

kConFab

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 READERS,

kConFab has now been recruiting families with breast cancer for almost 10 years, and in that time we have built up a world-class resource for research. More than 50 research projects around the world depend on kConFab, and more than 30 papers have so far been published in international journals from that research.

The laboratory-based publications are mainly concerned with identification of new breast cancer susceptibility genes, developing ways to understand whether a change found in a breast cancer susceptibility gene is a disease-causing fault, or just a normal, harmless genetic variant, and defining the risk associated with the disease-causing faults (in particular what percentage of women with these faults will develop breast cancer in their lifetime). There has also been a lot of active psychosocial research based around kConFab. This has shown that women from high-risk families cope well with their risk status, reporting no more anxiety and depression than women from the general population. Women who receive a genetic testing result report several advantages (such as reduce uncertainty, making it easier to make decisions about surveillance and

prevention, feeling prepared for any outcome) and some disadvantages (such as increased worry).

Because of the quality of the kConFab resource, it is relatively straightforward for individual researchers to win competitive grants to carry out their research projects using the resource. What is more difficult is to continue to attract funds to maintain and develop the core resource. This is because the funding agencies, while fully recognizing kConFab's value, prefer to spend money on research projects than on long-term support of infrastructure. We have just been awarded a further five years of funding from the National Health and Medical Research Council but the budget (\$693,000 in 2006, declining to only \$300,000 in 2010) indicates their lack of support for long-term research resources.

Because kConFab is a study of families, we anticipate that it will continue until we have satisfactorily resolved all the problems associated with familial breast cancer which, unfortunately, is likely to take much longer than five years. We have therefore initiated a fund-raising arm, Friends of kConFab, to be launched later this year, and which we hope in time will be able to secure a firm financial future for kConFab.

Because of the reduction in our budget from 2008 onwards, it is going to be difficult for us to continue to keep in contact with currently enrolled families, recruit additional families, and start some new initiatives that we think are important to maintain kConFab as a world class resource for research. However, we are seeking new funding mechanisms, as well as initiating Friends of kConFab, and we hope to start several new initiatives in the next twelve months. These may include collection of blood samples at the time of surgery for the removal of cancer (so we can compare them to samples that we collected previously), collection of mammograms, and recruitment of control women with no personal or family history of cancer as a comparative group (we may ask you to invite your friends to participate).

As we have mentioned previously, please phone the toll-free number (1 800 221 894) to notify us of changes in address, or impending surgery, or just to ask questions about kConFab.

Sincerely,
Georgia Chenevix-Trench
Chair, kConFab Executive
Committee

Below: front cover of the Friends of kConFab information brochure

WHO'S AT RISK?



THE EXPERIENCES OF MEN FROM HIGH RISK BREAST CANCER FAMILIES

Principal investigator: Associate Professor Elizabeth Lobb, WA Centre for Cancer & Palliative Care, Perth, Western Australia

This study will help us understand what it means to a man to belong to a high risk breast/ovarian cancer family, and will assist in the development of genetic counselling models that are sensitive to men's needs. Although the risk of cancer in males carrying a breast cancer gene mutation is lower than for women with the same fault, these men may be at higher risk of developing cancer than for men in the general population. 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 sons or daughters.

Between February and May 2005 we conducted thirty two telephone interviews with both carrier and non-carrier men to explore their experiences of genetic counselling, their risk perception, information needs, expectations, awareness of breast cancer genetics, decision-making on genetic testing, coping and support, family communication, and where appropriate, screening intentions. These men had attended one of six familial cancer clinics in Queensland, New South Wales, Victoria and Western Australia.

Contrary to previous studies overseas, the men we interviewed indicated high awareness of their family history of breast and/or ovarian cancer and listed detailed information on affected family members. They reported that they initiated and sustained communication between family members around clinic attendance and receiving testing results. Similar to previous studies, most of the men interviewed attended genetic counselling because of concern for their daughters and other female family members. Many were not aware that they or their sons were at increased risk of cancer. Those that

were aware indicated a "fatalistic" or pragmatic approach to their own risk of developing cancer. When asked where they got their support, many of the men saw themselves as the provider of support, rather than being in need of it. In terms of communication in the family, many of the men interviewed said they talked about the family history when it came up in discussion, but it was not an issue until there was a problem. They reported they coped with their family history and risk by trying not to think about it and drawing support from selective male friends and other family members. Men reported they had few expectations of genetic counselling and most expressed a limited knowledge of breast cancer genetics prior to attending genetic counselling. They expressed "surprise" at the level of emotional support offered when they went for genetic counselling and reported it as being a positive experience.

The information gained from these telephone interviews was used to develop a questionnaire that was mailed to a larger sample of 479 men in December 2005. A reminder letter, along with another copy of the questionnaire, was mailed out in February, 2006. To date 182 men have responded and we thank them for their important contribution to this study.

It is not too late for men to send back their questionnaire for this study

Some men returned the questionnaire noting that genetic testing indicated they were not carrying a breast cancer gene mutation. However, we would like to hear from all men where a breast cancer gene mutation has been found in their family, whether or not they have attended a family cancer clinic for genetic counselling

or genetic testing or had a individual positive, negative or non-informative test result.

For further information please contact:

Associate Professor Liz Lobb on (08) 9273 8728 or the toll free number 1800 993 311 or e.lobb@ecu.edu.au

MOTHER'S DAY CLASSIC

The Mothers Day Classic is a walk/run for breast cancer research. In 2006 it will be held on Sunday 14 May in Melbourne, Sydney, Brisbane, Adelaide and Hobart. The event is organised by Women in Super, a networking group of women in the superannuation industry. All proceeds from the event go to the National Breast Cancer Foundation. (The NBCF has funded kConFab research for almost ten years.) Since inception in 1998 the event has raised over \$1.7 million for breast cancer research. Over 21,000 men, women and children are expected to participate in the Mothers Day Classic this year. Participants can walk or run 4 km or 8km.

Starting locations:

Melbourne: Gosche's Paddock and the Tan. Phone 03 9819 9225

Sydney: The Domain
Phone 02 9439 6060

Brisbane: Southbank Parklands, Cultural Forecourt.
Phone 07 5449 0711

Adelaide: Pinky Flat.
Phone 08 8232 1847

Hobart: Queens Domain and Domain Athletics Centre. Phone 1300 762 241

SURGERY FOR BREAST CANCER IN WOMEN AT HIGH RISK – SOME ISSUES TO CONSIDER

Christobel Saunders, Professor of Surgical Oncology, QEII Medical Centre, Perth

For “high risk” women diagnosed with breast cancer, decisions about if, when and how to have breast surgery are complex - what are the surgical options?

For the breast:

A Wide Local Excision (WLE) or ‘lumpectomy’ means the removal of the breast cancer and a margin of normal tissue. It leaves a small, semicircular scar on the breast which fades with time. Your breast may change in shape or size, depending on how much tissue is removed compared to the size of your breast, and the change in shape and size may become more pronounced with radiotherapy. Hospital stay is usually one to two days. Surgery is followed by a five to seven week course of radiotherapy: five to ten minutes a day, five days a week. The treatments together are known as breast conserving therapy. Recent studies have shown that there is no increased radiation sensitivity (skin damage) or additional risk of causing further cancer from the exposure to radiation in women with a BRCA mutation. This means that for high risk women, this may be an acceptable choice of surgery if they don’t wish to consider a mastectomy.

A mastectomy is the removal of the whole breast, which leaves an angled scar across the now flat chest. This is often the recommended treatment for women who have a large cancer, cancer in more than one area of the breast, a recurrence after breast conserving therapy (you can’t irradiate

an area more than once), or is the woman’s preference. Hospital stays vary from a couple of days to a week, and it can take at least three weeks before returning to normal activities. While your scar is healing you can wear a temporary prosthesis (a soft, fluffy fabric shape) to give you a breast shape. A permanent prosthesis is a silicone mould resembling the size and weight of your breast which fits into a pocket inside your bra.

Some women will still need radiation therapy (to the chest and/or armpit) after a mastectomy.

Axillary surgery

If the cancer is invasive you will need some lymph nodes removed from the ‘axilla’ or armpit to see if the cancer has spread. This leaves a scar in your armpit, and you will usually have a drain (plastic tube) for a few days to remove the blood and lymph fluid. A relatively new technique, ‘sentinel node biopsy’ is where surgeons locate the first lymph node in the armpit that the breast drains to and remove it to check if there are any cancer cells present. If the sentinel node is clear, it is thought that the other nodes will be cancer-free. This technique usually means a smaller scar in the armpit, no need for a drain, and greatly reduces the chance of ‘lymphoedema’, or swelling of the arm.

WHO ARE THE FRIENDS OF kConFab?

In June 2005, we established ‘Friends of kConFab’, a group of business people from financial, accounting, publishing and other commercial enterprises that are willing to work on kConFab’s behalf to raise funds to support our long term aims. We plan to remain in close contact with our families for many more years – at least until 2030. Because the risk of cancer is passed from generation to generation, our work is long-term.

Friends of kConFab plans to raise funds through several different avenues, including:

- Family Foundations
- Bequests
- Pay-roll Deduction Schemes such as Workplace Giving

The National Breast Cancer Foundation will administer all funds raised by Friends of kConFab, for kConFab’s use. Because kConFab is a national research group, national management of funds is appropriate. The National Breast Cancer Foundation fills this role perfectly for kConFab as they have provided funds to kConFab since its initiation in 1997. An information brochure describing our research and how to make a donation can be found on the kConFab home page at www.kconfab.org/Documents/Friends.pdf. If you plan to hold a fundraising function for breast cancer research, please contact the kConFab office on 1 800 221 894 so that copies of the information brochure can be sent to you. All funds raised by the Friends of kConFab will be used for research so we can reach our long term goals

SOME ISSUES TO CONSIDER – CONTINUED

Reconstruction

Women who have a mastectomy for either prevention or treatment of breast cancer can choose immediate, delayed (for months or years), or no breast reconstruction. Breast reconstruction is an operation to rebuild the shape of a breast using an implant (internal prosthesis) or tissue from another part of the body, such as the back (LD flap) or tummy (TRAM flap) muscle. A reconstruction often requires more than one operation – to create a nipple, modify the other breast, or to insert a permanent implant. Women need to consider the cost of the operation in a private hospital, and the length of the waiting lists in public hospitals.

Special Issues for the High Risk Woman diagnosed with Breast Cancer:

If I am at high risk but have never been tested for a mutation can this be done prior to having my surgery for breast cancer?

Obviously it would be best to know if a woman who potentially carries a family gene mutation does indeed do so, or not, when she is diagnosed with breast cancer. Having this knowledge may make a difference to a woman's choice of surgery (see below).

Should I have breast conserving surgery if I can, or should I have a mastectomy?

Women who carry a known or suspected genetic mutation for breast cancer are at higher risk of developing a second, new breast cancer (50-60% for BRCA 1 carriers and about 50% for BRCA 2 carriers). However, no studies to date have shown that those who choose breast conservation compromise their chance of cure, and women may be reassured that other options they have for treatment, such as Tamoxifen and suppressing ovary function, will reduce this risk. It

is known, however, that women who know they carry a mutation are much more likely to opt for mastectomy when diagnosed with cancer.

If I choose or need mastectomy for my treatment, should I have both breasts removed (contralateral prophylactic mastectomy)?

Again, for women choosing to minimize their risk of a second cancer as much as possible this may be a reasonable option. In both cases reconstruction can be considered.

Should I have my ovaries removed at the same time as my breast surgery?

For younger women who carry a family mutation for breast cancer, removal of the ovaries will reduce the risk of developing breast cancer by up to 50% (and obviously reduce the chance of ovarian cancer substantially more). However if you have already been diagnosed with breast cancer, will ovary removal increase your chance of cure? Well it may if your tumour carries oestrogen receptors and you still have your periods. It may also decrease your chance of a second breast cancer, so could well be considered either at the same time or at some point after breast surgery. It can usually be done laparoscopically ("key hole" technique) and recovery is quite quick. It may be safe to consider hormone replacement therapy (HRT) afterwards for up to two years, because research studies show that this does not seem to increase breast cancer recurrence. However there are many other options available to help menopausal symptoms.

Finally, what about follow up?

Certainly it is important that you get regular checkups by your surgeon and/or oncologist with a mammogram every year. If you are under 50 and your breast tissue (if you still have breasts) is very dense it may be possible to also have a regular ultrasound or breast MRI.

BREAST CANCER NETWORK AUSTRALIA

The Field of Women – Live in 2005 at the Melbourne Cricket Ground was simply amazing.

11,500 women and 100 men brought the breast cancer statistics to life in a powerful and stunning visual display.

Visit our website

www.bcna.org.au to see photos and read people's reactions to this event.
1800 500 258

CONTACT BCNA

Address:

BCNA 293 Camberwell Rd
Camberwell Vic 3124 Australia

Telephone: (03) 9805 2500

Free call: 1800 500 258

Facsimile: (03) 9805 2599

Email: beacon@bcna.org.au

MY JOURNEY KIT:

A free resource for women newly diagnosed with breast cancer.

Request line -

1300 785 562



IDENTIFICATION OF MEN WITH A GENETIC PREDISPOSITION TO PROSTATE CANCER AND THEIR CLINICAL TREATMENT: THE IMPACT STUDY

Men who carry alterations in the BRCA2 gene, and possibly men with alterations in the BRCA1 gene, are at increased risk of prostate cancer over their lifetime. The exact level of this risk is uncertain and depends to a degree on the exact position of the alteration in the gene. The risk is in the order of a few times the average population risk and prostate cancer tends to occur at younger ages in men with BRCA2 alterations, with the risk starting to rise in the late 40's early 50's. In order to give a greater understanding about the risks of prostate cancer, its nature in this group and whether we can detect it at an early stage, an international study of targeted screening for prostate cancer in men at increased risk due to the presence of mutations in BRCA1 and BRCA2 has been developed, the IMPACT study.

What is the study?

In brief, the study is looking to see how useful a yearly blood test looking for the marker PSA (prostate specific antigen) is in detecting prostate cancer at an early stage in men with inherited alterations in their BRCA1

or BRCA2 genes. In order to do this, eligible men will be offered a yearly PSA blood test for 5 years and if the PSA level is raised, they will be advised to have a prostate biopsy which will be arranged for them through the study coordinators.

Who will be eligible for the study?

Men between the ages of 40-69 years who carry inherited alterations in their BRCA1 or BRCA2 genes OR who have tested negative for their known family alteration will be eligible for the study. We do know that some men have taken part in kConFab and have decided that they do not want to know their genetic test results when these are available to them. We are currently discussing this issue with various ethics committees to see whether these men are still eligible for the study without them having to find out their genetic status beforehand.

Who will be running the study?

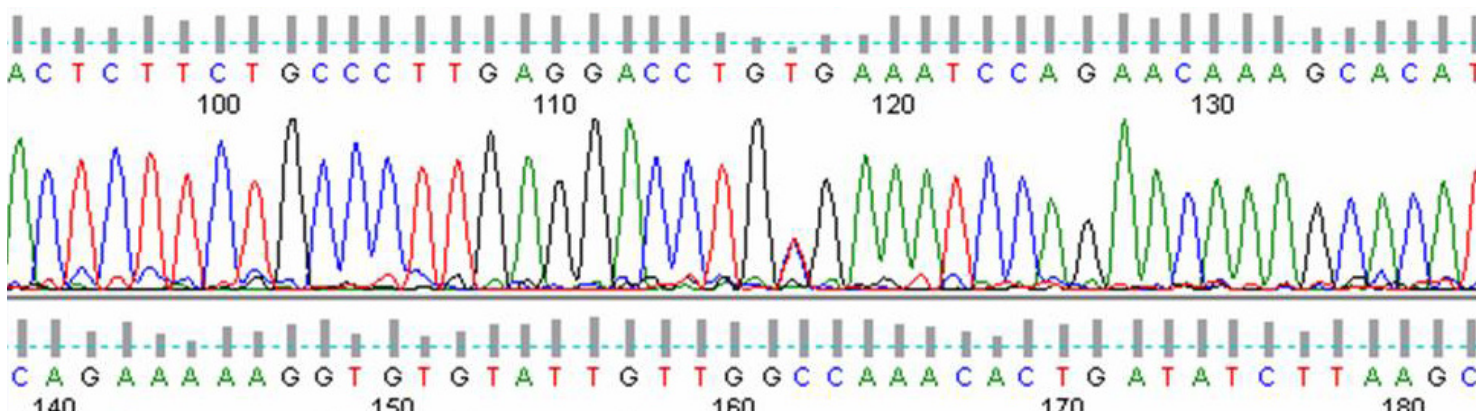
Dr Gillian Mitchell, Assoc Prof Geoffrey Lindeman and Dr Alan Stapleton have been awarded funding through the Cancer Councils of South Australia and Victoria to run the Australian arm of the IMPACT study. We are in the process of appointing

research nurses to help with the running of the project and applying for ethical permission to run the project through centres in Victoria, South Australia, New South Wales, Queensland and Western Australia. When these are in place we will be able to start to recruit eligible men to the study.

What can I do if I am interested in taking part in the study?

We cannot start to recruit to the study until the ethics approvals have been granted, so the purpose of this article is simply to let people know that the study is going to start this year. You do not need to do anything at this current time and can wait to hear from us, but in the meantime you may like to contact kConFab on the toll free number 1800 221 894 or your Familial Cancer Centres to register your interest so that we can contact you when the study starts.

If you think you need any further information about the risk of prostate cancer associated with BRCA1 or BRCA2 alterations, please contact your local Familial Cancer Centre for advice.



RESEARCH UPDATES

kConFab Psychosocial Study

A common belief within the wider community appears to be that stress is a risk factor in developing cancer, in particular breast cancer. From past research, it is still unclear what role stress and other psychosocial factors (such as anxiety, depression, social support and personality) have on the risk of developing breast cancer. The aim of the kConFab Psychosocial Study is therefore to explore how these factors contribute to the risk of developing breast cancer, in addition to other factors such as family history and genetics.

To answer this question we are focusing on women who do not have cancer. Participants involved in our Psychosocial Study are contacted once every 3 years, and asked to complete a questionnaire (usually takes about 15 minutes) and a telephone interview (usually takes about 45 minutes) about stressful (and positive) life events over the past three years. Since mid-2001, approximately 2040 women have taken part in the Psychosocial Study. Our latest news is that 380 women have also completed the first follow-up questionnaire and interview three years after recruitment. In addition, in May this year, we also commenced another part of the study, comparing women who have recently chosen to have prophylactic surgery (i.e. breast and/or ovaries removed to reduce the risk of cancer) with those who have not. In this part of the study we are looking at how women are feeling three years after surgery, in particular their satisfaction with their decision, and the impact on their physical and emotional wellbeing, and whether the surgery has reduced their concerns about being at risk of cancer.

While the results of the Psychosocial Study will not be available for some years to come, we have been able to examine levels of general distress, anxiety and depression in women in the Psychosocial Study. We found that women from kConFab families, who do not have cancer, have similar levels of psychological distress to women without a strong family history of cancer who were visiting their general practitioner (for any reason).

Thank you to all of you who have taken the time and effort to complete the questionnaires and share your personal stories in the life event stress interviews. The success of the Psychosocial Study depends on this contribution and we appreciate your generosity. Please do not hesitate to call our toll free numbers below if you have any questions or concerns about the study.

Melanie Price

kConFab Psychosocial Study Team

Toll-free call Australia:

1800 772 838

Toll-free call New Zealand:

0800 888 340

The role of stem cells in breast cancer – the use of kConFab fresh frozen breast tissue

Victorian Breast Cancer Research Consortium scientists, led by Drs Jane Visvader and Geoff Lindeman at the Walter and Eliza Hall Institute in Melbourne, have discovered rare breast stem cells. These are the 'seeds' from which breast tissue is formed. Drs Visvader and Lindeman, whose work was recently published in the prestigious journal *Nature*, are active members on kConFab sub-committees. Dr Lindeman is also a medical

oncologist and head of the Familial Cancer Centre at The Royal Melbourne Hospital.

This important discovery is likely to provide clues about how breast tissue develops and how a normal process can become derailed in breast cancer. Adult breast stem cells or their 'daughter' cells may be the source of some breast cancers. It is possible that these cells might be more resistant to chemotherapy and could provide one explanation for why tumours sometimes regrow after treatment.

This work has so far been carried out in mice, but Drs Visvader and Lindeman are now also studying human breast tissue and tumours. Their long-term hope is to identify a key difference between normal and cancerous stem cells that could lead to a drug to selectively target cancer cells.

Do stem cells play a role in hereditary breast cancer, such as those arising in BRCA1 or BRCA2 carriers? "This is an important question", said Dr Visvader, "as certain features of BRCA1 tumours have led scientists to speculate that the tumours arise in a distinctive cell, perhaps even the breast stem cell".

Drs Visvader and Lindeman have obtained approval to study de-identified breast tissue donated by kConFab women at the time of surgery for breast cancer or prophylactic mastectomy. Samples for research are taken from breast tissue that is removed as part of standard surgical treatment and would otherwise be destroyed. "We are grateful for the generosity and foresight of anonymous kConFab donors", said Dr Lindeman. "Rather than being simply discarded, the donated tissue represents a crucial resource to fuel our breast cancer research and offers hope to the next generation of kConFab women".

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 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. Please use the toll free number to pass on these updates 1 800 221 894
- Please remember that fresh tissue specimens obtained at surgery are extremely valuable for research. Please ring your local kConFab research nurse to inform them of any surgery planned for treatment or prevention
- 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 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
- Please tell your research nurse if you change your address

How can interested families join kConFab?

Ring any of the research nurses or the kConFab manager listed below, or, view our home page to determine if your family meets our selection criteria:

<http://www.kconfab.org/epidemiology/1eligibility.asp>

Editor's note:

A big thank you to the many kConFab families who have helped us by speaking about their own family's risk of breast cancer, and their involvement in kConFab at the many National Breast Cancer Foundation breakfasts held in every State and Territory over the past few weeks. Although new scientific updates presented by the kConFab team are

an important way of updating the community about our work, a personal story and a human face has so much more meaning! From many families we have heard of the difficult logistics in getting treatment, especially for women who live in the Northern Territory and need to travel to other States for genetic counselling services and treatment, and so need to arrange for extended time away from young children and work. These women indeed have a lot more to battle than just breast or ovarian cancer. Let us hope that, as a group, we can raise the profile of women who live in regional and remote areas to best assist them, and their families, so that they can receive improved, local health care.

NEWS FROM THE FAMILY CANCER CLINICS

The Westmead Hospital Family Cancer Clinic welcomes a new genetic counsellor Georgina Fenton. Karen Robinson, who many of the NSW families will know as she was one of the first kConFab research nurse's, has returned to establish the Westmead Hospital's risk management clinic which has been funded by the NSW Cancer Institute.

The Hereditary Cancer Clinic at Prince of Wales Hospital in Sydney is fortunate to have a new member of staff Janet Tyler who can be reached on 02 93822609 as the Associate Genetic counsellor taking over from Angela Overkov. Angela will be missed but we understand that our loss is Perth's gain.

Illawarra Cancer Care Centre in Wollongong now have a cancer associate genetic counsellor who is responsible for the genetic counselling and organisation of the Telehealth

Service with Dr Kathy Tucker in Sydney. She can be contacted on 02 42225576

We are also proud that Belinda Creighton, the genetic counsellor at St George has now finished her Part 2 training as a genetic counsellor and is now fully qualified.

The Hereditary Cancer Clinic at the POWH is currently participating in the International Gynaecologic Oncology Group Trial 199 comparing preventive removal of the ovary and tubes versus screening in women at high risk for ovarian cancer. There is also a breast MRI trial for women at risk between ages 30-50 which is proceeding. We are, as ever, grateful to women and men such as you who come for a clinic appointment but then agree to participate in research such as kConFab.

UPCOMING EVENT

Familial Cancer 2006: Research and Practice

A Combined meeting of kConFab, Australian Ovarian Cancer Study (AOCS), the Family Cancer Clinics of Australia and New Zealand
Venue: Couran Cove Island Resort, Queensland

Dates:

Tuesday 16th August – 19th Saturday August

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

left to right: kConFab nurses at the 10th kConFab Anniversary – September 05



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: Tina Saegi
Phone: 03 9342 4257

Victorian Clinical Genetics Service
Monash Medical Centre
Clayton
Contact: Dr Marion Harris
Phone: 03 9594 2026
kConFab research nurse:
Beth Spear
Phone: 03 9656 1903

Sydney

Familial Cancer Service
Westmead Hospital
Westmead, 2145
Contact: Assoc. Prof. Judy Kirk
Phone: 02 9845 6947
kConFab research nurse:
Monique Dyson
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:
Helen Conlon
Phone: 02 9382 2607

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

St Vincent's Hospital
Family Cancer Clinic
Darlinghurst, 2010
Contact Dr Robyn Ward
or Ms Rachel Williams
Phone: 02 8382 3395

The John Hunter Hospital
Hunter Valley, NSW
Contact: Dr Tracey Dudding
Phone: 02 4985 3132

kConFab research nurse:
Helen Conlon
Phone: 02 9382 2607

Brisbane

Queensland Clinical Genetics
Service
Royal Children's Hospital
Bramston Terrace
Herston, 4029
Contact: Dr Michael Gattas
Phone 07 3636 1686
kConFab research nurse:
Vicki Fennelly or Allison Wicht
Phone : 07 3636 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:
Meryl Altree
Phone: 08 8161 6821, or,
Susan Schulz 08 8161 6393

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

The Royal Hobart Hospital
The Launceston General Hospital
The North West Regional Hospital,
Bernie
Contact: Dr David Amor
c/o VCGS Royal Children's Hospital
Melbourne, 3002
Phone: 03 8341 6300
or Dr Jo Burke
Royal Hobart Hospital
Phone: 03 6222 8296
kConFab research nurse: Tina Saegi
Phone: 03 9342 4257

Auckland – New Zealand

Northern Regional Genetics
Services
Auckland Hospital
Auckland, New Zealand
Phone 0800 476 123 ext 7232
kConFab research nurse:
Jane Wylie
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
kConFab research nurse:
Jane Wylie
Phone International international 64
9 307 4949 EXT 5530
NZ local call 0800 476 123

kConFab Manager
Heather Thorne
Peter MacCallum Cancer Centre
Research Division
Phone: 03 9656 1542
Email: heather.thorne@petermac.org

USEFUL WWW SITES

kConFab – www.kconfab.org
National Breast Cancer Foundation – www.nbcf.org.au
Breast Cancer Network Australia – www.bcna.org.au