in numerous countries, and activities worldwide. Elected officers guide the Association, with help and suggestions from an advisory board of medical professionals and others. The Association, founded in Milwaukee in 1980 by Mary Lou Ballweg and Carolyn Keith, was the first group in the world dedicated to helping women with endo.

The Support Program provides a range of services to help girls, women, and their families. These services include a social contact network, counseling, a Medical Assistance Call, help in finding knowledgeable doctors, a prescription drug savings plan, EA-Select vitamins and supplements, the topical pain reliever ProStrong, and other help and services.

The Education Program provides a wide range of literature, books, DVDs, Internet-based outreach, March Endometriosis Awareness Month, conducted since 1993, and other educational efforts to help individuals and the public learn about the disease. Members of the Association receive a popular newsletter covering the latest treatment and research news, as well as Association activities. The Association also provides ongoing help to the media and community to aid in the dissemination of accurate information about endometriosis.

Taking charge of your own health is the most important step in coping with endo.

The Association’s Research/Translational Medicine Program includes maintaining the world’s largest database on the disease, major research partnerships with Vanderbilt University School of Medicine and the U.S. National Institutes of Health, and support for promising research worldwide. The Association also serves as a clearinghouse for information on the disease and conducts programs to alert healthcare providers about the latest research and clinical findings on endo.

Donations to help continue the work of the Endometriosis Association are needed and appreciated.

HOW YOU CAN GET MORE INFORMATION

Contact us—we’re here to help! We also invite you to join - be part of our mission to cure and prevent this disease! A wide variety of informative, accurate, and highly acclaimed literature on endo and related health problems is available to you through the Association. Resources include our third book, Endo-Info: The Complete Reference for Taking Charge of Your Health. It is available from the Association for $15.95 U.S., plus shipping & handling ($5.75 first class, $3.66 media rate for U.S. address), or from your local or online bookstore, and on Kindle.

The Endometriosis Sourcebook, our second book, is almost 500 pages of authoritative information on endo (now in its seventh printing). It is available from the Association for $12.95 U.S., plus shipping & handling ($6.75 first class, $3.50 media rate for U.S. address), or from your local or online bookstore.

The Association also has available educational DVDs of speeches by leading experts on the disease, as well as books, kits, and newsletters, or a free information packet, including our “Materials to Help You” catalog, call, write, fax, or e-mail the Association, or click on the red button below for “Free Information Packet” on our homepage.

If you have not been diagnosed with endo but wonder if you might have it, you can order the Association’s Diagnostic Test Kit, “How Can I Tell If I Have Endometriosis?” Send $4.75 U.S. plus $1.50 for U.S. shipping and handling charges.

(Note: All of the above listed postage rates are for shipping within the U.S. Please contact us for international rates.)

To become a member, go to: www.EndometriosisAssn.org; membership_cart.html

or fill out the membership form inside this brochure and mail it with your dues to:

Join Us Today! You’ll Be Glad You Did.

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This brochure is available in quantity to healthcare providers, hospitals, pharmacies, and women’s clinics. Please specify the quantity and language(s) desired. Brochures available in Arabic, Bulgarian, Cantonese, Croatian, Danish, Dutch, English, Farsi, Finnish, French, German, Greek, Hebrew, Hindi, Hungarian, Italian, Japanese, Korean, Lithuanian, Malay, Mandarin, Norwegian, Polish, Portuguese, Russian, Spanish, Swedish, Thai, and Turkish. Preteen, teen, and menopause versions also available.

WHAT IS ENDOMETRIOSIS?

Endometriosis is a puzzling hormonal and immune disease affecting girls and women from as young as eight to postmenopausal age. The name comes from endometriosis, which is the tissue that lines the inside of the uterus and builds up and sheds each month in the menstrual cycle. In “endo,” as this disease is called for short, tissue like the endometrium is found outside the uterus in other areas of the body. In these locations outside the uterus, the tissue develops into what are called “nodules,” “tumors,” “lesions,” “implants,” or “growths.” These growths can cause pain, infertility, and other problems.

The most common locations of growths are in the abdomen—invading the ovaries, fallopian tubes, ligaments supporting the uterus, area between the vagina and the rectum, outer surface of the uterus, and lining of the pelvic cavity. Sometimes the growths are also found in abdominal surgery scars, on the intestines, in the rectum, or on the bladder, vagina, cervix, or vulva (external genitals). They have also been found outside the abdomen, but this is uncommon.

It is possible, though relatively rare, for endo lesions to become malignant. In addition, research has indicated that women and girls with endo and their families are at greater risk for cancer, particularly ovarian and breast cancer, as well as melanoma, non-Hodgkin’s lymphoma, brain, thyroid, and other cancers. They and their families are also at risk for certain autoimmune diseases, such as multiple sclerosis and rheumatoid arthritis, in which the immune system attacks the body’s own tissues. Research has also shown that endometriosis is a risk factor for heart disease. Because of these risks and the life-disrupting nature of endo in many cases, women and girls are encouraged not to ignore symptoms.

Like the lining of the uterus, the growths of endometriosis usually respond to the hormones of the menstrual cycle. They build up and shed each month and break down. The result is internal bleeding, degeneration of the blood and tissue shed from the growths, inflammation of the surrounding areas, and formation of scar tissue (adhesions). Other complications can be rupture of cysts (which can spread endo to new areas), intestinal bleeding or obstruction (if the growths are in or near the intestines), interference with bladder function (if the growths are on or in the bladder), and other problems. Symptoms seem to worsen with time, though cycles of remission and recurrence are the pattern in some cases.
SYMPTOMS

The most common symptoms of endo are pain before and during menstrual periods (usually worse than “normal” menstruation cramps), pain during or after sexual activity, fatigue, infertility, and heavy bleeding. Other symptoms may include painful bowel movements with periods, lower back pain with periods, and diarrhea or constipation and other intestinal upset with periods. Many women with endo also experience a range of autoimmune diseases, including allergies, asthma, eczema, and certain autoimmune diseases. Infertility affects about 20-40% of women with endo and is a common result with progression of the disease.

The amount of pain is not necessarily related to the extent or size of the growths. Tiny growths (called “petechial”) have been found to be more active in producing prostaglandins, which may explain the significant symptoms that often seem to occur with small implants. Prostaglandins are substances produced throughout the body, involved in numerous functions, and thought to cause many of the symptoms of endo.

THEORIES ABOUT THE CAUSE

The cause of endo is not known with certainty, but a number of theories have been advanced. One theory is the retrograde menstruation theory. According to this theory, during menstruation some of the menstrual tissue backs up through the fallopian tubes, implants in the abdomen, and grows. Research shows most, if not all, women experience some menstrual tissue backup, so experts believe that an immune system problem and/or hormonal problem allows this tissue to take root and grow.

Another theory suggests that the tissue is distributed from the uterus to other parts of the body through the lymph or blood. A genetic theory suggests that certain families have predisposing factors for the disease.

Yet another theory suggests that remnants of tissue from when the woman was an embryo may later develop into endo or that some adult tissues retain the ability they had in the embryo stage to transform under certain circumstances. Surgical transplantation has also been cited as a cause in cases where endo is found in abdominal surgery scars. However, endo has also been found in such cases where direct accidental implantation seems unlikely.

Research spearheaded by the Association since 1992 has shown that environmental toxins such as dioxin and PCBs, which act like hormones in the body and damage the immune system, can cause endometriosis. These are highly toxic chemicals which come from production and use of pesticides and herbicides; municipal, medical, and hazardous waste incineration; chemical and plastics manufacturing; and pulp and paper production. Dioxins readily concentrate in the food chain, contaminating animals and fish; thus is the primary source of dioxin exposure for humans.

DIAGNOSIS

Diagnosis of endo is generally considered uncertain until a laparoscopy is performed and procedure done under anesthesia. The patient’s abdomen is distended with carbon dioxide gas to make the organs move and protrude, and a laparoscope is inserted into a tiny incision in the abdomen. By moving the laparoscope around the abdomen, the surgeon can check the condition of the abdominal organs and, if careful and thorough, see the growths.

A doctor can sometimes feel implants during a pelvic examination, and symptoms will often indicate endo, but it is not possible to determine the extent of the growths without surgery. (Ovarian cancer, for instance, sometimes has the same symptoms.) A laparoscopy also locates the location of the growths and determines the extent of the disease, confirming any others that were suspected. The surgeon will also check for other problems, including allergies, asthma, eczema, and certain autoimmune diseases. 

Infertility affects about 20-40% of women with endo and is a common result with progression of the disease.

TREATMENT

Treatment for endo has varied over the years, but no sure cure has yet been found. Hysterectomy and removal of the ovaries (if not all, visible) can help remove some growths. Tiny growths (called “petechial”) have been found to be more active in producing prostaglandins, which may explain the significant symptoms that often seem to occur with small implants. Prostaglandins are substances produced throughout the body, involved in numerous functions, and thought to cause many of the symptoms of endo.

For as long as possible, and can sometimes force the disease into remission during the treatment of endo. Hormonal therapies aim to stop ovulation and production of hormones for as long as possible. One of the drawbacks of this treatment is that the disease can reactivate by estrogen replacement therapy or continued exposure to hormones. Research also shows there are family links in endo, and allow pregnancy to occur in some cases. As with other treatments, however, recurrences are common.

Other factors may also make the pregnancy decision difficult for women with endo. This has now been shown to be untrue. Often not only women, but also men, are affected by endo and need to take care to have endo diagnosed.

Another myth about endo is that very young women do not get it—an idea that probably arose because formerly teenagers and younger women endured menstrual pain (often one of the early symptoms) in silence and did not get diagnosed until the disease progressed to unbearable proportions. It was also believed in the past that endo more often affected not to postpone pregnancy. However, this is a myth that has been proven inaccurate. Endo is a chronic and ongoing disease, and one can only obtain explanations for their symptoms.

The cause of endo is not known with certainty, but a number of theories have been advanced. One theory is the retrograde menstruation or transtubal migration theory.

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