PREMATURE OVARIAN FAILURE (POF) FACT SHEET

Who: Approximately 1- 4% of the female population has Premature Ovarian Failure (POF). That equates to about 250,000 to 1 million women in the United States alone.

What: Women are generally born with enough eggs in their ovaries so that they ovulate one each month from puberty until about the age of 50. At that time, the supply of eggs is used up and menopause occurs. But, in girls and young women with POF, something has happened to the supply of eggs in the ovaries at a young age. It could be a loss of eggs, a dysfunction of the eggs or the removal of the ovaries at a young age. Unlike menopause, this is not a natural occurrence. This loss of ovarian function is occurring at too young an age to be considered a natural, although premature, menopause. Premature Ovarian Failure usually occurs in women under the age of 40 and can happen as early as the teen years.

Symptoms: Women with POF stop having periods. Sometimes their periods may be normal for a few months and then skip a few months. They may also have hot flashes or night sweats. It is possible to still have periods and have hot flashes. Other symptoms may include sleeping problems, mood swings, vaginal dryness, energy loss, low sex drive, painful sex, and bladder control problems.

Causes: Many times the cause behind POF is unknown. For a few women, however, a cause can be found. Some causes include:

Chromosomal/Genetic

Turner syndrome Swyer syndrome

Androgen Insensitivity Syndrome Associated with Fragile X syndrome

Familial

Enzyme defects/Metabolic

Galactosemia

Thalassemia major treated with multiple blood transfusions

Hemochromatosis

Chemotherapy/Radiation therapy related

Surgical - removal of the ovaries

Viral infection

Abnormal gonadotropin (FSH and LH) secretion or action

Autoimmune disease. Some of the diseases <u>associated</u> with POF:

Thyroid dysfunction

Polyglandular failure I and II

Hypoparathyroidism Rheumatoid arthritis

Idiopathic thrombocytopenia purpura (ITP)

Diabetes

Pernicious anemia Adrenal insufficiency

Vitiligo

Systemic lupus erythematosus -also called

SLE or Lupus

Diagnosis: If you skip your period or have hot flashes, see your doctor <u>soon</u>. POF is more than a GYN problem. It is an endocrine disorder and has serious health consequences that must be addressed. Make sure you prepare for your visit. Be ready to tell your doctor about your menstrual cycle changes, symptoms like hot flashes, and whether you've had ovarian surgery or radiation therapy. Tell him/her whether you have any endocrine disorder, any recent infections such as pelvic inflammatory disease, or a family history of POF. Some doctors may try to blame your symptoms on stress. Be prepared to insist on testing to eliminate POF as a problem. Take this fact sheet with you, show it to your doctor, and ask for a work-up that includes two FSH tests done a month apart. FSH stands for follicle stimulating hormone and is a blood test that indicates if the ovaries are working correctly. Normal FSH levels are 10-15 mlU/ml and under; women with POF often have FSH levels above 40 mlU/ml (post-menopausal range). For a more thorough list of tests done to diagnose POF and its causes, visit the POF WebSite.

Consequences: Health concerns for women with POF include osteoporosis and an increased risk of heart disease. POF is sometimes associated with autoimmune disorders (such as thyroid problems, diabetes or adrenal problems) that may require further medical treatment. Because of the problem with the eggs, infertility is a major consequence that is often quite devastating. Many women say that before they even had time to make a decision about having children, the choice was taken away from them. About 6 - 8% of women with POF will become pregnant. There is no way to tell who these 6 - 8% will be.

Treatment: Generally, POF is treated with hormone replacement therapy at a higher dose than that given to women who are in menopause. It is started at a low dose so that you can get accustomed to having these hormones in your body again, and is gradually increased to the proper dose. Hormone replacement therapy is generally estrogen and progesterone but sometimes also includes testosterone. Birth control pills are sometimes substituted for hormone replacement therapy. Additionally, women with POF are encouraged to eat a healthy diet and exercise regularly (aerobics and weight-training) to decease health risks of osteoporosis and heart disease. At this point in time, there is no treatment to restore fertility for someone diagnosed with POF.

Support: You may be tempted to make a decision NOW about what to do about having children, taking HRT or an alternative route. Please give yourself enough time to get a definite diagnosis and do some research. The POF Support Group can help. Our goals are to provide community, support, and information to women with Premature Ovarian Failure (POF) and their loved ones; to increase public awareness and understanding of POF; and to work with health care professionals to better understand this condition.

Please contact us at: