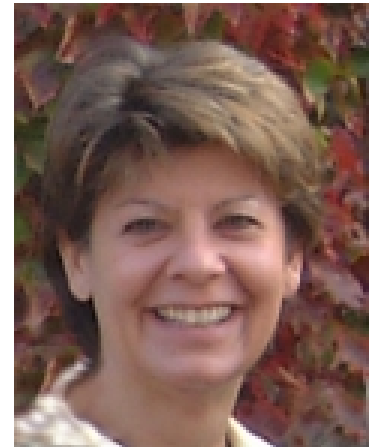


The Northern California Family Registry for Breast Cancer Studies

An Interview with Dr. Esther

SUMMER 2002



Dr. Esther John is Co-Principal Investigator of the Northern California Family Registry, as well as Director of Epidemiology at the Northern California Cancer Center. Having grown up in Switzerland, she came to the US in 1980 to complete her graduate studies. She has been with NCCC since 1994. Her research focuses on breast and prostate cancer in minority populations.

Principal Investigator:

Dee West, Ph D.
Chief Scientific Officer

Co Principal Investigators:

Esther John, Ph D.
Director of Epidemiology

Alice Whittemore, Ph D.
Stanford University
School of Medicine

Frederick Li, MD.
Dana Farber Cancer Institute,
Boston

As a woman yourself, what would you say are your greatest questions concerning breast cancer?

I am particularly interested in the relationship between lifestyle factors that are modifiable and breast cancer risk, and the interplay between lifestyle and genetic factors. Some of my biggest questions are what changes can we make in our way of living that would reduce the risk of breast cancer, what things should we teach and encourage in our daughters while they are still young.

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Describe the challenges and surprises of your work.

I think a major challenge is the feeling that there is so much to do, and we can do only so much research in our lifetime. I have been at a number of meetings with active participation by breast cancer patients – they have certainly greatly inspired my work. A lot of our research is done collaboratively and I admire many of my colleagues and get inspired by their work and enthusiasm.

In addition to her work with the Family Registry, Dr. John is also the Principal Investigator on a number of other studies. We asked her to describe one of them known as the migration study...

The migration study is a study in Latina women living in the Bay Area that I started in 1995. By next summer, we will have collected interview data on 1150 cases (women with breast cancer) and 1400 controls (women without breast cancer), one of the largest studies ever conducted in Latina women. It has been long known that breast cancer incidence rates increase as women migrate from low risk countries (such as Latin America or Asia) to high risk countries (such as the US). These patterns suggest that changes in lifestyle associated with migration may play an important role in the cause of breast cancer. The focus of our study funded by the California Breast Cancer Research Program is on better understanding the role of various lifestyle factors among Latina women who were born in the US and Latinas who came to the US in childhood or later in life.

How has your research translated the way you see the world and the people in it?

Through my research I have become more aware of my own lifestyle and the lifestyle of my family, paying more attention, for instance, to physical activity. Since my childhood I have always enjoyed

Newsletter Editor:

K. Hannah

Do you have questions about:
Clinical Trials?
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Access to Mammograms?
Cancer Care?

Call the Cancer Information Service
1-800-4-CANCER
for free information

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Spotlight on FRBC Participants: Lydia Olson

For Lydia Olson being a teacher isn't just a profession, it's a life philosophy. Between her jobs as Associate Professor of Chinese at the Defense Language Institute and being an English tutor at Monterey Peninsula College, she made time to speak with the Family Registry's Jeanne Boxley and Debbie Sohn about her experience with breast cancer and her remarkable discovery that "cancer is not a personal thing."

Lydia grew up in Beijing, China, one of five children in a tightly knit, unusually open family. "My father was a very strong person, and my mother, my sisters, all very strong. I was brought up under great influences. During the cultural revolution I went through it like everybody else...I understand quite a bit about suffering...about human beings." She avidly read books about people's lives and studied Buddhist philosophy. Today, she cites these experiences as the cornerstone to her survival. "I learned that if we want to live in this world happily we have to face everything with a positive attitude."

"I just told myself, maybe God tests my will to see if I can be stronger than I was. And my answer is YES!"



Lydia Olson (left) and Debbie Sohn (right).

In August 2000 when she was diagnosed with breast cancer, she and her husband Gene had just moved to Monterey —she to start a new job, he to retire. Not wanting her diagnosis to interrupt her life she asked her doctor if she could postpone her operation until winter break. His answer was an emphatic "no". Wednesday of that week she had her mastectomy. The very next day she went to work. "My friend said 'when people have cancer they're lying in bed for months! You just don't want to live!' I told her, 'I want to live like an ordinary person.'" At that same time her eldest sister, Chong Min, was also struggling with what was later found to be breast cancer. "She was diagnosed the same year as me. I suspect because we look just alike — our feet, our smiles — that she must have breast cancer, too. But she didn't realize." Lydia's participation in the Family Registry is something she believes Chong Min would have agreed with. "I understood her so well. If she were alive she would have the same wish that I do. *Help other people.* Yes I had cancer, but it's not a personal thing."

Her generosity was also extended to the Family Registry. When Debbie Sohn invited her to participate in our research study she eagerly accepted. Debbie, a wise and shining gem at FRBC who'll be leaving us this year, had this to say to Lydia "You're a teacher by profession but it's your nature, too. It's within your spirit. You look outside yourself to your concern for others and it comes across in your teaching, wanting to share with us, just being there for other people."

"I just told myself maybe God tests my will to see if I can be stronger than I was. And my answer is YES! That's the spirit of women. They have that kind of character. They want to realize their goal. Best to work. Work and fight. If you have a positive attitude you can turn out to be different. I was so happy I had the chance to study here, live here, work here. This country's so beautiful! I think my life just started! I think life is so beautiful. And I have to fight, you know, to enjoy life!"

"You're a teacher by profession but it's your nature, too. It's within your spirit. You look outside yourself to your concern for others and it comes across...in your just being there for other people."

A Fond Farewell to Debbie Sohn

Debbie, a registered nurse, could have chosen from a number of professional opportunities five and a half years ago but it was the Family Registry for Breast Cancer's good fortune that she chose to work at the Northern California Cancer Center. Debbie's gentle, open nature has helped to enroll over 950 participants into the Family Registry. She has elected to continue her education in Missouri. It is with heart-felt emotions we say goodbye to an exceptional professional and friend.

NEW PILOT STUDY

Family Registry participants will soon be invited to be part of a new pilot study aimed at understanding whether childhood illnesses might be involved in the development of breast cancer in some women.

The answer to the question of whether breast cancer is related to common childhood infections is not clear and more research must be done. This new study, supported through the generosity of funds raised for NCCC by the Plumpjack Golf Tournament, will explore these questions.

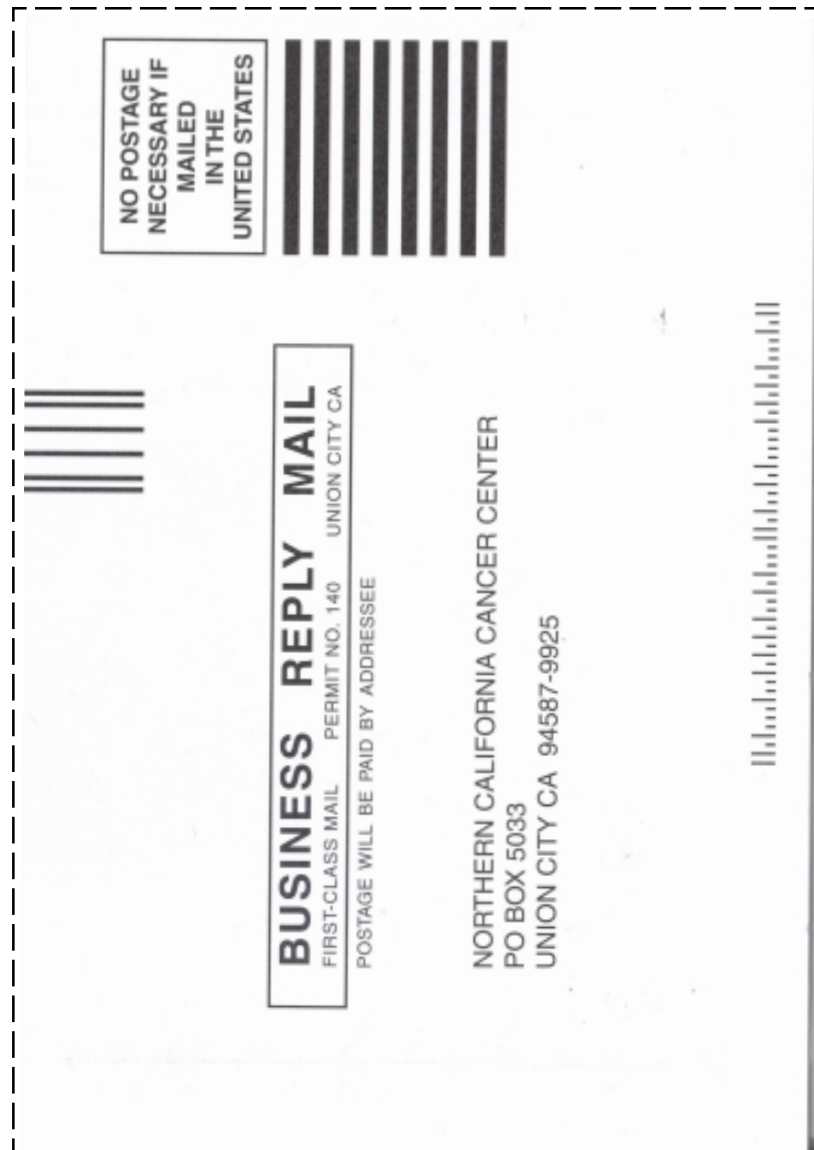
At the end of each participant's usual annual follow-up, the opportunity will be extended to be a part of this new study by answering a few additional questions, the responses to which will be compared with those from an earlier NCCC study.

This exploratory study promises to yield useful findings regarding this

Regina Lagman: Focus on Asian Pacific Islanders



The Family Registry is glad to welcome Regina Lagman, joining us as an intern through the NCCC Minority Training Program. Regina, born in San Francisco's Mission District and now living in Pacifica, is currently pursuing her MPH in Community Health Education at San Francisco State University. Recently she faced a family member's battle with and death to cervical cancer. "Early detection would have saved her life," says Regina. "Ever since, I have become interested in advocating for early cancer detection and prevention. I have a deep sense of love for my Filipino culture. Even though I was born in America, I can still communicate fluently in my parents' home dialect." When asked what she sees as the main link between cultural values and health care needs she acknowledges the huge gap between the two but says, "Working to eliminate health disparities among people of color and immigrant groups is crucial because they comprise more than half of California's population." She is most interested in the Asian Pacific Islander community and in addressing "cancer awareness through education, screening, early detection and timely, quality cancer care and support."



FRBC TO BEGIN EXTENDED FOLLOW-UP

Within the next few months, we will be re-contacting Family Registry participants who have been involved in the study for at least five years, to complete an extended follow-up questionnaire. The questionnaire is very similar to the lifestyle questionnaire completed at the time of initial enrollment and the purpose is to update information collected at that time. For the many participants who are already familiar with being re-contacted, the extended follow-up will take place at the time of the annual follow-up phone call.

Research and Cancer Care Resources:

Northern California Cancer Center: www.nccc.org

Intercultural Cancer Council: www.iccnetwork.org

National Alliance of Breast Cancer Organizations: www.nabco.org

Share: www.sharecancersupport.org

CHANGE OF ADDRESS?

The Northern California Family Registry wants to keep you up to date for several years to come. Please clip and save this postage paid postcard and return it to us if your name or address changes.

Your name:

Your new address:

New phone number:

Effective as of: _____

Please use this space to tell us what you would most like to see in future issues of the newsletter:

THANK YOU VERY MUCH!

Dr. Esther John:

Continued from front page...

sports. The role of physical activity in breast cancer has turned out to be a primary focus of my research and a major motivator for myself to keep physically active and to encourage my daughters and my busy husband to participate in sports.

What are your thoughts about the women participating in the study? Is there anything in particular you'd like to say to them?

One of the most satisfying aspects of my work is finding so much interest on the part of the women who give us their time to participate in our studies. Many women lead incredibly busy lives, with jobs, children, long commutes, or care of other family members, and it often takes a lot of effort to make 1-2 hours available for our studies. Without their help, it would be impossible to advance our knowledge about causes of breast cancer. I am most grateful to the many women who have helped and participated in our studies.



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