

Primary Ovarian Insufficiency

Introduction

Primary ovarian insufficiency was a topic I thought I knew nothing about. If one is not familiar with the more “medical” term, as I was not, it seems like a disease or chronic illness. I learned quickly that primary ovarian Insufficiency, sometimes called premature ovarian insufficiency or simply ovarian insufficiency, is almost another name for premature menopause. Menopause, the cessation of menstrual periods and production of eggs thus diminishing a woman’s ability to get pregnant, is normal with aging. The problem that comes with Primary ovarian insufficiency, hereby referred to as POI, is that this process takes place in women less than 40 years of age, thus presenting a problem for women of childbearing years. Though it is not premature menopause in a sense that women may still have monthly periods and have a chance to become pregnant, it is not likely, and it brings along more health issues.

POI is devastating especially to women who are of childbearing age or who want to start a family, as the capability for fertility drastically is diminished. 1 to 4% of women are affected by this disease and because of it; only 6 to 8% of those cases will ever bear children. POI has no set group of women who it traditionally affects and its root cause is still unknown.

- **Web site #1 Name:** (Note: Healthy People 2010 does not provide any information about this topic, therefore I was able to find information regarding POI on the following site) International Premature Ovarian Failure Association (http://www.pofsupport.org/information_center.asp)
- **Web address:** <http://www.runmyclub.com/IPOFA/ClientFiles/English%20Fact%20Sheet.pdf>
- **Background Information:**
 - POI is a disorder in which the cause is mainly unknown. It “is an endocrine disorder and has serious health consequences that must be addressed”. Symptoms of the disorder range from skipped periods and hot flashes to mood swings, energy loss, dry eyes, and even sleeping problems. This disorder affects anywhere from 1 – 4% of the female population. One of the most interesting things about POI is that the cause is unknown, and there is no set group that it traditionally always affects. Sometimes, POI is a result of preexisting conditions that it comes from, and sometimes it occurs on its own. Because the disorder sometimes strikes women of such a young age, the news that one has this disorder can be devastating especially if the POI is permanent and she finds herself unable to be able to bear children.

- **Web site #2 Name:** New England Consortium of Metabolic Programs
- **Web address:** <http://newenglandconsortium.org/for-families/galactosemia/galactosemia-and-primary-ovarian-insufficiency-poi/>
- **Background Information:**
 - Because of POI, a woman's ovaries are not producing estrogen. This estrogen is vital to keeping a woman healthy because it keeps her bones strong. This deficiency of estrogen brings along many bone-related health problems such as osteoporosis. The lack of estrogen also affects heart health. POI sometimes though, is not permanent, and a woman may find herself ovulating on and off for a period of time. This is what makes it different to actual menopause. In menopause the cessation of egg production is generally permanent, and in POI there is chance for that to change.
- **Web site #3 Name:** Project Vital Sign
- **Web address:** <http://www.projectvitalsign.org/>
- **Background Information:**
 - It is important to diagnose POI as soon as possible, which is why women should look for the signs as soon as one arises. If a woman suspects that she does have POI there are a few tests to confirm or dismiss the possibility of it. One such test would measure levels of follicle stimulating hormone (FSH). If the FSH level was high, it could be a possibility. Another test would be an Anti-Mullein hormone (AMH) test to check to ovary itself. A large problem with POI is that many women don't know they have it until it's too late, as the signs are disregarded and overlooked. This is why it is important to raise public awareness to this issue and educate women on how to get help as soon as possible.

Section 2: Research

Web site #1 Name: The Journal of Clinical Endocrinology & Metabolism - High Prevalence of Primary Ovarian Insufficiency in Girls and Young Women with Nijmegen Breakage Syndrome: Evidence from a Longitudinal Study

- **Web address:** <http://jcem.endojournals.org/cgi/content/abstract/95/7/3133>
- **Summary of the research:**
 - This study sought to monitor the "growth and sexual development, along with hormonal assays, were evaluated in girls and young women with NBS homozygous for c.657_661del5 mutation". The test subjects were females aged from one year old to 24 years old. In the results of this study "none of the patients presented a typical growth spurt; the adult height ranged between the 3rd and 25th centiles". The conclusion to this study identified that "primary ovarian insufficiency and the associated hypergonadotropic hypogonadism are hallmark manifestations in girls and young women with NBS. Our findings emphasize the need for long-term endocrinological and interdisciplinary supervision of these patients".

- **Web site #2 Name:** The Official Journal for the American Society for Reproductive Medicine - Sexual function in young women with spontaneous 46,XX primary ovarian insufficiency
- **Web address:** [http://www.fertstert.org/article/S0015-0282\(07\)03222-0/abstract](http://www.fertstert.org/article/S0015-0282(07)03222-0/abstract)
- **Summary of the research:**
 - This study wanted “to assess sexual function in women with spontaneous 46, XX primary ovarian insufficiency after at least 3 months of a standardized hormone replacement regimen”. The hormones would replace those not being created by the ovaries as a result of POI. What this study found was that “women with primary ovarian insufficiency had significantly lower DISF-SR composite scores compared with control women”. This allowed the experimenter to conclude that “as assessed by the DISF-SR, sexual function is in the normal range for most young women with 46, XX spontaneous primary ovarian insufficiency who are receiving physiologic E2 replacement. However, as a group, these young women score significantly lower on this sexual function scale than control women”. So the theory was proven.

- **Web site #3 Name:** Eunice Kennedy Shriver National Institute of
- Child Health and Human Development (NICHD) - Most Young Women with Menopause-like Condition Retain Store of Eggs
- **Web address:** <http://www.nih.gov/news/health/apr2010/nichd-26.htm>
- **Summary of the research:**
 - Inability to retain the store of eggs is the problem women with POI face that is their main struggle against fertility. The study found that women who have this actually do “have immature eggs remaining in their ovaries... raising the possibility of developing treatments for the infertility that accompanies the condition”. This raises hope for women that they will actually be able to have children. “The findings expand on earlier research showing that ovulation is possible in this group of patients.” When ovulation is possible then fertilization is possible.

Section 3: Statistics

- **Web site #1 Name:** International Premature Ovarian Failure Association (http://www.pofsupport.org/information_center.asp)
- **Web address:** <http://www.runmyclub.com/IPOFA/ClientFiles/English%20Fact%20Sheet.pdf>
- **Summary of the statistics:**
 - Statistically, POI affects anywhere from 1 – 4% of the female population. This would translate to about 250,000 to 1,000,000 women in the US alone who this disease would affect. A worse statistic regarding POI is fertility rate. Because of POI hormones are imbalanced and egg production is inhibited. This may make women who would normally be considered of ‘fertile age’ incapable of pregnancy. Of those diagnosed with POI, only 6 – 8% of all cases will actually

ever become pregnant. This brings great stress to women who do want to start families as they are incapable of doing so.

- **Web site #2 Name:** American Pregnancy Association
- **Web address:** <http://www.americanpregnancy.org/womenshealth/pof.htm>
- **Summary of the statistics:**
 - “Approximately 1 in every 1000 women between the ages of 15-29 and 1 in every 100 women between the ages of 30-39 are affected by premature ovarian failure (POF) also called premature menopause.” Still, a woman can be affected by POI at any time in her life. “Menopause usually occurs on average around age 51. Premature ovarian failure can occur at any age before 40, usually on average around age 27.” Even though this is a median age, POI still affects women a variety of ages, but the increase significantly jumps once woman hits 30.

- **Web site #3:** Project Aware – Premature Menopause
- **Web address:** <http://www.project-aware.org/Experience/premature.shtml>
- **Summary of the statistics:**
 - POI affects those that have it in a difficult way. Many women find themselves unable to cope with this if they are trying to have children and must face the fact that their chances to do so may be impossible. There are many support groups that allow women to share stories and help each other to cope with the difficult news of POI. The support groups advocate the use of estrogen and artificial hormones and explain how even using BCP (birth control pills) would have an opposite reaction on someone with POI and actually would enable them to become pregnant.

Section 4: Consumer Information

- **Web site #1 Name:** Stanford IVF
- **Web address:** <http://www.stanfordivf.com/poi.html>
- **Summary of the information:**
 - “Primary Ovarian Insufficiency (POI) is a condition in which a woman is running low on her egg supply or is completely out of eggs before the age of 40.” Though sometimes confused with early menopause or menopause itself, “many experts now believe that POI is a more accurate term because in many cases the ovary has not completely “failed” and instead may still function to produce hormones or release eggs”. IVF treatments are sometimes needed and required to help with this. In IVF, “oocytes (eggs) are retrieved from the ovary and placed in a Petri dish with active, motile sperm. Because fertilization occurs in the Petri dish rather than in the woman’s body, this process has been called “in vitro.” This gives women a higher chance at fertility.

- **Web site #2 Name:** Mayo Clinic - Premature Ovarian Failure

- **Web address:** <http://www.mayoclinic.com/health/premature-ovarian-failure/DS00843/DSECTION=lifestyle-and-home-remedies>
- **Summary of the information:**
 - “When premature ovarian failure does cause infertility, however, fertility treatment is unlikely to be successful. Restoring estrogen levels helps prevent other complications of premature ovarian failure, such as osteoporosis”. Pregnancy is always the most devastating complication of POI. Risk factors of POI include both age and family history. 10% of cases are due to family history, and with age, the risk rises significantly as women get older. “The incidence of developing premature ovarian failure is about one in 250 by age 35 and one in 100 by age 40”. POI’s complications go further than infertility and osteoporosis but also include depression or anxiety. “The risk of infertility and other complications arising from low estrogen levels may cause some women to become anxious or depressed”.
- **Web site #3 Name:** Orphanet Journal of Rare Diseases
- **Web address:** <http://www.ojrd.com/content/1/1/9>
- **Summary of the information:**
 - “Premature ovarian failure is defined as a primary ovarian defect characterized by absent menarche (primary amenorrhea) or premature depletion of ovarian follicles/arrested folliculogenesis before the age of 40 years (secondary amenorrhea)”. Also, the symptoms to POI may have a sudden onset that feels like it came out of nowhere, or the symptoms may be a slow developing process of a period of time. The sooner POI is found, the better. “The early diagnosis of familial POF will provide the opportunity to predict the likelihood of early menopause, and allow other reproductive choices to be made, such as freezing embryos or having children earlier.”

Section 5: Solutions to the Problem (or Issue)

- **Web site #3 Name:** Project Vital Sign
- **Web address:** <http://www.projectvitalsign.org/>
- **Summary of the information:**
 - “The most common treatment option to help alleviate some of the symptoms caused by lack of estrogen is Hormone Replacement Therapy (HRT). HRT consists of two types of hormones called estrogens and progestins. There are different prescription medicines available that contain these hormones”. This hormone replacement therapy works to do what the ovaries cannot. Even if it cannot actually help a woman to get pregnant it can help her avoid the secondary health issues that come with POI. Women who have POI must also work to keep healthy. “A woman diagnosed with Primary Ovarian Insufficiency / Premature Ovarian Failure should get plenty of weight bearing exercise on a regular basis and stay as fit as possible. In general, weight bearing exercise is good for the bones and muscles. Also, cardio-based exercise is good for the heart and lungs”. Exercise helps to keep a woman’s already affected bones healthy.

- **Web site #2 Name:** Endocrine Online
- **Web address:** <http://www.endocrineonline.org/pdf%20box/pof.pdf>
- **Summary of the information:**
 - “Progesterone is required for all women with an intact uterus in order to avoid endometrial hyperplasia induced by unopposed estrogen. Testosterone supplements are rarely required when the adrenal gland continues to supply androgens.” These artificial hormones help to keep the woman healthy. Sometimes, if a woman is sexually active but does not wish to become pregnant, the hormone therapy will be accompanied by an IUD (intrauterine device) to prevent pregnancy while still allowing the woman to take her hormones. This mix of hormones and contraceptives would allow the woman to get the estrogen that her body needs while still avoiding pregnancy.

- **Web site #3 Name:** National Center for Biotechnology Information -
- **Web address:** <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1502130/>
- **Summary of the information:**
 - “Patients with POF have infertility and hormone deficits. At present, fertility cannot be restored if the diagnosis is made after complete follicular depletion. In some cases, early diagnosis by genetic investigation may instead lead to advice for early conception or oocyte harvesting and preservation.” One solution, if found early enough, would be to freeze eggs which would be saved until the woman did want to have children.

Conclusions

Primary Ovarian Insufficiency occurs when a woman who should be considered in the range of child bearing age, is unable to produce estrogen in her ovaries. This has health effects which include health risks of the bones and heart due to a lack of estrogen and also depression and anxiety both from the lack of hormones and from infertility. Infertility is the most devastating effect, as only 6 to 8% of all cases of women with POI will ever be able to bear children. There are some proposed solutions in order of treatments. Hormone therapy, usually referred to as HRT or hormone replacement therapy, is necessary to keep a woman with POI physically healthy but also may provide hope that if she is one of the few of the percentage that can become pregnant, she may be able to do so. Risk factors of POI include both age and family history. 10% of cases are due to family history, and with age, the risk rises significantly as women get older. There are also some risk factors, for example using a BCP for a long period of time or even smoking, are known to onset menopause earlier. Still POI has no exact cause and a woman can't completely blame herself. Though news of the disease is devastating, with support from those around her, a woman can get through POI and live a full, happy life.

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