kConFab

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Kathleen Cuningham Foundation
CONsortium for research into FAmilial Breast Cancer

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Dear kConFab families

Since our last newsletter there have been many advances made from our research work and we are keen to update you with this progress. The importance of our work is reflected in the number of active national and international research projects, 42 in number and growing, that focus on the search to find genes associated with familial breast and ovarian cancer, investigations into whether psychosocial factors like stress, anxiety, depression, social support and personality are risk factors for breast cancer and to find out how lifestyle factors might influence the chance of developing cancer. We have also continued to expand our work in prostate and pancreatic cancer as these cancers can also occur in our kConFab families.

Whilst we are recruiting new families via the national Family Cancer Clinics, we are also re-contacting previously recruited family members as our research relies on accurate and up-to date information about all of the cancers, changes to family history and preventive surgeries in members of our participating families.

As of June 2014:

- We have now enrolled 1,607 high risk cancer families from all parts of Australia and New Zealand.
- 13,256 people have donated blood samples and 13,627 have completed our lifestyle questionnaire.
- There are 135 approved national and international projects using the biological samples and data we have collected.
- There are 227 high ranking medical and scientific research publications that resulted from the use of the kConFab resource.

I wish to highlight the updates about the new breast cancer related genes that have been found by our national researchers. In our last edition we updated you about families that carry a particular ATM gene fault (mutation) and these families have all been sent a kConFab mutation notification letter recommending that they attend a Family Cancer Clinic if they wish to know their personal mutation test result and what effect this mutation has in the development of cancer. As detailed in this newsletter (page 4) we will soon be sending kConFab mutation notification letters to our families that carry a particular mutation (fault) in another new breast cancer gene known as PALB2. Once again, individual results will not be given by kConFab but the letters will explain that a referral to a Family Cancer Clinic is all that is needed for family members to receive updates about the PALB2 facts and then each person can decide whether they want to have a genetic test. The search continues to discover even more new breast cancer genes and we will translate our research findings to our families as soon as it is possible to do so.

An exciting area of our work is the translation of our kConFab research findings into clinical practice and we have three such updates detailed in this newsletter. One of our clinical researchers, Professor Geoff Lindeman, describes a new breast cancer prevention trial now open via his hospital to women who are ***BRCA1*** or ***BRCA2*** mutation carriers. Due in part to the generous donation by kConFab women of their normal breast tissue obtained at risk-reducing mastectomy over the past 15 years, this team can now extend their research findings and explore this new cancer prevention medication in ***BRCA1*** and ***BRCA2*** mutation carriers (page 2).

Professor Kelly-Anne Phillips. in collaboration with colleagues, has extended upon evidence that tamoxifen can reduce breast cancer risk by up to 50% in women with a family history, but her research group has recently published new evidence demonstrating that taking tamoxifen was associated with a similar reduction in breast cancer risk in women who carry a ***BRCA1*** or ***BRCA2*** gene mutation (page 3).

Please do not hesitate to enquire if you would like any additional information about the BRCA-D trial or tamoxifen use as cancer prevention mediation.

Whilst still in laboratory investigation, Professor Georgia Chenevix–Trench has identified a new breast cancer gene that could be a promising "target" for another cancer prevention medication. You can read about this on page 4 of the newsletter. We would like to congratulate Professor Chenevix-Trench as she was recently awarded an NBCF new novel concept award for her investigations in this area.

Our close colleague, Professor Martha Hickey is looking to enroll women into her "WHAM" (Women's Health After surgical Menopause) study. This is a world first study into the side-effects and benefits of risk-reducing salpingo-oophorectomy (removal of the ovaries and fallopian tubes) that will collect information about some of the other effects such as menopausal symptoms, sexual function, bone and heart health and psychological well-being after such surgery (page 5). Please contact this research team if you, or even a friend who might be eligible, are interested in finding out more about this research study.

kConFab continues to receive funding from the National Breast Cancer Foundation (NBCF) which has been a generous and long-time supporter of our national research

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work. Recently kConFab and three national researcher groups have been involved in five breast cancer grant submissions to the European Commission under the Horizon 2020 grant funding scheme. We wish our national researchers and the kConFab management well in their endeavours to obtain this grant funding to pursue their research work.

In closing, because of the generosity and co-operation of our families, kConFab has become one of the world's best resources for research into familial aspects of breast, ovarian and, in recent times, prostate cancer. Your communications to us about new family members who become eligible to join kConFab, new diagnoses of cancer in your family and about impending surgery for the removal of both normal and cancer (breast, ovarian and prostate) tissue have enabled us to continue to support the research community. So, on behalf of the entire kConFab team, I want to thank you most sincerely for your ongoing support. We hope that you find this newsletter informative and we welcome your feedback.

Professor Stephen Fox, chairperson
kConFab executive committee

The Forgotten Cancers Project

Through extensive research, significant progress has been made in understanding, treating and preventing the most commonly diagnosed cancers; prostate, breast, bowel, lung and skin, however less common cancers remain considerably under-researched. Cancer Council Victoria believes now is the time to improve our understanding of less common cancers and their causes so we can be in a better position to prevent these cancers and support people who are diagnosed in the future.

With the help of 15,000 participants the project will study the role of genes, lifestyle and early life environment in the development of less common cancers such as non-Hodgkin's lymphoma, leukaemia, multiple myeloma, kidney, bladder, stomach, brain, liver, oesophageal, pancreatic, endometrial/ uterine, thyroid, gallbladder, small intestine, bone and other rare cancers.

Any Australian diagnosed as an adult with a less common cancer is invited to participate in the Project. Participants are asked to complete online (or paper) questionnaires and provide a saliva sample for DNA analysis. A saliva collection kit will be mailed to all participants and can be returned in a reply paid envelope provided.

For more information about The Forgotten Cancers Project, or to find out whether the Project might be suitable for you, please contact the team on **1800 068 289** or **ForgottenCancers@cancervic.org.au** or visit The Forgotten Cancers Project website *www.forgottencancers.com.au*

BRCA-D – A new study exploring breast cancer prevention.

Professor Geoff Lindeman and
Dr Sheau Wen Lok, The Royal Melbourne Hospital, Melbourne

Women who carry a BRCA1 or BRCA2 gene mutation (fault) have an increased risk of developing breast cancer. Although risk-reducing mastectomy is a very effective strategy for reducing breast cancer risk, surgery is not an acceptable or suitable option for many gene mutation carriers. In fact, a recent study by Professor Kelly Phillips found that approximately 20% of female BRCA1 or BRCA2 mutation carriers in kConFab opted for such surgery.

Most *BRCA1* or *BRCA2* carriers elect to be closely monitored through a combination of breast checks, mammograms and MRI scans. Regular surveillance will increase the chance that a breast cancer is detected at an early stage, where treatment is likely to be much more effective. This approach, however, does not prevent breast cancer - a 'holy grail' for women at increased breast cancer risk.

A team of clinicians and scientists at the Royal Melbourne Hospital and Walter and Eliza Hall Institute (WEHI), Melbourne, are conducting a research study to investigate if a new medication called denosumab is effective for reducing the risk of breast cancer in *BRCA1* and *BRCA2* mutation carriers. Using the kConFab resource, WEHI scientists previously discovered the cell type in *BRCA1* normal breast tissue that appears to be the culprit cell that goes awry, i.e. leads to cancer. These cells are known as 'progenitor' cells and are the descendants of breast stem cells. The current study, called **BRCA-D**, will test whether denosumab can switch off the 'progenitor' cells in the normal breast tissue of *BRCA1* and *BRCA2* carriers.

Denosumab is a drug that has been approved to treat 'thin bones' (osteoporosis) or breast cancer that has spread to the bones, and has been very well studied. BRCA-D will investigate a possible new role for this drug on normal breast tissue as a cancer prevention medication. The study, which was independently developed by the investigators, will be carried out in Melbourne through the Federal government NHMRC-funded Centre for Translational Breast Cancer Research.

The **BRCA-D** study will recruit women who are *BRCA1* or *BRCA2* mutation carriers who are planning to undergo risk-reducing mastectomy (or who are prepared to undergo two breast biopsies). They will be able to have their planned mastectomy through their own surgeons at other hospitals.

Women will receive four doses of denosumab over three months, given as simple injections under the skin. The researchers will compare breast tissue samples collected before and after treatment to determine whether denosumab has switched off growth signals and progenitor cell activity. Some patients will also have two breast MRI scans to see if their breast 'density' is modified by denosumab.

Up to 30 *BRCA1* and *BRCA2* carriers will be recruited for this study, which is expected to commence in July 2014. If results from this study are encouraging, this could pave the way for a large multi-centre clinical trial to see if denosumab is indeed an effective option as a breast cancer prevention drug for *BRCA1* and *BRCA2* carriers.

If you are interested in participating in the study, or would like more information, please contact:

Professor Geoff Lindeman
lindeman@wehi.edu.au
(Principal Investigator)

Dr Sheau Wen Lok
sheau.lok@mh.org.au
or (03) 9345-2805 (Research Fellow)

Ms Kylie Shackleton
shackleton@wehi.edu.au
or (03) 9345-2805 (Research Office)

A Tablet A Day Helps Keep Breast Cancer Away.

NEW INFORMATION FROM THE KCONFAB FOLLOW-UP PROJECT.

Professor Kelly-Anne Phillips.
The Peter MacCallum Cancer Centre, Melbourne

The kConFab Clinical Follow up Project continues to use information collected from kConFab participants to answer important questions about how to optimize your health.

Last year our study received a lot of positive media attention after our publication in the Medical Journal of Australia (1). This described how kConFab participants with a *BRCA1* or *BRCA2* gene mutation (which puts them at high risk for breast and ovarian and fallopian tube cancer) have chosen to manage their cancer risk. We found that 21% have had both breasts removed to prevent cancer. Sixty-six percent of those aged over 50 had their ovaries and fallopian tubes removed to prevent ovarian and fallopian tube cancers. This operation can also reduce breast cancer risk by up to 50% if done when a woman is pre-menopausal. It is generally strongly recommended for women with a gene mutation by age 50 at the latest, but preferably earlier, particularly for *BRCA1* mutation carriers. This is because there is no reliable screening test for ovarian and fallopian tube cancers and current treatments usually do not result in a cure.

Interestingly, only 3% of women had taken oestrogen blocking tablet medications, such as tamoxifen, to reduce their breast cancer risk. This is an option that we believe could prevent hundreds of breast cancers every year in Australia if more women were using it. It has been known for some time that tamoxifen can reduce breast cancer risk by up to 50% in women with a family history, but it was not clear whether this was also true for women at very high risk of breast cancer because of a *BRCA1* or *BRCA2* gene mutation. In 2013 we published a landmark study in the Journal of Clinical Oncology (2) which showed that taking tamoxifen was associated with a similar reduction in breast cancer risk in women who carry these gene mutations. This global study, led by us, included almost 2500 women from kConFab and other similar studies in Europe and North America. This study received international attention in the media and among the scientific community because it means there is now a non-surgical breast cancer prevention option for gene mutation carriers who do not want to have a bilateral mastectomy.

In light of our findings, it is clear that women at high risk of breast cancer should review their management plan with their specialist and re-discuss the options available to them to lower their cancer risk.

Some of you have been answering our mailed out 3-yearly questionnaires for 15 years now, which makes our study detailed and valuable. We sincerely thank all who have completed questionnaires over the years, and hope that you will continue to do so. With your generous ongoing participation in this study we will be able to continue to make discoveries which will help future generations fight breast cancer.

To view Professor Kelly-Anne Phillips recent interview on the Today show about the kConFab Clinical Follow-up Project that you participate in, please go to:

http://petermac.org/news/peter-mac-research-shows-preventive-measures-under-used-women-increased-risk-breast-and-ovarian

(1) Collins IM, Milne RL, Weideman P, et al.Preventing Breast and Ovarian Cancer in Women at Highest Risk; Long-term Follow-up of Participants In the Kathleen Cuningham Foundation Consortium for Research into Familial Breast Cancer (kConFab). MJA 2013, 199 (10): 680-683

(2) Phillips KA, Milne RL, Rookus MA, et al. The International BRCA1 and BRCA2 Carrier Cohort Study (IBCCS, including EMBRACE, GENEPSO, HEBON), the Kathleen Cuningham Foundation Consortium for Research Into Familial Breast Cancer (kConFab) and the Breast Cancer Family Registry (BCFR). Tamoxifen And Risk Of Contralateral Breast Cancer In *BRCA1* And *BRCA2* Mutation Carriers. J Clin Oncol 2013; 31: 3091-3099.

kConFab Clinical Follow-up Project
Toll free phone numbers:
Australia 1800 111 581 and
New Zealand 0800 230 029

RESEARCH UPDATES:

PALB2 - a new gene associated with breast cancer risk

Professor Judy Kirk, Director
Familial Cancer Service,
Westmead Hospital, Sydney

There are many reasons why families choose to participate in the kConFab research study. Some families already know the genetic cause of breast and/or ovarian cancer in their family. They may have learnt this directly from a Family Cancer Clinic (FCC) or it may be that kConFab has alerted them that research has identified a gene fault (mostly in either BRCA1 or BRCA2) that causes the high risk of cancer in the family. This means that each person can go to a Family Cancer Clinic for information, after which they can decide whether or not they want to have a diagnostic genetic test to clarify their own risk. The staff at the FCC can arrange for a test to tell you whether or not you have the "family gene fault". This is a service that should be covered by the clinic with no cost for the genetic test. No individual genetic test results are given directly by kConFab as the samples they have are not tested in an accredited clinical laboratory.

Although this free service is available, we know that some people who are notified by kConFab that there is a genetic test available, don't attend a clinic for testing. However, once they have the necessary information given at the clinic, most people then do proceed with testing. The families who already have a definite genetic diagnosis (for example a mutation in the *BRCA1* or *BRCA2* gene) know that their participation in kConFab will help further research designed to understand how to improve their clinical care, reduce cancer risk and reduce death from cancer. Further, input from these families helps us to understand the emotional impact of genetic testing in a family so that we can improve your care within the Family Cancer Clinics.

However, at this stage, the majority of families in kConFab do not yet have a known gene fault that accounts for their family history. Their major concern is "finding out what the problem is so that we can do something about it". Clinicians and researchers understand this frustration. It is possible that the cancers in the family occurred by chance alone or that there is a combination of genetic and environmental causes underlying the family history.

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RESEARCH UPDATES:

But progress has been made!

After much work by very dedicated Australian kConFab researchers over the years it is now clear that some cancer family histories of families participating in kConFab are due to mutations in genes other than BRCA1 or BRCA2. We have already highlighted the work of Professor Georgia Chenevix-Trench (QIMR, Brisbane) and others in finding that changes in the gene ATM generally cause a moderate risk of breast cancer, but one specific mutation in the ATM gene, known as the ATM (c.7271T>G) mutation can cause a significantly high risk of breast cancer, about the same as that caused by BRCA2 gene faults. KConFab notified the families with this ATM mutation last year and some have now been to a clinic to seek testing.

Further to this, the work of Professor Melissa Southey (The University of Melbourne) and others has have identified a specific mutation in PALB2 (known as PALB2 c.3113G>A) that causes a breast cancer risk about the same as for mutations in *BRCA2*. There does not seem to be a high risk of ovarian cancer in these families. We have been cautious about notifying families with this gene change until the information was firm and until the heads of clinics around Australia agreed on the advice that should be given to such families. Now that this has been done, the families with this particular PALB2 mutation will soon be sent notification letters from kConFab. Once again, individual results will not be given, but the letters will explain that a referral to a Family Cancer Clinic is all that is needed for family members to hear about the PALB2 facts and then each person can decide whether they want to have a genetic test.

We anticipate that these families will be much relieved that a genetic cause has finally been found. For other families new gene sequencing technology, now being applied in kConFab research studies, may find further new gene mutations that will help find the answers for many more families with multiple-cases of breast cancer.

A new breast cancer susceptibility gene may be a target for a breast cancer prevention medication.

Professor Georgia Chenevix-Trench,
QIMR Berghofer Medical
Research Institute, Brisbane

Professor Georgia Chenevix-Trench, QIMR Berghofer Medical Research Institute, Brisbane, being presented with the National Breast Cancer Foundation "new novel concept award" by Ms Sarah Murdoch, February 2014.

The ultimate aim of breast cancer research is to find a way to prevent breast cancer arising in the first place. Given that this does not appear to be possible by lifestyle or dietary changes, the alternative is the radical option of surgical removal of the breasts, or the much more acceptable strategy of taking risk reduction medication. The current options for risk reduction medication are imperfect because they only reduce the risk of breast cancer by about 50%, and have some side effects, including increasing risks of other cancers. We have identified a new breast cancer susceptibility gene whose action can be blocked by a medication that has previously been shown to be safe in the treatment of patients with an inherited blood disorder. We propose that this medication will be useful for the prevention, and treatment, of breast cancer, and in particular the kind of breast cancer that is most common in women who carry a fault in the BRCA1 gene, or are diagnosed at a young age. Our aim is to test the effect of this drug on breast cells grown in the laboratory, and injected into laboratory mice, in order to determine if we can justify carrying out a clinical trial to determine whether it can work as a risk reduction mediation in women at high risk of breast cancer, particularly those who inherit a fault in the BRCA1 gene.

WHAM: World first study into the risks and benefits of risk-reducing oophorectomy

By Professor Martha Hickey,
The Royal Women's Hospital,
Melbourne

Women at high inherited risk of breast and ovarian cancer face a difficult decision about whether and when to have their ovaries/fallopian tubes removed for risk reduction. The benefits in terms of cancer risk reduction are clear, but the other effects such as menopausal symptoms, sexual function, bone and heart health and psychological wellbeing are less clear.

This new study aims to help those women by understanding how this operation might impact on their physical and emotional health in the future.

The Women's Health After surgical Menopause study (WHAM), will look at the impact of risk reducing oophorectomy on a wide range of physical and emotional outcomes in young (premenopausal) women. The study will involve 210 Australian women aged between 18-50 years, who will be recruited through hospital sites in Melbourne and Sydney. Study participants will be required to make 4 hospital visits over 2 years during which time they will be asked to complete questionnaires, perform tests for memory and learning, provide blood for testing, and have bone density scans.

The study needs to enrol high risk women who are planning to have surgery in the very near future and also those choosing to delay surgery for 2 years. Women who have no known genetic risk of ovarian or breast cancer will also be enrolled as members of a control group.

Leader of the WHAM study, Professor Hickey says: "Although surgery reduces fear of cancer in high risk women, there is still very little information available to help women make an informed decision about having their ovaries removed and what to expect in the future".

"Women want to know what to expect after surgery and how to get the right care to ensure that they maintain good health and this is the aim of the study. WHAM will help us to provide accurate, evidence-based advice to help women make an informed choice and get the right care in the future".

The study is now actively recruiting and women interested in making a difference can contact the WHAM study team on

(03) 8345 3719 or at gynaecology.research@thewomens.org.au

Our kConFab research suggests that male breast cancer appears to be a different entity to female breast cancers.

By Dr Siddhartha Deb,
Trainee Pathologist and PhD graduate
Melbourne Health & The Peter MacCallum Cancer Centre, Melbourne

While female breast cancer has been well studied, only recently have we begun to look at the disease in males. While rare, accounting for less than 1% of all cancers in men, male breast cancer is as serious as female breast cancer. Unfortunately, the rarity of the disease has resulted in a lack of male breast cancer specific national or international research and as a result, little is still known about male breast cancer with all treatment taken from knowledge attained from female breast cancer studies, which is not ideal. Large male breast cancer collections, such as that assembled by kConFab containing cancer tissue linked to related clinical data are invaluable to study this disease further.

Our study has aimed to explore both the clinical characteristics and genetics of male breast cancer. At its simplest, our aims were to explore:

1) differences and similarities between male and female breast cancer
2) differences between male breast cancers that arise in families with a history of breast and ovarian cancers vs. families with no history of these cancers
3) differences between male and female breast cancers that arise in breast/ovarian cancer families

Our studies have shown that male breast cancers occur more frequently in *BRCA2* mutation carriers (and to a lesser extent in *BRCA1* carriers) from kConFab families when compared to male breast cancers that occur in the general population without a family history of cancer.

There appear to be differences in the molecular pathways and make up of some of these cancers, particularly cancers that arise in males who carry a *BRCA2* mutation. Significantly, in kConFab women who develop breast cancer we see a strong effect when the *BRCA1* gene fails to function normally, thus leading to the development of aggressive breast cancers, but this genetic failure does not seem to be as influential in the development of male breast cancers.

Currently, male breast cancers are treated using protocols and knowledge gained from female breast cancer, but it is hoped that our preliminary findings may form the basis upon which more targeted and male breast cancer specific management may be developed for improved health care. Furthermore, some of the differences seen between male and female breast cancers may also help us to understand female breast cancer.

Updates from the Breast Cancer Network Australia (BCNA).

Breast cancer in men

Although most Australians diagnosed with breast cancer are women, around 125 men are diagnosed with breast cancer every year.

A number of factors can increase a man's risk of developing breast cancer including age, a known *BRCA1* or *BRCA2* gene mutation, a strong family history of breast cancer, and higher oestrogen levels caused by obesity, long-term liver conditions such as cirrhosis, and some genetic conditions such as Klinefelter's syndrome.

In 2013, Breast Cancer Network Australia (BCNA) investigated issues affecting men diagnosed with breast cancer and found there was very little written information addressing their specific needs, and that there was poor awareness generally that men can develop breast cancer. Men reported feeling isolated, shocked, distressed and even embarrassed by their diagnosis.

I found it hard that everything is geared towards women. Pink doctors' surgeries, pamphlets, magazines – everything (and rightly so – I sure don't want to undermine that in any way). It did add to that experience of isolation for me though, and made me feel much, much less of a man. – Craig

My surgeon gave me a pile of brochures about breast cancer but only one pamphlet was about male breast cancer. – Ron

In response, BCNA developed an information booklet for men diagnosed with breast cancer. BCNA consulted men with breast cancer and their family members, medical oncologists, surgeons and psycho-oncology practitioners to ensure the information in the booklet meets men's needs.

Men get breast cancer too, provides tailored information about breast cancer and its treatments, follow-up care, lymphoedema, secondary breast cancer, and ways to deal with some of the common challenges that men may face including:

- coping with their diagnosis
- sharing their diagnosis with others
- financial and practical concerns
- changes in sexual wellbeing
- depression and anxiety
- concerns about the cancer coming back
- finding a 'new normal'.

The booklet lists other resources and services available for men diagnosed with breast cancer.

The booklet can be ordered or downloaded by visiting *www.bcna.org.au > News > Resources > Fact sheets and booklets.*

The booklet absolutely hits the nail on the head. I wish that I had this information years ago. I pretty much ticked every single situation outlined when it comes to my breast cancer experience. I also learnt from it information that I did not already know. – Craig

Men in Australia can also order BCNA's My Journey Kit, a comprehensive information resource for people newly diagnosed with early breast cancer. While primarily for women, it is also useful for men. My Journey Kit can be ordered through BCNA's website *www.bcna.org.au.*

About Breast Cancer Network Australia

Breast Cancer Network Australia is the peak national organisation for Australians affected by breast cancer, and consists of a network of more than 90,000 individual members and 300 Member Groups.

BCNA works to ensure Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs.

Involving Breast Cancer Consumers in Decision Making

Research has found that meaningfully involving consumers in health research, policy making, program development and service delivery contributes to improved outcomes and helps ensure that decisions will be relevant and appropriate for those most closely affected by the various policies, programs and services.

Since 2000, Breast Cancer Network Australia (BCNA) has run its internationally recognised consumer representative program, Seat at the Table. Through Seat at the Table, BCNA invites, trains, appoints and supports women who have had breast cancer to become BCNA Consumer Representatives.

BCNA Consumer Representatives work on a variety of projects, including:

- supporting grant applications
- helping with clinical trial ethics and consent documents
- providing consumer input on research projects

Breast Cancer Network Australia

- assisting with clinical trial recruitment
- representing the views of those affected by breast cancer on advisory committees
- assisting with the development of information resources and publications.

All BCNA Consumer Representatives have strong communication skills, knowledge of breast cancer issues and the ability to reflect the needs, viewpoints and concerns of Australians affected by breast cancer. They have completed BCNA's Science & Advocacy Training, which includes sessions on breast cancer treatment, the genetics of breast cancer, psychosocial issues, clinical trials, survivorship and how to represent the diverse perspectives and experiences of those diagnosed with breast cancer.

The BCNA Policy Team provides Consumer Representatives with ongoing support and advice.

Examples of projects our current Consumer Representatives are involved in include:

- The kConFab Executive Committee
- A research project exploring the impact of women's choices about breast reconstruction on their quality of life
- A project examining the effects of tamoxifen on women at high risk of breast cancer.

Two BCNA Consumer Representatives also sat on the Cancer Australia working group developing clinical guidelines to assist in the management of early breast cancer in women with an identified *BRCA1* or *BRCA2* gene mutation or at high risk of a gene mutation, which were recently released.

I have found the support and opportunities given to me during my time as a Consumer Representative rewarding and encouraging, it keeps me inspired to continue to apply my passion to breast cancer advocacy and to continue to advocate for regional, rural and remote communities.

For more information about Seat at the Table, please visit: *http://www.bcna.org.au/about-bcna/advocacy/consumer-representatives.*

PINK HOPE

The founder of Pink Hope, Ms Krystal Barter, has written her first book – The Lucky One. It is her story as young women facing her risk of hereditary breast cancer; a disease that her Mum, her Nan and Great Grandma have all experienced.

At 22 Krystal undertook genetic testing and tested positive for a BRCA1 gene fault. At 25 with her husband and two children beside her she decided to have a risk-reducing double mastectomy. While recovering from her surgery Krystal founded the charity Pink Hope, a community dedicated to inspiring, supporting and informing women at high risk of breast and ovarian cancer.

Pink Hope has helped countless high risk women and their families by ensuring they have the knowledge and support needed at a crucial time in their lives.

The Lucky One reveals Krystal's whole story of love, courage and transformation. She writes, for the first time, of her troubled teenage years and struggle with drugs and body issues; of meeting and falling in love with her husband Chris and discovering she was pregnant at only 21; of the support she has received from her family and husband; of undergoing IVF only to fall pregnant naturally with her daughter Bonnie; and of where to next for Pink Hope and herself as she faces her increased risk of ovarian cancer.

'I feel lucky I was born with cancer in my DNA. Crazy as it sounds, I consider myself lucky that, when I was just twenty-two years old, I discovered I had a ninety per cent chance of developing breast cancer: the same, insidious disease that had attacked my Mum, and my Nan before her and my Great-Grandma before her.'

The book will be available in all good retail and online book stores. Proceeds from the sale will support *www.pinkhope.org.au*

Take a snap of yourself on social media with the book using #krystaltheluckyone and let us know "why you are lucky".

Messages from the kConFab team

To keep kConFab running smoothly, we would greatly appreciate if you would remember the following:

- **kConFab has approval to access Medicare and PBS data.**

  kConFab has gained approved from the Federal Department of Information Strategy & Delivery Section Strategic, Department of Human Services to gain access (with your written consent) to the Medicare/PBS data they hold. For kConFab, the on-going clinical follow up details are important information about our participants and are essential (de-identified) information we provide to researchers accessing our biological samples and/or data for their research studies. The access to the Medicare/PBS data will provide a lot more information than we currently obtain as we can't know about, or even try to cover, all records from hospital sites that our participants attend. The data will also contain specialist areas such as radiology reports for mammograms and MRIs. Should any participant approached decide not to sign the Medicare and PBS consent form it will not affect your involvement in the kConFab research study.

- We send information to you by post and email, therefore it is very important to keep your contact details up to date. Please call **1 800 221 894** (toll free) or email (**heather.thorne@petermac.org**) to pass on these updates, or ring your local kConFab research nurse. Contact details are on the last page of this newsletter.

- Please remember that **fresh tissue specimens of all tissue types, whether normal or cancerous, obtained at surgery** are extremely valuable for our research. In addition to the tissue collections, sometimes, in the course of breast or ovarian cancer, women experience the build-up of fluid in their abdomen (this fluid is called ascites) or lungs (pleural effusion). The ovarian or breast cancer cells in these fluids can be used in our research studies. If you find yourself needing to have ascites or lung fluid drained at any time, we would greatly appreciate being contacted by either yourself or your medical staff in advance, so that we can arrange to collect any fluid not required for diagnostic use. Our team would make all the necessary arrangements.

- It is very important that we are notified of any new cases of cancer in your family. Research relies on accurate and up-to date information about all the cancers in each of our participating families. We appreciate your help with this.

- Please notify kConFab if, at any time, you prefer not to have more contact with our study

- **Are there other family members eligible to join kConFab?** Once a family has been counseled at a Family Cancer Clinic about a genetic (fault) mutation in the family, additional family members may become eligible for recruitment into the kConFab study.

  Once a family member, female and male turns 18 years of age they may also be eligible to be recruited into the kConFab study

Please call one of our research nurses (see the contact list at the end of this newsletter) if you would like to confirm if other family members are eligible for recruitment.

Kathleen Cuningham Foundation
CONsortium for research into FAmilial Breast Cancer
kConFab

Collaborating Family Cancer Centres

Melbourne

Familial Cancer Centre
Peter MacCallum Cancer Centre
St Andrews Place
East Melbourne, 3002
Contact: Dr Sue Shanley
Phone: 03 9656 1199
kConFab national manager: Heather Thorne
Phone: 03 9656 1542

Royal Melbourne Hospital
Familial Cancer Centre
Parkville, 3050
Contact: Professor Geoffrey Lindeman
Phone: 03 9342 7151
kConFab national manager: Heather Thorne
Phone: 03 9656 1542

Monash Medical Centre
Clayton, 3168
Contact: Dr Marion Harris
Phone: 03 9594 2009
kConFab national manager: Heather Thorne
Phone: 03 9656 1542

Austin Health
Heidelberg Repatriation Hospital
Heidelberg West, 3081
Contact: Professor Martin Delatycki
Tel: 03 9496 3027
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St George Community Hospital
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