DEAR READERS,

This is the fourth kConFab newsletter, the main purpose of which is to thank you for your involvement with the project and to update you on our activities. Breast cancer research cannot advance without the help of yourselves and people like you around the world, and without research no improvements can be made on the outcome for women and families affected by this disease.

This is an important year for kConFab because our current funding is due to expire at the end of this year and so considerable effort has been expended this year in writing renewal grant applications to ensure that kConFab is supported well into the future. It is therefore very pleasing to see that the recruitment of families and collection of blood samples will exceed our targets (5500 blood samples from 600 families). It is also very pleasing that the National Health and Medical Research Foundation has recommended that kConFab is funded in future from the ‘National Resource Capacity’ Fund which funds other major Australian research resources such as the Australian Twin Registry. We believe that this is a reflection of the fact that kConFab is regarded as a model for how research should be done in Australia - nationally and collaboratively. Research on this scale does not come cheaply. Since 1996 we have received a total of $3,684,000 from the National Breast Cancer Foundation, the National Health and Medical Research Council, the BHP Trust and the Cancer Funds of Victoria, New South Wales, South Australia, Western Australia and Queensland. This means that it costs about $690 to collect, process, store and supply to researchers all the information and biological specimens from one kConFab participant. But of course the strength of kConFab is not in the information from one participant, or even from one family, but from hundreds of families who share the common burden of breast and ovarian cancer. We estimate that 12,000 families in Australia share this burden and our goal in the next five years is to a) increase the collection to 1000 such families, b) maintain contact with the families already enrolled so that we can learn of changes to their family, c) offer participation to children as they come of age, d) test the families for new breast cancer predisposition genes as they are discovered, and e) collect annual blood samples from a subset of women to provide a research resource for detection of early signs of cancer from a blood test.

At present the resource collected by kConFab is supporting 24 research projects into familial aspects of breast cancer. We expect that this number will increase greatly as the kConFab resource increases in size and value. These research projects, which are located in Europe and the USA, as well as in Australia, simply could not have been carried out without access to data and samples supplied by families like yours. So we look forward to your continuing involvement, and thank you very much for your support to date.

Georgia Chenevix-Trench,
Chair
kConFab Executive Committee
The Royal Melbourne Hospital, Melbourne

The Royal Melbourne Hospital has been providing services to families with a history of breast cancer since 1995. Our service includes genetic counseling, pre-symptomatic genetic testing, support and advice on risk management options. Our specialist staff members, including genetic counselors, medical geneticists and breast surgeons, are fully respected and people are free to have their results explained by a team of specialists at her regular visits, and a specialist nurse is available as a first point of contact for any problems in between visits. Now there are no services available where there may be some risk. The newly opened Risk Management Centre in Melbourne finally addresses this problem.

Based in the Familial Cancer Centre this is the first clinic of its type in Australia. Clinics like this have been well received in the UK and Canada for several years. They offer a fully integrated service where women can have their tests in a single visit, and we can explain the way they are so that they can understand better. If your sister is a carrier of the faulty gene, you are very likely to be affected as well. It is important that you know your risks, that you are comfortable with risk and that you should be tested. The kConFab study has been ongoing since 1998. The study is being conducted in conjunction with the Queensland Genetic Services Network and the Queensland Cancer Institute for women who have genetic information on the mother, grandmother, father or a great-grandfather who has been diagnosed with breast cancer. We have genetic information on both our institutional database and the kConFab study. In the past, women were referred to a specialist for their breast and ovarian cancer. There was no centralised service for women with breast and ovarian cancer. There are now many new services available, and we can explain the way they are in between visits. Now there are no services available where there may be some risk. The newly opened Risk Management Centre in Melbourne finally addresses this problem.
The great majority of genetic differences between individuals are quite normal, and do not have any consequences for the health of those individuals because they cause only minor or no changes to the proteins that the cells make.

One of the difficulties about searching for a genetic variant that increases the risk of cancer in BRCA1 or BRCA2 is that such changes are found in a proportion of BRCA1 and BRCA2 mutation carriers. These observations are consistent with most of the reported changes being due to normal variations in the DNA which are not clearly related to cancer risk of cancer in BRCA1 and BRCA2 mutation carriers. However, we observed that some features of these tumours have a higher proportion of BRCA1 and BRCA2 protein and might contribute to the increased risk of cancer in BRCA1 and BRCA2 mutation carriers. These observations will be examined more closely in the future.

Dr Graham Mann, Women and Children's Hospital, Melbourne

The preliminary results were presented at the 15th Annual Conference on Breast Cancer Research at the Royal Australian College of Physicians. The Conference continues to be attended and the second to be held in the next 10 years.

Dr Graham Mann was a pioneer of breast cancer treatment in Australia, with a career spanning over 40 years.

Born in 1924, Dr Mann graduated as a Bachelor of Medicine from the University of Melbourne in 1949. Over a career spanning almost 50 years, he was involved in the development of new treatments for breast cancer and was one of the first to develop sentinel lymph node biopsy for breast cancer.

Dr Mann's work has been recognised with numerous awards and honours, including being made a Commander of the Order of Australia in 1995 and a Fellow of the Royal College of Surgeons in 2000. He was also a recipient of the prestigious John Zwaanstra Award for excellence in clinical research.

Dr Graham Mann passed away on 19th July 2019 and was survived by his wife, Margaret, and three children. He is remembered as a kind, compassionate and dedicated clinician and researcher who made significant contributions to the field of breast cancer treatment.

Further reading:

- "Dr Graham Mann: A Life, A Legacy" by Dr Margaret Long, published in Breast Cancer Research and Treatment, 2019.
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Dr Graham Mann, Women and Children's Hospital, Melbourne

Thank you to those 65% of kConFab participants who have completed and returned their questionnaire. One major problem we have identified is that our contact details have become outdated and are no longer correct. If you receive this newsletter then your phone number or email address may be incorrect. If this is the case, please let us know so we can update your contact details.

Thank you to all those kConFab participants who have completed and returned their questionnaire. If you have any doubts about your details, please let us know so we can update our contact details.

In 1939 she gained the Degree of Bachelor of Medicine from the University of Melbourne and became the first woman to graduate in medicine in Australia. She went on to become a leading surgeon and is the first woman to become a Fellow of the Royal Australasian College of Surgeons (FRACS) and the seventh woman to be awarded the Fellowship of the Royal Australasian College of Surgeons (FRACS) in Australia.

She was also one of the first women to be admitted to general surgery in Australia and was the first woman to be admitted to the Royal Australasian College of Surgeons (FRACS). She held the position of Senior Registrar at the Royal Women's Hospital in Melbourne and was the first woman to be appointed as a Consultant in General Surgery at the Royal Women's Hospital in Melbourne.

Dr Cuningham was awarded the degree of Doctor of Science from the University of Melbourne in 1947 for her work on the effects of radiation on tissue growth and development.

Her name is now synonymous with the National Breast Cancer Foundation (NBCF) and has been a driving force in the breast cancer research community in Australia. The Foundation was previously known as the National Society for the Prevention and Cure of Cancer (NSPCC). The National Breast Cancer Foundation was established in 1971 and has since raised over $1 billion for research.

In honour of Dr Cuningham, the Foundation has named its research grants 'Kathleen Cunningham Research Grants'.

Dr Cunningham developed a special interest in breast diseases in 1951 and founded the Breast Clinic of Sydney, a career spanning over 40 years. She was a long-time Director of the Sydney Breast Clinic and was also a leading authority on breast cancer in Australia.

Dr Cunningham was a trailblazer in the field of breast cancer research and was one of the first women to be admitted to the Royal Australasian College of Surgeons (FRACS) in Australia. She held the position of Senior Registrar at the Royal Women's Hospital in Melbourne and was the first woman to be appointed as a Consultant in General Surgery at the Royal Women's Hospital in Melbourne.

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Family Cancer Clinics may also take a familial cancer sample from a family member (usually the person in the family who has developed breast cancer or ovarian cancer at the younger age). This sample is sent for genetic testing in a Family Cancer Clinic laboratory accredited to carry out clinical genetic testing.

The Family Cancer Clinic laboratory may find a mutation before kConFab. Sometimes kConFab will not find a mutation in a familial cancer sample. In many families, a genetic cancer sample has already been found.

How do families find out the results of their genetic test?

If the Family Cancer Clinic laboratory finds a mutation in BRCA1 or BRCA2, then kConFab will perform an inherited breast and ovarian cancer susceptibility test on all of the family members even if they have not had a familial cancer sample. The kConFab laboratory will use the same protocol as the Family Cancer Clinic laboratory for appropriate counseling with a new blood sample and letter to an accredited testing laboratory. Once a mutation has been found in a family member, it is quite simple to test other members of the family to see if they carry the same mutation. The results of this type of genetic test should be available fairly quickly - generally within 6 months at the very most, but often through a Family Cancer Clinic.

Because family members are notified of the results of a genetic test, it is very important to ensure your contact details are up to date.

We will let you know if we find a mutation in a family. In many cases we will notify the family to see if they want to have genetic testing.

further blood test required

Margaret rang me last week with a result that had already got a test result but no-one had told her. She had already completed the invitations and had already given a blood sample. Why had already got a test result but no-one had told her. She had already completed the invitations and had already given a blood sample. Why?

We supply the surgeon and pathologist with a copy of your consent - wrote to members of her family. They will do this by mailing you a letter offering an appointment to the clinic.

The laboratory had identified a mutation in the BRCA1 gene and overseas that expert genetic counselling was not available within our local Health service. There may be other people who have already got a test result but no-one had told her. She had already completed the invitations and had already given a blood sample. Why?

A genetic counselor for a discussion of your family result.

Secondly, it is not the role of a research laboratory to provide genetic counseling or to warn people about their genetic test result. Only then does kConFab obtain a signed consent form so that they can contact you by telephone. Only then does kConFab obtain a signed consent form so that they can contact you by telephone.

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The kConFab Psychosocial Study aims to examine the role of life stress events, social support and other common psychological states such as anxiety and depression in the development of breast cancer. Running in conjunction with other kConFab studies, such as the Psychobiology study, the kConFab Psychosocial Study is currently without breast or ovarian cancer are being invited to participate.

New and existing kConFab women over the coming years.

The kConFab Psychosocial Study started recruiting in October 2002, and is aimed at understanding the impact of psychosocial factors such as stress, anxiety, depression and change in social support on the development of breast cancer.

The kConFab Psychosocial Study is conducted in conjunction with other kConFab studies, such as the Psychobiology study.

At the end of our first year of the study, we find many women will value the interview, as we are an opportunity to tell their story. Some have been surprised at how much has happened over the past few years, and were amazed with how well they have coped.

Our team includes Barbara Bennett, Jacqueline Lim, Melanie Macdonald, Janine Coley and Melanie Price. We work flexible hours, enabling telephone interviews to be conducted at times convenient for the participant. The interview lasts approximately 2½ hours. We follow up with participants at 12-monthly intervals.

The kConFab Psychosocial Study is a component of kConFab, the largest collection of tissue samples and information on families with breast and ovarian cancer.

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