

familyMatters

Ontario Familial Breast Cancer Registry



Photography: Lucine Bosnyan

The OFBCR – Your Ontario Connection to Breast Cancer Studies Around the World.

We're Glad You're Part of Us!
The Ontario Familial Breast Cancer Registry (OFBCR) is made up of information and samples collected from families with breast cancer.

Everyone invited to join the OFBCR has been asked to provide their family history, personal and diet information and donate a blood and/or tumor sample for research looking into the genetic and environmental causes of breast cancer.

The OFBCR isn't just a single research study itself, but much larger than that.

By agreeing to join the OFBCR, the information and biological samples donated by you and your relatives are serving to benefit a great number of breast cancer studies in Canada and worldwide.

By deciding to share your information with the OFBCR, we are working to see that you make a difference in many cancer studies, without having to be repeatedly contacted for participation in each study.

It's also our job to protect your privacy and see that only the best cancer studies and scientists

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OFBCR STAFF: (from left to right clockwise) Dr. Norman Boyd, Elaine Maloney, Dr. Irene Andrulis, Kevin Keast, Dr. Anita Bane, Amy Thompson, Katrina Pillow, Rohini Gosai, Aysen Pakel, Nayana Weerasooriya, Gord Glendon, Kelly Turnbull, Jennifer Batchelor, Dr. Libertad Puy, Danielle Hanna, Lynn Anson-Cartwright.
ABSENT FROM PHOTO ARE: Nicola Osman and Mariel Edwards

New Season – New Newsletter

With signs of spring all around us, what better time to introduce something new.

Here at the OFBCR, it's our goal to be more in touch with our families. Since the registry's success in advancing cancer research is due to the generous participation of your family and others across Ontario, *FamilyMatters* is our way of giving something back.

FamilyMatters is designed to inform, entertain and keep in touch. It will be delivered twice a year – just enough to give you a heads up on OFBCR research information you won't want to miss, Web sites and books that are sure to be useful, personal stories you'll relate to, and lots more.

In addition, we've put together a special column to appear in every issue, called 'Carrier Corner'. If you're interested in information regarding a positive genetic test, then you'll want to check out Carrier Corner for the latest in BRCA1 / BRCA2 research, new cancer screening studies, Web sites and other news.

In this issue, you'll learn more about the OFBCR, why we're glad you're part of it. Also discover it's international connection and help clear up any confusion about the use of your blood sample if you have provided one.

**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

YourPlace

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



Why? Well, why not, was my first thought. I was an ordinary woman, no better or worse than my female relatives and friends.

Married in 1960, the Saturday after completing high school to my childhood friend and soul mate, Robert. Stay-at-home mother, loving four children – two sons and two daughters. Grandma, adoring five grandchildren. Four siblings: three younger brothers and one sister who was sixteen years my junior.

In my mid-thirties, I had a benign “solid mass” removed from my right breast, and over the next couple years, some cystic ones drained of their mud-like liquid (yuk).

Colleen, my younger sister, at age thirty-six, was diagnosed with breast cancer. I was devastated and wished there were some way that I could take some of the burden off her shoulders. Be careful what you wish for.

I must admit, being a full breasted, short-statured, fifty-two year old woman, I was scared of that ‘C’ word.

I have since become comfortable with the word and the situations that accompany it.

Like a lot of women, I relied on my man to detect any changes in my body make-up. When my doctor told me I had breast cancer, I did not cry. I had no tears left from the flow of worry concerning Colleen, a mother of two young children.

I had a happy life, long marriage, four grown children and grandchildren – a very full life. My thought was, ‘so be it, now what do we have to do?’ The “we” being myself, my husband and family.

My yearly mammogram had shown another cyst, but also a tumor of a different kind, hidden deep in my breast.

Lumpectomy and lymph node surgery, five weeks of radiation and medication followed. The morning of my first radiation treatment, my husband dropped me

If you are an OFBCR participant

who has had breast cancer or their caregiver, we invite you to mail or e-mail your story in 500 words or less. Tell us how breast cancer has affected your life, good or bad, and share where possible why you’re committed to being part of the OFCBR.

Mail to Family Matters, c/o Amy Thompson, OFBCR, 610 University Ave. Rm 8-502 A, Toronto, ON M5G 2M9 or email OFBCR@cancercare.on.ca

right at the hospital entrance to avoid the pounding rain as he parked the car. I got out of the vehicle, looked at the overhead sign, ‘Kingston Cancer Centre’. My legs would not move. What am I doing here? I learned a lot about myself and my personal strengths during this time.

My husband was my ‘rock’, ‘sounding board’, and ‘hugs in the quiet of night’.

Colleen and I differed about the dark of night. She found it unnerving and scary. I found the dark of night to be comforting and peaceful.

The hardest part of the whole ordeal was telling my grown children and my mother and sister that I too had breast cancer.

But sharing my breast cancer with family and friends helped me... and them. Every time I told someone, the weight on my shoulders became less to bear.

We are all responsible for our own physical and mental being. It is my strong belief that the ‘battle’ is first won in the head!

My family was invited to be part of the OFBCR study from the beginning. It was uneasy to talk to our children and family about joining the study, but they wanted to play a part, and know that this [research] is the only way to battle the war.

I have been described as a happy, jolly person, but as many women and men with breast cancer know, you have to be to get through each day.

What will be, will be. And I will only live today fully.

The sun is brighter in my world now. I try not to sweat the small stuff.

Colleen died six months after I was diagnosed.

Now at age sixty-two, I continue to embrace each day.

Submitted by Jackalynn Lee

Valued OFBCR participant since 1996 ♥

Photography: Lucine Bosnoyan

CarrierCorner

*Information for
BRCA1 and
BRCA2 carriers*



This regularly appearing column is not meant to replace the personal advice of your genetic counsellor, geneticist or doctor. We urge you to contact your genetic counsellor at least once a year for an update on what’s new in the field and to find out what information may specifically apply to you or your family.

Study Results – Female carriers discuss the process of “telling” their children about the BRCA1/2 mutation in the family.

When 31 women were asked about the ideal age range a child should be told

about BRCA1/2 mutations in the family, most said between age 19-25. The women in this study who shared their results

mostly had children above this age range while those who decided against telling, had younger children. Women who disclosed their result tended to do so alone (without their spouse), within a week of learning their result, equally to male and female children. Since revealing their result, they expressed that their relationship with their children had strengthened, bringing their family closer. Some reasons for waiting to tell included fear of possible insurance discrimination, not wanting to cause worry, the children’s gender and still being confused about results themselves. (Segal, J. et al. *Am.J.Med.Genet.* 125A: 267-272, 2004)

Pancreatic Cancer Screening Study

FACT: People who carry a mutation in the BRCA2 gene have a higher chance to develop pancreatic cancer over their lifetime, compared to people who don’t carry the mutation.

WHO’S ELIGIBLE: men and women over age 50 with BRCA2 mutations living in Ontario, OR under age 50 with a family history of pancreatic cancer.

TYPE OF SCREENING: abdominal ultrasound and MRI, done once every year for 5 years.

WHERE: Mount Sinai Hospital in Toronto

FOR MORE INFORMATION, CONTACT: Heidi Rothenmund, Genetic Counsellor at 416-586-5119 or email hrothenmund@mtsina.on.ca

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have access to your information without having access to information that could identify you.

Where we stand right now

More than 2500 women and men with breast cancer, and over 5000 of their concerned family members have answered our call to join the OFBCR. They have completed questionnaires and donated much appreciated blood and tumor specimens since 1996.

That’s almost 10 years of progress, since the OFBCR opened its doors in 1995. We want to thank you and your relatives for saying YES to the OFBCR and for your continued support over the years. We know it’s not easy to stay on board year after year, filling out follow-up

questionnaires, but it’s dedication from people like you who are making the OFBCR a research success.

Where we’re going...

Soon our focus will be to invite more of your relatives to join the OFBCR. We can’t stress enough how important it is for mothers and fathers, brothers and sisters, and in some cases, aunts and uncles to get involved, even if they haven’t had cancer!

Our Unique Family Approach

By studying entire families, and comparing those relatives with and without breast cancer, much more information about what causes cancer will be discovered.

For a list of studies already made possible by your participation in the OFBCR, please visit www.cfr.epi.uci.edu/ic_registries/breast/breast_publications.htm

Check it out online

FORCE
(Facing Our Risk
of Cancer Empowered)
www.facingourrisk.org

When we understand the causes, we can work toward more effective treatments and prevention.

In an attempt to quicken the pace of cancer research, and answer questions that apply to more people, the OFBCR along with it’s five international partner sites in three countries has set out to gain a broader understanding of both the genetic and environmental factors leading to breast cancer.

By joining the OFBCR, you are a critical part of the bigger picture.

We thank you for making the biggest donation to research beyond dollars – YOURSELF! ♥

OFBCR Research Update

Since 1996, the OFBCR's team of dedicated epidemiologists, molecular biologists, molecular geneticists, geneticists, genetic counsellors, statisticians, pathologists and behavioural scientists have made important discoveries using the OFBCR resource of information and biological

samples you've helped to build.

► Early on, we found that risk factors like family history of breast and/or ovarian cancer and young age at cancer diagnosis increased the chance of finding a BRCA1/2 mutation. Since then we've studied actual breast tumors and found that characteristics such as high grade, estrogen receptor negative status, and medullary breast cancer may be suggestive of a BRCA1 mutation.

► Those in the lab have uncovered new and improved ways to carry out BRCA1/2 genetic testing and continue to hunt for BRCA3 and other new genes that may be linked to breast cancer risk.

► The OFBCR strongly supports psychosocial research into the support and informational needs of women across all levels of breast cancer risk – from general population, to those with family history, to women carrying BRCA1/2.

Answers to commonly asked questions

Q: What is my blood sample being used for?

A: The answer may be best understood if we begin with a few definitions.

'PROBAND': describes a person in a family who is usually the first to be invited into the OFBCR. Probands have been diagnosed with breast cancer between the years of 1996 to 1998 or 2001 to 2002, or before that if of Ashkenazi Jewish ancestry.

'KIN': describe a proband's family members. Kin are usually invited to join the OFBCR by the proband. Kin may or may not have had cancer.

'BLOOD FOR GENETIC TESTING': describes a blood sample given for the detection of "disease causing clues" also known as 'mutations' in the genetic material (DNA). The OFBCR is most interested in testing two

specific genes that cause inherited breast and ovarian cancer - called BRCA1 and BRCA2. However, genetic testing is only offered to SOME OFBCR participants.

► MOH Testing - If your family history of cancer meets the testing criteria set out by the Ministry of Health (MOH), your sample is sent for genetic testing in one of the MOH's seven testing facilities spread out across Ontario with results usually available within 6 months – 1 year.

► OFBCR Testing - If your family history doesn't meet the MOH testing criteria, but does meet the OFBCR criteria for genetic testing, then your sample will be tested, but through the OFBCR research arm where results may take an unspecified amount of time to complete.

'BLOOD STORED FOR CANCER RESEARCH': Blood samples donated for future cancer research are specially preserved and stored for later use. It's these research samples that are put to good use in OFBCR approved scientific studies.

► ALL OFBCR participants, probands and

kin alike, are asked to donate a blood sample to be stored for use in important cancer research. Each and every research sample collected is valuable, raising the quality and number of breast cancer studies that can be done.

► ALL KIN samples are banked for cancer research. Kin will not receive any genetic test results from the sample they provide, but their sample will definitely work to help strengthen breast cancer research.

► ONLY those probands whose family history meets specific testing criteria will be offered genetic testing. Not all probands are given this option. Eligible probands interested in genetic testing must first attend a genetic counselling appointment to learn more. A proband may decide against genetic testing, but still be encouraged to donate a blood sample for cancer research.

If you have an OFBCR-related question that you would like answered, call 1-800-832-5949 or e-mail it to OFBCR@cancercare.on.ca



Web sites, Books n' Stuff

WEBSITES

www.cfr.epi.uci.edu/ic_registries/objectives.htm

is the official site for the Cancer Family Registries, where you'll find more information about the OFBCR and it's 5 partners by clicking under Breast CFR on the sidebar.

www.breastcancer.org

is a nonprofit organization dedicated to providing the most reliable, complete, and up-to-date information about breast cancer.

www.breastcancer.net

is the place to go to subscribe to daily or weekly e-mail summaries of all breast cancer related research and treatment news being published across the globe. Try it free for two weeks first!

BOOKS

The Breast Cancer Care Book: A Survival Guide for Patients and Loved Ones (spiritual) [Zondervan, 2004]

By Sally Knox, MD

Songs from a Lead-Lined Room (funny)

[Crown Publishing, 2004]

By Suzanne Stempek Shea