kConFab

MAY 2016

Kathleen Cuningham Foundation
CONsortium for research into FAmilial Breast Cancer

Published by kConFab, Peter MacCallum Cancer Centre, St Andrew's Place East Melbourne, Vic 3002 Tel: (03) 9656 1542 Website: http://www.kconfab.org

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 some of this progress. The importance of our work is reflected in the number of active national and international research projects, 155 in total with 49 currently active, 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. We have six project updates in our research updates section of this edition that covers some of our new findings and leads being explored about breast, ovarian and prostate cancer.

The major strength of our work is that we have now been in contact with many of our families for up to 19 years. That means we have all of the treatment and health outcomes for either cancer prevention strategies or cancer treatment over many years. The accumulation of such long term data makes our resource unique and extremely valuable world-wide for research studies.

The major focus of our work over the past 14 months has been re-contacting previously recruited family members as our research relies on accurate and up-to date information about treatments given and the response, preventive surgeries that may have occurred and changes to the family cancer history.

As of April 2016:

- We have now enrolled 1,681 high risk cancer families from all parts of Australia and New Zealand.
- 13,591 people have donated blood samples and 13,840 have completed our lifestyle questionnaire.
- There are 155 approved national and international projects using the biological samples and data we have collected. Many of these projects have been active and adding to the research findings for 10 plus years.
- There are 281 high ranking medical and scientific research publications that resulted from the use of the kConFab resource.

An exciting area of our work is the translation of our kConFab research findings into clinical practice. One of these studies is being run by our clinical researcher, Professor Kelly-Anne Phillips who in collaboration with colleagues, are looking for women and men who have been diagnosed with breast cancer and who carry a BRCA1 or BRCA2 gene mutation (fault) to participate in an international clinical trial, known as OlympiA. The OlympiA clinical trial is investigating whether taking a medication known as olaparib (a tablet) twice a day for 12 months can reduce the risk of breast cancer recurring (coming back). The trial is open to women and men diagnosed with HER-2 negative breast cancer who have an inherited BRCA1 or BRCA2 gene fault (page 5). Please do not hesitate to enquire if you would like any additional information about the OlympiA clinical trial.

kConFab continues to receive funding from the National Breast Cancer Foundation (NBCF) who have been a generous and long-time supporter of our national research work. In addition to the funding we receive for our main research work, the NBCF Board has recently approved the awarding of the Professor Joe Sambrook, post-doctoral prize at our annual conference. This award is in recognition of Professor Joe Sambrook, the founder and executive director of kConFab until 2008, along with his major contribution to the NBCF national strategic research plan. Joe's long-term influence in research policy, strategic planning and as a mentor to Australian breast and ovarian cancer researchers has enabled many to consolidate their careers and raise their profile to become international leaders in breast and ovarian cancer research and to engage in high-profile, collaborative international clinical research studies. The award will enable one of our best and brightest post-doctoral students to travel to a conference of their choice to meet with international leaders which will help develop their career and lift Australia's profile in cancer research.

We would like to congratulate our national researchers, Professor Melissa Southey and Assoc. Professor Amanda Spurdle, and the kConFab management team, who were recently awarded funding by the European Commission under the Horizon 2020 grant scheme for a breast cancer project known as *Breast Cancer Risk after Diagnostic Gene Sequencing (BRIDGES)*. It is an outstanding effort on their behalf to obtain this highly competitive international funding to pursue their research work. Please see details of the planned work on page 2.

We mentioned in the 2012 newsletter a new program known as CASCADE, page 4. The research performed in this

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program (where our participants give consent to an autopsy at the time of their death) is helping to explain why cancer becomes resistant to treatments and we would like to give you some of the research updates that we now have. We realise that this program will not be of interest to everyone but if you live in Victoria and are interested in finding out more about this program, please ring Heather in the kConFab office, toll free 1800 221 894 or 03 9656 1542.

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

"We would like to congratulate our national researchers, Professor Melissa Southey and Assoc. Professor Amanda Spurdle, and the kConFab management team, who were recently awarded funding by the European Commission under the Horizon 2020 grant scheme for a breast cancer project known as Breast Cancer Risk after Diagnostic Gene Sequencing (BRIDGES). It is an outstanding effort on their behalf to obtain this highly competitive international funding to pursue their research work"

Breast Cancer Risk after Diagnostic Gene Sequencing (BRIDGES)

By, Professor Melissa Southey, The University of Melbourne, Melbourne and Assoc. Professor Amanda Spurdle, QIMR Berghofer Medical Research Institute, Brisbane.

Working in partnership with 15 other international breast cancer research groups we have been awarded a European Commission Horizon 2020 grant known as "BRIDGES".

BRIDGES focuses on the increasing number of new and suspected breast cancer susceptibility genes. This five-year program aims to determine if faults in these genes increase the risk of breast and ovarian cancer and if so, how high the cancer risk is. BRIDGES will also work to find the best ways of providing this new information to women and their families who carry inherited faults in these new breast cancer genes.

The reason for this new study is that research has shown that the identification of women at high risk of breast cancer can lead to disease prevention through screening, prevention medication or prophylactic surgery. We now also know that breast cancer risk is determined by a combination of genetic and lifestyle risk factors. We have made great progress by improving our understanding of how the BRCA1 and BRCA2 genes are important to breast (and ovarian) cancer risk - BRIDGES aims to provide similar information for the additional breast cancer susceptibility genes.

This new study will use the biological samples, clinical and lifestyle information contributed by participants from all 17 international sites, to generate new information for more than 20 known or suspected breast cancer susceptibility genes in a sample of 30,000 women with breast cancer (including kConFab families), and 30,000 women without breast cancer (controls).

BRIDGES will link the new genetic data with other laboratory and lifestyle data to generate a risk prediction tool that could, in the future, be used to calculate breast cancer risk for all women (with or without a cancer family history).

This risk prediction tool will be available online so that it can be used by genetic professionals to aid the interpretation of genetic tests and help women make informed decisions about their care.

Two Australian research awards, linked to the BRIDGES grant, have also been obtained to enhance the contribution of Australian breast cancer families and Australian researchers.

1. The Australian Academy of Science awarded a two year grant to kConFab that will facilitate the supply of biologicalsamples and data to the BRIDGES research program.
2. The Australian National Health and Medical Research Council (NH&MRC) awarded a European Union Collaborative Research grant to enable the inclusion of data from additional Australian families, increasing the relevance of the BRIDGES findings to the clinical management of Australian women.

More accurate prognosis for newly diagnosed breast cancer

By Dr Jodi Saunus and Professor Sunil Lakhani, University of Queensland Centre for Clinical Research, Brisbane.

While BRCA1 mutation (gene fault) carriers are at far greater risk of developing breast cancer than the general population, the prognosis for women who do go on to develop the disease can be highly variable. This is particularly evident for triple-negative breast cancer, i.e. breast cancers that are negative for Estrogen, Progesterone and Her-2 receptors, a sub-type of breast cancer that is over-represented in the familial breast cancer group. Irrespective of the familial component, estimating the risk of recurrence or distant cancer spread (metastasis) is extremely important for patients facing a long wait after their initial diagnosis and primary treatment.

Molecular Pathology researchers at the University of Queensland Centre for Clinical Research in Brisbane are studying hundreds of breast cancer samples donated to kConFab by patients with a BRCA1 mutation (gene fault), and hundreds more from those with no known familial susceptibility, to find breast cancer cell markers that could be used for more accurate prognosis. The team is focusing on triple-negative breast cancer, and a nuclear 'transcription factor' called SOX10, which controls how primitive (embryonic) or differentiated (adult form) cells in the normal breast are controlling the expression of other genes. They found that the levels of SOX10 expressed in breast cancer cells

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can predict patient survival, depending on the overall background level of cell growth. The team hopes their findings will provide new knowledge about breast cancer development, and are conducting more research to determine whether SOX10 testing could be incorporated into standard histopathology assessment of tissue obtained from breast biopsies, since it is already routinely assessed in the diagnosis of some types of melanoma.

Dr Jodi Saunus, University of Queensland Centre for Clinical Research, Brisbane.

Getting to the causes of familial breast cancer

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

Although we have known about the importance of the BRCA1 and BRCA2 genes in causing familial breast cancer for 20 years or more, only in the last 10 years have we been able to find other genetic factors that contribute to familial breast cancer risk. This has been done, through huge international consortia (of which kConFab is a member) by comparing the DNA of women with breast cancer, to those without. These comparisons have found about 200 'flags' which very slightly increase a woman's risk, but in aggregate carrying a large number of these "flags" can quite substantially increase risk. One of the major challenges is now to understand what those "flags" are doing, and how they influence the activity of genes nearby. Much of this detective work has been done at the QIMR Berghofer Medical Research Institute, in the laboratories of three dedicated researchers – Stacey Edwards, Juliet French and Georgia Chenevix-Trench. Some of the genes that they find to be affected by these "flags" are those we already know play a role in breast cancer such as the estrogen receptor, but others are genes about which absolutely nothing was previously known, or that we only knew of in some other context, but had no idea were involved in breast cancer. Similar efforts are ongoing around the world for many other common diseases, including auto-immune diseases, diabetes and other cancers. One of the most exciting findings of the year is that the likelihood that a new drug will succeed in clinical trials is doubled if the drug is aiming to interrupt a gene product known to be involved in the risk of that disease. This has very important ramifications for the pharmaceutical industry who invest billions of dollars in getting a drug to market, and so a doubling in their success rate would be very welcome. For this reason, breast cancer researchers think that it is vital that we understand how each one of these breast cancer risk "flags" is working, because we never know which of them might provide the path to better drugs to prevent or treat breast cancer.

A kConFab prostate cancer study has identified a cancer cell associated with a poor outcome.

By Professor Gail Risbridger, Dr Renea Taylor, Monash University and Heather Thorne, kConFab @ The Peter MacCallum Cancer Centre, Melbourne.

In 2008 the kConFab prostate cancer research team reported that men belonging to kConFab families were at an increased risk of developing an aggressive form of prostate cancer if they carry a BRCA2 gene fault (mutation). Since this time it has been pleasing to see many of our men attend one of the national cancer genetic clinics to see if they are BRCA2 mutation carriers (if a BRCA2 gene fault has been detected in the family), and partake in active surveillance programs for the early detection of prostate cancer by having regular PSA testing and consultations with their GP and urologist. This important work has been recently extended using prostate cancer tissue samples collected from the operating theatre linked to the related clinical data. Significantly, laboratory experiments demonstrated that the fresh prostate cancer tissue un-expectantly grew a prominent cell type known as IntraDuctal Carcinoma of the Prostate (IDC-P), in addition to typical prostate cancer cells. A review of 33 prostate cancer tissues from BRCA2 mutation carriers found that the men with IDC-P present in their cancer tissue had a poor outcome, regardless of the curative treatment received, compared to men without IDC-P. The IDC-P cancer cell type has previously been under-diagnosed and under-reported in routine biopsy and radical prostatectomy specimens but this study is changing clinical practice with many pathologists now reporting these cells and urologists now looking to see if the IDC-P cell type is present or absent in their patients' prostate cancer specimens. This finding also suggests that IDC-P may be an important, new clinical marker in these patients to improve their clinical outcome, thereby, providing new avenues for the research team to explore.

Family Matters study improves communication and leads to new relatives being tested

By Emma Healey, Illawarra Cancer Care Centre, Wollongong Hospital, NSW.

A recent study of BRCA1 and BRCA2 carriers provided a better understanding of the difficulties in passing the news onto relatives. Research genetic counsellor Emma Healey (with team Kathy Tucker, Rachel Williams, Sian Greening, Linda Warwick, and Claire Wakefield), interviewed 202 BRCA1 and BRCA2 gene mutation carriers about their experience of telling their relatives that there was BRCA gene fault in the family. A number of families had done a great job of telling all of their siblings, children, aunts, uncles, nieces, nephews and cousins. However 53% of families had still not been able to let one or more of their relatives know that they may be at risk of carrying the BRCA fault.

The main challenge was that families had lost contact with these relatives. Some BRCA carriers thought their relative would have been told by another family member. Others avoided telling their relative because they felt the news would be a burden. Sometimes the BRCA carriers weren't sure who in the family needed to know – the men too? YES!

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The larger the family, the more difficult it was telling everyone. The process was also harder if there were lots of relatives living out of state or overseas. Individuals found the process more challenging if they felt distressed or anxious.

Emma talked to BRCA carriers about potential strategies to ease the process. She recorded the plan in a Family Communication Tool. When Emma followed up with the participants a few months later, 120 relatives had been informed. These relatives now had important information to reduce their cancer risk. In the months after the study, 66 family members booked into a clinic to have their own BRCA testing. The research team estimated that this had potentially prevented 14 breast cancers and 9 ovarian cancers. This shows the importance of touching base with BRCA carriers and providing extra support with informing relatives. The Family Communication Tool is now being incorporated into clinics, and used in other cancer genetic syndromes.

The study also provided an opportunity to see what choices BRCA-positive women were making to manage their risk of breast and ovarian cancer. In women who had already been diagnosed with breast cancer, bilateral mastectomies were the most popular choice (70% elected for this). However in women who hadn't had a breast cancer, screening was more common, with only 30% having risk-reducing mastectomy. Importantly, 97% of women had either had their ovaries and fallopian tubes removed, or the surgery was planned for the upcoming year.

This rate is much higher than what is seen in other countries, suggesting the national BRCA risk management guidelines (eviQ) have been successfully implemented and patients are motivated to prevent this cancer.

The research team is in the process of publishing this work.

The Family Matters team from L to R, Emma Healey, Rachel Williams, Dr Kathy Tucker, Claire Wakefield.

A CAncer tiSsue Collection After Death (CASCADE) program to Improve our Understanding of the Progression from Primary Stage Cancer to Metastatic Disease.

By Heather Thorne, kConFab national manager.

The treatment of cancer is becoming increasingly successful with the discovery of new treatments and improvements in the old ones. Unfortunately though, not all patients are cured of their cancer, and it can spread to other sites in their body. This kConFab program that has now been running for 3 years, aims to understand why some cancers behave in this way, and become resistant to treatment.

During life, it is often not possible to obtain samples of the cancer from different organs to understand how a cancer has become resistant to treatment and gained the ability to spread to other organs like the bone or the liver. We have been seeking permission to obtain and study samples of tissue from patients shortly after they have died of their cancer. This is providing important information to help develop more effective therapies for patients in the future. kConFab has successfully established:

- A Tissue Donor Program for people to consent to donate their cancer tissues to the kConFab tissue bank after their death
- This cancer tissue is being used by research groups with approved kConFab research projects
- Links with clinical specialists, pathologists, allied health professionals and patient support groups have been established to facilitate greater understanding of cancer development and progression.
- As of April 2016, 11 kConFab participants have been involved in this program.

Using advanced DNA analysis technologies, we have already observed in our participants' cancer tissue which has spread to other areas in the body, that the cancer cells are able to change dramatically over time as the cancer develops to an advanced stage, i.e., the DNA profile of the primary or original breast cancer compared to the advanced cancer tissue collected during the autopsy can be dramatically different. Remarkably, cancer tissue collected during the autopsy from different sites (for example the breast and lung), frequently have many different DNA profiles even within the same tissue site. Our challenge now is to find ways to overcome all of the cancer gene changes for more effective therapies. Having access to this type of tissue collection is invaluable to our work and makes our program unique world–wide. It is also enabling our researchers and clinicians to have the opportunity to be world leaders working towards improved health outcomes.

The study is open to kConFab participants with breast, ovarian or prostate cancer who live in Victoria. If you are interested in finding out more about this program, please email or ring Heather on:

Email: heather.thorne@petermac.org or telephone 03 9656 1542 or toll free number 1800 221 894

CLINICAL TRIAL FOR WOMEN AND MEN WITH A BRCA GENE MUTATION

Australia & New Zealand Breast Cancer Trials Group

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

Australian researchers are looking for women and men who have been diagnosed with breast cancer and who carry a BRCA1 or BRCA2 gene mutation (fault) to participate in an international clinical trial.

The OlympiA clinical trial is investigating whether taking olaparib tablets twice a day for 12 months can reduce the risk of breast cancer recurring (coming back). The trial is open to women and men diagnosed with HER-2 negative breast cancer who have an inherited BRCA1 or BRCA2 gene fault (mutation).

Approximately 80% of all breast cancers are HER-2 negative, and about 5% of these breast cancers also have inherited abnormalities in the breast cancer genes, BRCA1 or BRCA2. While many people diagnosed with HER-2 negative breast cancer are successfully treated with currently available treatments (including breast surgery, chemotherapy and radiotherapy), in some the breast cancer will recur and so new treatments are needed.

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

As part of OlympiA, people with HER-2 negative breast cancer will receive genetic testing to see if they have an abnormality in the BRCA1 or BRCA2 gene. This will not only determine whether they might be eligible to join the trial, but will also give them information about the genetics of their cancer, which could help with their broader breast cancer treatment, even if they don't join the trial.

The study is being coordinated in Australia by the Australia and New Zealand Breast Cancer Trials Group (ANZBCTG), the largest, independent, oncology clinical trials research group in Australia and New Zealand. The OlympiA trial will enrol 1,500 participants from 23 countries, including 15 locations in Australia.

Australia's involvement in this international research is great news for our patients.

Women and men with HER-2 negative breast cancer diagnosed in the past year and who are interested in participating in the OlympiA clinical trial should speak to their cancer specialist. More information about the study is available at **www.anzbctg.org** or the Australian New Zealand Clinical Trials Registry at **www.anzctr.org.au.**

PINK HOPE ANNUAL CONFERENCE 2016

By Sue Jones, Program manager.

Following the success of last year's Pink Hope Conference, the preventative health organization has announced this year's conference dates – Friday June 3rd to Sunday June 5th at The Blackman Hotel in Melbourne.

The Pink Hope Annual Conference 2016 will feature expert speakers providing information and research, Q&A panels, sessions for men, personal stories and a new attendee session.

Pink Hope works tirelessly to ensure every individual can assess, manage and reduce their risk of breast and ovarian cancer, while providing personalized support for women at increased-risk.

The conference is open to everyone interested in hereditary breast and ovarian cancer – including those at increased risk due to their family history, BRCA gene mutation carriers and support people such as friends or family members.

Expert speakers including a Genetic Counsellor, Breast Surgeon, Plastic Surgeon, Gynecologist and Urologist will run sessions providing the latest information and research. This year will also feature question and answer panels, sessions for men, personal stories and a new attendee session.

The conference is a fantastic opportunity to meet and connect with other women and men at increased risk of cancer.

Registration is $95 per person. For men who wish to attend the Sunday morning sessions only the registration fee is $25. Registration is via the Pink Hope website and is required to attend the Pink Hope conference: **https://pinkhope.org.au/events/pink-hope-conference-2016/**

A conference pack containing information on the agenda, speakers, registration, accommodation, travel and parking, packing tips, awards and past conferences is available for download from the Pink Hope website: **http://pinkhope.org.au/get-support/conference/**

Pink Hope

For further information regarding the conference please contact Sue Jones, Programs Manager on 0402 066 365 or sue@pinkhope.org.au.

"The program organized by Pink Hope was simply brilliant. Such dynamic, informative (and often funny) speakers! To have the opportunity to listen to so many experts in their field was absolutely invaluable. The conference also gave me the opportunity to forge some wonderful connections with other high risk women. For the first time I felt like I was not alone on my journey. I belonged in this room." – Natasha

Australian Breakthrough Cancer (ABC) Study

By Theresa Whalen, ABC coordinator

Like many of us, Rachel and her family have been touched by cancer.

"Both my sister and brother were diagnosed and passed away from the disease, leaving children and other family behind," she said.

The mother of three wanted to do something so that others don't have to go through the trauma of losing a loved one to cancer.

Rachel and her mother have taken part in Cancer Council's Australian Breakthrough Cancer Study to help us find out more about the causes of cancer and other diseases.

With nearly 130,000 Australians diagnosed with cancer each year, it's never been more important for us to find out more information so that we can improve its prevention, detection and treatment.

The ABC Study will help researchers understand more about cancer by studying the lifestyles and DNA of 50,000 Australians who have not been diagnosed with cancer, and then comparing those who go on to develop cancer with those who don't.

Professor Graham Giles is leading the ABC Study and hopes that collecting the data will lead to the prevention of cancers and improved treatments.

"By collecting information about participants' lifestyles, we'll be able to use the latest genetic technologies to investigate the role that our genes, lifestyle and environment play in the development of disease," he said.

"By more accurately predicting cancer risk based on an individual's genetic profile and lifestyle, we will be able to deliver more customised health advice and better targeted public health messages.

"Importantly, prevention strategies such as screening may be targeted only to those who may benefit from them, sparing a large proportion of the population from unnecessary investigations."

The ABC Study is an epidemiological study that attempts to identify the factors that lead to disease, and factors that prevent disease, so that steps can be taken to prevent it.

Similar epidemiological studies, such as the Cancer Council's Health 2020 study that began in 1990, discovered the link between smoking and the increase in lung cancer and the link between obesity and a higher risk of developing cancers such as breast, colon, kidney and pancreas.

"Studies like this are not only important for the prevention and treatment of cancer, but also for other chronic diseases such as heart disease and diabetes," Professor Giles said.

The ABC Study needs people aged 40 to 74 years that haven't had cancer to complete online questionnaires. To enrich the study with genes related to cancer risk we would like to encourage people to participate who have a family history of cancer.

All participants are asked to provide a saliva sample, and some will also be asked to supply a blood sample.

"The ABC Study is an easy way to make a difference," Rachel said. "The more Australians who take part, the closer we get to knowing more about this devastating disease."

A small amount of your time will help make a difference.

Simply visit **www.abcstudy.com.au** to get started.

Cancer Council | Australian Breakthrough Cancer Study

Rachel and her boys

The National Breast Cancer Foundation shares research with community of volunteer speakers.

The National Breast Cancer Foundation (NBCF) recently brought together its community of speakers, who help NBCF raise much-needed funds by voluntarily sharing their breast cancer experiences, to a motivational conference in Sydney.

The event included a mix of topics such as health, lifestyle and resilience, workshops on speaking tips, and an update on the latest in breast cancer research – all designed to inspire, inform and support them in their roles as speakers for NBCF.

It was also an opportunity for NBCF to give back to the community of supporters who have dedicated their time and stories for many years.

One of the most valued presenters on the day was Associate Professor Jeff Holst from the Centenary Institute who was funded by NBCF for his research into more effective treatments for the hard-to-treat triple negative breast cancer subtype.

A/Prof Holst's project examined the role of protein pumps responsible for bringing essential nutrients into breast cancer cells, and led to the discovery that one of these protein pumps could be a target for a new treatment.

This successful research has now moved on to the next step, which includes designing a treatment that acts like a nozzle on a hose to block the flow of these pumps and starve the cancer cells of an essential micronutrient, called glutamine.

"Unlike normal cells, many cancer cells rely on glutamine instead of glucose for the energy they need to divide and grow. Not only did we find that triple negative breast cancer cells have more glutamine pumps on their surface, but also that blocking these pumps stopped the tumours from growing," said Associate Professor Holst.

NBCF CEO Sarah Hosking also attended the conference and meet with supporters. "It's so important to bring our community together so they can network amongst themselves, keep connected with our goals and stay up-to-date on the life-changing research they are helping to raise funds for," she said.

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 contain 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 1800 221 894 (toll free) or email (heather.thorne@petermac.org) to pass on these updates.

- We will be approaching approximately 380 women over the coming months to ask if they still have the x-ray films or discs associated with their mammograms pre cancer diagnosis for a new mammographic density program that is about to commence. This new study will be integrating and analyzing data on environmental, mammographic breast density, genetic risk factors, pathology, and the clinical outcomes. The pilot study to date indicates that 50% of women still have their films at hand and have been willing to post the films to us for review. If we formally approach you about this study, kConFab will provide details and cover all costs for you to send the films to us in Melbourne for scanning with the return of the films to you as soon we have finished with them.

- Please remember that **fresh tissue specimens of all tissue types, whether normal or cancerous, obtained at surgery** are extremely valuable for our research.

- 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 counselled 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.

UPDATES FROM THE FAMILY CANCER CLINICS:

kConFab currently only has one research nurse who is based in the Family Cancer Clinic in Perth. If you are a kConFab participant who lives in another State or Territory and you need to speak to a kConFab representative, please contact the main kConFab office on 1800 221 894 (toll free) or email heather.thorne@petermac.org

Collaborating Family Cancer Centres

Melbourne

Familial Cancer Centre
Peter MacCallum Cancer Centre
St Andrews Place
East Melbourne, 3002
Contact: Ms Mary-Anne Young
Phone: 03 9656 1199

Royal Melbourne Hospital
Familial Cancer Centre
Parkville, 3050
Contact: Professor Geoffrey Lindeman
Phone: 03 9342 7151

Monash Medical Centre
Clayton, 3168
Contact: Dr Marion Harris
Phone: 03 9594 2009

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

Victorian Regional Family Cancer Clinics:

Albury/Wodonga
Austin Health Family Cancer Clinic
Prof Martin Delatycki
Tel: 03 9496 3027

Ballarat
Austin Health Family Cancer Clinic
Prof Martin Delatycki
Tel: 03 9496 3027

Bendigo
Peter MacCallum Cancer Centre
Family Cancer Clinic
Ms Mary Anne Young
Tel: 03 9656 1199

Geelong
Royal Melbourne Hospital
Family Cancer Clinic
Professor Geoffrey Lindeman
Tel: 03 9342 7151

Mildura
Peter MacCallum Cancer Centre
Family Cancer Clinic
Ms Mary Anne Young
Tel: 03 9656 1199

Moe/Traralgon
Monash Medical Centre
Family Cancer Clinic
Dr Marion Harris
Tel: 9594 2009

Shepparton
Austin Health Family Cancer Clinic
Professor Martin Delatycki
Tel: 03 9496 3027

Warrnambool
Royal Melbourne Hospital
Family Cancer Clinic
Professor Geoffrey Lindeman
Tel: 03 9342 7151

Sydney

Familial Cancer Service
Westmead Hospital
Westmead, 2145
Contact: Professor Judy Kirk
Phone: 02 9845 6947

Prince of Wales Hospital
Hereditary Cancer Clinic
High Street
Randwick, 2031
Contact: Dr Kathy Tucker
Phone: 02 9382 2577

St George Community Hospital
Hereditary Cancer Clinic
Kogarah, 2217
Contact: Dr Kathy Tucker
Phone: 02 9382 2577

St Vincent's Hospital
Family Cancer Clinic
Darlinghurst, 2010
Contact Dr Allan Spigelman
Phone: 02 8382 3395

The John Hunter Hospital
Hunter Valley, NSW
Contact: Dr Allan Spigelman
Phone: 02 4985 3132

Brisbane

Genetic Health Queensland
Royal Women's and Children's Hospital
Bramston Terrace
Herston, 4029
Contact: Rachel Susman
Phone 07 3646 1686

Wesley Medical Centre
Suite 28, Level 2
40 Chasely St
Auchenflower, QLD 4066
Contact: Dr Michael Gattas
Phone: 07 3217 8244
brisbanegenetics.com.au

Canberra

ACT Genetics Service
Level 5, Building 1
The Canberra Hospital
Yamba Drive, Garran 2605
Contact: Dr Linda Warwick
Phone: 02 6244 2133

Adelaide

South Australian Clinical Genetics Services
Women's and Children's Hospital
North Adelaide, 5006
Contact: Dr Nicola Poplawski
Phone: 08 8161 6995

Perth

Genetic Services of Western Australia King Edward Memorial Hospital
374 Bagot Road
Subiaco, 6008
Contact: Professor Jack Goldblatt
or Dr Nicholas Pachter
Phone 08 9340 1525
kConFab research nurse: Anna Nash
Phone: 08 9340 1610

Tasmania

The Royal Hobart Hospital
The Launceston General Hospital
The North West Regional Hospital, Burnie
Contact: Dr Jo Burke
Royal Hobart Hospital
Phone: 03 6222 8296

Auckland – New Zealand

Auckland - New Zealand Genetic Health Service NZ – Northern Hub
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