

familyMatters

Ontario Familial Breast Cancer Registry

Time to FOLLOW-UP

IT'S true that OFBCR research is only as good as the information we've collected, so it's extremely important for us to touch base, person to person, every couple of years to make sure our records reflect natural changes to your health and family history.

If you are an OFBCR participant (male or female) who was diagnosed with breast cancer in 1996, 1997 or 1998, we will be calling you and your participating relatives over the next few years to complete a Follow-up Interview by telephone.

We will ask questions about your breast and ovarian cancer screening practices, surgeries, medications, new disease, and lifestyle factors, as well as update your family history of new births, deaths and cancer diagnoses.

Your answers will be combined with information you gave us previously to help scientists better estimate cancer risks and possibly develop more effective strategies to prevent and treat breast cancer.

We know you're busy, so your Follow-up Interview will be completed at a time most convenient for you (mornings, evenings or weekends) – just let your telephone interviewer know what works best, if you agree to complete it. Other things you might like to know are that where possible, the same telephone interviewer will contact all participating members of your family; but don't

worry, your answers will be kept strictly confidential and not shared among family members.

Have questions or concerns? CONTACT Ms. Elaine Maloney, OFBCR Coordinator toll-free at 1-800-832-5949 Ext 4413 or email OFBCR@cancercare.on.ca

Introducing our friendly FOLLOW-UP voices:

Leigh-Anne Ward joined the OFBCR as an inter-



Leigh-Anne Ward

viewer in February 2007 after completing her Honours Bachelor of Science degree in Biology at York University. She has had a great deal of experience at Princess Margaret Hospital in Toronto, working for four years as a patient flow coordinator for the chemotherapy and transfusion outpatient units. She loves traveling, reading, and playing soccer and plans to pursue a Masters degree in Epidemiology in the future.



Rohini Gosai

Rohini Gosai is a Data Analyst who joined the OFBCR back in October 2001 after completing her Honours Bachelor of Science degree in Biology at the University of Toronto. She brings a passion for research and healthcare experience gained

through volunteering at North York General Hospital and working with the elderly in long term care. She is involved in many aspects of the registry, including the follow-up. Spare time is spent enjoying her family, cooking, doing Yoga, and enjoying movies and music.

OFBCR Past, Present, Future

In 1995, the National Cancer Institute (NCI) of the U.S. National Institute of Health funded the creation of six Breast Cancer Family Registries – including our very own OFBCR.

Your unstoppable loyalty and commitment over the past 12 years, has enabled the OFBCR to become a valuable resource of information and samples, attracting breast cancer researchers worldwide.

In 2006, the OFBCR received good news of 5 years of additional NCI funding. Since then, we've restructured and re-focused and are pleased to bring you the exciting plan of what's happening in 2008 and beyond.

First off, our team has been busily preparing to get back in touch with you and your family to update Registry records through our telephone Follow-up Interview. Completing this interview together over the phone means fewer questionnaires for you to fill out and remember to mail back!

In this issue of familyMatters, you'll hear from one supportive teen who stood by her aunt's side through her battle with breast cancer, meet a handful of innovative Canadian Researchers who are taking their quest for answers to the next generation, and hear from ongoing local studies using the OFBCR resource to uncover important findings.

Tell us what you think of
FamilyMatters
1-800-832-5949
OFBCR@cancercare.on.ca

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OFBCR
Ontario Familial Breast Cancer Registry

A grade 12 student reflects on her aunt's journey with breast cancer

IT was a typical December day eight years ago. She never thought it could happen to her. She wasn't a smoker and there was no history of it in her family. It was just a lump to be removed; surely it would show up benign. Life would go on; but it didn't go exactly like that.

Even though she hadn't been persistent about self-breast examinations and had only one mammogram in her life, she wasn't worried. It couldn't be cancer. Within two weeks of finding that lump, she had met with her doctor and was scheduled for surgery. But the deciding factor was the needle biopsy. The results were words no one would ever want to hear – malignant. It was cancer.

The emotions ran high. She was angry, frightened and thought her world had stopped. But even though she was feeling all this, she was determined to beat it. She wasn't going to let cancer take over her life.

The results of the surgery were in. The tumour was cancerous but had not spread anywhere else; all 13 lymph nodes were clear. She was out of the hospital in one day and began the road to recovery. The drainage tubes and surgical dressing required continual care. She wore loose-fitting clothing to remain comfortable but still made her way up north for Christmas. She continued to live as she always had. She brought me back to the city with her and my uncle on Boxing Day, as they had got me tickets to see the Nutcracker. I remember the day of the production.

I was sitting on my aunt's bed as she went in and out of her walk-in closet trying on different sweaters and blazers, seeing which one was the most comfortable and was able to hide the drain. I wasn't scared at all. The drain and drainage didn't scare me. It still surprises me that it didn't have a huge effect on me as I was only 9 years old and

YourPlace

*Personal stories from
women and men
with breast cancer and
their caregivers*



didn't fully understand cancer and how powerful it was. But we had a great day. My aunt hasn't forgotten this day either.

A few weeks after the surgery, Aunt Helena met with her oncologist. He had analyzed the type of cancer she had, and his recommendation's hit my aunt hard. She thought the surgery was all she would need, but the form of cancer she had was very aggressive and given the fact that it grew so rapidly, an aggressive treatment of chemotherapy and 25 radiation treatments was recommended.

She remained positive throughout this whole ordeal. She continued to work, took each day one at a time and researched and read about the disease as much as she could; she wanted to know what to expect. She bought a wig and went to her hairdresser and got her head shaved after one morning in the shower when lumps of hair began coming out. She wanted to be ahead of the situation; no unexpected occurrences.

Even though she could have been

pessimistic about what was happening in her life, she chose not to. She remained optimistic and completed an amazing journey. She met new and amazing people who were dealing with the same things she faced. Even though her family and friends had been there to support her every step of the way, she discovered that the best thing was talking to someone who had been through the same thing. It created a sense of belonging and allowed her to realize that she was not alone, that many others were facing the same thing.

She learned to not worry about things outside her control, that a positive outlook helps each day become enjoyable, just how much her family and friends loved her, how much she loved them, and that it's the small things that people do that really matter. Whether a funny card, a phone call, or someone just being there by your side through a treatment, it was the little things that brought light to the darkest moments.

It has been eight years this December since her diagnosis and she has remained cancer free. She has become a stronger person from her journey and continues to help fight for those who have the disease. For the last three years she has joined thousands of people for a weekend in the fall for a 60-km walk to fight breast cancer. This disease may be gone from her body, but it has not left her heart.

*Submitted by Stephanie Pierre, niece of
Helena Taylor, valued OFBCR participant
since 1997 ♥*

Share your story

in 500 words or less. Tell us how
breast cancer has affected your life.
Mail to Family Matters, c/o Danielle Hanna,
OFBCR, 610 University Ave. Rm 8-502A,
Toronto, ON M5G 2M9 or e-mail
danielle.hanna@cancercare.on.ca.

LEGACY

DR

Irene Andrulis, Director of the OFBCR, and her team of researchers have

begun piecing together the early stages of an exciting, new, internationally, collaborative research study called LEGACY (Lessons in Epidemiology and Genetics of Adult Cancer from Youth).

LEGACY is the first breast health study in Canada planning to look to the next generation for answers by following daughters as young as age 5 through 17 years, whose mothers or aunts have had breast cancer.

LEGACY involves sensitive and challenging work, but studying girls while still young and developing may be the key to finding potential risk factors and habits, that if caught early, could result in ultimately fewer diagnoses of breast cancer.

What do parents think about LEGACY?

The first step in designing a breast health study involving daughters, ages 5 to 17 years, was to ask mothers and fathers what they think of the idea. With funding from the Canadian Breast Cancer Foundation, we interviewed a total of 85 parents (mostly mothers who had breast cancer), 47 of which who were participating in the OFBCR and the rest from the Breast Cancer Registries in Utah and Northern California.

Results

- Parent's demonstrated a high level of interest in the LEGACY study and would support their daughter's decision to take part, believing LEGACY may increase the understanding of breast cancer as well as benefit their daughter's future health by encouraging the pursuit of a healthy lifestyle.
- 92% of parents welcomed the idea of LEGACY collecting questionnaires about daughter's birth information, exercise and diet patterns, details of illnesses and current health status, and said they would be happy to help their daughters fill them out.
- 87% of parents welcomed the idea of their

*Studying breast cancer
before it develops*



daughters giving a mouth swab or blood sample to look at hormone levels and common genetic changes (not testing BRCA1/BRCA2 genes).

- 64% of parents welcomed the idea of a physical breast exam to determine their daughter's pubertal stage of breast development if performed by a trained professional.

Parental thoughts and considerations

- Parents would respect their daughter's decision about whether or not they would participate in the study.
- Parents want to be the key people discussing enrollment and aiding in the collection of data from their daughters so they could gauge their comfort level and understanding of the study.
- Parents understood that their daughter's potential worries about health or pubertal awkwardness would need to be minimized by study design and the availability of sensitive professional staff.

Parent's practical suggestions

LEGACY may want to provide female staff for the collection of sensitive data, use experienced blood takers, create easy to understand study materials for parent and child and allow participants to complete only the parts of LEGACY their daughter feels comfortable with. We've listened carefully and taken all parental suggestions seriously in creating The Early Breast Health Study.

The Early Breast Health Study – Inviting daughters to get involved.

Dr. Cara Mulhall and her team from Cancer Care Ontario, Mount Sinai Hospital and the Hospital for Sick Children are leading the Early Breast Health Study through the OFBCR.

The Early Breast Health Study will:

- Test a safe, new, pain-free technique using light to measure early breast development.
- Help us better understand how young girls grow and develop into healthy women.
- Lead to improved ways to prevent and detect breast cancer in women.
- Help us plan future, larger research studies with young girls and their parents.

WHO's invited? Over 300 daughters (between the ages of 7 to 17) of OFBCR participants living in the greater Toronto area will be mailed personal invitations.

WHAT? & WHERE? Daughters and parents or legal guardians will be invited to Princess Margaret Hospital, downtown Toronto, for a single, one-hour visit, where our registered nurse will measure height, weight and breast development and ask for a small blood sample. We will also ask questions about daily exercise, other health related factors, and invite daughters to tell us in their own words, what they think about being in the Early Breast Health Study.

Contact Lara Spiteri, Registered Nurse and Early Breast Health Study

**Co-ordinator at 416-946-4501 Ext.5226
or e-mail: lightstudy@cancercare.on.ca,
to learn more.**

This important work is supported by grants from the Susan G. Komen Breast Cancer Foundation, the Canadian Breast Cancer Foundation (Ontario Chapter), the Ontario Centres of Excellence, and through generous donations from local businesses ♥

OFBCR Research Update

Breast Screening Study

With support from the Canadian Breast Cancer Research Alliance and the National Cancer Institute of Canada, Dr. Anna Chiarelli and team of telephone interviewers at Cancer Care Ontario are asking the question, "Do you go for regular mammograms

Prophylactic Mastectomy Study

FACT: Women carrying a BRCA1 or BRCA2 gene mutation have a higher chance to develop breast cancer. Prophylactic (preventative) mastectomy is one option available to considerably lower breast cancer risk.

WHO'S ELIGIBLE: Any woman with a BRCA1 or BRCA2 gene mutation, who has made the decision to have prophylactic mastectomy.

STUDY PURPOSE: To identify future targets for breast cancer treatment and detection by looking for differences in breast tissue from mastectomy samples taken from high risk women compared to the general population.

WHERE: Mount Sinai Hospital and Princess Margaret Hospital, Toronto, Canada

For more information contact:

Ms. Seema Panchal, Genetic Counsellor,
at 416-586-4800 Ext.4856 or email
SPanchal@mtsina.on.ca



BREAST SCREENING STUDY STAFF: (from left to right): Elizabeth Arbour, Lindsay Stewart, Sheetal Nanda, Anna Chiarelli ABSENT FROM THE PHOTO IS: Jennifer Kohn

and breast exams?" to over 1500 women, from 848 OFBCR families, where a female family member has had breast cancer diagnosed between the years 1996 to 1998.

The study's purpose is to compare breast screening behaviours and risk perceptions among women with at least one first degree relative with breast and/or ovarian cancer. Dr. Chiarelli hopes to learn how routine breast screening among women with different degrees of family history can be beneficial by finding benign breast conditions or breast cancers earlier.

Results so far...With 85% of women contacted by the study having finished their first interview, early findings suggest that a woman's screening behaviour may be influenced by her risk. After classifying women into three risk groups (high, intermediate and low) based on family history of breast, ovarian or bilateral breast cancer and ages at which relatives were diagnosed, we can see that 75% of women at highest risk had a mammogram in the past 3 years; compared with 73% at

intermediate risk; and 56.5% from the lowest risk group.

Participants will be followed for two more years, with a questionnaire completed each year to collect additional information on changes in screening practices. Final results will be available once the study is finished. The Breast Screening Study thanks all the wonderful women and their relatives for participating and making the study a great success so far.

How you can help...

► Our biggest challenge has been finding women who have moved! If you or your participating relatives have a new address, please call and let us know and encourage your relatives to do the same.

► Please drop your pink consent form in the mail ASAP using the supplied envelope, if you haven't already done so. If you have misplaced either, we'd be happy to send a replacement.

Contact the study coordinator:

Ms. Lindsay Stewart at 416-217-1228
or toll free at 1-866-989-0031.

Please Say Yes to Blood Donation...



Each and every blood sample donated to OFBCR research is like gold! Using blood samples along with questionnaire data you have already provided is the only way the OFBCR can answer important questions about the role of genetics and lifestyle factors in the development of breast cancer.

If you've already donated your blood sample, **THANK YOU!** For those of you who are still not sure, we encourage you to contact Jennifer Batchelor to learn more.

Call toll-free at 1-800-832-5949, Ext 5224.

Jennifer Batchelor has been with the OFBCR for more than 7 years! She is the OFBCR's go to person for all things administrative and a key member of the FOLLOW-UP team of telephone interviewers. Jennifer especially enjoys her summers at the family cottage, going hiking and fishing.

♥ The Early Breast Health Study THANKS the following businesses across the Greater Toronto Area for their generous donations:

Boston Pizza	McDonalds
Cause & Affect	Mr. Greek
(Keyring of Hope)	Ms. Toni Prinss (art)
Ganz (Webkinz)	Rogers Video
Ken's Picture	Scholastic books
Frames (art)	Silvercity Yorkdale