



*Presents*

# **Endometriosis Screening & Education Kit**

*Empowering Materials for Understanding and  
Living Well with Endometriosis*

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*Originally Developed in Collaboration With*  
The United States Department of Health & Human Services Office on Women's Health  
*In Celebration of the National Women's Health Week Initiative*

## **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:**

*About Our Education, Awareness, Support & Research Facilitation Programs*



## 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 Endometriosis. 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 two 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 for Endometriosis; 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.
- Endometriosis can only be accurately diagnosed via surgery; diagnostic tests like MRIs and ultrasounds are not definitive.
- 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**

### **Background:**

Endometriosis is a painful reproductive and immunological disease afflicting over 7 million women and teens in the United States alone (twice the number of Alzheimer's patients and seven times those with Parkinson's Disease),<sup>1</sup> with an estimated 70 million more worldwide. The disease is a leading cause of female infertility, chronic pelvic pain and gynecologic surgery, and accounts for more than 120,000 of the 500,000 hysterectomies performed annually.<sup>2</sup> It is more prevalent than breast cancer,<sup>3</sup> 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.<sup>4</sup>

There is no cure for Endometriosis, 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.

### **What is Endometriosis?**

Endometriosis is a disease in which tissue like 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, and even the brain.



***There is no cure for Endometriosis.***

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.<sup>5</sup>

According to lead study author 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."<sup>6</sup>

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 Endometriosis patients in the United States and Canada<sup>7</sup> 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.<sup>8</sup> 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 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, 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.<sup>9</sup>

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.<sup>10</sup> Recent research released in March 2002 shows that Endometriosis may have even deeper genetic roots than previously thought. In studies presented in the March issue of *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."<sup>11</sup>

Immunology: according to Dr. Paul Dmowski of The Institute for the Study and Treatment of Endometriosis in IL,<sup>12</sup> "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 at University of Texas Southwestern may have found another genetic link to the disease.<sup>13</sup> According to an article published in earlier issue of The Journal of Clinical Endocrinology & Metabolism, ERC Advisory Board Member Dr. Serdar E. Bulun (currently with the University of Chicago) 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 Albee of the Center for Endometriosis Care in Atlanta<sup>14</sup> believe that it may actually be "a combination of several factors."

### ***What are some symptoms of Endometriosis?***

The amount of pain or infertility rates associated with the disease is not related to the extent or size of the implants. Some women with Endometriosis have no symptoms, others have debilitating pain and even infertility. Some signs that may lead you to suspect Endometriosis include - but are by no means limited to - any of the following:

#### **Reproductive Area Endometriosis:**

chronic or intermittent pelvic pain	miscarriage(s)
dysmenorrhea (painful menstruation is not normal)	ectopic (tubal) pregnancy
infertility	

#### **Cul-de-Sac ("Pouch of Douglas") Endometriosis:**

The Cul-de-sac is one of the most common (top 5) areas for Endometriosis implants. As outlined in the "GI symptoms" section of this Fact Sheet, Endometriotic implants have an "irritating focus." 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).

**Uterosacral/Presacral Nerve Endometriosis:**

Backache  
leg pain  
painful intercourse

**Gastrointestinal (rectosigmoid colon, rectovaginal septum, small bowel, rectum, cecum, large bowel, appendix, distal ileum, gallbladder, intestinal tract) Endometriosis:**

According to Dr. David Redwine, renowned Endometriosis specialist who heads up the St. Charles Endometriosis Treatment Program, "irritable bowel syndrome" is common in Endometriosis patients. In a 1991 Program Newsletter, it was 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."<sup>15</sup>

**Other GI tract symptoms include:**

nausea	painful bowel movements
vomiting	blood in stool
abdominal cramping	rectal bleeding
diarrhea	sharp gas pains
rectal pain	bloating
constipation	tailbone pain

**Urinary Tract (bladder, kidneys, ureters, and urethra) Endometriosis:**

blood in urine	urinary frequency, retention, or urgency
tenderness around the kidneys	hypertension
painful or burning urination	
flank pain radiating toward the groin	

**Pleural (lung/diaphragmatic/chest cavity) Endometriosis:**

coughing up of blood or bloody sputum, particularly coinciding with menses	shortness of breath
accumulation of air or gas in the chest cavity	collection of blood and/or pulmonary nodule in chest cavity (revealed under testing)
constricting chest pain and/or shoulder pain	deep chest pain
shoulder pain associated with menses	

**Sciatic Endometriosis:**

pain in the leg and/or hip which radiates down the leg (this symptom is concurrent with that of inguinal Endometriosis (groin area) as well.

**Skin Endometriosis:**

painful nodules, often visible to the naked eye, at the skin's surface. Can bleed during menses and/or appear blue upon inspection.

Fatigue, chronic pain, allergies and other immune system-related problems are also commonly reported complaints of women who have Endometriosis.

It is quite possible to have some, all, or none of these symptoms with Endometriosis. Because Endometriosis 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 infants<sup>16</sup> and in menopausal women, so the disease clearly knows no age boundaries.

### ***How is it diagnosed?***

Currently, 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.<sup>17</sup>

### ***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 an Endometriosis patient can do is to find a specialist who treats the disease, such as an experienced gynecologist with a history of treating Endometriosis patients or a reproductive Endocrinologist, especially if infertility is a concern. 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 EndoDocs Listserv at <http://health.groups.yahoo.com/group/EndoDocs>.

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 Endometriosis and fertility expert, Mark Perloe, MD,<sup>18</sup> 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, Director of the Division of Reproductive Endocrinology in the Department of Obstetrics and Gynecology at the University of Illinois at Chicago, 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 nonestrogenic and bone-protecting medications.

If you are interested in learning more about Aromatase Inhibitors or about the study, please request the ERC Aromatase Inhibitor Overview. You can email [ENDOF@aol.com](mailto:ENDOF@aol.com) with the subject heading AROMATASE OVERVIEW and include your full name, email address, snail mail address and phone number. You will also be placed on a list to receive the further information as it becomes available. Thank you for your interest in our Advisor, Dr. Bulun's, research.

**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.<sup>19</sup>

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

For in-depth information on this topic, please obtain a copy of the ERC's "GnRH" Fact Sheet and be sure to request our "Surgery versus the Use of Lupron Depot as Treatment" and "Use of Lupron Depot Prior to Surgical Diagnosis" Fact Sheets.

#### **Other Medications:**

**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. As of March 2005, Pfizer has been 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. For in-depth information on this topic, please obtain a copy of the ERC's articles on Birth Control pills.

Pain management options include non-steroidal anti-inflammatories (NSAIDs) such as Anaprox or Toradol. Stronger narcotics and anti-depressants are often used as well. For in-depth information on this topic, please obtain a copy of the ERC's "Managing Chronic Pain" article.

Immune therapy: according to a monograph by Clare Conway of Stanford University,<sup>20</sup> 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. Konetzki, along with ERC Advisory Board Members Deborah Metzger, MD, PhD., and Andrew Cook, MD (of Helena Women's Health Center,<sup>21</sup> and Athena Women's Health Center, respectively) recently conducted a clinical trial to confirm his findings.

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.<sup>22</sup> 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. American businesses lose millions of dollars each year in lost productivity and work time because of the disease, and the cost of surgery required to diagnose Endometriosis in each patient adds greatly to the financial burden of both consumers and companies alike. However, disease awareness is growing, thanks to efforts of such foundations as the ERC.

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 / Bulemia / 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)\_\_\_\_\_



# ERC *Endometriosis Research Center*

## GET HELP

### *About the Endometriosis Research Center*

The Endometriosis Research Center is an established 501(c)3 tax-exempt, tax-deductible organization that was founded by Executive Director Michelle E. Marvel in early 1997, in order to address 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. There is no other organization offering free Endometriosis support and information to the lay and professional communities concerning this disease.

With world headquarters located in South Florida, USA, the 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 all those interested in the disease. In addition, the ERC assists medical industry leaders with developmental studies and data collection on the disease; lobbies the National Institutes of Health and similar foundations in support of various research grants; and so much more.

The ERC has the privilege of working with leaders in the ongoing study and treatment of the disease. An Executive Board of Directors and a Medical & Professional Advisory Panel consisting of pioneers in Endometriosis research and treatment govern all ERC programs and operations. The organization is also implementing a unique program for Professionals only, which is designed to encourage global collaboration on, and advance the study and treatment of, all aspects of Endometriosis for researchers, physicians, scientists and healthcare professionals from all over the world.



On the clinical front, the ERC is pleased to engage in various research collaborations with the International Scientific community and several prominent biotechnology corporations, including Amgen Praecis; EmerGEN; Neurocrine Bioscience; the International OxeGENE Study Group; Claire Ellen, Inc.; FemmePharma; A-Fem Medical; Recently, the ERC 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 recent product focus study involving a unique, all-natural topical product designed specifically for menstrual cramping.

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, in late 2000, we 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, the states of New York, Colorado, Florida, Michigan, California and Pennsylvania have all passed Resolutions officially recognizing the Month of March as "Endometriosis Awareness Month." Our most gratifying success, however, came in late October 2002 when Congress unanimously passed our Country's first-ever National legislation, House Concurrent Resolution 291.

Introduced on behalf of the ERC by Congressman Howard "Buck" McKeon and supported by numerous Co-sponsors, H.Con.Res.291 formally proclaimed March as National Endometriosis Awareness Month. H.Con.Res.291 also expresses the sense of the United States Congress that it "strongly supports the ERC's efforts to raise public awareness of Endometriosis throughout the medical and lay communities and recognizes the need for better support of patients with Endometriosis, the need for physicians to better understand the disease, the need for more effective treatments, and ultimately, the need for a cure."

In addition to research facilitation and patient education programs, ERC also offers a vast support network for those with the disease and their loved ones. The ERC is pleased to host nearly 50 active, in-person support groups worldwide, and is the owner of the Internet's largest electronic Endometriosis support group, with nearly 3,000 participants from around the globe.

In honor of young women with Endometriosis ages 25 and under, the ERC offers 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 are also the only organization to offer specifically tailored materials to the under-addressed community of lesbians with Endometriosis, through our "Women 2 Woman" program.

The ERC enjoys collaborative relationships with similar like-minded foundations, including the National Endometriosis Society (United Kingdom), Associazione Italiana Endometriosi (Italy), the Endometriosis SHE Trust (United Kingdom), the Endometriosis Care Centre of Australia (ECCA), and RESOLVE, a national infertility organization. Additionally, the ERC is represented in the World Endometriosis 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, and a member of 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.

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://groups.yahoo.com/group/erc>  
ERC General Support Listserv

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

<http://www.hcgresources.com/allercgroups.htm>  
ERC Listing of Local Support Groups

<http://health.groups.yahoo.com/group/EndoDocs/>  
To obtain patient to patient doctor referrals

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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The Endometriosis Research Center & Women's Hospital is a 501 (c) 3 non-profit organization. A copy of the official registration and financial information may be obtained from the Division of Consumer Services by calling 1-800-435-7352 toll-free within the State of Florida. Registration does not imply endorsement, approval or recommendation by the State. Registration #SC-07844. Donations are received 100% by the ERC.

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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/](http://www.centerforEndo.com/)
- 15, 16 - David B. Redwine, MD, St. Charles Medical Center Endometriosis Treatment Program, Bend, Oregon - 800/486-6368 or [www.scmc.org/Endo.html](http://www.scmc.org/Endo.html)
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- 21 - Deborah Metzger, MD, PhD.; Helena Women's Health Treatment Center for Chronic Pelvic Pain and Endometriosis, Phone 650-833-7900.

## Disclaimer

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## Disclosure

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