

Kathleen Cuninghame 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

It has been 18 months since we published our last newsletter. We apologise for the delay in updating you about our recent progress but due to funding shortfalls during this period, we cut back on many day to day expenses that included the printing of our newsletter. It is with pleasure that I am able to announce that we were awarded in June this year a National Breast Cancer Foundation grant to continue our work. Along with funding from the Federal government, this means that our long term future is once again secure to continue work on our original aims: the search to find genes associated with familial breast and ovarian cancer and to find out how lifestyle factors might influence the chance of developing cancer. The new funding also gives us an opportunity to expand and introduce some new projects not only in breast but other hereditary cancers such as prostate and pancreatic cancer.

Whilst our recruitment of new families over the past 18 months slowed a little, we continued to make progress:

- We have now enrolled 1,507 high risk cancer families from all parts of Australia.
- 12,747 people have donated blood samples and 13,092 have completed our lifestyle questionnaires.
- There are 122 approved national and international projects using the biological samples and data we have collected.
- There are 170 high ranking medical and scientific publications that

have used the kConFab resource to generate their research results.

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.

During the past 18 months we have formed successful collaborations with other cancer groups similar to ours. This has provided economies by removing duplication of work efforts, that leads to a better understanding of our common goal of cancer development, how we can prevent it but if it does develop, how to best treat it. We have included stories from two of the external groups we are working closely with, The Australian Familial Pancreatic Cancer Cohort (page 6) and Lifepool (page 4).

I wish to highlight the updates in this newsletter about the new cancer genes that have been found by our national researchers. Families that carry an ATM gene mutation (fault) have recently 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 to be updated about what effect this mutation has in the development of cancer. Some new cancer gene mutations (faults) have been identified and mentioned in the popular media in recent months such as PALB2, FANCC, BLM, HOXB13. Our national network of clinicians in

the Family Cancer Clinics are working together as a new group known as eviQ, to develop guidelines (page 2), that assess the clinical significance of these new genes, that is, do they cause cancer. If there is enough evidence that these genes are involved in cancer development, we will let the relevant families know as soon as possible.

In closing, a new program known as CASCADE, (page 7), has started. The research performed in this program will help explain why cancer becomes resistant to treatments. 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.

We hope that you find this newsletter informative and we welcome your feedback. Once again, thank you for your support.

**Professor Stephen Fox, chairperson
kConFab executive committee**

"our long term future is once again secure to continue work on our original terms"

A new PARP inhibitor study for BRCA1 or BRCA2 associated breast cancer patients.

Recent research has identified a promising new class of drugs, called PARP inhibitors. PARP inhibitors are being evaluated in clinical studies for multiple cancer types including BRCA1 or BRCA2 associated cancer. A DNA repair mechanism is negatively affected in BRCA1 or BRCA2 associated cancer. PARP inhibitors switch off an additional DNA repair pathway. The result is that cancer cells have lost two important DNA repair pathways, making them potentially more vulnerable to chemotherapy. This means that these patients could respond better to chemotherapy if a PARP inhibitor is added to the treatment.

Further work still needs to be done to establish whether PARP inhibitors are effective, and in which subset of patients, to determine whether

they should be approved. The best way to achieve this is through a randomised clinical trial, where a promising new drug can be compared to 'standard of care' chemotherapy.

A new PARP inhibitor called veliparib (ABT-888; under development by Abbott Laboratories) is currently being evaluated in clinical studies in combination with standard chemotherapy in several centres around Australia and overseas. A new study is comparing whether the addition of veliparib to chemotherapy improves the outcomes for patients with BRCA1 or BRCA2 associated breast cancer whose breast cancers have recurred. Patients who are eligible and agree to participate in the study will be randomly assigned to one of three chemotherapy treatment arms (two of these will also include treatment with veliparib).

The study is seeking to recruit patients who are BRCA1 or BRCA1 mutation (fault) carriers whose breast cancer has relapsed and is metastatic (has spread). As for all clinical studies, there are certain 'inclusion' and 'exclusion' criteria and risks. Your oncologist will be able to discuss with you whether you might be eligible for any of this study and to explain risks. For more information contact:

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The eviQ group - helping to understand the significance of a genetic fault.

By Dr Gillian Mitchell, Peter MacCallum Cancer Centre, Melbourne.

With the new technological advances rapidly becoming available to a wide range of researchers, we are finally finding new genes that could help to explain why women in some families are more at risk of breast cancer than in other families. It is now 18 years since the BRCA1 gene was discovered, closely followed by the BRCA2 gene, but there have been few new genetic

discoveries in the intervening years, which is why it is now exciting to think that new genes are starting to be uncovered.

The problem that we now have is how to make the decision whether these new genetic discoveries are ready for use in the clinic – in other words, do we understand enough about these new genes that we can usefully offer genetic testing to families, and for women in those families be able to use that genetic information to make choices about their healthcare? It is also important that there is agreement between medical professionals across Australia about using information about these new genes in the clinic and the nature of the advice we give about the genes, as families are often spread across many Family Cancer Clinics and we don't want to cause confusion within a family if different family members are given different pieces of advice by different clinics.

We have now set up a structure for all the Family Cancer Clinics to come

together and make decisions about using information about these new genes, and the associated cancer risks and risk management advice. This is called eviQ and was the brainchild of Professor Robyn Ward who is a medical oncologist based in Sydney. As well as making decisions about the use of information about new genes, eviQ also has very helpful advice about known cancer genes as well as cancer treatments. While eviQ is mainly for use by doctors and other medical professionals, there are some sections for use by non-medical people, including patients and their families.

Here is the web-link to eviQ and you will be able to access material on it after completing a simple registration process – there is no cost to access eviQ: <https://www.eviq.org.au/>

By using the eviQ structure we hope to be able to bring new genetic tests to the clinic in the near future and bring more clarity to some of the families we help to look after.

The ATM gene mutation (fault) and breast cancer

By Professor Georgia Trench,
 Queensland Institute of Medical
 Research, Brisbane.

About one third of families in kConFab have a gene mutation (fault) in BRCA1 (BRest CAncer gene one) or BRCA2 (BRest CAncer gene two). In addition, very rare alterations in other breast cancer genes, including TP53, PTEN, and ATM occur in a small number of families.

The ATM gene (Ataxia Telangiectasia Mutated gene) instructs the cell to make a protein which helps control the rate at which cells grow and divide, as well as assisting cells in recognising damaged or broken DNA strands. The ATM protein then helps to coordinate DNA repair by activating enzymes that fix the broken strands. People who have two mutated (faulty) ATM genes, one inherited from each parent, develop a rare disease called ataxia-telangiectasia (AT) that affects brain development and the immune system.

Over 20 years ago it was observed that female relatives (who have just one faulty ATM gene) of patients with ataxia-telangiectasia had an increased risk of breast cancer. Details regarding the actual breast cancer risk and the mutations involved remained unknown and controversial until recently when it was shown, by researchers using kConFab material, that people who carry certain types of rare ATM variants have an increased risk of developing breast cancer compared to the general population. The most well known ATM gene fault associated with breast cancer is called 'V2424G'. Women who carry one copy of this ATM gene fault have a 60% chance of developing breast cancer by 80 years. However, V2424G is very rare: despite extensive testing of over 100,000 women this variant has been identified in only 16 families world-wide, including seven families enrolled in kConFab.

kConFab has notified families who carry the V2424G ATM variant to tell them that mutation testing is now available for members of their family. Genetic counsellors working in all of the Family Cancer Clinics will provide a thorough explanation about the role of an ATM mutation (fault) and will provide the best clinical advice for you and your family.

BREAKING NEWS:

NEW CANCER GENES IDENTIFIED: PALB2 MUTATIONS AND BREAST CANCER

By Associate Professor Melissa Southey
 University of Melbourne.

Mutations in the gene PALB2 increase the risk of breast cancer. It was first thought that mutations in this gene only increased the risk of breast cancer moderately. However, we now know that at least some PALB2 mutations increase the risk of breast cancer substantially. Although mutations in PALB2 are very rare (found in about 1.5% of Australasian multiple-case breast cancer families) a large proportion (~75%) of families in Australia that carry a mutation in this gene carry the same mutation (called PALB2 c.3113G>A). This has enabled researchers to conduct rapid and inexpensive genetic testing for this mutation and to more precisely define the risks of developing breast cancer for carriers of this specific mutation. This work has shown that risk of developing breast cancer for carriers of the PALB2 c.3113G>A mutation is comparable to the risk associated with carrying a BRCA2 mutation. Work is underway to make this testing and

information available to Australian women attending Familial Cancer Centres throughout the country.

However, despite recent advances, the majority of breast cancer occurring in families is still not explained by mutations in genes that we already know about. Research programs applying new technology called massively parallel sequencing or "next generation sequencing" are identifying additional genes that when mutated increase the risk of breast cancer. Mutations in these new genes are extremely rare and very large studies are required to understand the associated breast cancer risks. A new international consortium, led by Professors Goldgar (University of Utah) and Southey (University of Melbourne) called COMPLEXO is working to progress this research via international collaboration and data sharing. This is an exciting period for research in the area of familial breast cancer. We look forward to being able to identify the genetic cause for the majority (rather than the minority) of breast cancer occurring in families and to making this information available to all women and their families through clinical genetic services.

HOXB13 gene mutation (fault) contributes to prostate cancer in multi-case breast cancer families and is associated with a good response to curative treatment.

Dr Liam Kavanagh and
 Dr Stephen Q Wong, Peter MacCallum
 Cancer Centre, Melbourne.

Homeobox (Hox) genes play a major role in development, regulation of cell death, receptor signalling, cell differentiation and motility. An association has been reported between the HOXB13 G84E gene mutation (fault) and hereditary breast and prostate cancer. The purpose of this kConFab study was to validate these findings by looking for any

association with familial breast cancer and assessing the clinical outcome of prostate cancer participants who are carriers of the HOXB13 gene mutation (fault). The researchers confirmed:

- An association of the HOXB13 gene mutation with good prognosis prostate cancer in non BRCA1 or BRCA2 breast cancer families.
- No evidence for an increased risk of familial breast cancer within the kConFab female participants.

LIFEPOL: Australian Women Finding Answers

By Lisa Devereux,
Manager, 'The LifePool Project',
NBCF BreastScreen Victoria Cohort
Demonstration Project

The Lifepool project is a new resource which will support research into breast cancer and other women's health issues. It is funded by the National Breast Cancer Foundation and is a collaboration between BreastScreen Victoria, Peter MacCallum Cancer Centre, University of Melbourne, The Royal Melbourne and The Women's Hospital and women in the Victorian community.

Lifepool aims to recruit 100,000 Victorian women into the project by the end of 2014. This will make lifepool one of the largest resources of its kind in the world and create an incredibly powerful resource for research. Research using the resources of lifepool will gather evidence to help better understand the subtle combinations of factors like family history, lifestyle, mammographic density (the white patterns on a mammogram) and environment that contribute to a woman's risk for breast cancer.

BreastScreen Victoria posts information about lifepool to women at the same time as they mail the letter confirming their mammogram appointment. No client details ever leave BreastScreen Victoria and the decision to join lifepool is entirely up to each woman. The information pack includes a Reply Paid envelope for return of documents to the lifepool office. Lifepool welcomes all Victorian women, with or without a diagnosis of breast cancer. Any woman who has had, or intends to have, a mammogram can join the project.

Women who agree to join complete the lifepool questionnaire which gathers information about health & lifestyle. Women give written permission for lifepool to collect mammogram results and also for their health to be followed through linkage to health databases like the Victorian Cancer Registry and Medicare. Importantly, each lifepool member gives permission for the data collected from



and about her to be made available to a wide range of research into breast cancer and other women's health issues.

Each lifepool participant is given a unique code. Using this code, the information can be made available to researchers whilst protecting the woman's privacy. Lifepool is open to application from researchers across the nation and international collaborators. The lifepool Access Committee, overseen by the National Breast Cancer Foundation, reviews each project carefully to ensure the resource supports innovative and cutting edge research and that all appropriate human research ethics approvals are in place.

At present there are just over 25,000 Victorian women participating in lifepool. A sub-group of these women, with and without a diagnosis of breast cancer, have donated blood or saliva for research. We currently have over 1,200 samples of DNA available for research.

The 'bottom line' is: If we can better understand the unique features of breast cancers in combination with detailed health and lifestyle, environment and mammographic density information, we may be able to personalise the preventative screening approach for women according to their individual risk. With the support of Victorian women we are laying the foundations of a powerful resource to support research into breast cancer: a disease that affects too many women and their families in our community and across the world.

For more information please visit: www.lifepool.org
Email lifepool@petermac.org
and speak to Lisa Devereux
Telephone: 1800 198 082

FANCC and BLM cancer genes

By Professor Ian Campbell,
Peter MacCallum Cancer Centre,
Melbourne.

Recent technological advances have opened up revolutionary new ways of finding cancer-causing genes. These new technologies are helping researchers to understand fundamentally important areas of breast cancer research that have the potential to change clinical practice in the near future. A major challenge is to understand why breast cancers can occur very frequently in some families. Through research we now know a lot more about how a BRCA1 or BRCA2 mutation (fault) can cause cancer but scientists believe there are many other genes that remain to be discovered that cause breast cancer in families. Uncovering these can be used to provide family members with better information about how they can reduce their risk of developing breast cancer in the future.

Over the last 3 years Peter MacCallum Cancer Centre scientists, assisted by kConFab, have been screening all 20,000 genes in over 130 women from high-risk breast cancer families. Recently they have identified mutations (faults) in two genes known as FANCC and BLM, which may explain the cancer in some of these families. This work has demonstrated the power of the new technology but has also underscored the fact that there are likely to be dozens of breast cancer genes that remain to be discovered, which is not what most scientists expected. For example, mutations in the two genes known as FANCC and BLM only explain 1 in 100 of the breast cancer families studied to date. Translating this discovery into the clinical area will take several more years as researchers need to validate their findings in much larger numbers of cancer families in order to accurately figure out how to manage the cancer risk in people who carry a fault in one of these genes. Although Peter MacCallum scientists and their international collaborators have much more work to do, they are aided by powerful new tools so we can expect rapid progress in understanding familial breast.

Adolescent Health

By Ms Mary-Anne Young,
 Peter MacCallum Cancer Centre,
 Melbourne.

It is now over fifteen years since Family Cancer Clinics started and our knowledge about the genetic contribution to breast and other cancers continues to grow. As well, we are now seeing an increasing number of young adults making contact with the Family Cancer Clinics seeking information about their risk or wishing to have

genetic testing. Often they are the children of men and women we have seen previously.

Adolescents and young adults (AYA's) who come for genetic counselling are already grappling with the developmental challenges that adolescence presents, and anxiety relating to a potential risk of genetic disease may add to their concerns. In other areas of health care it is well recognised that AYA's have particular needs and health professionals need to consider different ways when working with this group.

There are no specific models of genetic counselling for AYA's, so to address

this problem a reference group was formed to develop a model of genetic counselling sensitive to the needs of adolescents and young adults. This group was comprised of experts in adolescent health and genetic counselling (practice and research). The group has developed a model of genetic counselling to assist genetic health professionals who work with AYA's. The model is inclusive of AYA's and their parents and provides very practical tips e.g. respect young people's developing autonomy throughout the testing process, allowing them to make decisions where possible (when the test will occur, who will be involved), see young people alone for part of each consultation, use cheek swabs rather than needles when possible.

If you have any questions about this article please feel free to contact Mary-Anne Young (03) 9656 1064.



REGISTER4 Fast tracking research

Helping researchers find suitable people for their projects is what the National Breast Cancer Foundation's online community called Register4 aims to do. It's delivering on its promise, and in some cases Register4 is recruiting for projects in less than a day.

Why take part in Register4?

It can sometimes take years for breast cancer researchers to find the right people to participate in their work—Register4 is a way to help fast track this process and make research happen faster.

Participant profile

- People from all walks of life
- You don't have to have had breast cancer
- Aged 18 or over
- It doesn't matter where you live

Register4 gives people the opportunity to take an active role in research. It brings people and researchers together for the joint purpose of finding answers sooner.

When a researcher needs people for a project, they'll get in touch with Register4, who will email Register4 members about potential projects they might like to consider taking part in.

Type of projects

The types of projects on Register4 vary. It could be as simple as filling in a questionnaire to something more involved such as providing a blood sample. Whatever projects you participate in, the choice is yours.

Register4 in action

An example of Register4 in action is a project led by Professor Sharon Kilbreath from the University of Sydney called 'Physical well-being for women with metastatic breast cancer'.

Professor Kilbreath and her team are exploring the relationship between symptoms experienced by women living with advanced breast cancer and their levels of daily physical activity, aerobic fitness and muscle strength.

The first arm of recruitment for this project occurred within just a few hours of Register4 sending out an email invitation to members. The minimum number of women living with advanced breast cancer needed for the study was recruited within twelve hours.

"We're delighted to use Register4 to fast track recruitment for the project. Through Register4 we were able to access a broader

population. It would have taken us about a year to find the people Register4 found in a day. We hope results of the study will assist in the development of guidelines regarding physical activity and exercise for all women living with breast cancer, including those with metastatic disease", said Professor Kilbreath. Results of the research will be fed back to Register4 for the benefit of all.

How to get involved

- Join at register4.org.au and check the current projects to see what may be right for you.
- **A project for everyone** - There's already a project waiting for every member - the Baseline Health and Lifestyle Questionnaire. Information from this project will help researchers look at potential links between breast cancer and factors such as lifestyle and genetics.
- **Spread the word** - Register4 urges current members to tell family, friends, colleagues and neighbors to get involved. No matter who you are, Register4 needs you.

Are you a researcher?

If you're a researcher and would like Register4 to help fast track your research, become a Researcher member of Register4. The National Breast Cancer Foundation initiative aims to free up the time and money researchers spend tracking down the right kind of people, so that more time can be spent on breast cancer research.

Where to find more information

Visit www.register4.org.au to see how you can take an active role in Australian medical research.

Is Pancreatic Cancer Hereditary?

By Skye Simpson, Clinical Research Coordinator, Australian Familial Pancreatic Cancer Cohort (AFPACC) Garvan Institute of Medical Research, Sydney

Cancer of the pancreas is a genetic disease, which means it is caused by changes in your genes and your DNA. These changes can be hereditary (we are born with them) or they can be acquired (they develop after we are born). It is now well known that pancreatic cancer runs in some families and that approximately ten percent of pancreatic cancers may be hereditary. A few genes have already been linked to this familial aggregation, such as the breast cancer gene BRCA2, although the majority of genes are still unknown.

The Australian Familial Pancreatic Cancer Cohort, or AFPACC, is a registry recently established at the Garvan Institute of Medical Research and is the first of its kind in Australia. The registry aims to identify families with one or more members affected by pancreatic cancer, including those who harbour mutations (faults) in genes such as BRCA2. By studying the DNA in families, we hope to identify new inherited gene changes that cause a predisposition to pancreatic cancer, and understand more about those changes already known to us. In addition, AFPACC will help us further understand risks to unaffected family members and identify those eligible for the new pancreatic screening trial at St Vincent's Hospital, Sydney.

It is very easy to become involved with AFPACC. Registration requires the completion of a family history questionnaire and possibly a blood sample for DNA studies. We are

liaising with Familial Cancer Clinics and hospitals to raise awareness; however to reach its full potential, AFPACC relies on willing participants in the community. If your family has had first hand experience with this devastating disease and you wish to join the fight against pancreatic cancer, there are a number of ways you can contact us:

- Fill out an online request via our website www.pancreaticcancer.net.au/afpacc/Request-to-join-AFPACC
- Send an email to screening@pancreaticcancer.net.au
- Phone the AFPACC Clinical Coordinator (02) 9295 8408

For further information contact:
Garvan Institute of Medical Research
Level 9, 384 Victoria St, Darlinghurst
NSW Australia 2010
Ph: +61 2 9295 8408
Fax: +61 2 9295 8375

kConFab Psychosocial update

By Dr Louise Heiniger, School of Psychology, University of Sydney, Sydney.

The main kConFab psychosocial study, investigating whether psychosocial factors like stress, anxiety, depression, social support and personality are risk factors for breast cancer, has now finished collecting data after 11 years! By next year the results should be available for us to let you know what we have found.

However, we can report now on the results of a sub-study which gives us valuable information about the emotional impact of being at increased familial risk of developing breast cancer, and the emotional impact of deciding (or not deciding) to undergo genetic testing. To be eligible for genetic testing, a mutation in a gene such as or BRCA2 needs to be identified in a family member who has been diagnosed with cancer. The majority of women in our kConFab psychosocial study do not have such a mutation identified

in their family and therefore are not eligible for genetic testing. Among the women in our study who DO have a mutation identified in their family, some choose to have testing, others are eligible for testing but decide not to be tested, and some delay making a decision about undergoing genetic testing for a period of time.

Women who undergo genetic testing are routinely offered genetic counselling and emotional support during this process, while many women who do not undergo testing, for a number of reasons, may not have access to the same level of counselling and emotional support. In fact very little information is available about the levels of distress in these women.

Our study compared levels of cancer-related distress in women who were not eligible for genetic testing with women who decided not to be tested and women who delayed testing at first but then decided to have genetic testing in the following three years. We found that the lowest levels of cancer-related distress were in the women who did have a BRCA1 or BRCA2 mutation in their family, and therefore could undergo personal genetic testing, but decided not to be tested. The women who did have a

BRCA1 or BRCA2 mutation identified in their family, but delayed making a decision as to whether they would undergo genetic testing or not, had higher levels of cancer-related distress.

We also interviewed women about how they adapt (or cope) with knowing that they are at increased risk of developing breast cancer. It seems time is important: the longer they know about this risk, the more it just becomes a part of who they are and how they view themselves. We found that women adapt (or cope) in a variety of ways - some women try not to think about being at risk while others cope by finding out all the information they can. Regardless of their approach, the vast majority of women attended regular screening and made healthy lifestyle choices to reduce their risk, and some had undergone prophylactic (preventative) surgery. Knowing they were doing all they could to reduce their risk was the key to adapting to the knowledge of increased familial risk.

Our thanks to all the women who have taken part in the psychosocial study. We greatly appreciate the time and effort you have volunteered to make this research possible. If you have any questions about the study, please feel free to contact us on (02) 9036 5291.

A new kConFab research program: A CAncer tiSSue Collection After Death (CASCADE) programme 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 of the old ones. Unfortunately though, not all patients are cured of their cancer, and it can

spread to other sites in their body. This new kConFab program 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 and in particular, to understand how a cancer has become resistant to treatment. We are seeking permission to obtain and study samples

of tissue from patients shortly after they have died of their cancer. This will provide 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 will be used by research groups with approved kConFab research projects
- Links with clinical specialists, pathologists, allied health professionals and patient support groups are established to facilitate greater understanding of cancer development and progression.

The new 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

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 obtained approval from the Federal department known as the "Information Strategy & Delivery Section Strategic, Department of Human Services", to gain access to the Medicare/PBS data they hold. For kConFab, the ongoing clinical follow up details are important information about our participants' overall cancer profiles and is 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 of information we would normally not obtain as we can't know about, or even try to cover, all hospital sites that our participants might 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.

- Because we send information to you by post and email, it is very important to keep your contact details up to date. Please use the toll free number or email to pass on these updates: **1 800 221 894** or heather.thorne@petermac.org and speak to Heather or ring your local kConFab research nurse. All contact details are on the last page of this newsletter.
- Please remember that **fresh tissue specimens, normal and cancer of all tissue types, 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 informed about a mutation (fault) in the family, additional family members may become eligible for recruitment into the kConFab study.
 - Once a family member, female or 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 whether other family members are eligible for recruitment.

Family Cancer Clinic Updates

The Westmead Hospital Family Cancer Clinic has a new genetic counsellor, Ms Leonie Noon, and the risk management nurse in this clinic is Ms Rosemary Winter.

Collaborating Family Cancer Centres

Melbourne

Familial Cancer Centre Peter MacCallum Cancer Centre

St Andrews Place
East Melbourne, 3002
Contact: Dr Gillian Mitchell
Phone: 03 9656 1199
kConFab research nurse: Dragana Prodanovic
Phone: 03 9656 1903

Royal Melbourne Hospital Familial Cancer Centre

Parkville, 3050
Contact: Assoc Prof Geoffrey Lindeman
Phone: 03 9342 7151
kConFab research nurse: Dragana Prodanovic
Phone: 03 9342 4257

Monash Medical Centre

Clayton, 3168
Contact: Dr Marion Harris
Phone: 03 9594 2009
kConFab research nurse: Dragana Prodanovic
Phone: 03 9656 1903

Austin Health

Heidelberg Repatriation Hospital

Heidelberg West, 3081
Contact: Professor Martin Delatycki
Tel: 03 9496 3027
kConFab research nurse: Dragana Prodanovic
Phone: 03 9656 1903

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

Dr Gillian Mitchell
Tel: 03 9656 1199

Geelong

Royal Melbourne Hospital Family Cancer Clinic

Assoc Prof Geoffrey Lindeman
Tel: 03 9342 7151

Mildura

Peter MacCallum Cancer Centre Family Cancer Clinic

Dr Gillian Mitchell
Tel: 03 9656 1199

Moe/Traralgon

Monash Medical Centre Family Cancer Clinic

Dr Marion Harris
Tel: 9594 2009

Shepparton Austin Health Family Cancer Clinic

Prof Martin Delatycki
Tel: 03 9496 3027

Warrnambool

Royal Melbourne Hospital Family Cancer Clinic

Assoc Prof Geoffrey Lindeman
Tel: 03 9342 7151

Sydney

Familial Cancer Service Westmead Hospital

Westmead, 2145
Contact: Assoc Prof Judy Kirk
Phone: 02 9845 6947
kConFab research nurse: Kate Mahendran
Phone: 02 9845 6845

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 Spiegelman
Phone: 02 8382 3395
kConFab Research Nurse: Anna Nash
Phone: 08 9340 1610 (Perth based)

The John Hunter Hospital

Hunter Valley, NSW
Contact: Dr Allan Spiegelman
Phone: 02 4985 3132

Brisbane

Genetic Health Queensland Royal Women's and Children's Hospital

Bramston Terrace
Herston, 4029
Contact: Drs Michael Gattas
& Rachel Susman
Phone 07 3646 1686
kConFab research nurse: Vicki Fennelly
or Alison Wicht
Phone: 07 3636 5200

Brisbane Genetics Chermide Medical Complex

Suite 12, Level 2
956 Gympie Road
Chermide, 4032
Contact: Dr Michael Gattas
Phone: 07 3861 5200

Adelaide

South Australian Clinical Genetics Services Women's and Children's Hospital

North Adelaide, 5006
Contact: Dr Graeme Suthers
Phone: 08 8161 6995
kConFab research nurse: Belinda Creighton
Phone: 08 8161 6821

Perth

Genetic Services of Western Australia King Edward Memorial Hospital

374 Bagot Road
Subiaco, 6008
Contact: Dr Ian Walpole or Professor
Jack Goldblatt
Phone 08 9340 1525
kConFab research nurse: Anna Nash
Phone: 08 9340 1610

Tasmania

Royal Hobart Hospital Launceston General Hospital North West Regional Hospital, Burnie

Contact: Dr Jo Burke
Royal Hobart Hospital
Phone: 03 6222 8296
kConFab research nurse: Dragana Prodanovic
Phone: 03 9656 1903

Auckland – New Zealand

Northern Regional Genetics Services Auckland Hospital

Auckland, New Zealand
Phone 0800 476 123 ext 7232
Family Cancer Clinic Staff
NZ local call 0800 476 123, international
64 9 307 4949 EXT 5530

Wellington – New Zealand

Central and Southern Regional Genetics Services Wellington Hospital

Wellington South
Contact: Dr Alexa Kidd
Phone 64 4 385 5310
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kConFab Manager

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