctors put it together. I'd like to change that. I'd like woman to know that PCOS exists and it can cause infertility, high blood pressure, heart disease, increased risk for some cancers, excess facial hair, hair loss, and diabetes I'd like woman to be educated and to pursue good health care. I'd like insurance companies to know that this is an endocrine disorder and therefore prevent them from denying treatment. I'd like my children to understand this disease, as it seems there is a hereditary link. I'd like doctors to understand that PCOS is not a fertility disorder, it is an endocrine disorder, and it can be treated. Maybe someday, it can be cured. Until that day, awareness is the most powerful weapon.

# FOR IMMEDIATE RELEASE

## **My Life with PCOS** **Deborah Cardoza**

Since the day I hit puberty at 14, I somehow knew I would have fertility issues, though at the time I had no idea why. My cycles have always been very irregular and I had facial hair. Being of German ancestry, I just assumed the facial hair was normal.

It wasn't till years later that I came across a short article in a magazine, I believe, that talked about PCOS and some symptoms. And those symptoms fit me! I went to my internist who ran some tests. While the tests didn't support a PCOS diagnosis, my doctor believed I did have it due to my symptoms. I was thin, young, and didn't know much so the only thing I did about my symptoms was to go for laser hair removal, which didn't wind up working and left me to start my face every morning, again. Boy, does that make a woman feel feminine.

Over the next few years I did not give my symptoms much thought. In 2001, my husband and I decided to start a family. Knowing I would have problems, we went straight to a reproductive endocrinologist. Pre-IVF testing this time showed I did have PCOS. The doctor put me on Metformin to help me lose weight before any cycles to conceive. I wasn't on it for long when my husband and I decided to build our family another way. My weight wasn't a big issue at the time, and I still didn't know all I do now about PCOS, so I stopped taking the Metformin.

To build our family, we chose surrogacy – traditional surrogacy. That involves having someone else carry your child and having that same woman donate her egg. When my husband and I were deciding on which option to pursue, it occurred to me one day that I might pass on PCOS and any other fertility issues to her. I realized it was no guarantee, but if I could avoid it, I was going to do it. I just wanted to be a mom and it truly didn't matter how that happened.

I'm now at a point in my life where I need to do something about my weight and my health. When I entered my second marriage, I was so incredibly embarrassed about having to shave my face every day. I don't think I told anyone ... and I mean anyone ... until about two years ago, not even my husband. Thankfully, he's an incredible man and it made absolutely no difference to him ... neither the hair nor the weight. But, I need to get and be healthy for my daughter. I want to be around for the long haul, especially since I'm an older mom. I have the self-confidence every woman should have because of who they are on the inside. I wish I had this all along and will do all I can to instill it in my daughter.

I'm lucky. I don't have debilitating symptoms that some women with PCOS do. Right now, I'm thoroughly educating myself on PCOS so I can help others, and to get the word out and educate the public so no woman with PCOS ever feels embarrassed by what others may think.

Knowledge is power, right?

## **FOR IMMEDIATE RELEASE**

### **One Woman aims to change the world's view on PCOS**

**(Glassboro, NJ) June 5, 2006** PCOS Awareness Advocate Ashley Tabelaing, after over six years of service to the PCOS Community is aggressively campaigning for more awareness, exposure and education for PCOS( Polycystic Ovary Syndrome)

For Ashley who was diagnosed with PCOS in 1999, PCOS Awareness has been played a key role in helping her learn to live and deal with Polycystic Ovary Syndrome. Ashley says, "PCOS Awareness has to happen now to ensure women and girls do not have to go through another day, month or year of silent suffering".

Up to 10% of women and girls worldwide have **polycystic ovary syndrome (PCOS)**, a complex hormonal disorder for which there is no cure. However, with proper education, diagnosis and treatment, effective management is possible. For many, like Ms. Tabelaing Polycystic Ovary Syndrome means having to face daily battles with a range of symptoms that can vary from woman to woman such as infertility, dark skin patches, obesity, acne, hair loss, excess facial and body hair and skin tags. " PCOS is a physical and emotional drain on many individuals with the syndrome due to the devastating external manifestations and hormonal imbalances produced as a result of this syndrome", says Mrs. Tabelaing.

Ashley plans to incite, inspire and empower the PCOS Community to speak very openly about their struggles, symptoms, and trials to overcome the illness, to help other women and girls understand the syndrome and seek the proper resources to help them manage their lives with PCOS. She hopes to be a driving force in changing the way the public, media and government views PCOS education, treatment and coverage for medical procedures and treatments, as a result of PCOS. " I find it very unsettling that male impotence medications are covered by most insurance companies but, women who have a legitimate endocrine disorder that requires the care of a doctor and specific medications have to struggle come up with money so they can receive the proper treatment!", says Mrs. Tabelaing.

Ashley 's desire to spread awareness stems from what she and many other women with PCOS have gone through, years without the proper diagnosis and not knowing what was truly wrong. Thousands of women from around the country have experienced the same lack of response from the medical community with little understanding of PCOS and the best way to treat it. Many medical professionals still view the syndrome as a gynecological problem and only address the syndrome when issues of infertility arise. As a result, single women, older women and those not trying to get pregnant often still have little chance of being diagnosed.

Prior to a few years ago, PCOS had been largely misunderstood and rarely diagnosed. "The information to make a proper diagnosis just wasn't there," said Ashley. "Your concerns, in many cases, would have been dismissed. Now the medical community is realizing it is more than menstrual irregularities, it's a lifelong condition that can take years off of your life", says Ashley. Part of the problem, then and now, is that the PCOS symptoms manifest themselves in different ways. In fact, not all affected women have polycystic ovaries. Women with PCOS can have any combination of symptoms of varying severity. As a result, researchers, doctors and women themselves looked at the symptoms individually rather than collectively.

"It Is my personal goal to ensure every medical professional makes the proper diagnosis. Furthermore, I think girls who are coming of age should learn about PCOS when they are learning about sex education in school ", said Ms. Tabeling, who continues to dedicate her life to PCOS Awareness and Advocacy.

For additional information including interviews and appearances with Ashley Tabeling and/or a medical professional specializing in PCOS, please contact:

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## **Backgrounder:**

Mrs. Tabeling has worked diligently with the PCOS Community over the past six years, starting with a Yahoo Group called PCOS Pals, now a sprawling community with over 1100 members!  
<http://health.groups.yahoo.com/group/PCOS-Pals/>

She also worked with The Polycystic Ovarian Syndrome Association from 1999-2004 in various capacities including Director of Development and Executive Director. Mrs. Tabeling continues to advocate for better treatment and awareness for PCOS with and online PCOS Awareness Petition and has made appearances to raise PCOS awareness including; Discovery Health Channel, TLC, Gloucester County Times, Woman's World Magazine and PCOS Today Magazine.