

REGISTRY METROPOLITAN NEW YORK

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www.METRONYREGISTRY.org

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Happy New Year IT IS OUR 10TH ANNIVERSARY

We want everyone to share in our celebration of this major milestone! We are also very proud to report that the National Cancer Institute has granted five more years of federal funding to our Metropolitan New York Registry. We invited our first families to join our research project in 1996. Now more than 1,400 families including more than 4,800 women and men are contributing to the New York Registry. The Breast Cancer Family Registry includes a total of 14,000 families from Canada, Australia and four American cities. Like our Registry, these registries all collect questionnaires and biospecimens required for many important studies.

In this newsletter we describe some of the current research that has recently been published based on the materials you provided. We hope you find the newsletter useful and we welcome any suggestions you have for future editions. You will find earlier newsletters on our Registry website: www.metronyregistry.org

Our Registry team has a new leader, Mary Beth Terry, PhD, who is an Associate Professor of Epidemiology at Columbia's Mailman School of Public Health. She will join Drs. Senie and Santella in leading our NY Registry for the next five years. Dr. Terry has focused her research on understanding whether pre and postnatal exposures can influence breast cancer risk many years later. She also studies how risk factors are related to molecular markers and mammographic density, a strong risk factor for breast cancer. She is very pleased to be directing the NY Registry and representing our NY families on many studies. Please contact her directly if you have any questions. Email: mt146@columbia.edu



Drs. Santella, Terry & Senie

Registry News-to-know - Registry Follow-up Questionnaire

We need your help!!!

Since the Metropolitan New York Registry has received renewed funding to continue its research efforts, part of the effort will be focused on re-contacting all of our participants. The follow-up interview will be conducted by phone to update demographic, reproductive, behavioral and medical history on all Registry participants. We are also eager to have additional members from your family participate in the Registry. We expect the call to take approximately 30 minutes. The information you provide will be essential to enhancing our resources to study cancer risk and prognosis within families. In helping us to accommodate your schedule for the call, we ask that you please respond to us by telephone or email to set up a convenient time for the telephone interview. Our local phone number is 212-304-6433 and our toll free number is 888-638-7608. You can also contact the Registry by email at: info@metroregistry.org

Meet the Metropolitan New York Registry Staff



Ms. Taroya
Sargent-Kirk

Ms. Taroya Sargent-Kirk has been our Registry Director since 2002. She manages the projects and ensures that all Registry data is maintained confidential and accurate. She is responsible for managing the project and ensuring that all Registry data is maintained confidential and accurate. Please also change patients to research. *Email: ts2119@columbia.edu*



Ms. Hope
Neal-Erarslan

Ms. Perla Serra has been a coordinator for the Metropolitan New York Registry for nearly 10 years. She is responsible for the recruitment of new Registry families. She is responsible for recruiting additional family members for the study. *Email: ps326@columbia.edu*

Ms. Hope Neal-Erarslan has been a coordinator for the Metropolitan New York Registry since 2002. Her focus in the Registry is to expand families and coordinate pathology. She is currently working on her R.N. degree and hopes to work in oncology. She will also be conducting follow-up interviews. *Email: hn2028@columbia.edu*



Ms. Perla Serra

Join us in Welcoming . . .



Sylvia Rickard

Sylvia Rickard represents American breast cancer patients on our Steering Committee. She has been a patient advocate with several community organizations for more than 13 years, ever since her diagnosis with breast cancer. She has also been very active as a Legislative Team Leader with the National Breast Cancer Coalition.

Ms Rickard also chairs the South West Advisory Committee of Redes En Accion, a program designed to reduce the cancer burden in Hispanic populations

Dr. Hulya Yazici of Istanbul University, Institute of Oncology in Turkey was selected as an Avon Foundation-American Association for Cancer Research International Breast Cancer Scholar in 2005 enabling her to spend two years in the laboratory of Dr. Regina Santella working on research projects



Dr. Hulya Yazici

using Registry resources. Dr. Yazici has worked in cancer genetics since 1988; she helped establish the first molecular cancer genetics laboratory in Turkey. As a post-doctoral fellow with NATO funding, she studied *BRCA1* and *BRCA2* mutations among Turkish breast and ovarian cancer patients. The Avon Scholar program is enabling Dr. Yazici to

learn about designing and conducting epidemiologic studies and managing laboratories for storing biospecimens donated by research participants. Dr. Yazici has been conducting exciting research with Dr. Santella. When these studies are completed, they will be submitted for publication and shared with you in a future publication. Dr. Yazici believes she is privileged to be in New York, enjoying her research at Columbia and life in the city with her almost 2 year old daughter.

Research Conducted by Registry Researchers



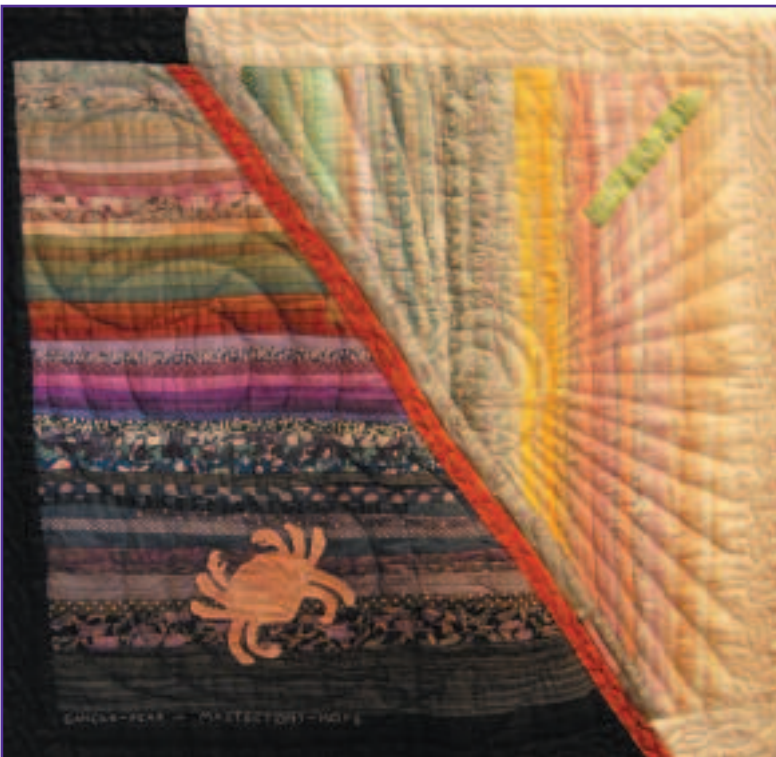
Dr. Heather Greenlee

A study by **Dr. Heather Greenlee** and other colleagues published in July 2006 in the *Journal of Breast Cancer Research and Treatment* suggests that women with specific genetic markers may be at increased risk for developing breast cancer based on how their bodies create and use estrogen – a key female sex hormone. This pilot study used urine and blood samples donated by women participating in our NY Registry. Blood samples were analyzed for genetic markers related to estrogen production and metabolism. Urine samples were analyzed for specific estrogen metabolites 2-hydroxyestrogen and 16 α -hydroxyestrone. 16 α -hydroxyestrone metabolites are thought to be more likely to stimulate the growth of cancer than 2-hydroxyestrogens. Our study results showed that women with specific genetic polymorphisms had different levels of 2-hydroxyestrogen and 16 α -hydroxyestrone metabolites in their urine compared to women without these genetic markers. Future genetic studies of markers that influence

estrogen production and metabolism may help identify women at higher risk who may benefit from new avenues for breast cancer prevention.

Dr. Mary Beth Terry and colleagues have recently completed several studies examining the role of alcohol on breast cancer risk. Using information from the Long Island Breast Cancer Study, she found that women who were faster metabolizers of alcohol had a higher risk of breast cancer than those that did not. She recently completed a study within the Breast Cancer Registry which did not find an increase risk of breast cancer among consumers of alcohol whether or not they were fast metabolizers. In a related study, Dr. Terry joined other Registry researchers to examine whether young women less than age 50 who were found to have a *BRCA1* or *BRCA2* mutation were at greater breast cancer risk from alcohol. More than 300 women with breast cancer were compared with almost 500 women who remained free of disease. Compared with non-drinkers, no increased risk was found associated with alcohol intake after considering the frequency of use and the quantity of alcohol consumed.

A Family Matter – Special Thanks to the Lander Family



This beautiful quilt was created by a participant in our New York Family Registry. Before her diagnosis with breast cancer in 1988 at age 75, Margaret Lander had enjoyed sewing quilts for friends and family. While still in the hospital recovering from her mastectomy, she remembered that she had registered for an advanced quilting class. Her teacher encouraged her to design a quilt reflecting her cancer experience.

In this photo you can see how Margaret Lander balanced light and dark colors to express her inner feelings. She explained that the crab representing cancer and images of surgery are reflected in the darker portion and the sun's rays with the green arrow in the brighter section represent hope for the future. The words cancer-fear-mastectomy-hope embroidered on the bottom clearly state Margaret Lander's feelings about her experiences.

This beautiful quilt, which her daughter now treasures, is the result of her unusual talent. We are sorry to have not

known of this treasure before she died in 2003 at age 89 from causes other than cancer. Cancer survivors often find meaningful avenues for expressing their inner thoughts about the experiences of diagnosis and treatment. We invite others to share their thoughts and experiences associated with being in families with a history of breast, ovarian and other cancers.

METROPOLITAN NEW YORK REGISTRY

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If this is not your correct address or if you have moved please contact us at 1-888-METRO-08 so we may update our files.



The National Institute of Environmental Health Sciences is inviting women ages 35 to 74 from all regions of America who have a sister treated for breast cancer to join the Sister Study. The goal of the research team is to have women from every state and from all backgrounds contribute to this very

large study of environmental and genetic causes of breast cancer. This is complimentary to our NY Family Registry. You are welcome to contribute to both research projects. If you are interested in participating, please call 1-877-4SISTER [1-877-474-7837].



The financial support we receive from the National Cancer Institute provides funds for our Registry staff who contact you by phone and newsletter, for collecting and storing your biospecimens, and for updating our computer files with your new information. We need additional funds to conduct studies using the data and resources you have provided. Therefore, we are very proud to have been selected by THE BREAST CANCER RESEARCH FOUNDATION [BCRF] to receive funds for some of the studies we have been conducting. BCRF was founded in 1993 by Evelyn H. Lauder as an independent, not-for-profit organization dedicated to funding innovative clinical and genetic research. This year the Foundation is awarding \$24.3 million to support 115 scientists at leading medical center worldwide whose research is focused on achieving prevention and a cure for breast cancer in our lifetime. A minimum of 85 cents of each dollar donated to the Foundation goes directly to breast cancer research and awareness program. In October 2005, \$22 million was awarded to 110 researchers across the U.S. and in Canada, Europe, Latin America, and Israel. For more information, visit www.bcrfcure.org or call 1-866-FIND.A.CURE.