November 2002
NEWSLETTER

kConFab

Kathleen Cuningham Foundation
CONsortium for research into FAmilial Breast Cancer
www.kconfab.org phone (03) 9656 1542

Published by kConFab, Peter MacCallum Cancer Institute, St Andrews Place, East Melbourne 3002

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 1995 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 $600 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 Australasia, 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

Below: kConFab executive committee meeting June 2002

IT'S A SMALL WORLD!

By Jane Wylie, the research nurse based in New Zealand

Talking with an older kConFab family member about earlier generations led to a surprising discovery for New Zealand research nurse Jane Wylie (nee Hawken). Their two pioneering families, she learnt, were friends and farming neighbours in Northland New Zealand. As children in the early 1900s the "Watson* girls" would stop off on their way home from school for a hot meal at the Hawken farm before carrying on with the trek home on their ponies.

Later, when earlier generations of Jane's family moved to the city, the "Watson girls" sometimes stayed with them - in the same house where Jane was to be brought up three decades later. There was also an early family association through nursing.

This large family of former dairy farmers, and now including a number of nurses and teachers, was initially thought of by kConFab as "Australian" because that's where the study had first contact. However, as the family tree was traced back, it became clear that this was really very much a Kiwi family, with a small branch-line across the Tasman!

Taken in the 1930s the picture shows grandmother Watson with one of her six daughters on the left (now the great-great-grandmother and great-great-aunt of the family's youngest generation) together with Jane's great-aunt on the right. It also shows that although the fashion for rimless specs might have gone full circle, clearly hats, coats and gloves were much more de rigeur.

* (Watson is no longer a name in this family)

MEN – WHAT USE ARE THEY TO kConFab? – LOTS!

Studying the males in breast cancer families helps us to track the disease through the families. Even though males rarely develop breast cancer, they have a 50/50 chance of carrying the faulty gene if a parent, brother or sister is a carrier of the faulty gene. If they inherit the faulty gene they have a 50/50 chance of passing it on to their daughters.

Males are often left out of the family discussions about genetic testing in breast cancer families and this can be isolating for them. Including the males helps them, their daughters and the study.... a win win situation!

Although the risk of cancer in males carrying a breast cancer gene mutation is lower than that for women with the same fault, these men may be at a somewhat higher risk of developing cancer than for men in the general population. Understanding what that risk is, and for which cancers, is likely to be helpful in planning appropriate screening. Looking at how the genes function in non-breast/ovarian tissue may help us understand their function.

ROD'S STORY

Why it is important for men to be involved in kConFab?

Even though I knew my maternal grandmother had died at an early age from breast cancer, my mother lived a very healthy life, well into her 80's, and no one in my immediate family ever considered that there may be a "fault" in our genes that could lead to breast cancer in our family. It was only when my much loved sister was diagnosed with breast cancer and sought advice from Dr Kathy Tucker at the Hereditary Cancer Clinic, Prince of Wales Hospital, Sydney that our family cancer history was documented.

For me personally, I was alarmed at how much cancer there was in the extended family on my mother's side. Whilst we all knew about each other, there was not a lot of family contact with the 1st and 2nd cousins and, as a result, health problems or cancer history had never been discussed between us. Once learning of our family's breast cancer history, my sister worked hard to promote awareness of breast cancer research. KConFab was one group that my sister was keen to support and she helped the kConFab research team recruit other family members, both females and males into the project.

The main reason I became involved in kConFab is that I have daughters and I realised that it was possible that I may have "passed on" a faulty gene to them. I also have nieces, the daughters of my sister with breast cancer, and it was important to me that my daughters and nieces all be fully informed about their own personal cancer risk and have the contact details of cancer specialists who could give them medical and surveillance advice. Being a male, giving advice to daughters and nieces about breast cancer isn't a role that I am very comfortable with and I certainly didn't want to interfere but it is advice that I feel they should have! Participating in kConFab was one way to link to this expert advice, and also help with new breast cancer research studies.

Unfortunately, my sister has passed away and she is still greatly missed by all of the family due to the wonderful, loving person she was, but her passion for breast cancer research lives on in one of my daughters whose tertiary study and work area is in breast cancer education. I hope my personal story as to why I am involved in kConFab might encourage other males to be involved - it is directly important for your daughters and nieces, and perhaps less directly for breast cancer research.

THE ROYAL MELBOURNE HOSPITAL, MELBOURNE

The Familial Cancer Centre at the Royal Melbourne Hospital has been providing services to families with a history of breast cancer since 1995. Our service includes genetic counselling, risk assessment, genetic testing, support and advice about risk management options. Our specialist staff members, including genetic counsellors, medical geneticists, oncologists and surgeons, are available to all clients. We also provide services for people with a family history of bowel cancer, melanoma, prostate cancer and rare cancer syndromes.

In the past year, our genetic testing laboratory has set up a new form of testing that will pick up more genetic changes than previously. This will give us more information about genetic changes leading to an increased tendency to develop breast cancer.

We are initiating research that will further improve all aspects of our services. Some of our exciting new initiatives include;

- Testing for newly discovered genes that may be involved in causing breast cancer;
- obtaining the information insurance companies request from individuals with a family history of cancer and
- improving access to familial cancer services for eligible women in public hospital clinics.

Of course, we also participate in other important research projects such as kConfab!

Ms Elly Edwards, genetic counsellor, Royal Melbourne Hospital.

QCGS, ROYAL BRISBANE HOSPITAL, BRISBANE

LIVING WITH GENETIC KNOWLEDGE : A STUDY OF PSYCHOSOCIAL WELLBEING OVER TIME

KConFab has kindly agreed to include this notice of a Queensland-based research study which is now underway and being conducted by Dr Sandy Taylor, from the School of Social Work and Social Policy, University of Queensland. The study, being conducted in conjunction with the Queensland Clinical Genetics Service, aims to talk, over time, with individuals who have secured genetic test information such as that relating to inherited breast cancer. The study has full Ethics Committee approval from the Royal Brisbane Hospital and the University of Queensland. Individuals who are 18 years or older, live in Queensland and who have recently received a genetic test result would be invited to contribute an interview (either face-to-face or telephone) soon after receiving their test result, as well as another at two, and finally four, months later. The study is interested in documenting the meanings, and potential impact, of genetic test result information in terms of individuals' wellbeing soon after receiving their result, as well as over several months. Interviews would last approximately one hour. Privacy and confidentiality are fully respected and people are free to withdraw from the study at any stage. If you would be interested in finding out more about this study, please contact me through any of the above channels and I will send out further information to you.

Many thanks and best wishes

(Dr) Sandy Taylor,
Phone: (07) 3365 2801
E-mail: s.taylor@social.uq.edu.au

Please note: This project is different to and separate from, the current kConFab Psychosocial Project, as it is Queensland-only based (for the moment) and is an in-depth interview study of the impact of genetic test information for inherited breast cancer.

PETERMAC, MELBOURNE

NEW INTEGRATED SCREENING SERVICE FOR WOMEN WITH A HIGH RISK OF BREAST AND OVARIAN CANCER.

Women with a high risk of breast and ovarian cancer have often complained that there are no services available where they can obtain all their cancer screening tests at one clinic without running from one specialist to another and various diagnostic laboratories in between. Now the newly opened Risk Management Clinic at the Peter MacCallum Cancer Institute in Melbourne finally addresses this problem.

This new clinic provides an innovative way of managing cancer risk. Women generally attend the clinic every 6 months where they can have their own personalised risk management plan developed in conjunction with a Cancer Genetic Specialist, Breast surgeon and Gynaecologist (specialising in Oncology) who are all at hand. They can then have the cancer health checks that have been recommended for them eg: mammograms, transvaginal ultrasounds, blood tests (eg CA125) and breast examinations all coordinated by the one clinic.

Based in the Familial Cancer Centre this is the first clinic of its type in Australia. Clinics like this have been running successfully in the UK and Canada for several years. They offer a fully integrated service where women can have all their tests in a single visit, can have their results explained by a team of experts and can be updated about advances in the fast-moving fields of familial breast and ovarian cancer. There are also opportunities for women to participate in research if they so wish. Each woman sees the same 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.

Many women enrolled in the kConFab study would be eligible to have services provided at this clinic.

For further information please contact: Mary Shanahan on 03 9656 1199

UPDATE ON CURRENT RESEARCH PROJECTS

WHEN WE FIND A CHANGE IN BRCA1 OR BRCA2, IS IT A CANCER-RELATED GENE MUTATION OR IS IT JUST NORMAL VARIATION?

Dr Georgia Chenevix -Trench, QIMR, Queensland

The great majority of genetic differences between individuals are quite normal, and do not have any consequences to the health of those individuals because they cause only small or no changes to the proteins that the cell makes.

One of the difficulties about searching for mutations (faults that increase the risk of cancer) in BRCA1 and BRCA2 is that often unusual changes are found in the DNA which are not clearly related to increased risk of cancer. This is because they only cause subtle changes in the BRCA1 or BRCA2 protein and might in fact represent normal variation between individuals. Alternatively these subtle changes could have quite substantial effects on how the protein works, and might therefore increase the risk of cancer in the individuals who carry them.

A new kConFab research project that has started this year is aimed at trying to determine whether these 'unclassified' changes are indeed mutations associated with an increased risk of cancer, or just normal variants of BRCA1 or BRCA2. The results of this study could have important consequences for some families who have been told by their Family Cancer Clinic that a "variation" in the BRCA1 or BRCA2 gene has been found in their family, but at that time, it was not possible to tell whether the change was responsible for the increased risk of cancer in their family. These variations will be examined more intensely in the study.

THE PILOT BRCA1 AND BRCA2 PATHOLOGY REVIEW

Dr Gelareh Farshid, Women and Children's Hospital, Adelaide

Four kConFab-associated pathologists are performing a histological review of a set of breast cancers from kConFab participants who are BRCA1 or BRCA2 mutation carriers. Initial results indicate that some features of these tumours may be helpful in predicting the likelihood of presence of a deleterious mutation in BRCA1 in some breast cancers. These observations are consistent with most of the reported experience of other pathologists working on similar projects around the world. The preliminary results were presented at the 5th Australian Conference on Familial Cancer. Judging from the feedback there is a great deal of interest in this issue.

HORMONE RESPONSIVENESS IN THE NORMAL BREAST OF WOMEN WITH BRCA MUTATIONS

Dr Christine Clarke, Westmead Institute for Cancer Research, Westmead Hospital, Sydney

The hormones, oestrogen and progesterone, produced by the female ovary, play a major role in the development of breast cancer. However, we do not know whether women who carry mutations in the breast cancer genes, BRCA1 or BRCA2, have disrupted hormone action in their normal breast tissue. We measured hormone receptors in the normal breast of women with BRCA mutations, who had agreed to donate some of their tissue removed at the time of prophylactic surgery for research, and compared this with normal breast from control women. We found that oestrogen receptor expression was not different in BRCA mutation carriers. However, we observed total loss of progesterone receptor (PR) in a proportion of BRCA1 and BRCA2 mutation carriers, and in the remaining PR positive cases, there was a significant loss of one progesterone receptor form, which may be important in the action of progesterone in tissues. These results may suggest that a mutation in one of the BRCA genes can lead to a disruption in the coordinated hormone activity in the normal breasts of women who have a genetic tendency to developing breast cancer. This disruption may result in changes in the shape or behaviour of cells and may be involved in breast cancer development. We are very grateful to the women participating in the kConFab study for their willingness to donate tissue for our study. KConFab participants are contributing in a very real way to improving our understanding of breast cancer in high-risk women, and this important work could not go forward without their support.

Patricia Mote, Jennifer Leary, Kelly Avery, Kerstin Sandelin, kConFab, Judy Kirk and Christine Clarke. Westmead Institute for Cancer Research, University of Sydney at Westmead Millennium Institute and Familial Cancer Service, Westmead Hospital, Westmead, NSW, Australia and Dept of Surgical Sciences, Karolinska Hospital, Stockholm, Sweden

Above: Dr Graham Mann

THE SEARCH FOR NEW BREAST CANCER RELATED GENES

Dr Graham Mann, Westmead Institute for Cancer Research, Westmead Hospital, Sydney

Work finally starts this month to see what genetic markers follow breast cancer risk in kConFab families with no BRCA1 or BRCA2 mutations. This is called a genome screen and will hopefully point to the location of new genes that cause increased risk of breast cancer. The work should be completed by the end of the year.

WHO WAS DR KATHLEEN CUNINGHAM?

AUSTRALIAN PIONEER IN BREAST CANCER TREATMENT

The National Breast Cancer Foundation was previously known as the Kathleen Cuningham Foundation. The decision to change the name to the National Breast Cancer Foundation was to indicate more clearly its national scope, its position as an organisation involved in raising funds for distribution to leading researchers throughout Australia and its focus on wider issues in breast cancer control.

In honour of Dr Cuningham, the Foundation continues to name its research grants 'Kathleen Cuningham Research Grants'.

Dr Kathleen Cuningham was a pioneer of breast cancer treatment in Australia, with a career spanning over 43 years.

Born on 2nd November, 1898, and educated at PLC Croydon and the University of Sydney, Dr Cuningham graduated as a Bachelor of Medicine in 1921, and in 1927 joined the Rachel Forster Hospital for Women and Children.

In 1939 she gained the Degree of Master of Surgery at the University of Sydney, an unusual accomplishment for a woman of her day, particularly one who carried on a busy general practice as well as honorary hospital duties.

In 1941 she was elected as a Fellow of the Royal Australasian College of Surgeons (FRACS), the seventh woman to be admitted and only the second to be admitted in general surgery.

Dr Cuningham developed a special interest in breast diseases in 1951 and founded the Breast Clinic at Sydney's Rachel Forster Hospital, the first of its kind in Australia. It was at this clinic that another famous medical woman, Dr Marjorie Dalgarno, working in conjunction with Dr Cuningham, introduced breast x-raying, or mammography, which was to become an important part of breast cancer diagnosis.

Dr Cuningham undertook research on the causes of hormonal breast pain and was also one of the first practitioners in Australia to advocate the treatment of advanced breast cancer by surgical removal of the ovaries and adrenal glands.

Dr Cuningham continued at the Rachel Forster Hospital whilst establishing a specialist surgical practice in Macquarie Street, where she remained until her retirement in the 1960s. She died soon afterwards.

Giving her name to the Foundation's research grants is a fitting tribute to a remarkable doctor who was ahead of her time in her approach to breast diseases. KConFab is very honoured to be associated with a remarkable Australian woman.

KCONFAB FOLLOW UP PROJECT

Principal Investigator, Dr Kelly Phillips, Peter MacCallum Cancer Institute, Melbourne

Many of you will have now received a follow-up questionnaire in the mail. Everyone in the study should receive a questionnaire approximately 3 years after their first kConFab interview. Over the last 12 months we have sent out over 2000 questionnaires. The questionnaire updates us on your health in the last 3 years and collects some lifestyle information such as cigarette smoking, exercise and alcohol intake. It also updates your family details, particularly if there have been any family members diagnosed with new cancers in the last 3 years. This information is extremely valuable to kConFab researchers.

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 over the last 3 years. If you have received this newsletter then your details are probably correct but if you know of someone in your family who may have moved recently, please fill in the form on this newsletter so that we can update their details.

There is no deadline for returning the questionnaire but we would be grateful if you could return it to us as soon as possible. If you foresee that you may be returning your questionnaire late due to a holiday, ill health or any other reason then just call us on our toll free help-line and let us know.

If you feel that you are unable to help with this follow-up project, we would be most grateful if you could return the reply paid "opt out card". If we don't receive the card or the questionnaire after a couple of weeks then we will contact you by telephone to make sure that you have received the information.

Our research assistants Prue and Ailsa are based in Melbourne. If you are calling from interstate and leave a message on our answering machine, please keep in mind that we need your STD code as well as your telephone number. Our telephone is manned during normal office hours and 3 nights a week until 7pm (EST) should you have any questions or require any assistance completing your form.

Unfortunately it is too early to report any results from this study. We hope to contact you every 3 years to continue this follow-up process (subject to funding). Thank you once again for assisting us with our research.

Ms Prue Weideman
Clinical Follow-up Project Coordinator

OBTAINING GENETIC TEST RESULTS

kConFab and the Family Cancer Clinics are Different Organizations

kConFab is a National consortium of researchers who are working to understand why breast cancer runs in some families. Some members of these families also attend Family Cancer Clinics, in Australia and New Zealand, where their risk of cancer is assessed. While kConFab and the Family Cancer Clinics work closely together, they are quite separate organizations: kConFab is involved in many research projects concerning genetic susceptibility to breast cancer and ovarian cancer, while the Family Cancer Clinics offer a medical service that includes genetic counselling, genetic testing and clinical advice.

Both kConFab and the Family Cancer Clinics Carry Out Genetic Testing

Families with a very strong history of breast and/or ovarian cancer are invited to contribute to kConFaB's research after their family history has been assessed in a Family Cancer Clinic. A kConFab researcher (usually a nurse) contacts the family to find out information about relatives, both close and distant, including individuals who may not have attended a Family Cancer Clinic. Many of the family members who enroll in kConFab provide a research blood sample. A portion of the blood sample may be used to search for mutations (faults) in genes involved in breast cancer. This process is known as genetic testing. Mutation searching is a slow process, initially involving careful screening of BRCA1 (standing for breast cancer 1 gene) and BRCA2 (breast cancer 2 gene) for mutations (faults) that may cause the increased risk of breast cancer within the family.

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

The Family Cancer Clinic laboratory may find a mutation before kConFab. However, sometimes kConFab is first to find a mutation in a family. In many families, a gene mutation has not yet been found.

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

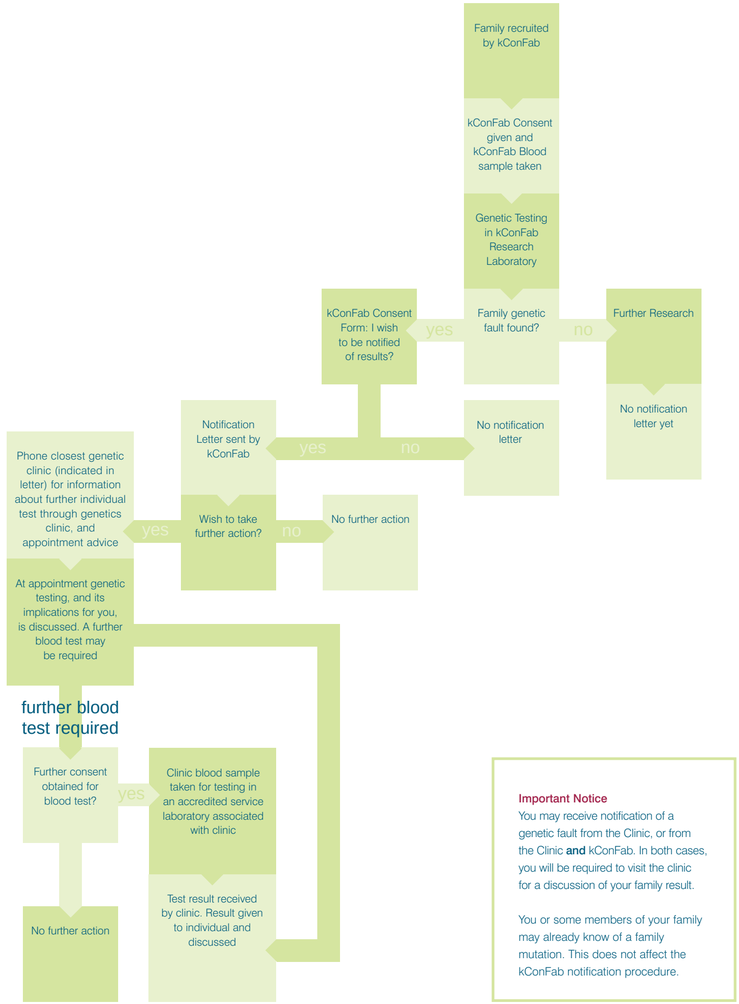
If the Family Cancer Clinic laboratory finds a mutation in BRCA1 or BRCA2, they will report the result directly to their local Family Cancer Clinic. The Family Cancer Clinic, in turn, informs the relevant family member(s), and provides appropriate genetic counselling. Often the family members themselves take on the task of letting others in the family know that genetic information has become available, though the Clinic may assist with this.

If kConFab finds a mutation, a different sequence of events is used to transmit the result. This is because kConFab is a research organization rather than a Family Cancer Clinic and therefore falls under different ethical rules. KConFab's project has been approved by Ethics Committees at many institutions. However, approval was given on condition that genetic information relevant to the family would be provided only through the Family Cancer Clinic system. When a mutation is discovered by kConFab, a letter is sent to all of the family members enrolled in the study, saying that information is now available that may be relevant to their health (or that of their family). KConFab is not allowed to inform individual family members about their own genetic testing results. However, enclosed with the letter is a list of Family Cancer Clinics where each family member may seek further information before considering whether they want to have a clinical genetic test. This is where the family moves out of the research study and back into the Family Cancer Clinic for appropriate counselling with a new clinical blood sample being sent 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 a month or two, but only through a Family Cancer Clinic.

Because family members are notified by mail, it is very important to keep your contact details up to date.

We may even ask you to send us the name of another contact person, in case we are unable to find you. Some family members may have told us that they do not wish to be notified if kConFab finds a mutation. These people will not receive a letter.

Obtaining individual genetic results from kConFab



Important Notice

You may receive notification of a genetic fault from the Clinic, or from the Clinic **and** kConFab. In both cases, you will be required to visit the clinic for a discussion of your family result.

You or some members of your family may already know of a family mutation. This does not affect the kConFab notification procedure.

"Can I tell you about a recent telephone conversation I had?"

Margaret rang me last week with a question, and a mixture of confusion, frustration, and irritation spilled over into our conversation. Margaret had agreed to be part of KConFab because her sister, Julia, their mother, and other relatives had had breast cancer. Margaret had not had cancer herself but was happy to respond to Julia's invitation to join the research project. She had completed the questionnaires and had had a blood sample collected two years ago.

I saw Julia at one of our familial cancer clinics late last year. I had arranged for a sample of Julia's blood to be tested by the genetic laboratory in the hospital. The laboratory had identified an inherited error in the BRCA2 gene in Julia. I had advised Julia and - with her consent - wrote to members of her family to let them know that genetic testing was now available in the family. Margaret had received one of these letters from our clinic.

Margaret was confused because she had already given a blood sample. Why would she need to have another genetic test? She was frustrated because Julia had already got a test result but no-one had told Margaret what her result was. And she was irritated because it seemed that the health services in South Australia weren't talking to KConFab or to each other.

Margaret and I eventually sorted the matter out. There may be other people who have had a similar experience, and the issues we discussed may be of interest to some of you.

The blood sample collected by KConFab is used for research into familial cancer. It cannot be used to provide you with your own test result. There are two reasons for this. First, research laboratories and hospital laboratories operate under different rules. The research laboratories need to be able to do a wide range of tests but run the risk of making an occasional error in some analysis. This will probably not matter in a large research project, but would be very serious if the test result was given to a person. Hospital laboratories do a smaller range of tests, but have very detailed procedures for preventing the occasional error.

Second, it is not the role of a research nurse to provide detailed genetic counselling about the outcome of a genetic test, and they do not undergo the specific training required to do so. There is general agreement in Australia and overseas that expert genetic counselling should be provided before a person has a genetic test.

What kConFab can do is tell you if a mutation in a gene has been identified in the family. They will do this by posting you a mutation notification letter. But KConFab cannot tell you what your result is. In Margaret's case, we have informed KConFab that a mutation has been identified in the family, and KConFab will be writing to all the members of the family to let them know that genetic counselling and testing is available for them through a local familial cancer clinic. But KConFab will not be telling Margaret the result of her blood test.

And the outcome? Margaret was relieved that things weren't as chaotic as they seemed! She accepted that it would be better to have such an important test result done through a hospital lab, and we will be seeing her at one of our clinics later this year.

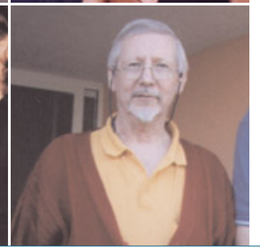
WHAT HAPPENS TO YOUR TISSUE SPECIMEN IF YOU CONSENT TO kConFab HAVING ACCESS TO IT?

We have requested in other newsletters that you contact us if you are having surgery performed, either for the removal of a suspected cancer or for prophylactic reasons as fresh tissue (breast or ovary) is invaluable to many of our research projects. We want to reassure our participants that kConFab will only have access to any 'left-over' tissue. When kConFab participants notify us about planned surgery, the kConFab team always takes the following steps:

- We contact the surgeon and the pathologist involved with your surgery and discuss the possibility of kConFab having any tissue that is left over after the pathologist has examined it.
- We supply the surgeon and pathologist with a copy of your signed kConFab consent form so that they can be confident that you have consented to our project and have given permission for us to access your surgical material.
- We attend theatre on the day of surgery.
- We liaise with the pathologist who takes all of the tissue that is required to make an accurate diagnosis on the tissue removed.
- Only then does kConFab obtain tissue for its research project
- kConFab **does not take any tissue until the Pathologist has taken everything needed for diagnostic purposes**
- On some occasions we do not collect any tissue as there is not enough left over, for example if a biopsy is taken from a small lump.

Far left: Sandra Picken (data manager, Melbourne), Meryl Altree (RN Adelaide), and Prue Weideman (Clinical Follow up co-ordinator)

Left: Prof Joe Sambrook (Peter Mac, Melbourne) and Assoc Prof Judy Kirk (Westmead Hospital, Sydney)



Far left: Dr Christobel Saunders (breast surgeon, Royal Perth Hospital, Perth) and Dr Rosemary Balleine (pathologist, Westmead Hospital, Sydney)

Left: Dr Ted Edkins (Senior Scientist, Princess Margaret Hospital for Children, Perth)

kConFab PSYCHOSOCIAL STUDY

Principal Investigator Dr Phyllis Butow, Royal Prince Alfred Hospital, Sydney

The kConFab Psychosocial Study aims to examine the role of life event stress, 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 Psycho-Immunology study and the Clinical Follow-up study, the Psychosocial study started recruiting in mid 2001 with funding from the National Health and Medical Research Council of Australia. We are based at the Royal North Shore and Prince of Wales Hospitals in Sydney and aim to recruit approximately 2,500 unaffected kConFab women over the coming years.

New and existing kConFab women currently without breast or ovarian cancer are being invited to participate. Detailed information and consent forms are mailed to potential participants outlining what is involved in the study before you need to decide about taking part. Briefly, participation involves completing a questionnaire asking about emotional responses, thoughts and feelings, and social supports. We also request a telephone interview in which we ask about recent situations of stress or change. While often these situations are cancer related family events, we are also hearing about wide and various sources of stress, related to work, other health issues, finances, relationships and other aspects of life.

This research has grown from a common belief that stress and other psychosocial factors may affect the risk of developing cancer, in particular breast cancer. The evidence, however, remains unclear. In particular it is unclear whether psychosocial factors clinically alter cancer risk, or the extent of the risk. In studying psychosocial factors in conjunction with the other components of kConFab, the Psychosocial Study provides a unique and important opportunity for us to understand more about how these factors may influence the risk of developing cancer and how psychosocial risk factors may interact with familial and other risk factors. In addition, this study provides the potential for identifying specific risk factors that may be modified to reduce individual cancer risk.

At the end of our first year of the study, we find many women value the interview as 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, Mariette Maclurcan, Justine Corry and Melanie Price. We work flexible hours, enabling telephone interviews to be conducted days, evenings and weekends, as best suits study participants around family and work commitments. If you have any questions or require assistance with any part of this study, please call us on our toll free numbers at Royal North Shore Hospital on 1800 772 838 or at the Prince of Wales Hospital on 1800 814 403.

Psychosocial Study Coordinator
Ms Melanie Price
Royal North Shore Hospital
1800 772 838
melaniep@med.usyd.edu.au

NEWS AND EVENTS

Familial Cancer 2003 - Research and Practice
3rd September – 6th September 2003
Couran Cove, Queensland (www.couran.com.au)
A combined meeting between the Family Cancer Clinics of Australia and New Zealand, kConFab and the Australian Ovarian Cancer Study.
For details, please contact Heather Thorne on h.thorne@pmci.unimelb.edu.au

COLLABORATING FAMILY CANCER CENTRES

Melbourne
Familial Cancer Centre
Peter MacCallum Cancer Institute
St Andrews Place
East Melbourne, 3002
Contact: Ms Mary-Anne Young
Phone: 03 9656 1199
KConFab research nurse:
Beth Spear
Phone: 03 9656 1903

Royal Melbourne Hospital
Familial Cancer Centre
Parkville, 3050
Contact: Dr Geoffrey Lindeman
Phone: 03 9342 7151
KConFab research nurse:
Marianne Griffin
Phone: 03 9342 4257

Victorian Clinical Genetics Service
The Murdoch Institute
Royal Children's Hospital
Parkville
Contact: Dr Mac Gardner
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INTERNET Cancer news on the net and other related newsgroups

KConFab – www.kconfab.org
The National Cancer Control Initiative – www.ncci.org.au
The National Breast Cancer Centre – www.nbcc.org.au
The National Breast Cancer Foundation – www.nbcf.org.au
Breast Cancer Network Australia – www.bcna.org.au