

TABLE OF CONTENTS

Introduction	1
Ginny’s Story	2
Answers to Commonly Asked Questions	4
What is Premature Ovarian Failure?.....	4
Failure seems like such an unfortunate word to use.	4
Why do I hear the term premature menopause used?.....	4
At what age do women normally enter menopause?	4
Why do we say that POF occurs in women under the age of 40?	4
How many women have POF?	4
Is this rare?.....	5
Why is 39 used as the cut-off age for the diagnosis?.....	5
What is the average age at which this occurs?.....	5
Is it true if you started your periods early you are more likely to have POF?	5
Earlier you said that one of the indicators of POF is an elevated FSH* level but what does that mean?.....	5
Back to FSH. Is there a problem with the FSH stimulating the follicles?	7
What has happened to the eggs?	7
Why does this happen?	7
Someone told me that I brought this on myself because I smoke.....	8
Is it true POF can develop before you even start menstruation?	8
What are some of the physical changes I might notice? I’ve been having what I would call “hot flashes” but I’m too young and my doctor thinks I’m a hypochondriac!	8
Are there any ways that the symptoms of POF can be different than the symptoms of menopause at a more usual age?.....	8

When I see my doctor what medical information should she/he ask me about?	9
Is there a special doctor I should see for POF?.....	9
What should I expect my doctor to do during an examination?	9
Are there any tests that I don't need to have done?.....	10
Do women have normal fertility before developing POF?.....	11
How often do pregnancies occur?.....	11
What do I need to do to get pregnant?	11
Can I use BCP instead of HRT?	12
Is there any hope that in the future there will be a cure for the infertility?	12
I am overwhelmed with the idea that I may never have a baby.....	12
When my doctor told me what the problem was, he immediately told me my options for a family were donor egg or adoption. I certainly wasn't ready for that then! Now, I think we should at least look at all our options. Do you have any resources?	13
I guess after my devastation (and I do mean devastation) about my chances for a baby I am still concerned about my health. Are there any problems I should be aware of?.....	13
Why should I be concerned about my bones?	13
What can I do to protect my bones?.....	13
If I have a bone-density study which one should I have done?	15
What about heart health?	15
How long should I take HRT?	15
Why isn't progesterone necessary if I've had a hysterectomy*?.....	15
My mother and I are both on HRT! Can you believe it? Why does she take Premarin 0.625 mg and I take 1.25 mg?.....	16
How should young women with POF replace the estrogen that their ovaries don't supply to them?.....	16
What is the difference between estrogen and estradiol?.....	16
What about progesterone?.....	17

What are the side effects of estrogen and progesterone?	17
Should I take continuous or cyclical HRT?	18
I had a blood clot. Should I take HRT?	18
What can I do instead?	18
I don't hear much about testosterone. Should I take it?.....	19
Why is there such hesitation about testosterone?	19
There are certainly some good aspects. When will there be additional information?	20
What are the long-term risks of taking HRT?.....	20
Several times you've mentioned research that is going on at The National Institutes of Health (NIH). Can you tell me what and where NIH is and what kind of research they're doing?	20
I seem to be getting a lot of migraines since I experienced POF, or since I started taking HRT. Is there a connection? What can I do to stop the migraines?.....	20
Glossary of Terms	22
Resources	25
References	36
Closing	37

PREMATURE OVARIAN FAILURE SUPPORT GROUP OVERVIEW & FAQ

Introduction

The International Premature Ovarian Failure Association, Inc. (IPOFA) started in the Washington, DC area in March, 1995. Seven women responded to an advertisement in the local newspaper, *The Washington Post*, and met in an adult education classroom at a local school. The women ranged in age from 19 to 43 years of age. One woman had been diagnosed just a week before we met. Another had been diagnosed in 1984. The causes of Premature Ovarian Failure (POF) varied and included autoimmune disorders, genetics, post-chemotherapy for breast cancer, and Galactosemia*.

Most of the women stated that they felt alone, as if they had been hiding a secret. In the words of more than one woman: "I felt like a freak," and "no one else has been able to understand how I'm feeling because no one else I know has this disorder." Finally, we were no longer struggling with this alone. At last, we had others with whom we could share our stories. It was a meeting of hope. At that first meeting, and in subsequent ones, we have discussed how POF has affected our relationships with our spouses, friends and family, hormone replacement therapy, the feeling of being old before our time, the doctor/patient relationship, how to cope during holidays when family with children join us, how to go to that first baby shower for a friend after we've received our diagnosis and many other topics. We have shared information, gained a greater understanding of this disorder and discovered how little is really known about POF. Most importantly, as we have gained knowledge and have been able to share our stories, our ability to cope with this disorder has increased.

Since that first meeting, we have grown beyond the Washington, DC area. The November, 1995 issue of *Marie Claire* magazine included an article, "My Menopause Started at Age 25." Our local support line phone number was included at the end of the article and we received over 120 telephone calls from across the country. Our group, which had been compiling materials about POF, put these articles together in a packet and sent them to the women who had contacted us. In addition, we asked women if they wanted to be included in our "share list." We continue to grow today primarily through word-of-mouth, internet searches, physician referral and mentions in popular magazines and television news stories.

Through a grant from the Endocrine Nurses Society, we have been able to create this booklet. We hope that you find the information helpful. Our goal is to provide you with information so that you have a better understanding of POF. This in turn will give you the knowledge you need to make informed decisions about how to deal with this disorder.

Ginny's Story

“My story is not that different from the stories of many women with Premature Ovarian Failure. However, I feel it has a happy ending. It did not start out that happy however. I am 34 years old and started suffering from menopausal symptoms approximately four months after the birth of my son. At the time I was 27 years old. I spent two frustrating years traveling between my gynecologist and family physician trying to find out what the problem was. They told me: “it’s all in your head, try taking birth control pills to regulate yourself, take this Provera for a month to get your period and have this hysterosalpingogram to see if your tubes are blocked.” Finally, I took matters into my own hands and insisted on getting a referral to see an endocrinologist. I was officially diagnosed based on three weeks of evaluation of my FSH/LH* levels and my symptoms. I immediately started on a low dose of Premarin on calendar days 1 - 25 and Provera on calendar days 16 – 25. I would then stop taking the hormone replacement therapy (HRT)* and get my period. Well, after several months the symptoms had subsided, but not completely, so my Premarin was increased. After two years of taking HRT, I also started to see a Reproductive Endocrinologist (RE)*. Unfortunately, many dollars later, the only success I had was a large ovarian cyst which had to be surgically removed. From the RE I did find out that my ovaries* are the size of raisins and that the additional blood work supported that I indeed had POF. The reason given was some type of autoimmune disorder, yet I was negative for Lupus, Multiple Sclerosis and a number of other illnesses. I also had no testosterone (no wonder I had no sex drive) as well as elevated cholesterol levels and low DHEA*.*

Through all of this, my husband was a rock of support and extremely understanding. We had discussed having a large family but realized that would not be our reality. We did think about adoption but decided that this was not the right option for us. I went through the motions of “how fortunate I was” and yet continued on secretly very unhappy and frustrated.

Over the years I went through many ups and downs. I could not bear to see a pregnant woman or hold a child. I looked at women with babies with such longing and loss. The menopausal symptoms started returning (hot flashes, night sweats, dryness, decreased libido, and sleepless nights). I went back to see the RE and he suggested the estrogen patch. I began to wear the patch and had much better results. However, at one follow-up appointment, my RE made two statements that angered me; “1) Don’t be surprised if this autoimmune disorder starts to attack other organs in your body and 2) That’s what KY Jelly is for.” Well, I almost fell off the exam table! How dare HE pass judgment on me and leave me

with the feeling of a death sentence. My mind began to reel. What if my body starts to attack itself and I am left a cripple and die at a young age!!

What I did next almost ruined my marriage. I secretly began seeing a RE for more fertility treatments. As a nurse, I could get syringes and inject myself with the drugs. The problem was how to pay for all of this. My HMO did not cover the cost of fertility drugs so I began to charge the drugs and write access checks against my account. My husband had no idea what I was doing as the credit card was in my name only. I hid this terrible secret for 18 months. He asked me several times why we kept getting bills in the mail from this credit card company. I was clever and blew it off. After 18 months of hiding bills and two days before we were leaving for our two-week vacation, the bill came and my husband opened it. He was alarmed to see a \$6,000 balance! He went crazy. I lied and said I had no idea what it was for. The next day I came clean and cried my eyes out over the deceit, lies and guilt over the past 18 months. I did feel better after telling the truth and despite it all he was understanding, loving and supportive and forgave me. I am truly a very fortunate person and I reached a turning point in my life.*

Upon returning from our vacation, I decided that POF is not a death sentence unless you make it one. It does not control your life unless you let it. You can come to terms with the diagnosis and decide for yourself how to live your life. I immediately enrolled in a toning program, changed my eating habits and pulled out articles I had received from the support group and re-read them to refresh myself of all the good and positive changes I can make. The most dramatic difference was that I began taking a nutritional supplement and saw results in about a month. I was sleeping better and my memory was improving (no more getting lost driving around the corner). I again enjoyed being married. In addition, I was off my Prozac and just had a general sense of well being. My husband and co-workers commented on how good I looked and how positive I was. I have to say that at last, after five plus years since I was diagnosed with POF, this is the BEST I have ever felt because I have taken control of my life and POF and have not let POF take control of me anymore. I have a beautiful, handsome 7 and 1/2 yr. old son and the most handsome, supportive and loving husband anyone could ever have.

(January 1998)

Answers to commonly asked questions

What is Premature Ovarian Failure?

POF is a loss of ovarian function in women under 40. Periods stop, estrogen is low and the follicle-stimulating hormone (FSH) * level is elevated. Generally, it is said that the diagnosis requires at least four months without a period and two FSH tests, taken at least one month apart that are greater than 40 (some doctors will use 30) mIU/ML.

Failure seems like such an unfortunate word to use.

Yes, it certainly is one of those loaded terms especially if we use the word failure to mean complete stopping of ovarian function. When we use the term “POF,” failure means that ovarian function is not normal. The failure can be permanent, temporary or periodic and there can be residual ovarian function. Even with high FSH levels, some women may intermittently produce estrogen and even ovulate.

Why do I hear the term premature menopause used?

Yes, you will probably hear this term commonly used. However, it is incorrect. The most important thing to remember is that this is NOT menopause. This term originated from early studies when it was thought that, like menopause, there was a total lack of eggs. It was called “premature” to signify that it started at an earlier than normal age. However, unlike menopause, which appears to be a permanent loss of ovarian activity, POF may not be permanent. When the ovaries* of women with POF are looked at on pelvic ultrasound, approximately 40 percent of the women have structures that appear to be ovarian follicles. This is why the term POF is preferred to premature menopause. Today, we know that most women with POF intermittently produce estrogen and ovulate. Menopause means complete cessation of periods. In some cases, POF may be reversible.

At what age do women normally enter menopause?

The average age of menopause is approximately 51 years. It generally ranges from 45 to 55 years.

Why do we say that POF occurs in women under the age of 40?

In 1986, Carolyn Coulam (et. al.) published an article “Incidence of POF.” Since that time, it has remained the standard by which researchers fix the incidence of POF. The study was conducted in Minnesota at the Mayo Clinic. Medical records of women who lived in Rochester, Minnesota, who were seen for medical care at the Mayo Clinic in 1950, and who were born about 1930, were followed from 1950 through 1986 for the age at which natural menopause occurred. It was discovered that natural menopause before age 40 is unusual because the incident rate in the 40 to 44 year age group was more than ten times larger than in the 30 to 39 year age group.

How many women have POF?

In the study cited above by C. Coulam (et. al.), it was discovered that POF occurs naturally in 1 in 1,000 women between the ages of 15 and 29 and 1 in 100 women between the ages of 30 and 39. In her study, she excluded women who had had chemotherapy, radiation therapy or any type of a hysterectomy*. We used these

* See Glossary of Terms

percentages and calculated that this affects a minimum of 250,000 women in the United States!

Is this rare?

Actually, it isn't. The National Organization of Rare Disorders (NORD) states that "a rare disease is one which affects fewer than 200,000 people in the U.S." There are less than 5,000 rare disorders. Some rare disorders you may have heard of are carpal tunnel syndrome, psoriasis and multiple sclerosis

Why is 39 used as the cut-off age for the diagnosis?

Many researchers will say that 39 is an arbitrary cut-off point. If we refer to C. Coulam's study again, it states that the incidence rate in the 40 to 44 year age group is more than 10 times larger than in the 30 to 39 year age group. Since there is such a great increase in the 40 to 44 year age group, this seemed a natural cut-off point. Although this is the landmark study, you may hear some researchers say that POF occurs before the age of 35. In yet another study, the age of 44 was used because when large populations of women are studied, 95 percent of all women will stop menstruation after age 44.

What is the average age at which this occurs?

The average age of onset is 27 years.

Is it true if you started your periods early you are more likely to have POF?

No, that isn't true. There is also no typical menstrual history for women with POF. Some women state that they feel as if they went to bed one night feeling fine and woke up the next morning with this problem. Some women start to miss periods. They know they are not pregnant but do not know the cause of the missed cycles. Some have normal periods but develop hot flashes and can't figure out what is going on. In some women the problem becomes apparent after they've had a baby but their periods never return. In others, it becomes apparent when they stop birth control pills (BCP) and, again, their period never returns. Use of the BCP may have hidden for years that a woman has POF but there is no evidence that BCP can cause POF.

Earlier you said that one of the indicators of POF is an elevated FSH* level but what does that mean?

This is a good time to talk about how the ideal menstrual cycle works. Yes, you've probably heard all this before. However, since we're going to need to refer to some of this information throughout the discussion on POF, it will be convenient to have this information nearby so you can refer to it when needed.

Starting at the beginning, a female fetus has somewhere around 7 million follicles at about 4 - 5 months gestation of a pregnancy. A follicle is the small fluid-filled structure in the ovary that contains the egg (ovum). Through a process of "atresia" (a mechanism of programmed loss) by the time a girl is born there are about 2 million follicles left and by the time the girl reaches puberty and is ready to have her first menstrual period there are only about 300,000 - 400,000 left. These are the only follicles she will ever have. No new follicles are produced after birth. Generally, there are enough follicles to last a

woman until menopause. If you're looking at that number 300,000, you may be wondering why the eggs even run out at the average age of 51. If you've calculated that you ovulate one egg per month (or 12/year) and an average woman has 40 menstrual years, this accounts for only 500 of the approximately 300,000 eggs. Although only one egg is selected for ovulation, hundreds or more eggs may start to mature each cycle. As a cycle progresses, there is basically a "race" for one follicle to become the largest. The follicle that becomes the largest is called the dominant follicle*. The other follicles, which had started to ripen, disintegrate through the process of atresia. The one maturing follicle keeps growing until ovulation occurs. At ovulation the egg is released from the follicle and it begins its journey from the outer surface of the ovary into the fallopian tube.

Although the ovaries* are in "resting" states from birth until the time of puberty, both estrogen and progesterone are produced by the ovaries in small amounts from birth. At puberty, activation of the ovaries begins because the parts of the brain involved with reproduction, the hypothalamus* and the pituitary gland, begin releasing their hormones. Why this happens when it does is still somewhat of a mystery. This activation allows sexual maturation, ovulation and possible pregnancy over the next decades until the time of menopause.

Let's look at what happens during a menstrual cycle. We count Day One as the onset of menstruation. The first part of a cycle from Day One to ovulation is called the follicular or estrogenic phase. The second phase of the cycle is called the luteal or progestational phase. This phase lasts from ovulation to the day before the new cycle begins.

During menstruation, blood levels of estrogen are low. The hypothalamus* responds to these low levels in the blood by sending a chemical message (it releases GnRH*) to the pituitary gland and tells it to secrete FSH*. The FSH stimulates the development of a number of follicles. The follicles begin to produce estradiol*, which is the major estrogen of the reproductive years. On about Day Five (when menstruation is ending) the pituitary also begins to release small but increasing amounts of luteinizing hormone (LH)*. As we said earlier, about 100+ follicles are going to start to develop but only one is going to become dominant and fully mature. The dominant follicle, which is now almost mature (and is called a Graafian follicle), signals that the egg wants to be released from the ovary. On approximately Day 12, the estrogen (estradiol) production in the cells of the ovarian follicle increases to its highest monthly level. In addition, the anterior pituitary releases a large amount of LH (called the "LH surge") and within 24 to 36 hours the follicle finishes maturing and the egg pops out into the abdominal cavity. This is called ovulation.

The egg is picked up by the fimbria, which are the petal-like fingers at the end of the fallopian tubes. The fallopian tubes are the four and a half-inch long structures connecting the ovaries and the uterus. When the egg is released from the follicle, the abandoned follicle fills with blood and turns into the corpus luteum*. The corpus luteum remains on the ovarian wall and produces progesterone. It is the progesterone that thickens the lining of the uterus. In the days following ovulation, the combination of high progesterone and low estrogen signals the pituitary and the hypothalamus* to slow the

production of LH* and FSH*. These will stay very low from ovulation until near the end of the cycle. If the egg is not fertilized, the corpus luteum* disintegrates and there is a steep drop in progesterone and estrogen. The decrease in progesterone triggers the disintegration of the endometrial wall and the beginning of your next period.

Back to FSH. Is there a problem with the FSH stimulating the follicles?

The problem is a lack of follicles. In POF there are either fewer than normal follicles or there is a dysfunction in the ovaries*. Remember that the FSH stimulates the development of a follicle and that as the follicles ripen they release estrogen. The estrogen in turn sends a signal back to the brain that it can turn the FSH off. If a follicle isn't stimulated, there isn't enough estrogen to go back to the brain to say "turn off." So in a vicious cycle, instead of being able to turn off the FSH, the pituitary is driven to send out even more FSH to try to get a follicle to develop. In turn, the FSH level rises.

If there is a dysfunction of the ovaries, it is thought that women produce antibodies to their own FSH or to their own ovarian substances.

What has happened to the eggs?

Women with POF have one of the following: 1) a low number of follicles to start with 2) the eggs are lost more quickly than normal or 3) a dysfunction of the follicles.

Why does this happen?

There are several different causes. Unfortunately, for most women a cause for their POF is never identified. About 25 to 35 percent of women with POF have an associated autoimmune disorder. After autoimmunity, the most frequent known cause is genetics. There are other reasons such as an end result of treatment for cancers with radiation or chemotherapy or hysterectomy* with removal of the ovaries (surgical menopause). In addition, infections have been associated with POF. A family history of POF is found in about four percent of the women.

Causes of POF

Unknown (Idiopathic) – for most women a cause is never found

Autoimmune disease (these are some of the autoimmune diseases associated with POF)

Thyroid dysfunction

Polyglandular failure I and II

Hypoparathyroidism

Rheumatoid arthritis

Idiopathic thrombocytopenia purpura (ITP)

Diabetes

Pernicious anemia

Chromosomal/genetic

Turner syndrome*

Enzyme defects/Metabolic

Galactosemia*

Chemotherapy/radiation therapy related

Other

Viral infection
Surgical
Inadequate gonadotropin (this is FSH and LH*) secretion or action

Someone told me that I brought this on myself because I smoke.

Many women tell me that they blame themselves for their POF. They say they should have gotten married young and had children as teenagers or in their early 20's, they shouldn't have used BCP or that they are being punished by God because they had an abortion. It isn't unusual for us to try to find a reason for something when we don't know the cause. You did not bring this on yourself. Back to smoking – it is true that smoking cigarettes is associated with an earlier age of menopause but only by two to three years. That would mean a smoker's menopause would start around age 47.

Is it true POF can develop before you even start menstruation?

Yes, this can happen. Approximately 10 to 15 percent of females with POF have never had a spontaneous period. This is called primary amenorrhea*. When primary amenorrhea happens along with delays in puberty (such as budding of the breasts and hair under the arms), about half of the girls have a chromosomal problem. Chromosomes* contain the genes that determine each person's characteristics. If there isn't a chromosomal problem, girls generally have normal puberty growth and development.

What are some of the physical changes I might notice? I've been having what I would call "hot flashes" but I'm too young and my doctor thinks I'm a hypochondriac!

You may see changes in your period – the flow may be different or the length of the bleeding may change. Periods may stop altogether. You may continue with a regular menstrual cycle and have other symptoms! You really may be experiencing hot flashes. In addition, some of the other symptoms you may experience include night sweats, irritability (because the night sweats disturb your sleep), poor concentration, decreased sex drive, painful sex, depression and thinning and drying of the vagina. Some women discover the problem when they go for fertility testing and discover that they have an elevated FSH*. They may not have had any symptoms. If your doctor isn't knowledgeable about POF, or isn't compassionate about its effects on you, it is time to educate them (take this information to him or her) and work together. If they are not interested in working with you, then find a new doctor!

Are there any ways that the symptoms of POF can be different than the symptoms of menopause at a more usual age?

Each woman's symptoms are different but it is possible that your symptoms might be different than the symptoms of "natural" menopause. For example, hot flashes and other symptoms may last for many more years for those who have POF than for those who reached menopause in their late 40s or early 50s. It is possible that your symptoms could be more severe as well. In addition, if you are surgically menopausal due to removal of your ovaries*, or have POF due to chemotherapy or radiation, symptoms tend to be worse than those for the naturally menopausal. There can be several reasons for this. One is that even when a woman goes through a natural menopause her ovaries usually continue to produce a small amount of hormones. This small amount of natural hormones are not

present if the ovaries* have been removed. Recent studies have shown that menopause due to chemotherapy and radiation resembles surgical menopause more than natural menopause.

When I see my doctor what medical information should she/he ask me about?

Your visit will be more productive if you've thought about the following and are prepared with as much information as possible. Your doctor should ask you about:

- * Menstrual cycle changes
- * Menopausal symptoms (see above)
- * Surgery you've had on your reproductive system, particularly ovarian surgery
- * Chemotherapy
- * Radiation therapy
- * Recent infections (an example is PID – Pelvic Inflammatory Disease)
- * Family history of POF
- * A history of autoimmune disorders in yourself or in your family such as:
 - Hypothyroidism
 - Addison's disease
 - Diabetes
 - Graves' disease
 - Vitiligo
 - Lupus
 - Rheumatoid arthritis
 - Sjogren's syndrome
 - Inflammatory bowel syndrome (IBS)
- * Deafness in yourself or a family member
- * Because symptoms of some diseases can start very subtly (such as Addison's disease) your doctor will ask you about loss of appetite, nausea, weight loss, vague abdominal pain, weakness, tiring easily, salt craving or increased skin pigmentation.

Is there a special doctor I should see for POF?

There is no medical specialty specifically for POF. However, a reproductive endocrinologist (RE)* is especially helpful and more likely to know something about POF with detailed knowledge of the different types of hormone replacements available. While we cannot recommend any particular doctor, the POFSG website keeps a list of doctors that others with POF have recommended.

What should I expect my doctor to do during an examination?

The Physical Examination might include:

- Physical inspection to see if you have the physical characteristics of Turner syndrome* (includes nails that are soft and turn up at the ends and short pinkie fingers)
- Physical inspection to look for physical characteristics of autoimmune disorders associated with POF such as:
 - Changes in pigmentation. They include: premature graying of the hair (associated with Hashimoto's thyroiditis); vitiligo; increased pigmentation of the gums or the skin folds of the hands (associated with Addison's disease)
 - Loss of axillary or pubic hair (associated with Addison's disease)

* See Glossary of Terms

- Butterfly rash on face (associated with Lupus)
- Thyroid enlargement (associated with Hashimoto's thyroiditis or Graves' disease).
- A pelvic examination

Blood tests generally include:

- FSH* – generally this is done at least two times and at least one month apart. There is debate about the time of the month the FSH is done (such as Day Two, Three or Four of the menstrual cycle). It is important that more than one test be performed. Obviously, if you're not menstruating how would you know when Day Two or Three was?
- Estradiol* (abbreviated as "E2" in many medical papers).
- Karyotype – some doctors will say that this does not need to be done if you've had children or if your POF occurred after the age of 35. However, neither age nor having children rules out a chromosomal abnormality. Some insurance companies may not pay for this test.
- Screening for associated autoimmune disorders might include:
 - Thyroid-stimulating hormone (TSH) – Ultrasensitive
 - Antithyroid antibodies (ANA)
 - Antinuclear antibody titer
 - Fasting glucose
 - Electrolytes
 - Corticotropin stimulation test – for women with signs and symptoms of adrenal insufficiency. Do not have a random plasma cortisol level done instead. They are not helpful because they can be in the normal range even with impaired adrenal reserve.
 - CBC (Complete Blood Count)
 - Urinalysis
 - In addition, these may be obtained if clinically indicated:
 - Sedimentation rate
 - Rheumatoid factor
 - Quantitative serum IgA - for women with a history of recurrent respiratory tract infections

Radiology:

- A bone-density study can be useful. The best available test is a dual energy x-ray absorptiometry (DEXA) of the lumbar spine and hip. Before starting HRT, a baseline study can document any bone loss and future studies can be compared to it. Remember, there is no way to predict a person's risk of having a future fracture by having a regular x-ray taken.

Are there any tests that I don't need to have done?

- Progesterone challenge test – this test is often done but it's not necessary. For this test women are given 10 mg of progesterone (pills) for approximately 10 days and at the end of the 10 days the woman is asked if she's had any vaginal bleed. However,

women with POF intermittently have estrogen levels high enough for endometrial growth and withdrawal bleeding in response to the progesterone. A positive withdrawal test suggests there's some estrogen secretion. Unfortunately, it is not enough to reach the threshold required to allow ovulation. If withdrawal bleeding occurs in response to a Progesterone challenge test, women may be falsely reassured that ovarian failure is a possibility. This can delay the timing of the diagnosis.

- Antiovarian antibody testing - one readily available test is positive in nearly 1/3 of the general population of women.
- Pelvic ultrasound - this detects structures that look like ovarian follicles in 30 – 40% of women with POF. Showing follicles on ultrasound doesn't change how it's treated so it's not routinely recommended. It can, however, rule out other conditions such as ovarian cysts and tumors that might be responsible for your symptoms. Ovarian cysts are very common in women of childbearing age, and you should be under the care of a physician if you have them.
- Ovarian biopsy - it is invasive, provides little information and is generally considered a research tool.

Do women have normal fertility before developing POF?

Yes. In general, women with secondary amenorrhea* have normal fertility before developing POF.

How often do pregnancies occur?

Just a few years ago, a woman with POF would have been told that she had absolutely no chance of a pregnancy. Today we know that pregnancies occur after the diagnosis of POF in about eight percent of women.

What do I need to do to get pregnant?

This is probably the worst aspect of this whole problem. Many different treatments have been tried but none has offered any hope of success. Use of GnRH*, estradiol* and corticosteroids (such as prednisone) haven't proved to be effective. Neither Clomid (Clomiphene citrate) nor human menopausal gonadotropins* (hMG*) have shown to be effective in stimulating follicles to ovulate. This is because it is likely your body already is producing large quantities of FSH* and LH* in an effort to get your ovary to respond. Adding more hMG is unlikely to produce a reaction, as that is not where the problem lies. Recently a study using Danazol on the theory that it would improve follicle activity and induce ovulation was tried but it hasn't shown any success either.

Generally, the women with POF who have ovulated and gotten pregnant have been taking HRT at the time of conception. However, it is likely that this is just a reporting issue. Since women are generally told they can't get pregnant unless they're on HRT, it is possible that if they've gotten pregnant without HRT they have been reluctant to tell their health care providers. It could also be that since most women with POF are on HRT, most women who become pregnant will be on HRT.

Can I use BCP instead of HRT?

Yes, however BCPs contain far more estrogen than needed for replacement. Also, no estrogen is provided during the “placebo” week. Women with POF should be taking estrogen every day. Women with POF can conceive while on both BCPs and HRT. However, if you are trying to become pregnant with POF, it’s better to be on HRT than BCPs.

Is there any hope that in the future there will be a cure for the infertility?

Infertility is treatable but not curable. With that said, there continues to be advances. It is likely that in the near future freezing eggs will be done routinely. As you probably know, eggs are very fragile and previously we weren’t able to freeze them like sperm. In order to survive, the eggs had to be fertilized with sperm to make embryos. A new technique called “Egg Vitrification” has been successful in freezing eggs with a very rapid freeze technique.

Unfortunately, this is not going to help the majority of women with POF. That is because POF generally takes women by surprise. It is unexpected. When freezing eggs becomes a routine practice it will benefit women undergoing chemotherapy, radiation therapy and those with a family history of POF.

Someday, due to the advances in genetic research, we may know which gene(s) cause POF. When the gene(s) is(are) discovered we would then be able to develop a test which will help women who have a family history of POF. It will identify which women in a family will be affected.

I am overwhelmed with the idea that I may never have a baby.

For the majority of women the most devastating part of the diagnosis of POF is the loss of fertility. “Before I’ve even had a chance to make a decision about having children that choice has been taken away from me” is repeatedly stated.

46 women completed a questionnaire concerning their reaction to their diagnosis of POF. The women were patients at The Lister Hospital in London or The Royal North Shore Hospital in Sydney, Australia Fertility and Endocrinology clinics. 40 percent of the women who completed the questionnaire had children prior to their diagnoses. 54 percent of the women reported that loss of fertility was the most distressing aspect.

If you haven’t completed, or even started your family, this diagnosis can be especially upsetting. You may have a sense of urgency to do something immediately to become pregnant. Though most pregnancies do occur within two years of the diagnosis, pregnancies have been reported as long as 16 years after the diagnosis. You do need time to come to grips with the diagnosis. It is OK to give yourself time to grieve that your family may not be created as easily as you thought.

When my doctor told me what the problem was, he immediately told me my options for a family were donor egg or adoption. I certainly wasn't ready for that then! Now, I think we should at least look at all our options. Do you have any resources?

If you decide to look into donor egg or adoption, there are resources listed at the back of the booklet.

Also, the POF Support Group can introduce you to women who've created their families through adoption and/or donor egg. Our addresses and phone numbers are listed at the end of the booklet.

I guess after my devastation (and I do mean devastation) about my chances for a baby I am still concerned about my health. Are there any problems I should be aware of?

Yes, several things. First, if an underlying health problem was discovered during your examination, such as thyroid disease, it needs to be addressed. Women with POF need to be attentive to their heart and bone health. To protect yourself, it is generally recommended that women with POF take HRT. You should take a combination of estrogen and progesterone. However, if you've had your uterus and ovaries* removed you do not need to take progesterone. In that case, estrogen alone is taken. If your ovaries and uterus are still there, you need to continue to take both to protect yourself from ovarian/uterine cancer.

Why should I be concerned about my bones?

Loss of estrogen plays a part in the more rapid decrease in bone density that is common after menopause. As women with POF, we face many more years without the protective action of estrogen. Loss of bone density can lead to osteoporosis and fractures. In addition, until the age of about 30, your body is supposed to be *building up* your bone density. If you do not have adequate estrogen throughout this crucial period, you may not achieve your peak bone density and your chances of getting osteoporosis are greatly increased above that of a women who goes into menopause at age 51.

What can I do to protect my bones?

There are a number of things that you can do:

- HRT
- Adequate calcium intake
- Weight-bearing and strength training exercise

More specifically:

Dietary changes that may be helpful: Look at your intake of protein and decrease it if it's too high. Excessive protein in the diet can increase the loss of calcium through the urine. Common sources of protein are meats and poultry. In general, we (Americans) consume far more protein than we need. Women should consume 44 to 50 grams of protein per day. A lean hamburger patty contains about 26 grams of protein. One-half of a roasted chicken breast (without the skin) contains about 27 grams of protein. With the addition of protein found in vegetables, breads and other foods a diet with more than one serving of meat or poultry per day can easily exceed 50 grams of protein. Drinks that contain caffeine (coffee, tea, or cola-based soft drinks) should be limited because excessive

caffeine causes the body to lose calcium through the kidneys into the urine. A general recommendation is to limit your drinks with caffeine to no more than two per day and if you want more of those drinks to switch to decaffeinated ones. Alcoholism is associated with osteoporosis. There are many reasons for the association between alcoholism and osteoporosis. Alcohol contains a lot of calories but they are “empty” calories, without nutritional value. Often alcohol is the “primary food” of people who abuse alcohol. So, instead of a nutritionally balanced diet they are deficient in a number of vitamins and minerals that can contribute to bone loss. There can be damage to the liver so that it may not be able to make a form of vitamin D which is necessary for calcium absorption.

Lifestyle changes that may be helpful: If you smoke, stop. If you don't smoke, don't start! Smoking limits the effectiveness of HRT. Estrogen levels in smokers taking HRT have been found to be significantly lower than in non-smokers who use HRT. Exercise protects against bone loss. Both weight-bearing and strength-training exercises should be included. Examples of good weight-bearing exercises are walking (at least three mph), running and jogging. Swimming and bicycling are not weight bearing exercises. Free weights or dumbbells, ankle and wrist weights, weight machines and elastic tubing can be used in strength-training exercises. It is important to know that exercise is site specific. If you want a strong spine you need to exercise the spine. If you want strong legs, you need to exercise your legs.

Nutrients that may be helpful: You need 1,000 mg of elemental calcium per day if you are taking HRT. If you're not taking HRT that amount increases to 1,500 mg per day. You can get it through your diet or through a calcium supplement. If your plan is to get enough calcium through your diet, make sure you really are getting enough. It would be a good idea to keep a “diary” of all the foods you eat for three to five days. The days should include both weekdays and weekend days because it is likely that you eat differently on the weekend than during the week. If you are not getting enough dietary calcium, a supplement should be taken. The majority of supplements are either calcium carbonate or oyster-shell calcium. When you are determining the amount of calcium a supplement has, make sure you look at the amount of elemental calcium that it contains not just the total. In addition, the product should meet the United States Pharmacopoeia (USP) standards for disintegration and dissolution. If the information isn't available on the packaging you can call the manufacturer or do “the vinegar test.” Vinegar test – place a calcium tablet in a glass of white vinegar (6 – 8 ounces) at room temperature. Stir it vigorously several times over 30 minutes. At the end of the 30 minutes, the tablet should have disintegrated into fine particles. If it hasn't, it isn't the brand to use as it will not be effectively absorbed in your stomach. The 1000 mg of elemental calcium cannot all be taken at one time. As your body can only absorb 600 mg of calcium at a time it needs to be divided over the space of the day. The calcium should be taken with a full glass (8 ounces) of water or juice in order for it to dissolve.

Vitamin D increases the absorption of calcium. The recommended daily allowance (RDA) for Vitamin D is 400 mg per day. An easy way to get Vitamin D is through 15 minutes of exposure to the sun (perhaps while you're outside walking or running!). Sunscreen can't be used during this exposure as it prevents the skin from making Vitamin

D. One problem with getting Vitamin D from sun exposure is that in winter in some parts of the country the hours of sunlight are short. Only a few foods naturally contain Vitamin D. They include liver, fish and egg yolks. Some foods in the U.S., such as milk, are fortified with Vitamin D. If you don't get exposure to the sun nor the necessary Vitamin D through food sources, a vitamin supplement can be taken. Check your calcium supplement because many calcium products have Vitamin D added to them.

Because other vitamins and minerals can enhance the absorption of calcium or help with bone synthesis, it is often recommended that women with POF take a multivitamin plus mineral supplement every day. Any major brand can be used. You don't need a prescription. This way you know you have received 100% of the RDA for all the major vitamins and minerals.

If I have a bone-density study which one should I have done?

The DEXA (dual energy X-ray absorptiometry) is considered the "state of the art" technique. Have this one done if at all possible. However, there is very good research showing that virtually any of the other tests (like SPA, DPA and QCT) can be used to measure the various areas of the skeleton and predict a woman's future risk of osteoporosis.

What about heart health?

The estrogen that dominates women's lives during the reproductive years also protects us from heart disease. After the loss of estrogen there is an increase in heart disease. Data from the Nurses' Health Study found that women who went through surgical menopause (removal of the uterus and the ovaries*) before the age of 35 have two to seven times the risk of heart attack; the risk is also high in women who go through a natural POF. However, there has been a recent controversy about the relationship between HRT and heart disease and strokes. This recent study (<http://www.nih.gov/PHTindex.htm>) showed that HRT in normally postmenopausal women may increase their risk of heart attacks and strokes. However, this data does not apply to women with POF (see <http://www.pofsupport.org/article15.htm> for a statement by doctors who specialize in the study of POF regarding their views on this study). At the present time, many doctors who specialize in POF are recommending that women with POF continue to take HRT.

How long should I take HRT?

Because women with POF face many more years than normal without estrogen it is recommended that they take HRT until age 51 and then make a "menopause" decision about continuing HRT.

Why isn't progesterone necessary if I've had a hysterectomy*?

For women with a uterus, the combination of estrogen and progesterone is effective in preventing endometrial cancer. If you've had a hysterectomy, endometrial cancer isn't a risk. In addition, we know that at least certain types of progestins can negate some of the cardiovascular benefits of estrogen so in general, women who've had a hysterectomy don't take progestins. Recent research has shown that taking estrogen without a progestin (unopposed estrogen) can increase the odds of developing ovarian cancer as well as

endometrial cancer. It is unknown how this information relates to women with POF, who may have a *lower* risk of ovarian cancer than the general population of women. However, even if you have had your uterus removed, if you still have ovaries^{*}, it may be advisable to take estrogen with progestin.

My mother and I are both on HRT! Can you believe it? Why does she take Premarin 0.625 mg and I take 1.25 mg?

One of our members calls the HRT her “granny pills.” It is really hard to be taking this “medicine” at such a young age. Generally a higher dose is needed: to control the hot flashes and other symptoms, to provide the vagina with enough estrogen, and to compensate for the deprivation of estrogen at a time in life when the ovaries produce most of the body’s estrogen. Younger women also have more estrogen receptors. The levels of hormones that are produced by the body during the reproductive years are much higher than those given through HRT at the dose recommended for the “menopausal woman.” However, each woman is different. Your estrogen dosage should be related to your symptoms.

How should young women with POF replace the estrogen that their ovaries don’t supply to them?

The National Institutes of Health (NIH) provided this information: “When the ovaries stop working in young women one could argue that the natural human hormone should be replaced just as natural human insulin can be replaced in people who have diabetes. It makes sense to try to replace exactly what the ovaries make and supply it in a way as similar to the way nature provides as possible. This means using the natural human hormone estradiol^{*}. This is the major hormone that human ovaries make. It also means giving the estradiol in a way that goes into the body through the veins (the normal human ovary doesn’t provide estradiol through the mouth, it provides estradiol by putting it into the ovarian vein). Well, you say, we obviously can’t give estradiol by putting it into the ovarian vein, now can we! True, but we can give it through veins in the skin by using a patch. This is what we recommend you do until we have better scientific information.”

Another benefit of the patch is that it releases estrogen continuously, rather than all at once like the tablet. This way the delivery of estrogen more closely resembles your body’s own estrogen production. However, not all women can use the patch. Some are allergic to the adhesive compound and some women don’t like the idea of “telling the world” they’re on HRT by wearing a patch. Still others find the form of dosage too strong and experience increased side effects. So don’t feel badly if a patch is not the ideal medication for you. The oral estrogens have worked effectively for years.

What is the difference between estrogen and estradiol?

Estradiol is a type of estrogen. There are many different types of estrogen in the human body. Estradiol is the most powerful. If you receive your estrogen transdermally, it will remain as estradiol. However, if you take it orally, it will be converted through digestion to a different type of estrogen called estrone/estriol. We recommend you look at earlymenopause.com and look at their excellent list of different types of hormones that are available from different pharmaceutical companies, compounding pharmacies and

* See Glossary of Terms

over-the-counter. You can learn which type of HRT contains which types of estrogen and make a more informed choice about the type that is right for you.

What about progesterone?

You asked about progesterone but I'm going to start off by giving you some information on the combination of estrogen and progesterone! We know that estrogen alone is the most effective way hormonally to increase the good lipids (HDL) and decrease the bad lipids (LDL). However, these positive effects of estrogen can be muted or counteracted by certain types of progestins. We use the word "progestin" rather than "progesterone" because the most popular medications in HRT are similar to, but not the same as, the progesterone the human body produces. It is necessary to take progesterone or a progestin to protect against uterine or ovarian cancer, unless you have had your uterus and ovaries* removed.

One choice is micronized progesterone, which is chemically identical to the type of progesterone produced by the human body. The findings of the PEPI (Postmenopausal Estrogen/Progesterone Intervention) Trial confirmed that the levels of the good lipids were highest in women taking estrogen alone but they were almost as high for women who took estrogen and a micronized form of the natural hormone progesterone.

The PEPI trial was a 3-year study of nearly 900 women on various forms of HRT. This was a study of postmenopausal women. Their ages ranged from 45 to 64. There is currently one large scale study of women with POF by the NIH but it is still on-going. One of the outcomes of this study was that potentially pre-cancerous lesions developed in one-third of the women with a uterus who only took estrogen! Also, the estrogen effect on the lipids is only one aspect of cardiovascular health. Look for more studies!

Micronized means finely ground. That it's been broken down into very tiny particles. It allows for a steady, even absorption of the medication. Natural means many things to many people but here we mean chemically identical to the hormones produced in your body. It doesn't mean that it's an organic product like you'd find in a health food store.

The dose used in the PEPI Trial was 200 mg of natural micronized progesterone for 12 days per month.

Until just a few years ago the only way to purchase micronized progesterone was through a compounding pharmacy. Micronized progesterone was sold as a bulk powder to pharmacies that specially prepare or "compound" the powder in capsules or tablets. Now you can have your doctor write a prescription and take it to your local pharmacy just as you do for your estrogen.

What are the side effects of estrogen and progesterone?

Side effects of estrogen include breast tenderness, headache, blood clots, worsening of astigmatism, intolerance to contact lenses, nausea, vomiting, diarrhea, bloating, weight changes, acne, decreased absorption of folic acid and increased gallstones.

Side effects of progesterone include headache, irritability, depression, nausea, vomiting and increased acne.

Several women state that they have fewer side effects on micronized progesterone than other types of progestin. Micronized progesterone should be taken at night because it often causes sleepiness.

Should I take continuous or cyclical HRT?

Generally, cyclical HRT is recommended. Again, from NIH: “Our feeling is that having a regular period helps to make young women with POF feel more normal, like every other young woman having monthly bleeding. Also, should you spontaneously ovulate and conceive, which does sometimes happen, you will miss a period, know to have a pregnancy test, and stop the hormones if pregnant.”

I had a blood clot. Should I take HRT?

No, women who’ve had blood clots should not take HRT.

What can I do instead?

If you cannot use HRT there are alternative therapies available. A healthy diet, an exercise plan and stress/symptom management can protect the heart, bones and relieve the symptoms of POF. In truth, those of us on HRT can benefit from alternative therapies also.

Diet: If you are used to eating the typical American diet (lots of fats, sugar, salts and artificial chemicals) you might consider making a change! A switch to a diet that more mimics the Asian diet appears to help to alleviate menopausal symptoms and protect your heart. Their diet emphasizes whole grains, beans/legumes, fruits and vegetables, foods that contain essential oils and fish. Unlike saturated fats, essential oils are not primarily used by the body for energy. Fatty acids help to provide moisture, softness and smooth texture to the skin. They are also a main structural component of all cell membranes. Sources of essential oils include sesame and sunflower seeds, walnuts, trout, salmon and green leafy vegetables.

There are also some vitamins and minerals that can be helpful. A daily supplement (as we stated above in the osteoporosis area) can be helpful. However, it is not enough to take a supplement while continuing an unhealthy diet! Vitamin E at 800 mg per day may help relieve hot flashes, night sweats and vaginal dryness. Vitamin B complex helps in several ways. They help regulate estrogen levels by promoting healthy liver function. They play an important role in the function of the nervous system.

Herbs that are beneficial include chamomile. Yes, like in the sleepy-time teas you may see at the store! Chamomile is a good source of tryptophan, which may help to provide a restful sleep and so it may be helpful if you have insomnia. If you do have insomnia, you may need to make the tea stronger than normal. Start with one tea bag and increase to two or three until you find the amount that works best for you.

Exercise plan: Refer to the osteoporosis section for exercise suggestions for healthy bones. These need to be done regularly - a minimum of three times per week. To strengthen the muscles of the urinary tract, vagina and anus, Kegel exercises can help. These can help to make sex more pleasurable and to prevent leaking of urine that can occur when you sneeze, cough or laugh. They are simple to do. First, you want to find where these muscles are. The easiest way to do this is while you're urinating. While you're urinating, stop the flow of urine. The muscle that stopped the flow is what we're looking for. However, now that you've "found the place" do not do this exercise by stopping the flow of urine because it can lead to bladder infections. Contract the muscle, hold for a count of five, relax for a count of five and repeat this 20 times. Do at least 10 sets of 20 every day. The nice thing about this exercise (this exercise may be unlike any you've ever done before!) is that it can be done anywhere. They can be done as you stop your car at a red light, while brushing your teeth or putting on make-up. You get the idea. See more information about Kegel exercises at <http://www.mckinley.uiuc.edu/health-info/womenhlt/kegel.html>.

Stress reduction and relaxation exercises: These can help with both the physical and emotional components. Some of the changes that are occurring are due to the lability of the hormones and some are due to the feelings of loss you may be experiencing due to infertility. Again, all women with POF can benefit from these. Stress reduction and relaxation exercises include abdominal breathing, visualization and meditation. Some women find that acupuncture, acupressure or yoga are helpful as well.

Books could be written just on alternatives and they have been! So, we would recommend that you buy at least one book that addresses alternatives to HRT. See the Resources section at the end of the booklet.

I don't hear much about testosterone. Should I take it?

There are certainly good reasons to consider testosterone replacement. Testosterone is often called "the male hormone." However, we know that testosterone, which is a steroid hormone like estrogen, is also produced in women. Women with POF have lower testosterone levels compared to women who don't have POF. Testosterone is known to arouse sexual desire. One of the common complaints women with POF have is a loss of interest in sex.

In addition, low testosterone levels are associated with greater bone loss in all women (premenopausal, perimenopausal and postmenopausal). In postmenopausal women, testosterone replacement along with estrogen has shown to increase bone density more than estrogen alone.

Why is there such hesitation about testosterone?

Because there are some distressing side effects even in small doses. They include facial and chest hair, acne, deepening of the voice and possible liver damage. The worst side effect is that it can increase cholesterol levels and raise the risk for cardiovascular disease.

There are certainly some good aspects. When will there be additional information?

Again from NIH: “We definitely need a lot more research in this area. We definitely can’t recommend male hormone replacement to everyone yet. This is why the NIH is conducting a long-term protocol to evaluate adding a testosterone replacement to the current estrogen/progesterone treatment for women with POF.”

What are the long-term risks of taking HRT?

Unfortunately, there have not been any studies regarding the long-term risks of HRT on women with POF. The studies that have been completed were in women at natural age menopause. Because women with POF are taking HRT to replace an estrogen deficiency (much like a diabetic takes insulin for diabetes) the risks associated with HRT in natural age menopause can’t be directly correlated.

The biggest fear about taking HRT is the risk of breast cancer. Although women are more likely to die from heart disease or from the complications related to osteoporosis than breast cancer, it is breast cancer we fear.

Several times you’ve mentioned research that is going on at The National Institutes of Health (NIH). Can you tell me what and where NIH is and what kind of research they’re doing?

On a campus of just under 300 acres, the National Institutes of Health is located in Bethesda, Maryland right outside of Washington, DC. NIH is part of the Public Health Service, which in turn is part of the Department of Health and Human Services. In addition to basic research*, NIH does a lot of clinical research. Clinical research involves people who are willing to volunteer for studies of diseases and experimental treatments.

Every patient who is admitted to NIH is enrolled in a scientific study known as a “protocol.” Protocols that are drawn up by a principal investigator and a team of associates pose a question aimed at coming closer to a complete understanding of the mechanisms and eventual cure for some disease or disorder. There are about 900 studies underway at any given time. We are fortunate that POF is one of the disorders being studied.

See the Resources section at the end of the booklet for more information.

I seem to be getting a lot of migraines since I experienced POF, or since I started taking HRT. Is there a connection? What can I do to stop the migraines?

There is a strong connection between hormones, particularly estrogen, and migraines. Recent studies have shown that a sharp drop in estrogen in the body can cause a migraine. When you develop POF, you can experience many hormonal fluctuations that can promote migraines. That is difficult to control. However, you can control the estrogen that enters your body via HRT. If you take oral estrogen, the estrogen in your body spikes as the pill is processed and then drops quickly as it is used up. This fluctuation can cause a migraine, typically 12-16 hours after swallowing the dose of oral estrogen, in migraineurs. Many migraineurs have found that the estrogen patch, which delivers a much steadier dose of estrogen, can help you to avoid migraine triggers. The patch that

you change twice a week gives you a steadier estrogen level than the patch that you change once a week and might be preferable. In addition, the patch that you change twice a week actually lasts for 3 1/2 days (84 hours). If you find yourself getting a migraine if you change it less frequently than every 84 hours, you might want to change it more frequently.

You didn't answer my question! I wanted to know about folic acid, about ...

You're right! There are so many questions we didn't answer! This is a booklet and it's meant as an overview of POF. We were concerned that if we kept answering all the questions readers had (and us too!) that we'd never get this booklet done. Now that you are armed with information about POF, use it as a base to increase your knowledge. As you can see from this booklet there is new information being presented all the time. You will probably find that soon some of this information will be outdated or updated.

There are resources listed at the end of the booklet. They can help you on your search for more information. We strongly encourage you to continue to read, research and ask questions on your journey to wellness.

Glossary of Terms

Amenorrhea - a condition in which a woman has no menstrual periods.

Primary amenorrhea – a woman who has never had a spontaneous menstrual bleed in her life.

Basic research – studies limited to the laboratory or to animals and aimed at understanding the human body and its diseases at the most fundamental level

Chromosomes – the thin strands of genetic material found in the nucleus of each cell that determine each person's characteristics. Every individual has 22 pairs of chromosomes and one pair of sex chromosomes (called X and Y). The sex chromosomes determine whether an individual is male or female. A female ordinarily has 2 X-chromosomes, while a male has one X and one Y chromosome.

Corpus Luteum – a yellow cellular mass that forms in the ovary from a follicle that has ovulated; secretes progesterone, hormonally regulates the second half of the menstrual cycle and is essential to sustaining the first seven weeks of pregnancy.

DHEA – Dehydroepiandrosterone (pronounced dee-hi-dro-epp-ee-ann-dro-stehr-own), or DHEA as it is more often called, is a steroid hormone produced in the adrenal gland. It is the most abundant steroid in the bloodstream and is present at even higher levels in brain tissue. DHEA levels are known to fall 90% from age 20 to age 90. DHEA is known to be a precursor to the numerous steroid sex hormones (including estrogen and testosterone) which serve well-known refunctions, but the specific biological role of DHEA itself is not completely understood as of yet.

Dominant follicle - the largest ovarian follicle that develops during each menstrual cycle. It is the follicle that will ovulate.

Estradiol - one of the three major estrogen hormones women produce. This estrogen dominates from puberty to menopause and is by far the most powerful estrogen. The ovarian follicle produces it as it develops during the first half of the menstrual cycle and by the corpus luteum after ovulation.

Follicle - stimulating hormone (FSH) - the hormone produced by the pituitary gland in response to GnRH released by the hypothalamus. It stimulates the follicles in the ovary to develop.

Galactosemia - a rare genetic metabolic disorder. A gene for Galactosemia must be inherited from both parents who are carriers. It is an autosomal recessive condition. Normally when a person consumes a product that contains lactose (for example, milk), the body breaks galactose down into galactose and glucose. Glucose is the sugar used by the body for energy. Galactosemia means too much galactose in the blood caused by the individual missing the enzyme to convert galactose into glucose. Men with Galactosemia have normal gonadotropin function. In women it is still unclear if the POF is due to follicle depletion or follicle dysfunction.

Gonads - in women these are the ovaries.

Gonadotropins – the hormones produced by the pituitary gland that regulate the gonads. In women they regulate the development of the eggs. The most important ones are follicle-stimulating hormone (FSH) and Luteinizing hormone (LH).

Gonadotropin releasing hormone (GnRH) - a hormone which is produced by the hypothalamus in the brain. It stimulates the pituitary gland to produce and release both LH and FSH.

Health Management Organization (HMO) - is a form of health insurance combining a range of coverages in a group basis. A group of doctors and other medical professionals offer care through the HMO for a flat monthly rate with no deductibles. However, only visits to professionals within the HMO network are covered by the policy. All visits, prescriptions and other care must be cleared by the HMO in order to be covered. A primary physician within the HMO handles referrals.

Human menopausal gonadotropin (hMG) - a hormone preparation used to stimulate ovulation in women who do not ovulate and who don't respond to Clomid. It contains equal amounts of FSH and LH, and until recently, was obtained from the urine of postmenopausal women, since FSH and LH are so high in such women. Recently they have developed a process to synthesize this in a laboratory, so most brands are no longer made from human urine.

Hypothalamus – an organ in the endocrine system located just above the pituitary gland in the brain. It produces and secretes gonadotropin-releasing hormone (GnRH) that influences the pituitary gland and regulates the development and activity of the ovaries among its many functions.

Hysterosalpingogram (HSG) – a test most commonly done to determine whether or not the fallopian tubes are blocked. It is a x-ray test that involves an injection of dye through the cervix and into the uterus.

Hysterectomy – this word literally means “removal of the uterus,” but in practice is used to refer to the removal of a variety of women’s reproductive organs: the uterus, the ovaries, the cervix, and/or the fallopian tubes. If you have had a hysterectomy, it is a good idea to be sure of which organs you have had removed and which remain.

Luteinizing hormone (LH) - produced by the pituitary. The production increases near the middle of the menstrual cycle and causes the maturation of the egg. Ovulation occurs approximately 24 – 36 hours after the LH surge.

Ovaries – female reproductive organs which contain the eggs and produce the female hormones, primarily estrogen and progesterone in addition to being responsible for about half of the testosterone produced in women’s bodies. There are two, one located on either side of the uterus. During a woman’s fertile years, the ovaries are about the size of the end of your thumb. After natural menopause, ovaries normally shrink. Likewise, women with POF often have smaller than normal sized ovaries. The ovary is both an organ and a gland. As an organ, it is a ball of eggs. As a gland, it produces hormones.

Reproductive Endocrinologist (RE) - has additional training, advanced knowledge and skill in the management of complex problems relating to hormone imbalances and difficulty in achieving or maintaining a pregnancy. It requires additional years of specialized, formal training with ongoing clinical competency testing after a four-year residency and board certification in obstetrics and gynecology. Many board certified Reproductive Endocrinologists are involved in clinical and basic science research.

Secondary amenorrhea - a woman who has menstruated spontaneously in the past but then has had no periods for six months or more.

Turner syndrome – is a chromosomal condition that exclusively affects females. It occurs when one of two ‘X’ chromosomes normally found in a female is missing or incomplete. The sex chromosomes determine whether an individual is male or female; they influence height as well as the development of sex organs. A female ordinarily has two ‘X’ chromosomes, while a man has one ‘X’ and one ‘Y’ chromosome. The reason for the total or partial loss of the chromosome usually cannot be found but the loss occurs soon after that baby is conceived. There is nothing either parent can do to prevent this from happening. It is a random genetic event.

Resources

Following is a list of self-help, resource organizations and writings that were recommended by members of IPOFA. Only resources that POFers suggested are included. We hope some of these will be useful to you. Be advised that some of the groups listed have little funding and often rely on volunteers. Addresses and phone numbers may change if coordinators relocate. The information is current as of our printing. If readers become aware of outdated or updated information, please contact IPOFA.

Compounding Pharmacies

Panorama Compounding Pharmacy
6744 Balboa Blvd.
Lake Balboa, CA 91406
<http://www.panoramapharmacy.com>
(800) 247-9767
Email: uniquerx@aol.com

Madison Pharmacy Associates, Inc. (Women's Health America)
1289 Deming Way
Madison, Wisconsin 53717
<http://www.womenshealth.com>
(800) 558-7046

College Pharmacy
3505 Austin Bluffs Parkway #101
Colorado Springs, Colorado 80918
(800) 888-9358

Park Avenue Chemists
1080 Park Ave.
New York, NY 10128
(800) 842-6600
(212) 289-5866
Open 7 days a week: M-F 8a-7p, Sat. 9a-6p, Sun. 9a-2p
Delivery in the Manhattan area plus global shipping

International Academy of Compounding Pharmacists
To find a compounding pharmacist in your area
<http://www.iaprx.org>
(800) 927-4227
Office hours are Monday through Friday 8 a.m. to 5:30 p.m.

POF/Premature Menopause**

Organizations

The Daisy Network

PO Box 183

Rossendale

BB4 6WZ

United Kingdom

membership&media@diasynetwork.org.uk

www.diasynetwork.org.uk

The Daisy Network Premature Menopause Support Group is the only UK group for women with this condition. It is a registered charity run by women who have had a premature menopause and provides advice and support. The Daisy Network allows members to share information about their personal experience of POF, provides a support network of people you can talk to, provides information on treatments and research within the fields of HRT and assisted conception.

The International Premature Ovarian Failure Association, Inc. (IPOFA)

P.O. Box 23643

Alexandria, VA 22304

703 913-4787

info@ipofa.org

www.ipofa.org

The mission of IPOFA is 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.

This is by far the BEST place for information and support for women, friends and family members dealing with POF. The message boards, listserv, doctors answer line, and annual conferences have been lifesavers for many women!

North American Menopause Society (NAMS)

Post Office Box 94527

Cleveland, OH 44101

440 442-7550

Fax: 440/442-2660

info@menopause.org

www.menopause.org

The North American Menopause Society (NAMS) is a nonprofit organization dedicated to promoting women's health during mid-life and beyond through an understanding of menopause.

Although membership is limited to professionals they provide information on perimenopause, early menopause, menopause symptoms and long-term health effects of estrogen loss, and a wide variety of therapies to enhance health to the general public.

They offer a lot of good, solid information about menopause, and they have a list of doctors who specialize in menopause.

Publications

Davis, Susan R., *Our Health, Our Lives* (Australia: Allen & Unwin, 1997).

This book presents a balanced appraisal of women's health issues ranging from risk factors for breast cancer and lifestyle prevention strategies to natural therapies for a variety of problems. Includes a chapter on POF.

Domar, Alice D. and Dreher, Henry, *Healing Mind, Healthy Woman* (Delta, 1997).

This book uses the mind-body connection to help control stress associated with infertility and menopause, as well as other women's health issues. This book helps to focus on what you can do to improve your overall health. Audiotapes are available as an adjunct to the book.

Lee, John R. and Hopkins, Virginia, *What your Doctor May Not Tell You About Menopause: The Breakthrough Book on Natural Progesterone* (Warner Books, 1996).

This book covers the benefits of natural progesterone, the history and politics of the medical and drug establishment, the biochemistry and dynamics of hormones and how they get out of balance, and how to prevent hormone imbalance and stay healthy. Geared to women in menopause.

Nelson, Lawrence M., MD, MBA, *Spontaneous Premature Ovarian Failure: Young Women, Special Needs*, (*Menopause Management*, July/August 2001).

Written in a medical journal, this article nonetheless is excellent reading for women with POF. Thorough discussion of all aspects of POF. Give a copy to your health care provider.

Petras, Kathryn, *The Premature Menopause Book: When the "Change of Life" Comes too Early* (Quill, 1999).

Written by a woman with premature menopause herself, this book covers health and emotional issues, HRT options and natural supplements, lists resources, Websites and support groups, and includes interviews from women in their 20s and 30s coping with this situation and sharing their experiences. There is also a site based upon the book at: www.earlymenopause.com. In addition to excerpts from the book, also includes information not in the book -- such as continually updated information on the current forms of HRT available, news items, and special articles on osteoporosis, hormone testing, birth control pills and a variety of other issues

POF Support Group, *Faces of POF: Learning and Living with Premature Ovarian Failure* (The International Premature Ovarian Failure Support Group, 2004).

A compilation of stories and poetry written by women with POF. The stories capture many aspects of different women and how they dealt with their diagnosis. The website discusses the book in further detail at www.pofsupport.org .

Singer, Dani, *Premature Menopause: A Multidisciplinary Approach* (Taylor and Francis, 2000).

Although written for health professionals, women with some knowledge of POF will get much out of it. The editors bring together experts from a range of disciplines including endocrinology, gynecology, general practice, nursing, psychotherapy, complementary medicine and clinical

psychology, as well as hearing from women themselves. Offers up-to-date information on the topic, as well as practical suggestions for improved health care. Catherine Corp, POFSG founder, contributed to the chapter, Self-help and support groups.

Vliet, Elizabeth Lee, *Screaming to be Heard: Hormone Connections Women Suspect and Doctors Ignore* (M Evans & Co., 2nd edition 2001).

Vliet convincingly defends hormone replacement therapy, although controversial, as a corrective and preventive treatment, providing it is individualized and integrated with alternative therapies. Aimed at health care professionals and informed lay readers.

Vliet, Elizabeth Lee, *It's My Ovaries, Stupid!* (Scribner, 2003).

This book offers a serious and comprehensive look at hormone dysfunction in women of all ages. Vliet provides a complete guide to ovaries, explaining how they work and what happens when they don't work properly, along with surgical and other treatment. Included are questionnaires so readers can self-diagnose and prepare themselves before visiting a doctor.

Vliet, Elizabeth Lee, *Women, Weight and Hormones* (M Evans & Co., 2001).

The author explains how estrogen and progesterone levels change and interact at mid-life to slow female metabolism, which may lead to weight gain. Through a combination of hormonal balance, healthy eating, exercise and improved self-esteem she states the pattern can be reversed. The cornerstone of her book is the "meal action plan" (MAP).

Connected with these books is:

HER Place®: -- Health Enhancement and Renewal for Women, Inc.

P.O. Box 64507

Tucson AZ 85728

520-797-9131

Fax: 520-797-2948

HerPlace4U@aol.com

<http://www.herplace.com/index.htm>

A women's health center located in Tucson, Arizona. The center offers a host of services focusing on the integration of hormonal changes with physical, emotional and social aspects of women's lives. The author is the founder and Medical Director for HER Place®

Websites

Center for Young Women's Health, Children's Hospital

333 Longwood Avenue, 5th floor

Boston, MA 02115

617-355-2994

Fax - 617-232-3136

cywh@tch.harvard.edu

www.youngwomenshealth.org/pof.html

Recognizing the urgent need for education, clinical care, research, and health care advocacy for adolescent girls and young women, Children's Hospital of Boston has created an initiative, the Center for Young Women's Health. International in scope and collaborative in nature, they are committed to improving the health and well being of adolescent girls. They invite you to learn

about their research projects and health care provider education, explore their clinical services, and visit their Resource Center. Publication: Premature Ovarian Failure: A Guide for Teens is available on their Website.

Project AWARE (Association of Women for the Advancement of Research and Education)
<http://www.project-aware.org>

A Website by women, for women offering objective and comprehensive health information, especially related to menopause, perimenopause, and postmenopause.

Adoption

Organizations

National Adoption Center
1500 Walnut Street - Suite 701
Philadelphia, PA 19102
800 TO-ADOPT
nac@nationaladoptioncenter.org
<http://www.adopt.org/>

The National Adoption Center expands adoption opportunities for children throughout the United States, particularly for children with special needs and those from minority cultures.

National Adoption Information Clearinghouse
330 C Street, SW
Washington, DC 20447
703 352-3488 or 888 251-0075
Fax: 703 385-3206
naic@calib.com
<http://www.calib.com/naic>

A comprehensive resource on all aspects of adoption. Maintained by the U.S. Department of Health and Human Services Administration for Children and Families.

U.S. Department of State
Bureau of Consular Affairs
Overseas Citizens Services
Office of Children Issues
<http://travel.state.gov/adopt.html>

Resource on international adoption. Includes country updates and country-specific adoption flyers.

Publications

Adoptive Families Magazine
42 West 38th St., Suite 901
New York, New York 10018
800 372-3300
Fax: 646 366-0842

letters@adoptivfam.com

<http://www.adoptivfamilies.com>

Adopting is a special act that requires a great deal of information both before and after the adoption. Adoptive Families fills this need, in a thorough and sensitive manner. Articles include legal issues, psychology, practical activities and methods for enhancing adoptive family life. Personal experiences of other adoptive parents serve as clear models, and reviews of books and other media keep parents current.

Hicks, Randall B., *Adopting in America: How to Adopt in One Year* (SCB Distributors, 2nd edition February 1999).

This book clearly explains all the ways to adopt, pros and cons for each, and describes the processes. It also contains state-by-state descriptions of adoption laws and recommendations for adoption resources in each state.

Johnston, Patricia Irwin, *Adopting after Infertility* (Indiana: Perspectives Press, 1996).

Information about all the losses you are experiencing, how to decide on possible solutions with your partner and all the aspects that involve choosing adoption. Even if you are barely considering the adoption option or if you are just starting to deal with infertility, you should read this book (and later give it to your partner, your family and your friends).

Wadia-Ells, Susan, *The Adoption Reader: Birth Mothers, Adoptive Mothers, and Adopted Daughters Tell Their Stories* (Seal Press, 1995).

Essays written by birth mothers, adoptive mothers, and adopted daughters. This book invokes strong emotions that people going through an adoption will experience whether they know about them ahead of time or not. Reading this book was instrumental in preparing for the extreme emotions of the adoption journey.

Websites

<http://www.adoption.about.com>

Comprehensive collection of online resources about adoption and adoption issues.

<http://www.adoptionforums.com>

Adoption-related message board. Covers many topics including international and domestic adoption issues

Donor egg/Surrogacy

Websites

Looking To Be A Mom Through Egg Donation

www.network54.com/Hide/Forum/57451

Interactive forum for those considering or undergoing IVF with donor egg and need emotional support.

Mothers Via Egg Donation Listserv and Online Support Group
TASC@surrogacy.com

www.surrogacy.com/online_support/mved/

A forum open only to women who have been, or are attempting to become, mothers through egg donation or surrogacy. Because this is a closed area, members can communicate freely and openly with each other without the worry of unwanted visitors.

Surrogate Mothers Online

Info@surromomsonline.com

www.surromomsonline.com

Online resource and virtual meeting ground for surrogates and intended parents.

Fertility/Infertility

Organizations

American Infertility Association

www.AmericanInfertility.org

InterNational Council on Infertility Information Dissemination, Inc. (INCIID)

P.O. Box 6836

Arlington, Virginia 22206

703 379-9178

www.inciid.org

INCIID (pronounced “inside”) is a nonprofit organization committed to providing the most current information regarding the diagnosis, treatment, and prevention of infertility and pregnancy loss.

RESOLVE: The National Infertility Association

1310 Broadway

Somerville MA 02144

HelpLine number: 888-623-0744

Office: 617-623-1156

info@resolve.org

www.resolve.org

RESOLVE is a national organization that provides timely, compassionate support and information, through advocacy and public education, to individuals who are experiencing infertility issues

Publications

Weschler, Toni, *Taking Charge of Your Fertility: The Definitive Guide to Natural Birth Control, Pregnancy Achievement, and Reproductive Health* (Quill; Revised edition, November 2001).

www.TCOYF.com

This book explains what “normal” reproductive cycles are supposed to be like for women, and what signs to look for that you may be having problems. For women with POF, it is helpful to know what should be happening and how to know if our bodies suddenly decide to start acting normal again!

Websites

About Infertility

<http://www.infertility.about.com>

Comprehensive collection of online resources about infertility and infertility related issues.

Child of My Dreams

<http://www.childofmydreams.com>

Provides online information and advice for people facing the challenges of infertility and adoption.

Conceiving Concepts Inc.

<http://www.conceivingconcepts.com>

A fertility products and services company. An advocate for those struggling with fertility problems. Their goal is to arm you with the tools and information to help you on your pathway to parenthood, from fertility products to a safe place to meet people who understand.

Fertile Thoughts

<http://www.fertilethoughts.net>

Help and support for infertile couples going through medical treatment of infertility, adoption as well as to support woman going through surrogacy. Provides information from finding the perfect doctor, to your diagnosis, to treatment and options to insurance issues. They also provide resources and links to childrearing material.

Hope For Fertility

<http://www.HopeForFertility.com>

A support group for the emotional needs of those challenged by fertility issues. Hope continues to pick up where most doctors leave off, by providing the type of support that only one fertility patient can offer another through understanding. Support is given through chat room, message boards, Hope Survival Guide, and Guardian Angel Program.

Infertility Resources

Provides extensive infertility information including IVF, ICSI, infertility clinics, donor egg / surrogacy programs, natural infertility treatment, male infertility doctors, sperm banks, pharmacies, infertility products, sperm testing, infertility support, and drugs / medications information. <http://www.ihr.com/infertility/articles/ovumdonation.html> is the online resource for information about egg donations and egg donors.

IVF Connections

<http://www.ivfconnections.com/>

Connects people going through IVF to information, support, and others going through the same experiences. IVF Connections features IVF bulletin boards, IVF email lists, IVF chat rooms, IVF questions and answers, IVF stories, IVF links and an IVF in Canada section.

Shared Journey
sharedjourney@sharedjourney.com
<http://www.sharedjourney.com>

Dedicated to providing quality information on topics such as infertility, miscarriage, surrogacy, pregnancy after infertility, living child-free, and adoption. Information is supplied by well known reproductive endocrinologists, psychologists, adoption professionals and links through various sites.

General Women's Health

Organizations

National Women's Health Resource Center, Inc. (NWHRC)
NWHRC
120 Albany Street, Suite 820
New Brunswick, NJ 08901
877 986-9472
Fax: 732 249-4671
vngethe@healthywomen.org
<http://www.healthywomen.org/>

The national clearinghouse for women's health information and resources. The information provided is comprehensive, objective, and supported by an advisory council comprised of the nation's leading medical and health experts.

Publications

Northrup, Christiane, M.D., *Women's Bodies, Women's Wisdom* (Bantam Books; Revised and Updated edition, March 1998)

This guide goes far beyond standard self-help books, assessing women's health within the context of their work, families and society. The author, a holistic physician specializing in obstetrics and gynecology, seeks to illuminate the basic conditions of women's lives that lead to their health problems.

Websites

Holistic online
<http://holisticonline.com>
Comprehensive information about health. Features conventional, alternative, integrative, and mind-body medicine.

JAMA & Archives Journals
<http://pubs.ama-assn.org/>

Register as a guest for access to selected free content to the Journal of the American Medical Association (JAMA) and *Archives* Journals from January 1998 forward.

Medscape Ob/Gyn & Women's health

<http://www.medscape.com/womenshealthhome>

Medscape is organized by medical specialty. Each specialty has its own Website. Specialty content is evaluated, created, and presented under the guidance of editorial and scientific advisory boards. General site about women's health, infertility and POF. Full text medical journals are available for download. Although directed at clinicians and other healthcare professionals here you'll find perhaps the most comprehensive access to medicine on the Internet.

Research

National Institutes of Health (NIH), Section on Women's Health, POF Studies

9000 Rockville Pike

Bethesda, Maryland 20892

Contact: Vien Vanderhoof, RN at 877-206-0911 to obtain information about enrollment in the studies.

<http://www.nih.gov/>

The Website contains articles and information about current POF research studies.

Participating in the research studies at NIH helped me learn more about POF than any other single resource. I learned more about my health through the initial diagnostic study lasting four days than through all my previous doctor visits combined! I also learned what happens physically, physiologically, psychologically and emotionally to women with POF, and what can be done to lessen the side effects.

Special POF concerns

Androgen Insensitivity Syndrome

Website

Androgen Insensitivity Syndrome Support Group (AISSG)

<http://www.medhelp.org/www/ais>

AISSG is a peer support organization. Their goal is to help people who have AIS, have good reason to believe they, or a family member has AIS or a closely related biological intersex condition; and clinicians.

Hysterectomy

Website

Hyster Sisters
2436 S. I-35 E. Suite 376-184
Denton, Texas 76205-4900
<http://www.hystersisters.com>

Hystersisters.com is a woman to woman support Website for hysterectomy recovery. It is neither anti nor pro hysterectomy. Rather, it is an online community of women who give and receive support for hysterectomy decisions and recovery. Hystersisters.com offers resources and kindness so that visitors can discover options and make decisions for themselves.

*Note that several entries cross organizations/publications/Websites within the resource section. We have included the resource only one time. For example, *The Premature Menopause Book*, by Kathryn Petras is listed under publications, her preferred primary entry but there is a Website connected with it. They are grouped together.

** The term, "Premature Menopause" although inaccurate, is a term that has been used for a long time by medical personal and lay people and so is included.

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Closing

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IPOFA
P.O. Box 23643
Alexandria, VA 22304

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