

The Endometriosis Support Experience

A How-To Guide for Getting Involved & How Support Groups Work

Presented on behalf of the Global Support Program Network of the



FOREWORD:

Endometriosis can be a chronically painful, ongoing disease. Life with this omni-present illness can be a stressful, debilitating time, not only for the patient but for her family, loved ones and caregivers. It is imperative that the patient and those who help and support her understand that resources exist which can ameliorate some of their burden. One important resource is that of a support group, such as those offered within the ERC's Global Support Program Network. This Guide is intended to offer assistance on how to start or become involved in a Group near you, and to share insights as to how our Groups work. Please do not hesitate to contact us with any questions or concerns you may have.

We hope upon reading this Guide you will consider getting involved. Our strength depends on you!

Fondly,

Endometriosis Research Center

an International 501(c)3 tax-exempt, tax-deductible organization

World Headquarters: 630 Ibis Drive | Delray Beach, FL 33444 | USA

Internet: <http://www.endocenter.org> | Phone: (561) 274-7442 | Fax: (561) 274-0931

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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.

ACKNOWLEDGING THE IMPORTANCE OF SUPPORT GROUPS:

Support Groups, also called “special interest groups” or SIG, are an integral part of our organization and a crucial foundation for those coping with Endometriosis. These Groups allow women and girls with Endometriosis, and when appropriate, their loved ones, to come together, share ideas, coping tips, experiences and most importantly, to exchange support. Registered ERC Support Group Coordinators ensure that the support needs of Endometriosis patients in their community are being met. It is imperative that no one living with this disease ever has to feel alone again.

Support Groups can be more than just a safety net for the patient. Indeed, they can even improve the health and wellness of participants. For example, according to Jack Dolcourt, MD (http://www.hkpp.org/physicians/self_help_groups.html), “*support groups have traditionally helped fill the void between the medical system and the daily grind of the everyday world. Support groups generally function to help patients cope, but clearly support groups do more than make patients feel good.*” Dr. Dolcourt further expounds on SIG, noting that “*they can serve as educators for new patients and for the community, and they can serve as a clearing house for disseminating news of important new advancements or therapies....support groups take on the additional roles of expert and advocate.*”

Further evidence of Support Groups readily exists from the scientific field as well. For example, one investigation led by Stanford University researchers evaluated 86 women with breast cancer that had already metastasized. 50 of the women attended weekly Support Group meetings for a year or more, in addition to receiving standard medical treatment, while 36 women received only medical intervention. Study results revealed that the women in the breast cancer Support Groups reported feeling “*less anxious, less depressed, and less bothered by pain*” versus those who had not participated in a SIG. Researchers later discovered even more remarkable findings: the women in the Support Groups survived an average of 18 months longer than the others. 4 years after the study began, one-third of the participants in the Support Groups were still alive, while all 36 of the other women had died. (data provided by the Harvard Health Letter via the United Ostomy Association - <http://www.ostomyok.org/newsletter/news9905c.html>).

Another study detailing the importance of Support Groups specifically for those coping with Endometriosis was published in the Journal of Reproductive Medicine in March 1998 (J. Reprod. Med. 1998 Mar;43(3 Suppl):331-4). Authors Whitney et. al. investigated the social support experience of 46 women in an online Endometriosis Support Group. They concluded that “*in general, the women with Endometriosis valued connections to other women with Endometriosis.*”

Furthermore, the ERC’s own legislative efforts have resulted in several official resolutions, bills and proclamations concerned with the need for better awareness of the disease, including the country’s first-ever national resolution, which in part “*recognizes the need for better support of patients with Endometriosis.*”

There is no question that the social support experience of women and girls living with the disease can be highly beneficial and even help lead to better care, increased coping mechanisms, and an overall improved outlook. The ERC invites all those concerned with Endometriosis to join and benefit from our Support programs (of course, for free).

GET STARTED:

Several off- and online Support Groups exist through the ERC. We are pleased to offer nearly 50 global Support Groups in the United States and around the world, many with internet access in addition to in-person meetings in their respective locations. For a complete listing of our many Groups, please visit <http://www.endocenter.org/supportgroups.htm>. There is never a charge to lead, participate in or benefit from any of the ERC’s programs.

The ERC is also pleased to host the Internet’s largest electronic Endometriosis support group, the ERC Angel Listerv. Located on Yahoo, the ERC Listserv offers access to over 3,000 participants from every part of the globe, where members can exchange experiences, news, ideas, information and, of course, daily support in a private, moderated setting. To join for free, please visit: <http://groups.yahoo.com/group/erc>.

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ABOUT THE ERC'S SUPPORT GROUPS:

ERC Support Groups are organized under the ERC umbrella and as such, use the name "Endometriosis Center of {name of Group}"; for example, the Endometriosis Center of the San Francisco Bay Area (www.sfendo.org). Groups are commonly referred to in the online community as "EndoCenters." Support group meetings are often held on a monthly or ongoing basis as determined by the Leader. Typically, the meetings are held at a local hospital, conference center, library, residence, or other location as determined by the Group. Through their respective Leaders, ERC Support Groups disseminate ERC fact sheets and information, articles, and educational materials at meetings, in addition to facilitating support, outreach and non-medical crisis care as necessary.

Leaders, and their Groups, also seek out public relations opportunities and publicize their Groups along with Endometriosis through local media outlets. Often, at the discretion of the Group Leader, expert speakers and guest presenters will be invited to special educational meetings. All speakers are approved in advance by the ERC executive team before attending or presenting at an ERC meeting. Groups also publicize their information and distribute ERC brochures in physician offices and other healthcare related resources. This helps to reach new members who may be in need of the Group's many services.

ERC Support Groups are also active in hosting, facilitating and/or attending fundraising events, Endometriosis conferences, and awareness initiatives on the local level. The ERC is unique in that we are the only free Endometriosis organization offering education, support and awareness to all those concerned with the disease; we exist solely on donations. Therefore, Groups may host or otherwise become involved in various fundraising efforts throughout the year.

Group Leaders and their members also perform important Patient Advocacy services where appropriate, attending doctor meetings with other patients and visiting surgical patients; some even host out-of-town national ERC members when coming to a specialist in their area on occasion.

Leaders report daily to the ERC, keeping headquarters informed of their efforts and program outcomes. The ERC offers reciprocal support to Leaders by assisting them in every endeavor and ensuring that the Leader has everything she needs to run an effective and successful ERC Support Group. We expect one-year commitments of all our Group Leaders to avoid unnecessary disruption to the local members who may be part of their efforts.

REQUIREMENTS & GUIDELINES:

Though no special skills are required to run an ERC Group, Leaders undergo thorough processing before being approved. They must have a willingness to improve the lives of those with Endometriosis and to help make positive strides in the Endometriosis community. References will be randomly checked on all our Group Leaders, and each Leader is expected to represent the ERC's principles of compassion, mutual respect, and strict confidentiality when dealing with Group members. Those found to be non-compliant with our Group Leader guidelines will be removed without notice.

Group Leaders spend approximately 6 ± hours per month on their group, though this varies greatly depending upon the individual Group and various opportunities that may present themselves. Groups are not required to offer in-person services where the need does not exist; many Groups are highly successful in offering support, raising of awareness and providing their services via email, their online Listserv, the telephone and on any other as-needed basis.

The ERC as an organization is sensitive to the fact that what works for one patient may not necessarily work for another. Therefore, Group Leaders and all other ERC representatives are required to remain unbiased when speaking to others about medications, treatments, etc. Additionally, because the ERC does not endorse any physicians, organizations, products or treatment methods, caution is exercised when recommending products, books, medications, etc. The ERC does not accept funding from pharmaceutical corporations, including the makers of Lupron®, Synarel®, Zoladex® or other GnRH agonists. We also do not charge for membership, materials or access to our Support Network, nor do we accept donations from practitioners in exchange for referring those practitioners to our members. Similarly, promotion of any products, medications or "sales pitches" of any kind is prohibited at ERC Support Group meetings or activities.

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Furthermore, due to the sensitive and confidential nature of ERC Support Group Meetings, and in keeping with the theme of "support," pharmaceutical company representatives are not encouraged to attend, unless they are attending as a person concerned solely with the disease on a personal level. External links on ERC Support Group pages are not permitted unless expressly cleared with headquarters first.

As a 501(c)3 nonprofit, tax deductible organization, the ERC has strict federal financial regulations it must adhere to. The ERC is not a fee-based organization, and there is never a charge to attend an ERC Group Meeting. As a nonprofit organization, the ERC does not have the funding to reimburse Group leaders for expenses incurred for production of such materials as newsletters and/or correspondence (i.e., postage, envelopes, paper goods, ink, etc.). Groups are run by those who donate willingly of their time, effort and in some case, expense to help others. However, Groups may elect to contribute small donations to their own Group fund in order to cover shared refreshments, etc. offered at the meeting. Strict, meticulous records must be kept of such donations, and costs must be balanced against contributions. Leaders are required to send them in to ERC headquarters along with summary sheets each month.

Group Leaders are not authorized to act on the financial behalf of the ERC and may not open, maintain or perform any transactions on bank accounts bearing the ERC name. Donations collected from Group attendees for purposes other than outlined above must be sent to the ERC world headquarters at 630 Ibis Drive, Delray Beach, FL 33444.

Tangible assets donated to Groups (such as software, computers, equipment, gift certificates, etc.) must be logged and registered with the ERC headquarters. A photo of the item along with accompanying correspondence must be sent to the ERC immediately upon receipt of the item. Notice of intangible donations, such as a waiver of fee for services, must also be copied to the ERC. All fundraising efforts and events must be first approved by and coordinated with the ERC's Director of Fundraising. Contact Denise Childs at FundraisingDirector@EndoCenter.org.

Leading or participating in an ERC Support Group can be a rewarding, mutually beneficial and overall positive experience for Leaders and members alike. If you would like to get involved and participate in – or start – an ERC Group today, we welcome and encourage you to do so. Please contact Marina Roberson, Director of the ERC's Global Support Program Network, at Marina@EndoCenter.org.

WHAT MEMBERS ARE SAYING ABOUT OUR GROUPS:

"Thanks for sharing your experience...your advice is invaluable." "Thank you from the bottom of my heart for your support and wisdom. I no longer feel so alone." "Thanks to this Group, I have found a new doctor and new help for my Endo. I am so grateful!" "The information I obtained here has helped me make the best decisions about my treatment. I'd be lost without you all." "Thanks again...I feel like someone in the world can relate." "What a wonderful resource this is. I wish I had found it sooner."

LEARN MORE:

To learn more about the help we offer and the many programs available through the ERC, please read "Who We Are" below and visit our website at <http://www.endocenter.org>.

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“TEN RESOLUTIONS”

Following is an incredibly helpful “checklist” for those living with a chronic pain condition, presented by Brian Grady, Ph.D. of Ten Resolutions. These Resolutions and other helpful data are available on Dr. Grady’s in-depth website at <http://www.tenresolutions.org>. We have reproduced his “Ten Resolutions” here for the benefit of our readers. © Copyright by Brian Grady, Ph.D. All rights reserved. Reprinted in accordance with Dr. Grady’s reprint guidelines. Though some of these Ten may not apply to your situation, the age-old adage applies: *“take what you need and leave the rest.”*

1. “I realize that my condition has not been completely cured or resolved by medical treatment, or the force of my will, by waiting, other sources of help, or by deciding it's not important. I am prepared to accept this and move in a new direction.
2. I recognize that I need a positive relationship with my body and symptoms. I have seen that some of my efforts to cope have not worked as well for me or others as I had hoped. I am learning positive ways to live with this condition.
3. I let go of parts of my past life that are over. I may grieve what is lost, but I am committed to living well with what is. I face my present reality with creativity and vigor. I find new ways to make my life rewarding.
4. I forgive myself for having had difficulties. I recognize that I am human, and have human limitations like everyone. I accept that I am imperfect, and can fall short even with the best intentions. I choose to develop the skills I need to deal with my condition and help myself live as well as I can.
5. I build and heal my relationships with others. Where I have made mistakes with others in my efforts to live with my condition, I am ready to seek new and even better relationships with them.
6. I forgive anyone I have blamed for my condition or for mistreatment. Forgiving others and letting go of blame, I am free to move forward. I take full responsibility for how I create the rest of my life.
7. I recognize mental and physical habits and reactions involved in my condition. Though I have tried my best, some habits are inefficient or not good for me. I am committed to developing ways of thinking and acting that better my situation.
8. I acknowledge ways my symptoms are reinforced. Sometimes, whether I have been aware of it or not, symptoms have had payoffs. I do not need to avoid or obtain things, protect myself, or deal with other people through them. I resolve to be assertive, courageous and honest in my dealings with the world.
9. I understand how I can become dependent in unhealthy ways -- on people, on medications, drugs, alcohol, on organizations, on objects, on ideas. I am willing to release these things and regain my power and control over my life. I rely on people and things only if they strengthen and nourish me.
10. I am ready to make hard but positive choices and to see them through. I am open to new ideas and ways of living. When I have made these changes part of my life, I can also help others.”

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WHO WE ARE:

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. 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.

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 their loved ones, 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 collaborated on several books, publications and videos pertaining to the disease over the years, as well working with the extended media to bring education and awareness to the forefront of society. 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.

On the clinical front, the ERC is 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 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 have also previously conducted a study of medical professionals in collaboration with Agile Therapeutics, using data collection and analysis to determine the formation of a birth control patch compound. Other collaborations include 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 more.

The organization is also currently 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. The ERC also seeks to further define Endometriosis epidemiology, and to that end is working with governing bodies to establish a formal disease registry, the first of its kind.

The ERC investigates 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 publicly confronted an "Expert Panel Consensus Report" in the Journal of Fertility & Sterility advocating the use of pre-diagnostic GnRH drugs. Our position on these matters can be viewed online at <http://endocenter.org/endostudy.htm> and <http://endocenter.org/pdf/PreDiagnosisGnRH.pdf>, respectively.

The ERC is a leader in Endometriosis awareness initiatives. 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 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, the states of New York, Colorado, Florida, Michigan, California, Wyoming and Pennsylvania have all passed Resolutions officially recognizing the Month of March as

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"Endometriosis Awareness Month." Our most gratifying success, however, came when the 107th Congress of the United States 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 over 3,000 participants from around the globe. In honor of young women with Endometriosis ages 25 and under, the ERC also 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 were also the first Endometriosis organization to address the unique perspective of, and offer specifically tailored materials to, the underserved 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, the national infertility organization. Additionally, the ERC is represented in the World Endometriosis Society, the 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 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.

The Endometriosis Research Center's Medical & Professional Advisory Panel provides oversight of the ERC's various programs and initiatives. This prestigious group of individuals provides the ERC with the benefit of their expertise in many different areas, and help guide, support and implement the mission and goals of our organization. Panel Members include individuals who volunteer their time and expertise from the medical,

scientific, financial, clinical research, media, corporate and legal professions. The ERC has the privilege of collaborating with such existing Medical & Professional Advisory Panel members as David B. Redwine, MD, global leader in Endometriosis treatment and research and Director of the St. Charles Medical Center Endometriosis Treatment Program in Bend, OR; Robert B. Albee, MD, Founder & Medical Director of the Center for Endometriosis Care in Atlanta, GA, internationally recognized for his expertise in Endometriosis care and treatment; Dr. Jennifer Ritchie-Goodline, Psy.D., a psychologist in private practice; Andrew Cook, MD, Director of the Vitalcare Institute of Health in Los Gatos, CA, world-renowned for his dedication to Endometriosis research and treatment; Deborah Metzger, MD, Ph.D., Director of the Helena Women's Health Center in Palo Alto, CA, known for her unique "4 Pillars of Healing" approach; Serdar Bulun, MD, RE, Director of the Division of Reproductive Biology Research at Northwestern University Feinberg School of Medicine in Chicago, IL, known for his groundbreaking research on Aromatase Inhibitors; Nancy Petersen, RN, Founder of the Endometriosis Treatment Program at St. Charles Medical Center in Bend, OR; Donna Laux, MA, Northside Medical Center, Atlanta, GA; Glenda Motta, RN, MPH, ET, of Washington, DC, Author of "Coping With Endometriosis" and "Successful Living With Endometriosis;" William Fleming, Ph.D., Vice Chairman of A-FEM Medical Corporation, also in Oregon; Linda Howard-Smith, Nurse Practitioner with Vitalcare Institute of Health in Los Gatos, CA; Armand Lione, President of Associated Pharmacologists & Toxicologists and author of the prestigious ReproTox Database, Bethesda, MD; Michael Ahearn, Esquire, legal counsel for ERC from the law firm of Shepard & Leskar in Florida; Joan Magill, Psy.D., Co-Director of the South Florida Institute for Consultation & Psychotherapy; Virginia Prystawski, ERC financial advisor and a Vice President of CitiBank Corporation; Mary Robinson Prody, RN, a Nurse Paralegal; Michael Clifford, M.S.O.M., Dipl. Ac. (NCCAOM), L. Ac., a health and wellness professional from Arizona; Melissa Buddeke, CPA, the ERC's accountant; and Maria Sherman, the ERC Art Director and a Graphic Artist. The ERC also draws on the expertise of such professionals as Mark S. Denker, M.D., Medical Director of the Palm Beach Fertility Center; Jeffrey C. Seiler, M.D., a gynecologist at Cleveland Clinic of Florida; Robert C. Siudmak, M.D., Department Chairman of ObGyn at Memorial Regional Hospital in Florida; Drs. Nabil Husami and Khaled Zeitoun of the Center for Endometriosis Research & Treatment at Columbia University Medical Center in New York City, NY; and many others.

The Endometriosis Research Center is freely open to all those concerned with Endometriosis: medical professionals, researchers, women of all ages with Endometriosis, and anyone interested in the disease. It is the ERC's goal to make a positive difference in the lives of the millions suffering from this disease. Please consider helping the ERC help others by supporting and getting involved in our worthy efforts today.

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