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F a m i l i a l O v a r i a n C a n c e r R e g i s t r y
news
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Hormone Replacement Therapy: Implications for Women with a Family History of Ovarian Cancer
- M. Steven Piver, M.D.

It has been rhetorically stated that why wouldn't any woman take HRT (estrogen plus progesterone) that is purported to prevent hot flashes, night sweats, insomnia, loss of libido, depression, mood swings, and lower the risk of heart disease and osteoporotic hip fractures while preserving mental acuity and result in an overall improved sense of "well-being". Although it was suspected that HRT slightly increased the risk of breast cancer, however, with heart disease the #1 killer of women in the United States, the overall advantage of HRT appeared to dwarf the possible small increase in breast cancer.

All of this changed in July 2002 in a report in the Journal of American Medical Association titled "Risks and Benefits of Estrogen Plus Progestin in Healthy Postmenopausal Women: Principle Results for the Women's Health Initiative Randomized Controlled Trial". The Women's Health Initiative randomized 16,608 postmenopausal women ages 50-79 who had not had a hysterectomy to Prempro (Premarin plus medroxyprogesterone) daily or a placebo. This so called "preventive trial" was to last eight and half years. However, the authors abruptly halted the trial at a little over five years when the interim results demonstrated a 29% increase in heart attack rate, a 41% increase in the rate of strokes, a two fold greater rate of leg and pulmonary blood clots and a 26% increase in invasive breast cancer. Although there was a 37% lower rate of colorectal cancer and a 23% lower rate of osteoporotic hip fractures in the HRT women, the overall risks were clearly felt to outweigh the benefits.

How do these percentages translate into real people? Based on these results, on an annual basis of every 10,000 women in the United States on HRT, eight more will develop invasive breast cancer, eight more will have strokes, eight more will have pulmonary blood clots, seven more will have heart attacks while six fewer will develop colorectal cancer and five-fewer will have osteoporotic hip fractures. Admittedly, these

numbers appear small but considering that some 13 million women in the United States are estimated to be on HRT, the seemingly small numbers loom large.

How does this report affect women with a strong family history of ovarian cancer? On the surface, it would appear not to effect such women since the women on Prempro in the Women's Health Initiative did not have an increased rate of ovarian cancer. However, it is now known that most cases of inherited or familial ovarian cancer are caused by one of two mutated genes, BRCA1 and BRCA2, that can be inherited from the mother or father. Mutations in BRCA1 are associated with the probability of developing ovarian cancer by age 70 or between 28-44% and mutations in BRCA2 with a risk of 27% by age 70. However, for female carriers the lifetime risk of BRCA1 or BRCA2 mutations carries a lifetime risk of breast cancer between 50-85%. And that fact is the apparent, and I stress apparent, implication of this study for women with a strong family history of ovarian cancer. With the Women's Health Initiative reporting a 26% increase in invasive breast cancer in the general population on HRT, the implications for women who may carry a deleterious gene that is already associated with a 50-85% chance of developing breast cancer are indeed worrisome. At the time of this writing, it is unknown whether HRT impacts adversely on the role of breast cancer in women who carry a mutated BRCA1 or BRCA2, higher than the reported rate of 50-85%. A cautious approach, in consultation with her own physician would seem prudent until more information is available.

It is important!

for our research projects for us to maintain an accurate, confidential medical history database of Registry families. If you have updated medical information on yourself or members of your family, please complete this form and return it to the Registry.

Name _____

Registry ID # _____

Address: _____

Phone # _____ E-mail address: _____

Comment: _____

Mail to: Gilda Radner Familial Ovarian Cancer Registry, Roswell Park Cancer Institute, Elm & Carlton Streets, Buffalo, New York 14263

Friends of the Registry!

We would like to thank those who have remembered the Registry in their time of loss and assure them of our sincere appreciation of these funds spent specifically for ovarian cancer research.

The Joyce Kozlowski Family
The Kathleen Madson Family
The Rhea Lamina Family
The Kathleen Kremer Family
Robert J. Calvino Annual Softball Tournament
Pedal for a Cure
The Erin Patricia Lockwood Family
Bill and Heather Beeman
The Judy Knox Family
The Bertha Murphy Family
The Linda Ghilardi Family
The Louise Mork Family
The Fredda Rothlein Family
The DeAnna Jones Family
The Lorraine Coppola Family
The Carol Lee Finnerty Family
The Tri-Color Open
The Delores Ortega Walker Family
The Sylvia Marlowe Family
The Pat Barrett Ride
The Elizabeth Gill Family
The Cynthia Esser Family
The Sue Spencer Family
The Judith Perlmutter Family
Marcy Stillman
The Janet Marcus Geller Family
The Robin Skiff Pittard Memorial Fund
The Emily Hunt Roe Family
The Arlene Coggburn Family
The Sylvia Marlowe Family
The Susan McMillan Family
The Barbara Lynn Swanson Family
The Francine Stenzler Family
The Merle Turkington Family
The Roseanne Sandler Family
The Maryann O'Brien Family
Nancy Duval

And a very special thank you to a young girl who painted hearts on rocks and sold them at a church bazaar and sent all the proceeds to the Gilda Radner Familial Ovarian Cancer Registry in memory of her Grandma.

And to hundreds more for their donations and words of appreciation and encouragement.

Recent Research Highlights

1. Familial ovarian cancer is the occurrence of two or more cancer cases in close blood relatives. About 10-15% of all ovarian cancer cases are familial. Inherited mutations in either the BRCA1 or BRCA2 genes are responsible for ovarian cancer in many of these families. Thus, healthy women who carry mutations in these genes are at greater risk for developing ovarian cancer than most healthy women in the general population. Use of oral contraceptives is associated with reduction of ovarian cancer incidence in the general population. It is not known if reduction in the chance for developing ovarian cancer also holds for healthy women who carry mutations in BRCA1 or BRCA2. We have studied this issue in families enrolled in the Gilda Radner Familial Ovarian Cancer Registry. We found that use of oral contraceptives reduces the risk for ovarian cancer among healthy women who carry mutations of BRCA1 or BRCA2. We found that use of oral contraceptives for six years was associated with a 50% reduction in the chance of developing ovarian cancer. Thus, use of oral contraceptives by women carrying mutations in BRCA1 or BRCA2 genes may be an effective measure for lowering the chance for developing ovarian cancer.
2. In many families with multiple cases of ovarian cancer, inheritance of mutations in either the BRCA1 or BRCA2 genes is responsible for the occurrence of ovarian cancer. In our research, we found that mutations in either the BRCA1 or BRCA2 genes are found in about one-half of all families with multiple cases of ovarian cancer. This suggests that inherited mutations in other genes may be responsible for disease in families with multiple cases of ovarian cancer and without BRCA1 or BRCA2 mutations. We have been trying to find out what these other genes are. Recently, we found that inheritance of an altered form of a gene called TP53 may be responsible for disease in such families. Currently, we are trying to get more information to prove this. If our initial promising results are validated, it would increase knowledge of the causes of inherited ovarian cancer and provide a new target for developing means to prevent, diagnose, or treat ovarian cancer.
3. The current recommendation for women who belong to hereditary breast ovarian cancer (HBOC) kindreds is to have bilateral salpingo-oophorectomy (removal of both tubes and ovaries) after childbearing is completed. Some medical groups believe that adding hysterectomy at the same time of prophylactic salpingo-oophorectomy may be beneficial. To provide further evidence and to assist doctors in making the decision if adding hysterectomy at the time of prophylactic salpingo-oophorectomy is beneficial, we are surveying women registered in the Gilda Radner Familial Ovarian Cancer registry who have already undergone the surgery.

Registry News

The Gilda Radner Familial Ovarian Cancer Registry Awareness Quilt. September being Ovarian Cancer Awareness Month, the Registry launched a project, one for which we need ALL OF YOU to participate. We are asking you to help us make the Gilda Radner Familial Ovarian Cancer Awareness Quilt. Everyone affected by ovarian cancer – from survivors to family members and friends of those who have suffered from ovarian cancer – is welcome to contribute a square. The squares should be sent to the Registry by March 2003.

Personalized quilt squares are coming in, but many more are needed. Please join us and be part of this caring project.

How to contribute to the Gilda Radner Familial Ovarian Cancer Registry Awareness Quilt

Make A Square - The quilt will be bordered in a solid teal (or print with significant amount of teal) so you may wish to choose colors to coordinate. The center square will be the Gilda Radner Familial Ovarian Cancer Registry logo. The finished square size will be 12 inches. Your square should have raw edges and measure at least 12.5 inches. If your design permits additional seam allowance (i.e., an appliquéd or other non-pieced design), it is preferable to send a 13-inch square including raw edges. Small 100% cotton prints, checks, etc. would be ideal, but velvets, velours and medium-weight upholstery fabrics are also acceptable, especially for appliquéd. You are encouraged to personalize your square with fabric scraps, photo-transfers to fabric, and other mementos (button, pins, beads, embroidery) that are significant to you as a survivor – or, if you are doing a square in memory of a loved one or in to celebrate a loved one. Paints, inks, or dyes should be permanent and suitable for use on fabric. Avoid using puffy pens, glitter or vinyl. All appliqués and dimensional add-ons should be securely sewn in place. Soft sculpture should not exceed 1½ - 2 inches in raised-up dimension. Pellon Wonder-Under may be used to fuse designs prior to sewing.

Tell Us About the Person Celebrated in the Square – Enclose a paragraph or two about the person (yourself or someone else).

Send your completed square to:

Gilda Radner Familial Ovarian Cancer Registry
Roswell Park Cancer Institute
Elm and Carlton Streets
Buffalo, NY 14263

If you have any questions, please feel free to call the Registry at 1-800-685-6825 extension 4503

Registry Receives Award

The Physicians Committee for Responsible Medicine has recognized The Gilda Radner Familial Ovarian Cancer Registry for the excellence of their service programs and its commitment to education, prevention, or life-saving research. The registry was selected for the PCRM first-ever "Top Ten Best Health Charities."

www.ovariancancer.com

We have a new webmaster, Jon Kiddy. We hope you continue to use our website to find information you need. Our Newsletters are on our website as well. If you have an ovarian awareness event coming up and would like it posted on our Calendar, please email gradner@roswellpark.org and let us know the details. Also, watch this site for ovarian awareness events happening throughout the year.



Help-Line for High-Risk Women

The Help-Line is a support service established by volunteers who have a personal or family history of ovarian cancer to assist callers in making decisions about their health care. Volunteers at the Help-Line provide callers with information, along with emotional and personal support. By calling 1-800-OVARIAN and asking for a Help-Line call, you will be placed in contact with concerned volunteers who have made the decisions you are now facing.

M. Steven Piver, M.D., Founder and Director – James Marshall, Ph.D., Epidemiologist – Richard DiCioccio, Ph.D., Basic Research Coordinator – Cathy Fahey, B.S., Project Director, – Alice S. Whitemore, Ph.D., Bruce Ponder, M.D., Ph.D. Consultants – Gene Wilder, Honorary Chariman

1-800-OVARIAN
www.ovariancancer.com
gradner@roswellpark.org