kConFab

June 2010

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

This year, kConFab has reached an important milestone. When we started, 12 years ago, one of our goals was to recruit at least 1,300 families with many cases of breast and/or ovarian cancer. We wanted to identify the genes that cause familial cancers and to find out how lifestyle factors might influence the chance of developing a tumour. As you will see from the list below, kConFab has now achieved its initial goal and, as of this month, has enrolled 1,342 families from all parts of Australia. 11,987 people have donated blood samples and 18,303 have completed our questionnaires.

Our Progress So Far...

- Distribution of families by State: VIC 330; NSW 310; QLD 129; SA 233; WA 214; NZ 56; NSW ABCFS 51
- Blood samples collected = 11,987
- Questionnaires completed = 18,303
- Total number of breast and/or ovarian cancers in kConFab cohort = 4,415
- Average number of breast cancers per family = 3
- Average number of ovarian cancers per family = 0.3
- Total number of male breast cancers = 89
- Number of families known to carry BRCA1 or BRCA2 mutation = 483
- Number of "BRCAx" families (no BRCA1 or BRCA2 mutation of clinical significance can be detected) = 870
- Average age of onset of breast cancer in female
  BRCA1 carriers = 44
  BRCA2 carriers = 48
  BRCAX families = 48
- Age of youngest case of breast cancer in a kConFab family = 19
- Age of oldest case of breast cancer in a kConFab family = 96
- Number of other cancers such as prostate, colorectal, pancreatic = 1,931

Because of the generosity and cooperation of our families, kConFab has become of the world's best resources for research into familial aspects of breast cancer, ovarian cancer and prostate cancer. We supply DNA, tumour tissue and lifestyle data to more than 90 research projects within Australia and overseas. As you know, any information that could identify you is removed before kConFab sends out these biological specimens and data. Your communications to us about new family members who become eligible to join kConFab, about new diagnoses of cancer in your family and about impending surgery have enabled us to grow. So, on behalf of the entire kConFab team, I want to thank you most sincerely for your ongoing support.

Our main focus will always be on the inherited mutations that cause breast and ovarian cancers. However, it turns out that some other cancers arise frequently in kConFab families. We have recently made important discoveries about the role of BRCA2 mutations in the development of a highly aggressive form of prostate cancer. Later this year, a group of kConFab clinicians will start work on pancreatic cancers that also seem to occur with a greater than normal frequency in some kConFab families. In all these cancers - breast, ovarian, pancreatic, prostate - we hope to understand how and why these cancers develop. We hope that this work will lead to new cancer treatments - and in the longer run, to drugs that will prevent tumours from arising in the first place.

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

Professor Joe Sambrook
Ph.D., FAA, FRS

Upcoming events:

Familial Cancer 2010: *Research and Practice*

A Combined meeting of kConFab, Australian Breast Cancer Family Study, Australasian Colorectal Cancer Family Study, Australian Ovarian Cancer Study (AOCS), the Family Cancer Clinics of Australia and New Zealand.

Venue:

Mantra on Salt Beach, Kingscliff, Queensland

Dates:

17th – 20th August 2010

Contact:

heather.thorne@petermac.org for further details or view the conference updates on the kConFab home page at http://www.kconfab.org

Research into FAmilial Breast Cancer
Kathleen Cunningham Foundation
CONsortium for research into FAmilial Breast Cancer
kConFabkConFabkConFab

Recent research findings about Mammographic Density and a new study is open for enrolment

By Dr Gillian Mitchell, Peter MacCallum Cancer Centre & Professor John Hopper, The University of Melbourne, Melbourne

Mammographic density refers to the white appearance of breast tissue on a mammogram (breast x-ray), such as those offered to women by BreastScreen. It is one of the strongest risk factors for breast cancer. It can only be measured from a mammogram and not detected by feel or touch.

Women with extensive mammographic density are 2-6 times more likely to develop breast cancer than women of the same age with little or no mammographic density. This also applies to women with a mutation in BRCA1 or BRCA2 – work by Dr Mitchell with colleagues in the UK showed that risk for carriers might be greater or less than average BRCA risks depending on their mammographic density.

It has been proposed that the genetic and environmental factors that determine a woman's mammographic density might also be associated with her risk of breast cancer. Understanding mammographic density should then improve our understanding of the causes of this disease just in the same way that studying blood pressure has led to great insights – and prevention – of cardiovascular disease.

Professor Hopper's team at The University of Melbourne, conducted a large twin study which showed that mammographic density is likely to have a large genetic component. Identical twin pairs have very similar mammographic density patterns. Non-identical twin pairs and sisters, who share on average half their genes, are about half as similar with their mammographic density patterns. It is also known that lifestyle factors, such as having children and taking tamoxifen, also change mammographic density.

Professor Hopper's team have been the first in the world to show that some of the genes involved with small risks of breast cancer are also influencing mammographic density. They did so by studying more than 2,000 twins and sisters.

Dr Mitchell's and Professor Hopper's teams are now widening their study of the genetic factors involved in mammographic density by asking women and families from kConFab who have had mammograms to allow the researchers to borrow them for a short time to measure mammographic density.

Although we know there is a link between mammographic density and breast cancer risk we do not really understand exactly how the density is linked to the risk or even what types of cells make up the different densities.

Dr Mitchell has started a new study which aims to investigate the nature of the breast tissue underlying mammographic density and determine the breast MRI and mammogram features that correlate with mammographic density. This will hopefully be able to tell us more about how breast cancers develop and how we can better understand and use mammograms and MRI scans in women at high risk of developing breast cancer.

What is involved in participating in Dr Mitchell's study?

Women who consent to take part:

- Donate a small amount of breast tissue either at the time of preventative mastectomy or have a "one-off" small breast biopsy (with local anaesthetic!)
- Give permission for the research team to access their routine mammograms and MRI breast scans
- Have a blood sample taken

The study is open in Victoria and Western Australia, so please contact our study coordinator, Jo McKinley on 03 9656 3503 (Joanne.McKinley@petermac.org), if you would like to find our more about the study.

Surveillance of women at high risk or potentially high risk of ovarian cancer.

By Associate Professor Peter Grant, Head, Gynaecological Oncology Unit, Mercy Hospital for Women, Melbourne.

Recent position statements and reports issued by the National Breast & Ovarian Cancer Centre (NBOCC) can be found at http://www.nbocc.org.au/

1. A position statement on screening for ovarian cancer for Australia developed at a consensus meeting with the NBOCC. October 2009
2. The NBOCC position document, December 2009: Surveillance of women at high or potentially high risk of ovarian cancer, outlines:

a) Ovarian cancer surveillance is not recommended for women at high or potentially high risk of ovarian cancer

b) Evidence shows that ultra sound or CA125, singly or in combination, is not effective at detecting early ovarian cancer

c) The most effective risk reducing strategy for ovarian cancer is bilateral salpingo-oophorectomy

In addition, there is no doubt that prophylactic risk reducing surgery must include removal of the fallopian tubes as a significant number of 'ovarian cancers' arise within the tube. The other very important requirement in this surgery is for the pathologist to know the reason for removal of the tubes and ovaries so that the entire specimen can be examined rather than just 1 or 2 sample blocks taken which is the standard practice.

The Friends of kConFab

If you would like to hold a fundraising function for breast cancer research, please contact the kConFab office on **1 800 221 894** or **03 9656 1542** as we will be able to assist you with the organisation of your event and provide copies of the kConFab "Who's at Risk" information brochure that describes our national research work and how our funds are managed by the National Breast Cancer Foundation. **All** funds raised by the **Friends of kConFab** will be used for **research** so we can reach our **long-term goals.**

Breast Cancer Network Australia

(BCNA) is the peak national organisation for Australians personally affected by breast cancer.

Dragons Abreast Melbourne team, known as DAM Busters. In the team are kConFab participants: left to right sister's Heather Drum & Elizabeth Perkins; sisters Gerda Evans & Philippa McLean; Jen Johnston, whose daughter Hayley was also in the boat, picture not shown . Information about dragon boat teams for breast cancer survivors and supporters is available at www.dragonsabreast.com.au

Through its advocacy work and services, BCNA seeks to ensure that women diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible – no matter who they are or where they live.

BCNA supplies free information resources to women affected by breast cancer, including the My Journey Kit - a comprehensive information resource for women newly diagnosed with breast cancer and the Hope & Hurdles Pack for women with secondary breast cancer. Brochures and fact sheets are also available covering a range of topics such as lymphoedema, hair loss and depression.

For more information on BCNA and their programs and services, please visit www.bcna.org.au or call 1800 500 258.

Attendance of men at the Familial Cancer Clinic: What they value from the consultation?

By Associate Professor Liz Lobb, Calvary Health Care Sydney and Cunningham Centre for Palliative Care, Sydney.

This study asked men from high risk breast and/or ovarian cancer families what they valued from attending a Familial Cancer Clinic. 100 men from families with a BRCA1 or BRCA2 mutation completed a self-administered questionnaire.

We found that most men attended the familial cancer clinic at the suggestion of a female family member. 14% men said that their attendance was at the suggestion of their GP or Medical Specialist.

Although men in our study were selective about informing family members that they planned to attend a clinic, the majority of men (87%) reported that they went on to have genetic testing and shared their test result with other family members.

Men's information and decision making preferences:
Most men said they wanted to receive all information relating to their own chance of developing cancer or their family's chance of developing cancer, regardless of whether it was good or bad news (70%). Less than half the men wanted to make a decision about genetic testing together with their doctor (43%), 19% wanted an active role i.e. to make the decision themselves, and 29% wanted the doctor to make the decision.

What men valued from the Familial Cancer Clinic:
Men's age, occupation, the number of biological daughters and the number of family members affected by cancer were unrelated to what men valued from the Familial Cancer Clinic. The vast majority of men valued receiving information about cancer genetics, prevention, surveillance and risk information for themselves and for their children. In addition they also valued receiving emotional support.

As the majority of men reported that they attended at the request of a female family member we recommend that health-related messages within BRCA1 and BRCA2 families may be effectively directed through the female members of these families to reach the at-risk men.

PARP inhibitors for people with BRCA gene alterations

By Dr Gillian Mitchell, Family Cancer Clinic, Peter MacCallum Cancer Centre, Melbourne

A very exciting new development has occurred in the treatment of cancers occurring because of a BRCA gene alteration. This is the discovery of a new type of drug called a "PARP inhibitor". PARP inhibitors are drugs designed to exploit the inherent weakness of cancers occurring because of BRCA gene changes.

Why do cancers occur with BRCA gene changes?

To explain why PARP inhibitors work in this setting it might be helpful to review what happens in cells when cancers form in people who have inherited an altered BRCA gene. The following example is for an altered BRCA1 gene, but the same holds true for BRCA2 genes:

Everyone inherits two copies of a BRCA1 gene (one from each parent)
- One copy is the inherited altered copy (red) that is not functioning
- The other copy is the inherited normal copy (black) that is functioning normally

Normal body tissues
- If even one copy of the gene is functioning normally, this is enough for normal BRCA function in these tissues

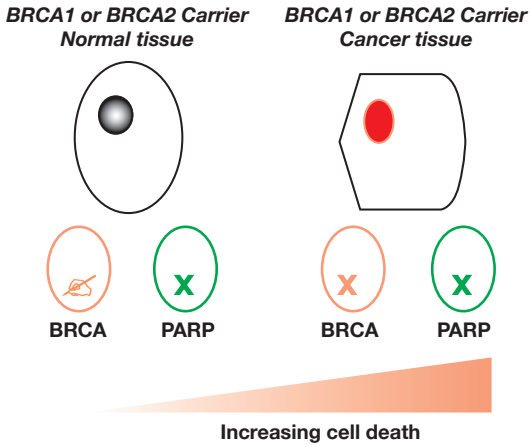
Cancer tissues
- If the remaining normal copy (black) is damaged and can no longer function
- cancer can develop
- (We do not know exactly why this normal gene gets damaged during day to day life)

Our DNA in both normal and cancer tissues is being damaged continuously during our lives and is usually repaired using specialised DNA repair pathways present in all of our cells. The repair pathways using our BRCA genes are the best at repairing DNA, but other pathways include PARP.

Why do PARP inhibitors work in cancers occurring because of BRCA gene alterations?

In cancer tissues, the BRCA pathway is not working so the cancer cells rely more on the PARP pathway for repair. In normal tissues, the PARP pathway is not nearly as important for repair because their BRCA pathway is working well.
If the PARP pathway is stopped by using a "PARP inhibitor", then the normal tissues carry on using the BRCA pathway as usual and see very little effect. However, the cancer cells now have no functioning BRCA or PARP pathway and will die as they cannot repair themselves.

So using a PARP inhibitor in cancers occurring because of a BRCA gene alteration is a very targeted cancer treatment that has nearly all of its effect on the cancer tissues alone and very little effect on the other normal body tissues.



What is the evidence supporting the use of PARP inhibitors?

We are now seeing the results of the first trials of PARP inhibitors in cancers linked to BRCA gene alterations and Australian women have taken part in some of these. The results are very exciting as they have shown that PARP inhibitors do work to shrink BRCA-linked cancers and do so with very few side effects. The linked article and summary gives you more detail about the first trial to be published and the results of other studies will follow this year.

Unfortunately the PARP inhibitors did not work for everyone and some tumours did not respond for as long as we might have liked, but these results certainly mean they are active drugs and we just need to continue to try to find the best way of using them through more clinical trials. PARP inhibitors are not available outside a clinical trial anywhere in the world while these studies are still ongoing.

There are a number of PARP inhibitor studies available in Australia and each trial is slightly different in the types and stage of cancer eligible for recruitment. Your oncologist will be able to discuss with you whether you might be eligible for any of these trials.

Research Update kConFab Psychosocial Study

By Dr Melanie Price, University of Sydney

We are now into year 10 of this study that is looking at whether psychosocial factors such as stress, depression, social support and personality play a role in increasing the risk of developing breast cancer. For this study, participants are contacted once every 3 years and complete a questionnaire (in about 15 minutes) and a telephone interview (about 45 minutes) to tell us more about their recent stressful life events. Over 2,392 women have completed the first interview and questionnaire, 1,745 women have completed the second, and 822 women have completed the third follow-up for this study, 6 years after they started the study. Since data collection for this main component of the Psychosocial Study is ongoing, the results are not available at this stage. However, we have been able to look at a number of questions along the way, which we have described in previous newsletters.

At the moment we are in the process of looking at some of the issues surrounding prophylactic surgery, about the decision itself and the long term effects, both emotionally and physically. Women participating in the Psychosocial Study who have chosen to have prophylactic surgery (i.e. breasts and/or ovaries removed to reduce their risk of cancer) have been invited to participate in this sub-study, completing some additional questionnaires and an additional one off telephone interview about three years after their surgery. The interview part of this sub-study is now completed, with over 40 women participating and we thank them for generously sharing their experiences. We hope to be able to report back on the results of this study next time, in particular about the impact of surgery on body image and sexuality. The questionnaire component of the prophylactic study is ongoing and we are also asking women who have not undergone prophylactic surgery to also answer these extra questionnaires.

Thank you to all women who have taken the time and effort to complete the questionnaire and share with us their life events in the interview. The success of the Psychosocial Study depends on them and we appreciate their generosity.

Please do not hesitate to call our toll free numbers below if you have any questions or concerns about the study so far. Also, please could you update us on any change of address or contact information.

kConFab Psychosocial Study Team
Toll-free call Australia: 1800 772 838
Toll-free call New Zealand: 0800 888 340

Pink Hope

Updates from our Family Members:

Many readers will remember the last kConFab newsletters feature story about Pink Hope, established by Krystal Barter. Pink Hope is specifically for women who are at a high risk of breast and ovarian cancer. The aim of the website is to inform, empower, inspire and support the high risk community.

Pink Hope is under the umbrella of the National Breast Cancer Foundation and is endorsed by National Breast Ovarian Cancer Centre and kConFab. All money raised through Pink Hope goes directly to kConFab and we have already received significant funds to support our research work.

Sign up and stay in touch with Pink Hope at www.pinkhope.org.au. Share your story or inspire other members on the Pink Hope forum.

Here is just one story from the Pink Hope Community ":....."Thanks so much for all your work on Pink Hope - I'm sure you hear this a lot, but I just don't know what I would have done if I hadn't found this site. It changed everything for me. I live in central Victoria and being in the country, not a metro city, made it very hard to find women who were going through the same thing.

My beautiful Mum was diagnosed with Breast Cancer when she was 37 years old. She was breastfeeding my baby sister at the time, and was immediately referred for chemo and radiation. She also had a unilateral mastectomy in the affected breast. Despite fighting like crazy, and going into remission twice, she eventually lost the battle in 1996, at the age of 42. I was 12 at the time, and had also lost my Grandma (my Mum's mum) in the year before, 1995.

Obviously, as I grew up, my understanding of breast cancer was poignantly aware. From a young age I started having mammograms and ultrasounds. When I was 21 I had two lumps removed from my breasts (benign) and it was then that my surgeon referred me to a Familial Cancer Clinic in Melbourne. As I live in Central Victoria, around two hours from Melbourne going down to see the team there required a full day off work. It took a few years, but after lots of searching through family history we determined that my risk of getting breast cancer was in the high risk category. My grandmother had eight sisters, and six of them had had breast cancer. My Mum was an only child.

I had originally intended on having a gene test for the BRCA1 and BRCA2 genes, but it was explained to me that unless I had a living relative who had survived breast cancer they couldn't do a comprehensive test. Unfortunately in my family breast cancer has claimed the lives of all it has touched.

I was given two options by the Familial Cancer Clinic team - I could remain vigilant with my testing every six months, or I could do something a little more drastic and have a preventive mastectomy. I am only 26 years old and I don't have any children so that played a factor in the decision making process.

After I processed all the available information I decided to have a preventive double mastectomy. I decided on the DIEP flap reconstruction. I had a team of twelve surgeons working on me for the operation. My surgery took around 12 hours in total - which was a little longer than planned, but all was completely successful and everyone was extremely happy with the result.

I am now six months in recovery from the operation, and I have never felt better - I am determined to be the first generation in my family not to be diagnosed with breast cancer - so far, so good.

MRI Update for women at high risk of breast cancer

By Professor Christobel Saunders, School of Surgery, QE11 Medical Centre, Perth

Since Feb 1st last year women at high risk of breast cancer are able to access a Medicare rebate for annual breast MRI screening worth $690 for each scan.

There are some caveats to this:

1. Firstly women must be referred from a specialist (not a GP) and can only get the rebate if the test is performed by a recognised eligible radiology practice. We strongly suggest women only get this screen in combination with a whole plan of surveillance by a high risk/genetic clinic or a breast specialist. This plan should include consultation, examination and mammogram as well as MRI.

2. To be high risk a woman has to EITHER have a proven gene fault on testing or fall into the high risk category as defined by the NBOCC (www.nbocc.org.au). This includes women with 3 or more first degree relatives with breast or ovarian cancer, or 2 relatives with one of those having had either bilateral cancers or breast cancer under 40 or ovarian cancer under 50. You may qualify with less affected relatives in special circumstances such as Jewish ancestry.

3. You must be under 50 to qualify for the rebate.

4. You can have had previous breast cancer (obviously with either one or both breasts still present) but you must not have current symptoms of cancer to get the rebate.

5. If the MRI does show an abnormality you can get a rebate for another MRI within 12 months if the radiologist needs to order this either to take a biopsy or to do a 6 month check up.

Book Review

Pieces of Me, Genetically Flawed, Surviving the Breast Cancer I May Never Have

A vibrant performer, film director and mum, when Veronica Neave tested positive for the BRCA2 'breast cancer gene', her result combined with her family's history, increased the probability of Veronica one day battling breast cancer to more than 85%.

Pieces of Me is a beautifully written and thought-provoking account of Veronica's personal journey from initial diagnosis with the BRCA2 'breast cancer' gene to the toughest, and possibly bravest, decision of her life, to remove her perfectly healthy breasts.

In a family ravaged by breast cancer for the last four generations, Veronica and her two sisters, who also carry the BRCA2 gene, hope that by sharing their story, they can provide a little information and personal insight into what is a confusing and confronting, yet potentially lifesaving discovery, and help others in this situation find their own way.

To read more on Pieces of Me visit http://www.bigskypublishing.com.au

Rhiannon says, "I was given your book by Pink Hope. I read it all in one day when I was in hospital. Just wanted to say it was my lifeline this past week as I too follow your footsteps and have had surgery last week."

Pieces of Me was an awesome read. It was like just having a coffee and a laugh.... and a cry... with a friend. And good on you all for what you are doing for Breast Cancer awareness!

Purchase Pieces of me and support breast cancer awareness, support and research.

Special Offer for kConFab members PLUS 10% of all sale proceeds go to KConFab

RRP: $24.99 kConFab price $19.99

Add Pieces of Me to your shopping cart and enter the promotional code "kConFab" to receive the special on-line price of $19.99 (RRP $24.99) and 10% of sales will go to KConFab. Purchase online at www.bigskypublishing.com.au

kConFab Clinical Follow-Up project

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

Thank you once again to all of our follow-up study participants who have returned their questionnaires.

Incredibly it is now 12 years since the first participants were recruited by kConFab hence some of you may receive a 4th round follow-up questionnaire through your mailbox in the near future.

As with all of our questionnaires it is very important that you complete all relevant questions even though it may appear to you that nothing has changed in the last 3 years. All of your information assists our researchers in piecing together the puzzle that is familial breast cancer.

If for any reason you are unable to help us by completing the questionnaire, please feel free to return the opt-out card included or leave a message on our toll free help line. We will contact you again in another 3 years unless you specify that you would prefer no further contact from us. In this way we have kept in touch with 80% of our participants.

Our research is continuing for at least the next 3 years thanks to ongoing funding from Cancer Australia in conjunction with the National Breast Cancer Foundation. We offer a big thank you to everyone who has supported the "pink ribbon" fund raising campaigns over the years for their support of breast cancer research.

We have recently published a paper reporting on women with BRCA1 or BRCA2 mutations who have had prophylactic mastectomies on the opposite side after a diagnosis of breast cancer. This paper showed significantly lower rates of new primary breast cancer development in women who had their healthy breast removed.1

We look forward to receiving your questionnaires. Your information, no matter how insignificant it may seem, is highly valued by the entire kConFab network.

Ms Prue Weideman
Clinical Follow-up Project Coordinator
Toll free ph no:
Australia: 1800 111 581
New Zealand: 0800 230 029

1. Kiely BE, Jenkins MA, McKinley JM, Friedlander ML, Weideman P, Milne R, McLachlan SA, Hopper JL, Phillips KA. Contralateral Risk Reducing Mastectomy in BRCA1/2 Mutation Carriers and other High Risk Women in the Kathleen Cuningham Foundation Consortium For Research Into Familial Breast Cancer (kConFab). Breast Cancer Res Treat. 2010 Apr;120(3):715-23.

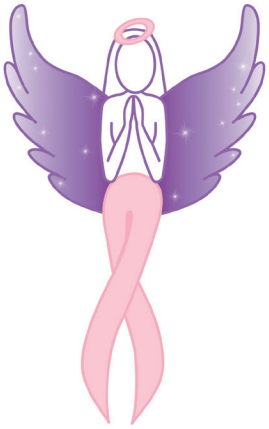
Messages from the kConFab team:

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

- Because we send information to you by mail, it is very important to keep yourcontact details up to date. Please use the toll free number to pass on these updates **1 800 221 894** and speak to Heather or ring your local kConFab research nurse.
- 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 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
  Please call one of our research nurses (see contact list at the end of this newsletter)if you would like to confirm if other family members are eligible for recruitment.



By Sharon Tregoning, Founder & Chairman and kConFab participant

breastANGELS is an Australian not for profit organisation that supports women in their decision making process around breast reconstruction, both post breast cancer and as a preventative measure with/without reconstruction for women at high risk.

We also aim to fund this surgery – hopefully commencing later this year - depending on fundraising and sponsorship efforts.

So that we are able to help as many women as possible, we need to identify the areas of greatest need. To do this we are trying to gather accurate data in relation to information provided around breast reconstruction information and waiting times. We are hearing anecdotally waiting times under the public system of anything up to 10 years. We have been in contact the various health departments and they do not collect/retain/make available the level of data we require.

We are asking for your assistance. We have 2 surveys that we have developed. One is designed for women who have been diagnosed with breast cancer and the other is for women at high risk to develop breast cancer, but have not actually been diagnosed. To access these surveys, please go to our website www.breastANGELS.org and click on the link to the survey page and then select the one appropriate for your situation.

Of course, all information is and will remain confidential.

Should you have any queries, please do not hesitate to contact us on support@breastANGELS.org

Family Cancer Clinic Updates

Changes to Familial Cancer Services in Victoria

Adult Familial Cancer Services in Victoria have been altered as a result of changes to the scope of practice of Genetic Health Services Victoria (GHSV), which is based at the Royal Children's Hospital in Melbourne. GHSV is no longer providing adult Familial Cancer services and their existing patients have been transferred to other Victorian Familial Cancer Services for their ongoing assessment and care. These changes mainly affect people who were attending GHSV-run clinics in regional locations outside Metropolitan Melbourne.

The Family Cancer Clinics affected and their new contacts are listed below:

Geelong
Royal Melbourne Hospital FCC
Assoc Prof Geoffrey Lindeman
Tel: 03 9342 7151

Warrnambool
Royal Melbourne Hospital FCC
Assoc Prof Geoffrey Lindeman
Tel: 03 9342 7151

Mildura
Peter MacCallum Cancer Centre FCC
Dr Gillian Mitchell
Tel: 03 9656 1199

Shepparton
Austin Health FCC
Assoc Prof Martin Delatycki
Tel: 03 9496 3027

Albury/Wodonga
Austin Health FCC
Assoc Prof Martin Delatycki
Tel: 03 9496 3027

Ballarat
Austin Health FCC
Assoc Prof Martin Delatycki
Tel: 03 9496 3027

Moe/Traralgon
Monash Medical Centre FCC
Dr Marion Harris
Tel: 9594 2009

Research into FAmilial Breast Cancer
Kathleen Cuningham Foundation
CONsortium for research into FAmilial Breast Cancer
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Collaborating Family Cancer Centres

Melbourne

Familial Cancer Centre
Peter MacCallum Cancer Institute
St Andrews Place
East Melbourne, 3002
Contact: Dr Gillian Mitchell
Phone: 03 9656 1199
kConFab research nurse: Rebecca Clark
Phone: 03 9656 1903

Royal Melbourne Hospital
Familial Cancer Centre
Parkville, 3050
Contact: Dr Geoffrey Lindeman
Phone: 03 9342 7151
kConFab research nurse: Rebecca Clark
Phone: 03 9342 4257

Monash Medical Centre
Clayton, 3168
Contact: Dr Marion Harris
Phone: 03 9594 2009
kConFab research nurse: Rebecca Clark
Phone: 03 9656 1903

Austin Health
Heidelberg Repatriation Hospital
Heidelberg West, 3081
Contact: Assoc Prof Martin Delatycki
Tel: 03 9496 3027
kConFab research nurse: Rebecca Clark
Phone: 03 9656 1903

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
kConFab research nurse: Belinda Zielony
Phone: 02 9382 2607

St George Community Hospital
Hereditary Cancer Clinic
Kogarah, 2217
Contact: Dr Kathy Tucker
Phone: 02 9382 2577
kConFab research nurse: Belinda Zielony
Phone: 02 9382 2607

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

The John Hunter Hospital
Hunter Valley, NSW
Contact: Dr Allan Spiegleman
Phone: 02 4985 3132
kConFab research nurse: Belinda Zielony
Phone: 02 9382 2607

Brisbane

Queensland Clinical Genetics Service
Royal Children's Hospital
Bramston Terrace
Herston, 4029
Contact: Drs Micheal Gattas & Rachel Susman
Phone 07 3636 1686
kConFab research nurse: Vicki Fennelly or Allison Wicht
Phone : 07 3636 5200

Brisbane Genetics
Chermside Medical Complex
Suite 12, Level 2
956 Gympie Road
Chermside, 4032
Contact: Dr Michael Gattas
Phone: 07 3861 5200

Adelaide

South Australian Clinical Genetics Services
Women's and Children's Hospital
North Adelaide, 5006
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