



Presents

Endometriosis Screening & Education Kit

Empowering Materials for Understanding and Living Well in Spite of Endometriosis

Developed in Collaboration With
The United States Department of Health & Human Services
Office on Women's Health

Updated Edition 2012

Endometriosis Self-Test: Do You Have Endometriosis?

Only Surgery can Diagnose the Disease, but this Test can Help You & Your Doctor

Endometriosis: Answers to Frequently Asked Questions:

Your Guide to Understanding the Enigmatic Disease

Endometriosis Pain Journal:

Monitor & Communicate Symptoms to Your Healthcare Provider

Where to Get Help:

The ERC's Free Education, Awareness, Support & Research Facilitation Programs

About this Publication

A painful reproductive and immunological disease for which there is no absolute cure, endometriosis affects an estimated 176 million women and adolescent girls globally. Often stigmatized and underserved by the lay and medical communities as merely “killer cramps” or “painful periods”, and largely ignored by the academic and research arenas, the effects of this disease can be life-altering in the extreme. Indeed, research has shown an elevated risk of certain cancers and autoimmune disorders in those with endometriosis, as well as malignant changes within the disease itself. While researchers remain unsure as to the specific causes of endometriosis, research implicates genetic aberration, immune system dysfunction and exposure to environmental toxicants as contributing factors. The economic impact is staggering; businesses lose billions of dollars annually in lost productivity and work time, and the costs of diagnosing the disease through requisite pelvic surgery and subsequent treatments represent a significant burden to the healthcare and socioeconomic systems.

Endometriosis is characterized by the atypical migration of aberrant tissue resembling endometrial lining. Unlike normal endometrium which exits the body through menstruation, this wayward tissue implants itself outside the uterus in other areas, including adjacent abdominopelvic organs and less commonly, extrapelvic regions like the lungs, diaphragm, and even brain. The result is painful inflammatory lesions, formation of adhesions and scar tissue, pain, development of large, debris-filled ovarian cysts called endometriomas, and quite often, infertility. The disease affects women from all walks of life and ages ranging from adolescence to post-menopause, and can be so painful as to render a woman or girl unable to go about her normal routine. It is commonplace for a patient to undergo repeated surgeries and embark on many different therapies in an attempt to treat her symptoms - none of which are curative.

A primary cause of chronic pelvic pain, female infertility and a myriad of related symptoms, endometriosis is a leading cause of gynecologic surgery, including more than half of the 600,000 hysterectomies – many unnecessary - performed in the U.S. annually. Symptoms include pelvic pain at any point in a woman or girl's menstrual cycle, infertility, pain with sexual activity, gastrointestinal difficulties, urinary tract difficulties, fatigue, allergies, and immune system dysfunction and more. Outdated medical myths such as pregnancy, hysterectomy and menopause are treatments or cures continue to beleaguer the illness.

The Endometriosis Research Center (ERC) was founded in early 1997 by Executive Director Michelle E. Marvel to continue the fight to raise awareness about the illness and advocate for early diagnosis and intervention. The ERC previously established the country's first-ever formal legislation recognizing March as Endometriosis Awareness Month in partnership with the United States Congress, and hosts a series of activities and events each year to mark the occasion. The organization works tirelessly to facilitate better patient support, increase physician understanding of the disease, raise research funding, and ultimately, find a definitive cure. In an effort to facilitate cross-collaborational efforts with various endometriosis and women's health organizations around the world, the ERC is a proud partner in and supporter of several campaigns designed to benefit those with the disease. One such effort is in conjunction with the United States Department of Health & Human Services Office on Women's Health. The ERC is very proud to support the Office on Women's Health's “National Women's Health Week” campaign through our annual submission of this informative Kit. We hope you find it helpful. – The Endometriosis Research Center Executive Board of Directors & Working Committee

ENDOMETRIOSIS SELF-TEST

Not sure if you have endometriosis? Pelvic surgery is the only current way to definitively diagnose the disease, but symptoms can lead you and your doctor to suspect it. Review the following and consider if any of these common symptoms apply to you. Review your answers with your gynecologist for further discussion.

Do you experience so much pain during or around your period that you find yourself unable to work, attend school or social functions, or go about your normal routine? YES / NO

Do you have any relatives diagnosed with endometriosis? YES / NO

Do you find yourself with painful abdominal bloating, swelling or tenderness at any time in your cycle? YES / NO

Do you have a history of painful ovarian endometriomas ("chocolate cysts")? YES / NO

Do you have a history of miscarriage, infertility or ectopic pregnancy? YES / NO

Do you experience gastrointestinal symptoms during your cycle, such as nausea or vomiting and/or painful abdominal cramping accompanied by diarrhea and/or constipation? YES / NO

Do you have a history of fatigue or feeling "sick and tired" all the time? YES / NO

Do you have a history of allergies, which tend to worsen around your periods? YES / NO

If sexually active, do you experience pain during sexual activity? YES / NO

Do you suffer from autoimmune diseases or other conditions (for example: thyroid disease, rheumatoid arthritis, lupus, fibromyalgia, multiple sclerosis, chronic migraines)? YES / NO

Have you ever undergone pelvic surgery like a laparoscopy, in which endometriosis was suspected but not definitively diagnosed? YES / NO

If you have answered "yes" to three or more of these questions, you may have endometriosis. Talk to your doctor about getting an accurate diagnosis and effective treatment today. Dull aching and cramping can occur during menstruation in many women and teens, due to uterine contractions and the release of various hormones, including those known as prostaglandins. However, period pain that becomes so debilitating it renders you unable to go about your normal routine is not ordinary or typical! Pain is your body's way of signaling that something is WRONG. If you are suffering from pelvic pain at any point in your cycle, an endometriosis diagnosis should be considered.

Know the Facts:

- Endometriosis can affect women and teens of all ages, even those as young as 10 or as old as 85.
- Hysterectomy, menopause and pregnancy are NOT cures; in fact, there is no definitive cure.
- Delayed childbearing is NOT what causes endometriosis; in fact, no one really knows for sure what causes the disease, but research points to multi-factorial origins like heredity, immunology and exposure to environmental toxicants.
- GnRH therapies like Lupron should never be administered in those patients younger than 18 yrs. of age or before a surgical diagnosis.
- You CAN live well in spite of endometriosis. WE ARE HERE TO HELP!

ENDOMETRIOSIS: ANSWERS TO FREQUENTLY ASKED QUESTIONS

Endometriosis is a painful reproductive and immunological disease afflicting over 176 million women and girls around the world (twice the number of Alzheimer's patients and seven times those with Parkinson's Disease)¹. The disease is a leading cause of female infertility, chronic pelvic pain and gynecologic surgery, and accounts for more than half of the hysterectomies performed annually.² It is more prevalent than breast cancer,³ yet continues to be treated as an insignificant, obscure ailment. Recent studies have also shown an elevated risk of certain cancers in women with endometriosis.⁴ There is no cure, but there are several methods of treatment which may alleviate some of the pain and symptoms associated with it. Following is an overview of endometriosis, possible symptoms that might lead you to suspect you may be suffering from the disease and common treatment measures.

Endometriosis is a disease in which tissue like, but chemically different from, the endometrium (the tissue that lines the inside of the uterus which builds up and is shed each month during menstruation) is found outside the uterus, in other areas of the body. These implants still respond to hormonal commands each month, and break down and bleed. However, unlike the lining of the uterus, the tissue has no way of leaving the body. The result is internal bleeding, degeneration of blood and tissue shed from the growths, inflammation of the surrounding areas, and formation of scar tissue. In addition, depending on the location of the growths, interference with bowel, bladder, intestines and/or other areas of the pelvic cavity can occur. While uncommon, endometriosis has also been found lodged in the skin, as "nodules" that present themselves as "blue bumps", in the arm, leg, the brain and beyond.



There is no absolute cure for endometriosis, but treatments can help.

Endometriosis lesions can present themselves in almost any color, shape, size and location. This includes clear, microscopic papules that can lodge themselves on the underside of organs or beneath the skin. Unfortunately, physicians who are less trained to recognize all manifestations often miss diseased areas, instead searching for visible, common "powder-burn" type lesions on the reproductive organs. In reality, the lesions can be black, red, blue, brown, clear, and raspberry colored, and microscopic in size. The lesions can be spread throughout the entire abdominal region, bowels, bladder, and other areas, and may not be visible without proper magnifying equipment.

Is Endometriosis malignant?

The disease itself is classified as benign. However, recent studies indicate that women with endometriosis may have a slightly greater risk of developing cancer of the breast or ovaries and a greater risk of cancers of the blood and lymph systems, including non-Hodgkin's lymphoma. Researchers caution that the cause of the relationship is unclear. The association may be due to drugs or surgery used to treat the condition rather than endometriosis itself, only women with the most severe form of the disease may have the excess risk, according to a report in the American Journal of Obstetrics and Gynecology.⁵

According to chief scientist Dr. Louise Brinton of the Cancer Epidemiology and Genetics Division of the National Cancer Institute in Bethesda, Maryland, the results are "provocative in suggesting that women with endometriosis may experience elevated risk of certain cancers."⁶ In the study of 20,686 Swedish women hospitalized for endometriosis, the women had a 20% greater risk of developing cancer overall, particularly of the breast, ovaries and the blood and lymph cells, during an 11-year period. The women actually had a lower risk of cancer of the cervix. "The endometriotic tissue and its surroundings will be enriched in growth factors and cytokines that might have a deleterious effect on the growth regulation of other cells, some of which may be in distant organs - for example, breast tissue," Brinton wrote. The growth factors might act as carcinogens, thus promoting cancer.

There are other possible explanations as well. Women with endometriosis are also more likely take certain drugs, such as progestogens and are more likely to have had their ovaries or uterus removed, another factor that influences hormone levels, and possibly cancer risk. It is also possible that women with endometriosis may be screened more often for breast cancer and therefore more likely to be diagnosed with the disease. Endometriosis has also been linked to a lack of physical activity and to exposure to the environmental contaminant, dioxin. These two factors might be to blame for the cancer risk, rather than endometriosis.

Findings of one survey conducted on over 4,000 patients in the United States and Canada⁷ indicated possible links to other serious medical conditions, including a 9.8% incidence of melanoma, compared with 0.01% in the general population, a 26.9% incidence of breast cancer, compared with 0.1% in the general population; and an 8.5% incidence of ovarian cancer, compared with 0.04% in the general population. Women with endometriosis who participated in the survey also had a greater incidence of autoimmune conditions and Meniere's disease.

How is Endometriosis Staged?

The surgeon determines the extent and severity of the disease once confirmation of diagnosis is confirmed and biopsy results have been obtained.⁸ Staging has been defined by the American Society for Reproductive Medicine (formerly the American Fertility Society), with criteria based on the location of the disease, amount, depth and size. These factors are all graded on a point system and classification is thus determined. The first classification scheme was developed in 1973, but since then it has been revised and refined 3 times for a more precise method of documentation. As of 1985, the stages are classified as 1 through 4; minimal, mild, moderate, and severe.

Some examples of staging: Stage 1 or minimal would show evidence of superficial endometriosis in the peritoneum, size between 1-3 cms, and on one ovary, with filmy adhesions, for a total of 4 points. Stage 2 or mild would show evidence of deep endometriosis (anything above 3 cms) in the peritoneum, both ovaries, and filmy adhesions, for a total of 9 points. Stage 3 or moderate would show deep endometriosis in the peritoneum above 3 cms., partial obliteration of the cul de sac, deep endometriosis on one or both ovaries, with filmy or dense adhesions, and perhaps tubal involvement, for a total of 26 points. Stage 4 or severe would show deep peritoneum endometriosis above 3 cms, both ovaries involved, complete obliteration of the cul de sac, tubal involvement, and dense adhesions spread throughout the cavity, for a total of 114 points. It is important to remember that the Stage of the disease is not indicative of level of pain, infertility or symptoms. A woman in Stage 4 can be asymptomatic, while a Stage 1 patient might be in debilitating pain.

What causes Endometriosis?

There are several theories, none of which have been proven. Following is just a sample of common ones.

Dr. John Sampson's flawed theory of retrograde menstruation, which he formulated in 1921: Dr. Sampson contended "during menstruation, a certain amount of menstrual fluid is regurgitated, or forced backward, from the uterus through the fallopian tubes and showered upon the pelvic organs and pelvic lining". There has been evidence to support Dr. Sampson's theory; however, studies have shown that most women experience retrograde menstruation and have evidence of a "tipped" uterus, not all women will develop the disease. His theory also fails to explain the presence of endometriosis in such remote areas as the lungs, skin, lymph nodes, gastrocnemius, breasts, and other areas.

Transplantation theory: endometriosis is spread through the lymphatic and circulatory systems. This would explain Endometriosis in most sites.

Another transplantation theory is Iatrogenic Transplantation-or "doctor caused". This is the accidental transference of the endometriosis tissue from one site to another during surgery. However, this is highly uncommon today due to advanced surgical management. It also does not explain the presence of the disease to begin with.

Coelomic Metaplasia: Drs. Ivanoff and Meyer's theory that "certain cells, when stimulated, can transform themselves into a different kind of cell". This would explain the presence of the disease in absence of menstruation, and further, the presence of the disease on the bladders of men who have undergone prostate removal and were treated with estrogens.⁹

Heredity: a very popular theory that "women with relatives who have the disease may be genetically predisposed to developing it themselves." This theory was suggested as early as 1943, and research is currently underway by Oxegene researchers at the University of Oxford.¹⁰ Research released in 2002 shows that endometriosis may have even deeper genetic roots than previously thought. In studies presented in Human Reproduction, a group of Icelandic researchers found that "having a sister or mother who had endometriosis increases your risk by fivefold. In addition, even having a second, third or fourth cousin with this disorder means your risk is greater than 50 percent."¹¹

Immunology: according to Dr. Paul Dmowski of The Institute for the Study and Treatment of Endometriosis in IL,¹² "two different arms of the immune system may be involved in the development of endometriosis. Cell-mediated immunity, in which specific immune cells fight disease; and humoral immunity, in which antibodies are formed to attack antigens." Studies by Dr. Dmowski and others suggest that migrating endometriosis tissue affects women who have "deficient cell mediated immunity." In women without the deficiency, the transplanted cells are destroyed.

Genetic makeup: A team of researchers – then at University of Texas Southwestern - may have found another genetic link to the disease.¹³ According to an article published in earlier issue of the Journal of Clinical Endocrinology & Metabolism, ERC Advisory Board Member Dr. Serdar E. Bulun (now at the Feinberg School of Medicine at Northwestern University) and his team found that some women's genetic makeup determines their predisposition for contracting the disease. An unusual estrogen-synthesizing enzyme called Aromatase was expressed in the endometrial tissue of women with the disease, allowing the wayward tissues to implant themselves to a woman's reproductive and nearby organs. In a further twist, the researchers uncovered that as this enzyme is induced by large amounts of prostaglandins in the area, the tissue makes its own estrogen, thus promoting its own further growth.

On the basis of these findings, the team conducted preliminary research on the use of Aromatase inhibitors as a treatment for endometriosis in post-hysterectomy patient. According to the study, "the response to treatment in this case was strikingly successful, exemplified by the rapid disappearance of pelvic pain and near-complete eradication of a 30-mm vaginal endometriotic implant."

There are many other theories being investigated. Experts such as Dr. Robert B. Albee, Jr. of the Center for Endometriosis Care in Atlanta¹⁴ believe that it may be "a combination of several factors."

The amount of pain or infertility rates associated with the disease is not related to the extent or size of the implants. Some women have no symptoms, others have debilitating pain and even infertility. Some signs include:

- chronic or intermittent pelvic pain
- dysmenorrhea (painful menstruation is NOT normal)
- infertility/pregnancy loss/ectopic pregnancy
- pain associated with sex
- nausea/vomiting/abdominal cramping
- diarrhea
- rectal pain
- constipation
- blood in urine
- tenderness around the kidneys
- painful or burning urination
- flank pain radiating toward the groin
- urinary frequency, retention, or urgency
- shoulder pain associated with menses
- deep chest pain
- pain in the leg and/or hip which radiates down the leg
- painful bowel movements
- blood in stool
- rectal bleeding
- tailbone pain

Cul-de-sac involvement: the cul-de-sac is one of the most common (top 5) areas for endometriosis implants. The cul-de-sac is surrounded by the posterior wall of the uterus, the supravaginal cervix, the upper part of the vagina, the rectum and the sacrum, the small intestine and the sacrolateral ligaments. Hence, this "irritating focus" of implants can aggravate all the areas named, including the bowel. This can account for IBS-type symptoms when there are no implants actually present on the bowels. The same is true for disease located on the appendix. Another common symptom is dyspareunia (pain associated with sexual intercourse). According to Dr. David Redwine, world renowned specialist, "irritable bowel syndrome" is also common in Endometriosis patients. He stated "...we agree, but not because endometriosis patients are "high strung" or "just crazy," but because endometriosis is an irritating focus which causes bowel symptoms. Constipation, diarrhea, and cramping are non-specific symptoms (can be caused by a number of things in addition to endometriosis) and improve in a high number of patients when endometriosis is removed. Pelvic pain, painful sex, and rectal pain are more specific and are improved at an even higher rate."¹⁵

Fatigue, chronic pain, allergies and other immune system-related problems are also commonly reported complaints. It is quite possible to have some, all, or none of these symptoms with endometriosis. Because symptoms are so inconsistent and non-specific, it can easily masquerade as several other conditions. These include: adenomyosis ("Endometriosis Interna"), appendicitis, ovarian cysts, bowel obstructions, colon cancer, diverticulitis, ectopic pregnancy, fibroid tumors, gonorrhea, inflammatory bowel disease, irritable bowel syndrome, ovarian cancer, and PID (pelvic inflammatory disease). Often, younger women and teens who present to their healthcare providers with symptoms are dismissed and told they have PID or that they are too young to have endometriosis. This is often not the case. endometriosis has been found in autopsies of infants¹⁶ and in menopausal women, so the disease clearly knows no age boundaries.

How is it diagnosed?

The gold standard for a positive diagnosis of endometriosis is via surgery, either a laparoscopy or the more invasive laparotomy (for in-depth information on either procedure, please obtain a copy of the ERC's Surgical Fact Sheets). However, we are making progress in this area. Groundbreaking research is currently underway in the area of non-invasive diagnosis, with researchers at the Garden State Cancer Center in New Jersey investigating the use of radioimmunotargeting technology. This technique holds enormous potential for the much-needed, specific, non-invasive detection and eventual treatment of endometriosis. The Endometriosis Research Center has joined the Cancer Center in lobbying the NIH in support of funding for this crucial research.¹⁷

Will diagnostic procedures show Endometriosis?

A sonogram might give indications to make a doctor suspect endometriosis, such as cysts or fibroids. It can also be helpful in diagnosing ruptured Endometriomas or cysts. The disease itself, however, cannot be positively diagnosed with a sonogram, CT scan, MRI or other diagnostic procedure. The use of high-power color sonograms are currently being investigated, but their detection rates seem limited at this time to confirming recurrence of the disease in previously diagnosed patients.

How can it be Managed?

The most effective thing a patient can do is to find a specialist who treats the disease, such as an experienced gynecologist with a history of treating endometriosis patients. Form a partnership with this professional, in which you make informed decisions regarding your treatment plan together. Endometriosis is a serious disease, which requires serious treatment.

While the ERC does not endorse, screen or recommend any physicians, we can aid you in your search. For in-depth information on this topic, please obtain a copy of the ERC's "How to Choose a Doctor" article and see our patient to patient referral board at <http://www.facebook.com/groups/278254388902031>.

There are several methods of removing the disease during surgery, regardless of stage and location of implants. These include (but are not limited to) excision, ablation, cauterization, fulguration or vaporization of the lesions. Sometimes, when a surgeon feels uncomfortable attempting to remove the disease in any of the above manners due to the size and/or location of the implants, another surgeon may be called in to consult, or a second procedure may be scheduled at such time as the proper professional can operate. Examples of this are GI tract or bladder endometriosis; sometimes these cases are referred to gastroenterologists or urogynecologists; however, there are gynecologic surgeons capable of performing such procedures themselves.

Mini or Microlap: according to renowned fertility expert, Mark Perloe, MD,¹⁸ microlaparoscopy is a minimally invasive surgical technique that offers a new way to diagnose and treat endometriosis. While a standard laparoscope is about a 1/2 inch wide, microlaparoscopes are approximately 1/10th of an inch. While previously small incisions were made inside the belly-button, now, certain surgical procedures can be performed with only a needle stick. Scissors, graspers, biopsy instruments or laser fibers can be placed through one or two additional 3mm needles, enabling the skilled physician to perform diagnostic laparoscopy or simple surgical procedures using a local anesthetic and sedation through an intravenous catheter. This means much less incisional pain after your surgery. It also means less anesthetic, no sore throat, and less nausea. In many cases you may be able to resume all normal activities in just a few hours.

Pain mapping is another useful microlaparoscopic technique. If you are suffering from chronic pain and previous surgical procedures have not localized the cause, a microlaparoscopic procedure may provide the answer. A microlaparoscopic diagnostic procedure is performed while you are sedated but still awake in order to assist your doctor with locating the source of your pain. Various structures such as the uterosacral ligaments, the ovaries, tubes, uterus, bladder or an adhesion will be probed to see if it duplicates your pain. If the source of your pain is located, surgery may be more effective at providing relief.

Hysterectomy: each individual considering a hysterectomy should fully educate herself. A hysterectomy is not a definitive cure for endometriosis; though some women have experienced relief of painful symptoms post-hysterectomy. Certainly, each case of endometriosis is different and each patient requires a different course of treatment. A hysterectomy is just one of the many surgical options that can be considered in your search for treatment. Research this option as thoroughly as possible and speak with others who have had the procedure. The decision is ultimately yours, and it is important that you feel completely comfortable in undergoing whichever method of treatment you choose. For in-depth information on this topic, please obtain a copy of the ERC's "Hysterectomy" Fact Sheet.

Aromatase Inhibitors: according to ERC Advisory Board Member Dr. Serdar E. Bulun, endometriosis is one of the most important public health problems in the US. Indeed, researchers have estimated that menstrual pain is responsible for nearly 600 million lost work hours and a staggering \$2 billion in lost productivity each year. Dr. Bulun's studies have shown that misplaced Endometrial tissues respond to ovarian hormones such as estrogen and go through a menstruation-like process (bleeding, shedding and inflammation) repetitiously in the abdomen of a woman. Estrogen is like fuel to fire for endometriosis, thus current treatments have been designed to stop estrogen secretions from the ovaries of a woman (gonadotropin releasing hormone agonists). Estrogen, however is made not only in the ovaries but also in adipose tissue, and most importantly, within endometriosis tissues. Thus, endometriosis tissue acts in a devious manner to make its own estrogen through the abnormal expression of Aromatase enzyme in this tissue. This may explain the high numbers of treatment failures and early recurrences after conventional treatments of endometriosis.

In mid 90s, new generation Aromatase inhibitors were introduced to successfully treat breast cancer, another estrogen dependent disease. Dr. Bulun was the first in the world to use an Aromatase inhibitor to successfully eradicate an unusually aggressive case of postmenopausal endometriosis. His team also uses this medication on a compassionate basis to treat women with endometriosis after failure to respond to conventional treatments, but the treatment is still in the clinical trial phase and is not readily available to the general public as yet. The treatment lasts 6 months. As in any estrogen-block type of treatment, bone loss is the most significant side effect. Dr. Bulun's team minimizes bone loss by adding back non-estrogenic and bone-protecting medications.

GnRH (gonadotropin-releasing hormone) agonists: these are drugs that are designed to suppress the endometriosis implants in the following way: during the first phase of treatment, the drugs stimulate the ovaries to produce more estradiol (the most potent form of estrogen). In the second phase, after anywhere from approximately 7 to 21 days of constant stimulation, the drugs shut down the "messenger" hormones sent from the pituitary gland to the ovaries. The result is that the ovaries shut down, estradiol levels drop sharply and rapidly, and the patient ceases to ovulate or menstruate; a condition similar to that of menopause.

Some women experience positive results with GnRH treatments, others do not. As with any treatment, each case will vary. Though the medications can shrink the lesions of endometriosis, they will not shrink adhesions or scar tissue, which often play a part in the symptomatic pain of the disease. Common side effects that have been reported by women undergoing treatment include hot flashes, headaches, insomnia, vaginal dryness, decreased libido, depression, mood swings, fatigue, acne, dizziness, nausea, short term memory loss, diarrhea, hair loss, anxiety, and bruising at injection site.¹⁹

Again, each case is individual in nature and there is no way of knowing in advance how the drug might affect you personally. There are several different GnRHs that can be considered for treatment. These include:

Lupron Depot (Leuprolide Acetate) - administered by injection
Synarel (nafarelin acetate) - administered as a nasal spray

Zoladex (goserelin acetate) - a subcutaneous implant placed into the abdominal wall
Suprefact (buserelin acetate) - administered as a nasal spray

Synthetic hormones:

Danazol – a dated treatment for endometriosis, this is a synthetic testosterone marketed under the names "Danocrine" or "Cyclomen." It is usually given in pill form. Please request our "Danazol Fact Sheet" if you would like further information. UPDATE NOTE: Danazol has recently been linked to ovarian cancer. Please request more information from our offices.

Contraceptives, such as, but not limited to:

Depo-Provera (medroxyprogesterone acetate) - injectible form of progestins. In March 2005, Pfizer was granted approval on a new pain-relieving compound for endometriosis, the injectable drug Depo-subQ Provera 104, which contains the same active ingredient as the contraceptive Depo-Provera, but in a new formulation.

Provera (same as above; administered in pill form). For more information on this topic, please request the informative article on Depo-Provera.

Any forms of oral contraceptives recommended by your doctor: popular ones include Alesse and Lo-Ovral, because of their low estrogen/high progesterone combination.

The newer extended-cycle pill, Seasonale, is also being used with success by some women and girls with the disease. Seasonale contains 84 days of active pills followed by 7 hormone-free days, allowing a woman to experience only four menstrual cycles per year, versus the normal number of 12.

Immune therapy: according to a monograph by Clare Conway of Stanford University,²⁰ Wayne Konetzki, MD, a renowned allergist, states that endometriosis is an allergic reaction to one's own hormones, either progesterone, estrogen or the leutinizing hormone. Dr. Konetzki tests his patients for sensitivity to each hormone and, if he detects an allergy, initiates a desensitization program. He exposes the patients to minute doses of the hormone by giving them tablets to dissolve daily under their tongues. By exposing patients to tiny amounts of the offending hormone, Konetzki aids the body in slowly building an immunity to it. Though evidence of the treatment's effectiveness is anecdotal to date, Konetzki says his patients' symptoms typically begin to lessen after three menstrual cycles, and pain may disappear entirely after a year.

Other patients have opted for less-traditional approaches to their treatment, such as alternative medicine, acupuncture, herbal therapy, massage techniques, and dietary measures. While not a cure for the disease, exercise (as indicated and advised under the guidance of a trained professional who is familiar with your condition), good nutrition, and adopting a generally healthy lifestyle may significantly improve symptoms. For in-depth information on this topic, please obtain a copy of the ERC's "Diet and Nutrition" booklet and our "Alternative Treatments" Fact Sheet.

Aren't hysterectomies or pregnancies the cure?

No. At this time, there is no definitive cure for endometriosis. Hysterectomy may provide pain relief for many women; however, many women still have problems with endometriosis that was left behind in the body. Additionally, HRT may induce post-hysterectomy raises some issues for some patients in which the disease was not completely removed. As for pregnancy, certainly many women with endometriosis have certainly been able to get pregnant and carry to term, though approximately 30-40% of women with endometriosis may experience problems with infertility.²² Some women who have achieved pregnancy reported short-term relief from monthly cramps during the pregnancy; others have had no relief at all. In many cases discussed, the endometriosis returned "in full force" within a year.

Endometriosis is one of the most prevalent illnesses affecting society today. Yet, it remains largely ignored. Support is one of the biggest components for coping well with endometriosis. Sharing experiences with others who understand in a supportive environment can be the key to finding effective ways to deal with the disease. The Endometriosis Research Center offers extensive community programs as part of their International mission for disease education, support, awareness and research facilitation. The ERC strongly advocates for early intervention, timely diagnosis and efficacy of treatment for endometriosis. Through their efforts to raise public awareness in the medical and lay communities, the organization hopes to facilitate better support of patients, increase physician understanding of the disease and raise research funding, leading to more effective treatments and ultimately, a cure. Contact us to learn more.

It is entirely possible to live well with - and in spite of - endometriosis. If you or a loved one suffers from pelvic pain, listen to your body. Pain is never normal, and it is your body's way of sending you the message that something is wrong. See your gynecologist and find out if endometriosis is the cause of that message. If that doctor won't take your pain seriously, find one that will. We can help.

WEEKLY PAIN & SYMPTOM JOURNAL

Print this weekly document out to record your daily experiences with your endometriosis pain and symptoms. Keeping this Pain Journal current will enable you to communicate extremely valuable information about your case to your health care practitioner. Be sure to take a copy of your Pain Journal with you when you visit your doctor, hospital or other care provider. Helpful hint: Print several blank copies of this page and keep them in an organized book for a true Journal experience!

PATIENT NAME: _____

DATE OF BIRTH: _____

PAIN & SYMPTOM JOURNAL FOR WEEK OF ____ (month) ____ (day) through ____ (day), ____ (year)

CURRENT HEIGHT & WEIGHT: ____ht ____wt

HAS THERE BEEN A RECENT FLUCTUATION IN THE ABOVE? IF SO, PLEASE EXPLAIN: _____

RECENT SURGICAL, DIAGNOSTIC OR OTHER PROCEDURES, IF ANY (be thorough; examples include laparoscopy or pelvic surgery, intravenous pyelogram, colonoscopy. Include dates): _____

NAME(S) OF PHYSICIAN(S) WHO PERFORMED THE ABOVE: _____

CURRENT OR RECENTLY STOPPED MEDICATIONS (include over the counter, prescription and herbs): _____

CURRENT MEDICAL CONDITIONS (circle all that apply):

Endometriosis / Thyroid disease / diabetes / heart disease / stroke / COPD / PCOS / Hypo- or Hypertension / Pregnancy / Candida / Lupus / Cancer / Fibromyalgia / Obesity / Anorexia / Bulimia / alcohol and/or drug abuse / Bowel disease / Menopause / Osteoporosis / Fibroids / Ovarian Cysts / other (please elaborate)

Approximate duration of pain and symptoms to date: Is pain chronic in nature, having occurred for ____ days/months/years to date? Or, is pain acute, having begun on ____ (approximate date)? Are you still experiencing symptom(s) at this time? ____ yes / ____ no

SPECIFIC PAIN AND/OR SYMPTOMS EXPERIENCED (circle all that apply):

chronic or intermittent pelvic pain / painful menstruation / infertility / miscarriage / tubal pregnancy / abdominal cramping, bloating, diarrhea, constipation, painful bowel movements, sharp gas pains / pain associated with intercourse / vaginal pain / backache / leg pain / blood in stool / rectal bleeding / tailbone pain / blood in urine / tenderness around kidneys / painful or burning urination / other (specify) _____

General, non-specific symptoms: Fatigue / chronic pain / allergies and/or other immune system-related problems /
Insomnia / Headache / Depression / Increased or decreased libido / other (please elaborate)

Some words to describe specific and non-specific pain (circle all that apply): dull ache / itching / cramping /
constricting / burning / stabbing / nagging / pinching / shooting / throbbing

Think about how much pain affects your daily activities. Describe:

How much pain do you have on an average day? _____

How often do you have the pain? _____

Is there any time of day that the pain is worse? _____

Do any activities set your pain off? _____

Does the pain come and go? _____

What helps alleviate the pain? _____

How upsetting and disrupting is the pain to you? _____

What do you believe causes the pain? _____

Does pain interfere with your personal routine? _____

Circle the appropriate following rating(s) to describe your overall pain at its worst during the week:

1-mild, 2-moderate, 3-distressing, 4-horrible, 5-unbearable.

COMMENTS/NOTES/DISCUSSION AREA: _____

You are encouraged to make copies of this Journal.

WHERE TO GET HELP

About the Endometriosis Research Center

Founded in 1997 BY a woman with the disease, FOR women with endometriosis, and run today by those who LIVE with endometriosis daily, your ERC is here to help you any way we can! Please read on to learn how we've been improving the lives of those with this insidious disease for more than 13 years, what our plans for the future are, how we can help you, how you can get involved, and how to become empowered over endometriosis. We hope you'll consider supporting our worthy efforts today.

WHY WE ARE DIFFERENT

YOUR Endometriosis Research Center is FREE. Founded by Executive Director Michelle E. Marvel in early 1997, the ERC has been tirelessly addressing the growing international need for endometriosis research, education, awareness and support. We are unique in that unlike similar organizations, there is no fee to join, participate in or benefit from the ERC's programs. We exist solely on donations; there is no other organization offering free endometriosis support and information to the lay and professional communities concerning this disease anywhere in the world.

With our world headquarters located in South Florida, USA, our organization is pleased to host a virtual network of staff and volunteers around the world who help implement the ERC's various programs in the online and local communities on a global basis. The ERC maintains and offers a vast database of accurate materials on every aspect of endometriosis to practitioners, researchers, patients of all ages and their loved ones, and all those interested in the disease. Unlike others, we also do not accept funding from GnRH-agonist manufacturers, nor do we accept donations from physicians in exchange for providing referrals. Similarly, no ERC executive staffer draws a salary; instead, those funds are put back 100% into YOUR organization.

WE ARE AN ESTABLISHED PRESENCE IN THE GLOBAL ENDOMETRIOSIS COMMUNITY

YOUR ERC works with the best of the research and healthcare industry, striving together to make a positive global impact. The ERC has the privilege of collaborating with Medical & Professional Advisory Panel from the global Endo community. Additionally, the ERC believes ALL research is worthwhile, no matter how large or small – or “popular” the study initiative may be. To that end, we assist industry leaders with developmental studies and data collection on the disease; lobby the National Institutes of Health and similar foundations in support of various research grants; and so much more. Our end goal is always the same – the promotion of research and finding new help and answers for those suffering, not the promotion of the ERC name!

We are actively involved in ongoing disease research, ranging from recruitment for clinical trials on proprietary new

treatments to participation in genetic research studies for various biotech companies focused on the discovery of novel therapeutics and diagnostics to address significant unmet medical needs in endometriosis. We were also involved in the A-Fem Medical pilot study conducted in the mid-1990s to validate *the world's first* self-collection kit and testing method to attempt to provide a screening system for endometriosis. The preliminary results were promising, particularly for undiagnosed women and adolescents, and this novel work has now become an area of focus for the global biotech community.

The ERC has previously conducted our own study into a potential relationship between the use of Menstrual Cup devices and endometriosis, in association with the esteemed President of Associated Pharmacologists & Toxicologists and Author of the prestigious ReproTox Database. Our organization also performed a large product focus study involving the first unique, all-natural topical product designed specifically for menstrual cramping. We recently embarked on a small-scale study into a specific biological sample concentration discovered in women with the disease in collaboration with a leading clinical diagnostic testing company, and completed a product focus study with the manufacturer of an item designed specifically for women with Endo. We have also previously conducted a study of medical professionals in collaboration with Agile Therapeutics, using data collection and analysis to determine the scientific formulation of a birth control patch compound, to name but a few efforts. Other collaborations include, but are not limited to, the PETAL Study, Amgen Praecis Corporation; EmerGEN; Neurocrine Bioscience; FemmePharma; the International OxeGENE Study Group; the National Women's Health Information Center; The Office on Women's Health/U.S. Department of Health & Human Services; Helica TC Corporation; Zonagen Corporation; and many others. Additionally, we were the first organization in the world to recognize, support and promote the groundbreaking research into Aromatase Inhibitors and Angiogenesis, growing areas of interest to the worldwide research community. Currently, we are assisting Juneau Biosciences Corporation in their groundbreaking efforts to isolate and determine genetic components for a non-invasive diagnosis.

We also investigate controversial issues in endometriosis research to ensure that all facets of the disease are adequately addressed; in some instances, even publicly challenging “popular” study conclusions. For example, we refuted Yale University's “Sexual Activity, Orgasm & Tampon Use are Associated with a Decreased Risk of Endometriosis” report in the Journal of Gynecologic & Obstetric Investigation, citing extensive evidence as to why this theory was flawed. More recently, we also publicly confronted an “Expert Panel Consensus Report” in the Journal of Fertility & Sterility advocating the use of pre-diagnostic GnRH drugs.

WE ARE LEADING THE WAY IN DISEASE EDUCATION & AWARENESS

YOUR Endo Research Center is the global leader in bringing endometriosis awareness to the forefront of society. The ERC has collaborated on countless books, publications, and videos pertaining to the disease over the years, as well working with the extended media to bring education and awareness to lay and professional societies alike. Additionally, the ERC was pleased to host the Internet's first free Endometriosis educational webcast during our Symposium and workshops held at the ERC Conference at our nation's capital in Washington, DC. We were also presenters at the country's first national "EndoWalk for Awareness." We are the proven leader in awareness initiatives, and ours was the first endometriosis advocacy organization in the country to undertake the important task of raising awareness among policymakers. Subsequently, the ERC is nationally renowned for our pioneering efforts and successes in the Legislative arenas, helping to raise recognition about issues pertinent to endometriosis education and research at the governmental level.

It is our belief that no one with this disease should ever suffer in silence, and we continue to strongly advocate for early intervention, timely diagnosis and efficacy of treatment. We raise awareness and provide education about endometriosis not only to patient and medical communities through our free Symposiums, meetings and materials, but on State and Federal levels as well. For example, we have testified before the California State Legislature at the invitation of Assemblyman Dennis Cardoza on behalf of Assembly Bill 2820, a crucial health bill calling for independent research into the presence of dioxins in feminine hygiene products and the subsequent risks these toxins pose to women and their children. AB 2820 was approved by majority vote and passed on to the Senate Committee on Health & Human Services.

Our organization has also been very successful over the years in working with concerned legislators and policymakers to establish Resolutions formally recognizing the need for disease awareness throughout society. To that end, in addition to the country's first-ever national resolution, the states of New York, New Mexico, Colorado, Florida, Michigan, California, Wyoming, Utah and Pennsylvania are among those that have all passed Resolutions with the ERC officially recognizing the Month of March as "Endometriosis Awareness Month" as well.

We also offer educational materials and monthly newsletters containing extensive, unbiased and timely information about all aspects of this disease to all those interested through our various on- and offline information portals. Articles, information, research news and updates, and much more are all available through our website (which freely features extensive data on the disease), through member mailings, via our online groups, and more – all for free, of course! Our educational library – which is not funded or supported by any companies, thereby influencing our editorial content - contains hundreds of fact sheets and articles on every scope of this confusing illness.

We are also the only organization in the world to offer health care professionals access to important and timely data through our Adopt-a-Doc program (for free, of course).

WE PROVIDE THE SUPPORT CRUCIAL TO LIVING WELL WITH – AND IN SPITE OF - ENDOMETRIOSIS

The Endometriosis Research Center is leading the way through our patient recruitment, education, and vast support programs. Not only for women with the disease but also for those who love them, YOUR ERC hosts many active, in-person support groups worldwide, and is the owner of the Internet's largest electronic endometriosis support group. The first formally endorsed, organization-sponsored online group of its kind, the ERC Endo Angel Listserv has thousands upon thousands of participants from around the globe. Leaders in Endo support and education post there too, so stop by and join today! And, because we recognize support needs are different, we also honor young women with endometriosis ages 25 and under through our "Girl Talk" Program, a specific support and education program tailored to meet the needs of young women and adolescents who have, or think they may have, the disease. In addition to providing patient advocacy and education, Girl Talk raises awareness about endometriosis and strives to improve patient care among practitioners offering healthcare services to young women. We're trying to change things for our daughters of tomorrow. The ERC also assisted John & Carey Blondin, founders of MENDO, with the implementation of the male support group, the first of its kind in the world for "Men Who Love Women With Endo."

WE BELIEVE THAT WORKING WITH OTHERS BRINGS ABOUT THE BEST RESULTS

The ERC enjoys collaborative relationships with similar like-minded foundations. We are grateful for the opportunity to collaborate with and support other worthwhile organizations, like the National Endometriosis Society (United Kingdom), Associazione Italiana Endometriosi (Italy), the Endometriosis SHE Trust (United Kingdom), Endometriosis.org, the global foundation, the Endometriosis Care Centre of Australia (ECCA), and RESOLVE, the national infertility organization, to name but a few. Additionally, the ERC is represented in the World Endometriosis Society, the World Endometriosis Research Foundation, the American Society for Reproductive Medicine, the American Society of Reproductive Health Professionals, the international PAX Society, the National Pain Foundation, and the American Chronic Pain Association. The ERC is also a Founding Partner in the Society for Women's Health Research, a collaboration sponsored by the Alliance for Women in Clinical Research. A cruelty-free charity, the ERC is also a member of the Physician's Committee for Responsible Research "Humane Charity" Initiative and the Primate Freedom Project's "Moratorium on Primate Research." The Guidestar Foundation, a Federal charity watchdog organization, formally recognizes the organization as a member in good standing. In 2010, the ERC was delighted to sponsor the first endometriosis scientific conference originating in the United States; the EFA's "Advancing the Art & Science of Endometriosis" academic symposium held in NYC at the Academy of Sciences.

The ERC believes it's not "all about one central figure": it's "about all of us." Led by an Executive Director who herself suffers from this disease, our close-knit team members work together towards our common goals and are highly visible and accessible in the Endo community. We also collaborate regularly with many individuals from different professional and patient organizations around the world. Our mission and our core team are committed to transparency and availability; when your support, education, awareness and research needs arise, we're there. When one of us has a success, it's a success for all of us in the Endo world!

YOU DECIDE WHAT YOU NEED FROM US – WE’LL DO OUR BEST TO PROVIDE IT

Your Endo Research Center is member-driven. Our programs and initiatives are directed by you, the woman or girl with Endo. We recognize that empowerment over this disease comes through action, and to that end, we offer opportunities for many different ways to get involved. Whether it be fundraising to support our initiatives, leading a support group, helping to raise awareness and promote Endo legislation, or volunteering for the ERC in any capacity, our programs are all directed by our members. We’ve held such fun and festive member-run events as luaus, awareness walks, picnics, golf tournaments and yoga days in the name of fundraising for a cure, to selling a wonderful, member-authored Endo cookbook and Endo-branded clothing/accessories, to collaborating on the best selling Endo books with leading authors, to holding serious, educational presentations and testimony before governmental organizations in the name of raising awareness and providing education.

We welcome and encourage all ideas and proposals on how you’d like to get involved and help make a difference; after all, this is YOUR organization. Anyone can be involved, on any level. How much - or how little - is up to you. Our existence depends on the donations of those who support our mission, so join us today! Please consider supporting us to help shape the future of YOUR Endo Research Center. Be sure to explore all the facets of our foundation to find out how to obtain free information about all aspects of the disease, obtain copies of our educational monthly newsletter, keep abreast on research, reach others with Endo who understand, get involved in any of our many efforts, or just to feel like you’re no longer alone with this chronic illness.

Please see our informative website, contact us, or refer to our various Listservs for additional assistance:

<http://www.endocenter.org>
Internet Home of the ERC

<http://www.facebook.com/EndoResCenter>
Facebook Interactive Site

<http://erc.activeboard.com>
ERC Global “Endo Angels” Support & Discussion Group

<http://groups.yahoo.com/group/ERCGirlTalk>
ERC’s Girl Talk Listserv, for those under 25

<https://www.facebook.com/groups/278254388902031/>
Surgeons & Patients Come Together for Advancement of Endo

It is the ERC's goal to make a positive difference in the lives of the millions suffering from this disease. Help the ERC to help others by supporting our worthy efforts today. Please let us know what questions you may have. We are here to help any way we can!

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Phone: (800) 239-7280

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14 - Center for Endometriosis Care, 1140 Hammond Drive, Bldg F Suite 6230, Atlanta, GA 30328, 877-212-9900, www.centerforEndo.com/

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