



THIS ISSUE:

- Research Update
- What's New
- Ruby Red Poppies
- Registry Activities
- Thank You
- Mission Statement

Gilda Radner

Familial Ovarian Cancer Registry

Due to numerous requests from you, our Registry members, we present our first bi-annual *Registry Update*. It is designed to keep you informed of the activities at the Registry.

Research Update

For the past three years, members of families from the Registry with two or more cases of ovarian cancer were selected for a research project in collaboration with Stanford University School of Medicine. A total of 670 individuals donated blood specimens and completed medical history questionnaires. By combining this information with similar information from families in the United Kingdom and Australia, we have assembled the largest repository of information to date regarding women from families with a history of ovarian cancer.

Because not all women in families with a history of ovarian cancer develop the disease, we are researching different combinations of environmental and hereditary factors found in these families in an effort to determine which factors may protect against development of ovarian cancer. Diet, physical activity and body size do not appear to play a major role in developing ovarian cancer. Use of oral contraceptives, however, has been shown to reduce by 50 percent the chance of getting ovarian cancer. One preliminary study has shown similar protection in families that carry the BRCA1 gene responsible for inherited breast and ovarian cancer, a 60 percent reduction in the development of ovarian cancer in women who have taken oral contraceptives for over 6 years. This encouraging news is consistent with the dramatic decrease in the number of cases of ovarian cancer in the US from 26,800 in 1997 to the predicted number of 23,100 in the year 2000. We are currently analyzing the pattern of oral contraceptive use of affected and unaffected women in our family study to confirm the existence of this protective effect. Other factors to be examined include number of children, age at first birth, history of tubal ligation, hormone replacement therapy, fertility drugs and age at menopause.

On another aspect of research, an article from the Registry titled, "Incidental, Serous Carcinoma In-Situ of the Ovary in a Woman with a Germline BRCA1 Mutation Exhibits Loss of Heterozygosity at the BRCA1 and TP53 Loci," was published recently by Werness BA, Parvatiyar P, Ramus S, Whittemore AS, Garlinghouse-Jones K, Oakley-Girvan I, DiCioccio RA, Wiest J, Tsukada Y, Ponder BAJ, Piver MS, in the *Journal of the National Cancer Institute* 2000; 92: 1088-1091. Copies available upon request.

The article presents the first data documenting molecular changes that occur in the earliest detectable ovarian cancer cells before invasive spread of tumor cells. These data provide a novel insight as to the sequence of molecular changes needed for progression of ovarian cancer. This kind of fundamental information about the behavior of ovarian tumor cells is critical for developing strategies for early detection and for improved treatment.

We would like to thank *Spoonful Productions* for their time and expertise in creating our Ruby Red Poppy logo.

Ruby's spirit lives on...

The Ruby Red Poppy design for this *Registry Update* is in memory of a woman whose story we would like to share.

Last April we were saddened upon opening our mail and learning that yet another woman had lost her battle with ovarian cancer. Tucked into the envelope was a small packet of Ruby Red Poppy seeds. Each tiny seed brought with it a touch of joy and hope.

This loving woman had been an avid gardener. When she passed away, she had Ruby Red Poppy seeds in her refrigerator waiting for spring planting. Her daughter took the seeds and put them in small envelopes and mailed them to all the people who sent cards and donations in her mother's memory.

We set our seeds aside as we waited through our long Buffalo winter. Just a few weeks ago we planted the seeds in a pot and put them on a bright windowsill. We now have Ruby Red sprouts growing strong and beautiful, just waiting for our weather to warm up so they can be put in our gardens.

Thus, we are reminded of each and every family who in the midst of great tragedy has so graciously shared themselves with us.

What's New

The 1- 800-OVARIAN hotline has been included in the Cancer Information Program at Roswell Park Cancer Institute. We have increased our staff of cancer specialists trained to answer your questions. Voice mail is available for after hour and weekend calls.

Registry Activities

In 1999 over 100 families met our research criteria and joined the Registry. To accrue these new families we sent out over 2,500 packets of information, prescreen forms, follow-up letters, and participation packets. We are expecting an even busier year in 2000. The Registry now has 1,554 families registered.

We would like to remind everyone that we are always interested in receiving updates from you whether it is a change in address, phone number or family medical history. We have listed our mailing address, phone numbers, and web site/email information for your convenience.

Thank You

We would like to THANK YOU. It is because you care enough about the future generations of women that we are able to conduct our research and continue to maintain this Registry. We are very appreciative of your efforts and would like to recognize your continued interest and dedication to this project.

Mission Statement

The Gilda Radner Familial Ovarian Cancer Registry is an international registry of families with two or more close relatives who have been diagnosed with ovarian cancer. In addition to ovarian cancer research, the Registry offers a Help-Line, education, information and peer support for women with a high risk of ovarian cancer. The Registry is pursuing research into the causes of familial ovarian cancer. Our goals are:

- to identify new genes associated with familial ovarian cancer,
- to improve genetic and psychosocial counseling for individuals and families,
- to identify lifestyle choices that reduce ovarian cancer risk in women who may be more susceptible to the disease.

We hope to acquire information that will lead to better methods for detecting ovarian cancer, for reliable predictive testing for cancer predisposition and ultimately, preventing the disease in future generations. We are continuing to collect family histories, medical records and tissue samples from Registry members.

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