

the Gilda Radner

FOOCR

ROSWELL PARK
CANCER INSTITUTE®

news

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



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GRFOCR Help-Line Celebrating 10 Year Anniversary

Ten years ago, being in a family with 6 maternal relatives diagnosed with ovarian cancer, Dianne was at high risk for developing ovarian cancer. A patient of Dr. M. Steven Piver, founder and director of the Gilda Radner Familial Ovarian Cancer Registry (GRFOCR), she discussed with Dr. Piver the lack of support for women like her that were facing frightening, confusing and crucial decisions about their future. Together in 1994, they created the Help-Line for women at high risk of ovarian cancer. Help-Line volunteers have helped hundreds of women face their fears and concerns over the threat of ovarian cancer. The purpose of the Help-Line is to have a volunteer listen to these callers, share their experience as they faced these decisions, help the caller to explore their alternative options, encourage them to research the medical information available to be well informed, and help direct them to medical professionals. Dianne wanted the women to have the facts, along with the emotional and personal support they need during this difficult time.

Who are the Help-Line volunteers? Joan expresses it best - "My lingering anxieties and a desire to connect with other women facing ovarian cancer led me to

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, including such things as,

- a tubal ligation
- oophorectomy
- genetic testing results
- benign ovarian tumor
- newly-diagnosed cancer and/or
- death in the family

please complete the reverse side, detach the bottom portion of the page and return it to the Registry in the self-addressed, stamped envelope.

Yes!

Contact me regarding family medical history.

(see reverse side)

volunteer at the Gilda Radner Familial Ovarian Cancer Registry. Becoming a member of the Help-Line has been extremely meaningful to me because I have been able to channel the emotions associated with my mother's death in a positive way. Through my work at the Registry I met a group of wonderful women who also volunteer for the Registry's Help-Line and was asked to become a volunteer myself. All of the women who take calls for the Help-Line have had close family members with ovarian cancer and are themselves at higher risk for developing the disease. One Help-Line volunteer was diagnosed with ovarian cancer in her early thirties."

Women, from across the country, who call the Help-Line are seeking information from women who have been there before them. The Help-Line volunteers are able to relay their own personal stories and thereby give the caller a gift from the heart. By calling 1-800-OVARIAN (1-800-682-7426) and asking for a Help-Line volunteer callback, women have been getting this support for the past 10 years.

September – Ovarian Cancer Awareness Month

The Gilda Radner Familial Ovarian Cancer Registry needs your help. We would like to make each woman aware of ovarian cancer. We are asking you to be our legs to reach out to all communities. We have newsletters, informational brochures, and bookmarks; we need you to get them out in the communities for us. They can be put in your doctor's office, your local library, and women's clubs and organizations. If you are interested, please contact the Registry (1-800-685-6825 ext. 4503) and ask us to send you the supplies!

That's What Friends Are For!

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.

Mr. and Mrs. Silas Bolef
Mr. and Mrs. John Power
Mr. and Mrs. Joseph Carberry II
Ms. Carolyn Rhatigan-Sullivan
Charlotte Girls Night Group
Roane Medical Center - Medical Staff
Mr. and Mrs. Steve Christie
Mr. and Mrs. Robert Steiner
The Family of Sharon Wood
The Family of Charlotte Zanaras
Mr. and Mrs. Mark Connelly
Mr. and Mrs. Joseph Trifiletti, Jr.
Pedal for a Cure
Mr. and Mrs. Richard Wood
Mr. and Mrs. Dennis Danforth
Mr. and Mrs. Eugene Wrzesinski
Edison International
The Joyce Kozlowski Family
IBEW Local No. 743
The Family of Susan Gowen
Joe Nardone's Gallery of Sound
The Robin Skiff Pittard Memorial Foundation
Mr. and Mrs. Charles Kremer and Family
Kathleen Pickard
Ortho Biotech Products, L.P.
Friends of Cheryl Vivian
Pfizer Foundation Matching Gifts
Daniela Bar-Illan
Pat Barrett Memorial Ride
Footsteps Toward Hope
Mr. and Mrs. James Pickard
Collin Kushner and Family
M.O.M. golf Event
Friends of Eileen Beauchamp
Pansy Daily
Sister Suzanne Franck
Mark Mack
Mr. and Mrs. George Behnen
The Family of Eileen O'Keefe-Germano
The Family of Nohemi Garza
The Family of Nancy Dynak
The Family of Nancy Burke

New Fundraising Initiative

The Registry is excited to announce a new fundraising initiative for the expansion of ovarian cancer research in partnership with the Development Office at Roswell Park Cancer Institute. Over the last 23 years, the Registry has contributed to many scientific advances in familial ovarian cancer including the discovery that ovarian cancer can be inherited and occur in different generations within families and the localization of the gene BRCA1 to a narrow area on chromosome 17. Now, because of the cooperation by so many families who participate in the Registry, we have enough data for more exciting studies. The Registry will focus on: 1) is there a simple test that we can perform to detect ovarian cancer during its first stage in order to save more women's lives; and 2) are there additional genetic markers that will identify women who are at risk for ovarian cancer?

Enclosed with this newsletter you have probably already noticed a letter from Dr. Piver asking for your help in bringing forth this research. Money raised from this effort will fund scientists and doctors working together in the most advanced laboratory facilities. They will be able to more quickly focus their efforts on specific needs for ovarian cancer families. These new donations will go to support this research, and will put us in a better position to receive federal research funding. Thank you in advance for considering a gift to fund research that will take us a step closer to the cure for ovarian cancer.

M. Steven Piver, M.D., Founder and Director
James Marshall, Ph.D., Principal Investigator
Richard DiCioccio, Ph.D., Basic Research Coordinator
Kerry Rodabaugh, M.D., Co-Investigator
Cathy Fahey, B.S., Operations Manager
Dianne Schuh, Help-Line Coordinator
Alice S. Whittemore, Ph.D.,
Bruce Ponder, M.D., Ph.D., Consultants
Gene Wilder, Honorary Chariman
1-800-OVARIAN
www.ovariancancer.com
gradner@roswellpark.org



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