

the Gilda Radner

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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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Gearing up for the 25 YEAR ANNIVERSARY of the Gilda Radner Familial Ovarian Cancer Registry

The Registry was established to track families with two or more diagnoses of ovarian cancer in 1981 by M. Steven Piver, MD, former Chairman of the Department of Gynecologic Oncology at Roswell Park Cancer Institute after a serendipitous occurrence of two families, each with five (5) close family members spanning three (3) generations came under Dr. Piver's care in the late 1970s. In an 1982 report Dr. Piver stated:

“Because of the seemingly increased incidence of familial ovarian cancer and the need for appropriate genetic counseling in such cases (in 1981) a Registry has been established at Roswell Park Cancer Institute. If autosomal dominant transmission is established, genetic counseling for prophylactic oophorectomy at an appropriate age may lead to a decrease in deaths from ovarian cancer.”

Twenty-five years later this appears to be a reality. The Gilda Radner Familial Ovarian Cancer Registry was initiated in an attempt to document the number of cases of familial ovarian cancer in the United States. On May 20, 1989, the great comedic actress, Gilda Radner, died of ovarian cancer. A report on Gilda Radner's death from ovarian cancer in the May 30, 1989 edition of the *Washington Post* stated *“Genetics could play a role in a very small number of cases.”* At Roswell Park Cancer Institute in Buffalo, NY, M. Steven Piver had collected a national registry of 200 ovarian cancer families where the disease reappears in each generation. With unanticipated media attention to ovarian cancer, the Registry enrolled over 450 families with familial ovarian cancer. The Registry was renamed in honor of Gilda Radner, the Gilda Radner Familial Ovarian Cancer Registry in 1990. As its 25 Year Anniversary soon approaches, the Registry has now enrolled over 1,850 families with familial ovarian cancer cases. Today the Registry continues to enroll families each year from around the world. The Registry's website www.ovariancancer.com contains information about ovarian cancer, how to enroll, the research being conducted by the Registry and links to other ovarian cancer informational websites. The Registry publishes a Newsletter, an 800-OVARIAN hotline staffed by cancer information specialists who answer ovarian cancer

questions, and a HELPLINE made up of volunteers – all women at high risk for ovarian cancer due to family medical histories – who listen, share experiences and provide information on where to go for answers. As the Registry continues its research to identify new genes associated with familial ovarian cancer, its goal is to acquire information that will lead to better methods for detecting ovarian cancer and for preventing the disease in future generations.

2006 will mark the 25th Anniversary of the founding of the Gilda Radner Familial Ovarian Cancer Registry, a milestone we are looking forward to celebrating with everyone who made that a reality.

Some highlights over the past 25 years:

- Observations from Dr. Piver and members of the Registry and information gathered from participants in the Registry helped to identify the link between BRCA1 and BRCA2 and ovarian cancer in 1994.
- In 1996, Dr. Piver and Gilda Radner's husband, Gene Wilder, published **Gilda's Disease: Sharing Personal Experiences and a Medical Perspective on Ovarian Cancer**.
- Researchers associated with the Registry have published over two dozen research articles in major medical journals. One recent breakthrough from the *British Journal of Cancer* (2004), *“Oral Contraceptive Use and Ovarian Cancer Risk Among Carriers of BRCA1 or BRCA2 Mutations,”* reported an approximate 40% reduction in ovarian cancer risk associated with long-term oral contraceptive use among carriers of BRCA1 or BRCA2 mutations.

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September - Ovarian Cancer Awareness Month

Last year the Gilda Radner Familial Ovarian Cancer Registry asked its members to help make women aware of ovarian cancer by being our legs to reach out to their community by handing out our ovarian cancer informational brochures and bookmarks to their doctor's office, local library, women's clubs and organizations. This was such a great success, we are asking for your help once again. If you are interested, please contact the Registry (1-800-685-6825, ext. 4503) and ask us to send you the supplies!

CA125 makes the news!

CA125 keeps making the news so we repeat part of an article Dr. Piver prepared for the **May 2002 Vol. 3 Issue 1** of the Registry's Newsletter.

In 1983, reporting in the *New England Journal of Medicine*, Robert Blast and colleagues were the first to report on a new blood test, CA125, for diagnosing ovarian cancer. Twenty-two years later, CA125 remains the best test available. Although elevated in 90% of advanced stages, Stage III (spread to the abdominal cavity) and IV (spread to the liver or beyond it), it is only elevated in 50% of early Stage I cases. Moreover, it is not specific to ovarian cancer, being elevated in other cancers such as breast and gastrointestinal malignancies. It is also elevated in such benign conditions as uterine fibroids, endometriosis, menstruation and pregnancy, but to mention a few. Admittedly, it is not a good test for screening for early staged ovarian cancer, but yet it remains the gold standard for possibly diagnosing ovarian cancer in its earliest, most curable stage.

Ten years ago the U.S. government took the official position that CA125 should be used along with ultrasound and pelvic exam to screen women with a hereditary ovarian cancer syndrome.

Continuing the Ovarian Cancer Fundraising Initiative

As you may already know, in September 2004 the Registry announced a new fundraising initiative for the expansion of ovarian cancer research in partnership with the Development Office at Roswell Park Cancer Institute. In addition to the Registry's ongoing ovarian cancer genetic research, thanks to generous donations, this year we are able to begin funding new ovarian cancer research here at Roswell Park Cancer Institute. We presently have a Request For Proposals out and expect to make possible new funding for ovarian cancer research projects here at Roswell. We will keep you informed of our progress through our Newsletters.

Last year's appeal raised over \$30,000 and we are hoping to raise even more during this year's campaign to continue to fund scientists and doctors working together in the most advanced laboratory facilities here at Roswell Park Cancer Institute.

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.

That's What Friends Are For!

We would like to thank those who have remembered the *Gilda Radner Familial Ovarian Cancer Registry* in their time of celebration as well as loss and assure them of our sincere appreciation of these donations made to continue our ovarian cancer research.

Friends & Family of Flora Alberts	Family & Friends of Joyce Kozlowski
Friends & Family of Natalie Ames	Friends & Family of Rochelle Krause
Charles & Jane Banta	Family & Friends of Kathleen Kremer
Friends & Family of Pat Barrett	The Estate of Jean Krieger
BEADAZZLED	Collin Kushner & Family
Friends & Family of Eileen Beauchamp	Friends & Family of Marjorie Lockwood
The Borealis Press	Mondragon McGrinder Medical Associates
Friends & Family in honor of Candance Carberry	Friends & Family of Janet Mitchell
Friends & Family of Faye Carlotti	M.O.M Golf Tournament
Friends & Family of Mary Ann Chiamonte	Friends & Family in honor of Lynn Musella
Friends & Family of Joan Daisey	The Pansy Daily Golf Event
Friends & Family of Linda Darling	Kathleen Pickard
Friends & Family of Judy Diehl	The Raynie Foundation
Friends & Family in honor of Linda English	Friends & Family of Nancy Reinisch
Friends & Family of Elizabeth Farrell	The Robin Skiff Pittard Memorial Foundation
Sister Suzanne Franck, Footsteps Toward Hope	Mr. & Mrs. Rosenthal
Jerry Gold	Friends & Family of Laura Severance
Friends & Family of Nancy Goodfellow	Friends & Family of Rachel Small
Friends & Family of Joan & Salvatore Grittani	Friends & Family of Margery Sturgill
Friends & Family of Dolores Haney	TEAL WE MEET AGAIN
Hopp Companies, Inc.	Friends & Family of Barbara Tucchio
Joel Hostetter	Friends & Family of Patricia Jennings Wilcox
Friends & Family of Bobbie Hosek	Friends & Family of Sharon Marie Wood
Friends & Family of Matha Jackson	Friends & Family of Ruth Wray
Friends & Family of Patricia Kalis-Larkin	Friends & Family of Ruth Younger
The Kieve Foundation	



M. Steven Piver, MD: Founder and Director

James Marshall, PhD: Principal Investigator

Richard DiCioccio, PhD: Basic Research Coordinator

Kerry Rodabaugh, MD: Co-Investigator

Cathy Fahey, BS: Operations Manager • Dianne Schuh: Help-Line Coordinator

Alice S. Whittemore, PhD & Bruce Ponder, MD, PhD Consultants

GENE WILDER: HONORARY CHAIRMAN

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

Name: _____

Registry ID #: _____

Address: _____

Phone Number: (_____) _____ - _____

E-mail Address: _____

Comment: _____

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