kConFab

2000 Newsletter

Published by kConFab, Peter MacCallum Cancer Institute, St Andrews Place, East Melbourne, Victoria 3002
Tel: (03) 9656 1542 Fax: (03) 9656 1457 Website: http://www.pmci.unimelb.edu.au/kconfab/

Olympic Torch Run

On Wednesday 9th August 2000, **Mrs Gerda Evans**, the community representative on the kConFab Executive Committee, ran 500 metres as an official Olympic torch bearer through the Victorian country town of Maffra, East Gippsland.

Gerda's family and friends from the Breast Cancer Network and kConFab were there to cheer her on.

Gerda earned this honour through her committed voluntary work for the Breast Cancer Network. She lives with her husband and four sons in the eastern suburbs of Melbourne, but has strong family ties to the Maffra region.

Gerda has made a major contribution to the kConFab Executive Committee since joining in 1998. With a background of nursing in oncology, her assessment of what is important and needs to be done for kConFab families, combined with a happy and positive outlook, have been invaluable.

kConFab members have come to value Gerda as a friend, and we were delighted that she has been acknowledged for her contribution to the fight against breast cancer.

Gerda is proud to be a part of kConFab and hopes that her involvement representing families affected by breast cancer will make an important contribution.

Mrs Gerda Evans runs with the Olympic Torch in Maffra, Victoria

Dear Readers

This is our second *kConFab Newsletter* and an opportunity to update all our families, Family Cancer Clinics and treating practitioners about the progress we have made over the past 12 months, and our future plans for the next 2 years.

kConFab is pleased to announce that the NHMRC and NBCF have renewed funding to continue research through to the end of 2002.

Currently, kConFab has 70 members drawn from 34 medical and research institutions in Australian and New Zealand.

The kConFab membership includes geneticists, clinicians, genetic counsellors, surgeons, pathologists, psychologists, molecular biologists, radiation and medical oncologists, statisticians and epidemiologists. They all believe it is best to work together in a coordinated fashion to solve the pressing medical and scientific problems of familial breast cancer.

In addition to basic research projects, kConFab supports behavioural research on finding the best ways to provide support to families who carry, or may carry, a mutation in genes relevant to breast cancer.

Once again I would like to thank all of the families for taking the time to be involved in the kConFab research study. With your involvement we hope to better understand breast cancer and improve the outcome of a disease that has such a major impact on so many Australian and New Zealand families. We and our colleagues in the Family Cancer Clinics are always available to answer any questions or concerns that you may have. *(See back page for contact details.)*

Professor Joseph F. Sambrook
Executive Director, kConFab

What's Inside

Sheryl's Decision

Sheryl Olney, a health professional working in South Australia, shares her story with us.

"As a child my perception of my maternal grandmother was of an elegant lady in a very chic 1930s evening gown. She lived on my mother's dressing table in a sliver frame. I never knew her because she died of breast cancer when she was only 37 years old. I did know her sister, Aunty Flossie (Florence) who was just a little older than my mother and her best friend. She was beautiful, tall, dark and elegant and my favourite aunt. She was always telling us girls how wonderful we were, but she died of breast cancer when she was about forty – a great loss to everyone. Later my mother told me that other great aunts of mine also had breast cancer; some survived but most died when early diagnosis was uncommon.

It was always in the back of my mind that nearly all the women on my mother's side of the family died of breast cancer. It really came home to me when Raylene, Aunty Flossie's daughter, who was only a few years older than me, was diagnosed with breast cancer and later died. A little later her sister was also diagnosed with the same disease.

Yes, I was aware that there was a familial link well before scientists found breast cancer genes, but life goes on, and I delivered the most beautiful daughter in the world. When she was only eighteen months old it was my turn to find a malignant lump in my right breast. With so much to live for, I felt very positive after the mastectomy, but three months later a lump appeared in my left breast. It was not a metastasis, it was a new primary.

After my second mastectomy I felt that as a nurse and sister I should ensure that my sisters were well informed and had themselves checked regularly. About four years ago two of my sisters were diagnosed with breast cancer within the space of one week.

It was then I became aware that genetic counselling was available through my dear friend who was a breast care nurse, as well as someone to whom I could confide my concerns and fears about passing on a genetic risk, if I had it – and it certainly looked as if I did! I was not sure that I wanted counselling. I was not sure that I wanted to know. At that time all I wanted was reassurance in this very unsure world of mine.

I finally decided to accept genetic counselling with Professor Eric Haan at the Department of Medical Genetics, Women's and Children's Hospital, Adelaide.

Although the facts and stats were not necessarily what I wanted to hear, there was solace in knowing them. It was also reassuring to find that my family would have priority for regular breast testing and treatment.

Some months later I decided to be tested for a breast cancer gene defect. It was not an easy decision. Who wants to know that you may have a potential killer genetic fault?

I finally decided that to be forewarned was to be forearmed. If you know your adversary I think you have a much better chance of beating it. There were a lot of anxious moments involved in coming to my decision — psychological, intellectual and emotional aspects of what it would mean for me and my family, and in particular for my daughter.

One of my greatest concerns was that I may have passed a genetic risk on to my daughter. My mother helped me through this by expressing the very same concern to me. I immediately responded by saying, "Why don't you ask me if I would prefer life with the breast cancer gene defect or no life at all?"

I would chose life every time. My mother and all my sisters over the past few years have decided to be tested for the BRCA1 and BRCA2 genes *(see page 4)*, even my two sisters who have not had breast cancer, and that takes courage. But whether they choose to be tested or not, it is their decision.

There is no right or wrong decision.

Some people take longer than others, some may choose not to make a decision at this stage, but whatever, it is their's to make. It is a very difficult time and I feel it must be emphasised that **each individual must do what is right for them.** I believe that family members can help by supporting one another in their decisions, even if they would choose differently themselves.

I would like to take this opportunity to thank Professor Eric Haan and the team at the Familial Cancer Clinic, Women's and Children's Hospital, Adelaide for their valuable support and information.

I would also like to dedicate these few words to my brave and beautiful sister, Yvonne, who as I write, is very close to leaving her body behind in this material world and becoming pure spirit."

Sheryl Olney, South Australia

Professor Eric Haan
Women's and Children's Hospital, Adelaide

each ***individual*** ***must do what is right for them***

kConFab Milestones

Some important developments of kConFab over the past year include:-

- By **August 2000** we had recruited 300 families and over 3,000 individuals. We are confident we will reach our target of 700 families within the next 2 years. Because of the enthusiastic support of the families already enrolled, we have provided biological samples and information from the questionnaires to 12 major Australian and international research groups with ethically-approved, scientifically valid and funded research projects. Some projects that have started in the past year are listed below *(see also page 6).*

- Pilot work has commenced on an expansion of kConFab to include clinical follow-up of the families enrolled. This new study is described on page 4.

- kConFab held a 3-day national meeting in **June 2000**. High profile researchers from USA, UK and Europe joined kConFab members to discuss recent laboratory and statistical results, and new trends in clinical practice for families at a high risk for developing breast or ovarian cancer. This meeting was an opportunity for kConFab members to strengthen national and international collaborations.

The meeting also provided the opportunity for our research nurses to come together to discuss all aspects of their work and future activities.

Below (L-R):Dr Georgia Chenevix-Trench, Qld; Professor Graham Giles, Vic; and Dr Mike Dean, National Institutes of Health, USA, at the National kConFab meeting, June 2000

What happens when a genetic fault is found in a participating family?

Individuals with a strong history of breast cancer enter kConFab after one or more of their family members attend a local Family Cancer Clinic. kConFab nurses may then enrol other family members from around Australia and New Zealand. Most families who participate in kConFab are aware there is a chance that they and some of their relatives may have a genetic fault which predisposes to cancer. In some families a fault has already been identified, while in others it is hoped that participation in the study will help locate a fault, if it exists, and eventually provide useful information for the whole family.

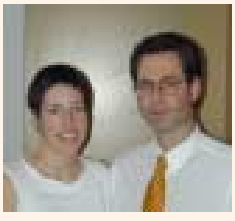
At the time people join the study, some indicate on the consent form that they wish to be informed when genetic testing information becomes available. If kConFab identifies a gene fault in a particular family, then letters are sent to all participants from that family who indicated that they wanted genetic testing information. However, under the present National guidelines, all research results must be verified by another test in an accredited genetic testing laboratory. Only then can we offer genetic testing for other adult family members.

If you receive a letter from kConFab, and if you decide that you want to find out your own genetic test result, you should contact a Family Cancer Clinic for genetic counselling and information. Family Cancer Clinic contact details will be supplied with your letter.

At the Family Cancer Clinic there will be discussion concerning the implications of a positive or negative test result, including possible medical decisions, psychological and social impact and any possible effects on the ability to obtain certain forms of insurance. If you wish to know your result, a fresh blood sample must be drawn and sent to an accredited laboratory for genetic testing. When the results of this test are available, the Family Cancer Clinic will arrange for another appointment to give you your results. This is standard practice for everyone receiving results from predictive genetic tests, whether the tests are negative or positive.

In addition to genetic counselling, the Family Cancer Clinic will answer any questions you may have and will explain particular issues concerning genetic testing that may be relevant to you. This, too, is standard practice.

In this way, we hope to provide choice for family members and to provide accurate information for those kConFab families who have the opportunity to have a genetic test as a result of their participation in the study.



Right: Dr Clara Gaff (left) and Dr Geoff Lindeman (right) both from The Royal Melbourne Hospital

BRCA1 and BRCA2

are genes located on chromosomes 17 and 13 respectively. They were discovered about 5 years ago.

Males, as well as females, have these genes. The normal function of these genes is to protect people from getting cancer.

Women who inherit one abnormal copy of either of these genes are at a substantially increased risk of developing breast or ovarian cancer, and perhaps other cancers. Men who carry an abnormal copy may be at increased risk for some cancers.

Why Do We Want to Study Men ?

Although we know that men who carry a BRCA1 or BRCA2 mutation appear to have a higher risk of prostate cancer, we don't yet know about their risk of other types of cancer. We are also unclear whether or not screening programs and preventive measures are effective and/or advisable.

Research on whether or not men want to know if they are gene carriers for themselves or their daughters, and whether men need support dealing with this information, will help us design better clinical services for men.

One way to search for new breast cancer genes is to track genetic markers through the family *(see page 5)*. Since about half of family members are males, genetic information is potentially doubled if we can trace the markers through men. If parents are deceased, the markers in brothers might allow us to make an educated guess about the markers present in a deceased parent. Therefore, having genetic information on the men can be invaluable for our studies looking for as yet undiscovered breast cancer genes.

These are just a few of the reasons why the participation of the male first degree relatives (brother, father, son) of a woman who has breast or ovarian cancer can greatly improve kConFab studies.

Dr Kathy Tucker, Clinical Geneticist, Prince of Wales Hospital, Sydney

kConFab Clinical Follow-up project

It is now possible to test people with a strong family history of breast or ovarian cancer for the disease-causing abnormalities in BRCA1 and BRCA2. However, the benefits of such genetic testing are currently limited. Only about 30% of such families have an abnormality in one of these genes. Other families with multiple cases of breast or ovarian cancer may have abnormalities in other, as yet undiscovered, genes. Even if an abnormality *is* found we know little about how best to prevent cancer or detect it early. This gap in our knowledge makes decision-making about medical and lifestyle issues difficult and causes substantial frustration, both for individuals in such families and for their doctors. Australian and New Zealand researchers are committed to improving this situation with the help of kConFab families.

We are seeking funding to commence regular (probably between 3 and 5 yearly) follow-up of all individuals, male and female, who have participated in kConFab. For this follow-up we plan to use a short questionnaire based on the questionnaire that participants filled out when they first enrolled in the study.

The follow-up questionnaire will *update* us on what has been happening *since* you first entered the study.

Some examples of things that it will be extremely valuable to know for each individual include:-

- what sort of health checks they are having and how often;
- if they or any of their relatives have had a recent diagnosis of cancer;
- (for women) whether they have had more pregnancies or perhaps have reached menopause; and
- whether they have started or perhaps ceased taking the oral contraceptive pill or hormone replacement therapy.

The questionnaire will be posted to participants, who will be asked to fill it out at their leisure, and return it in a reply paid envelope. A dedicated research assistant will be available via a toll-free telephone number to cover questions about the process or to help those having trouble with answering questions.

We are very excited about this follow-up phase of the kConFab study. By following people forward and getting updated information as described above, we should be able to determine which lifestyle factors influence the risk of cancer in individuals who have a strong family history. Ultimately this should help us to better understand how to prevent cancer, or at least how to detect it early in such individuals. In turn, this should make it easier for people and their doctors to make decisions about lifestyle and medical issues, and help them to live better and longer.

Dr Kelly Phillips, Medical Oncologist, Peter McCallum Cancer Institute; Professor John Hopper, Genetic Epidemiologist, University of Melbourne

So, where is BRCA3?

Identification of the first two breast and ovarian cancer susceptibility genes, *BRCA1* and *BRCA2*, has led to genetic testing in families with strong histories of breast or ovarian cancer. However, in only a proportion of these families has a mutation in one of these genes been identified as the cause. At the recent kConFab meeting we were presented with Australian data which supported the idea that there are other, yet to be identified, genes involved in risk of breast cancer.

Up to now, most work has focussed on identifying genes, like BRCA1 and BRCA2, involved with a dominantly-inherited risk; i.e. inheriting one fault from either the mother or father is sufficient to place an individual at high risk. The new Australian work has suggested that there may also be genes involved with a recessively-inherited risk; i.e. the individual must inherit a fault from both their mother and father to be at increased risk.

So, where is BRCA3 – as the next-to-be-found breast cancer gene is already being called – and what progress is being made to identify other genetic components of breast cancer?

As for the successful hunts for *BRCA1* and *BRCA2*, a large international consortium of researchers – including kConFab – is in full swing. They are using DNA samples from families who have entered breast cancer research programs throughout the world, but whose breast cancer cannot be attributed to mutations in *BRCA1* or *BRCA2*. Genetic analysis (known as linkage) is now underway and is searching for the location of BRCA3. At least one strong possibility has been found from studies of Scandanavian families, and we are now seeing if this finding applies to Australian and New Zealand families.

Studies looking at breast cancer cells (removed during surgery) under the microscope may also provide insight. Specific patterns of cells in breast cancers have already been found to predict those women who have a mutation in *BRCA1* or *BRCA2*. A third group of cancers, all with a similar cellular pattern, has now been seen in women with a strong family history of breast cancer but who do not have a BRCA1 or BRCA2 mutation. This group of cancers may have the same underlying genetic fault – but in another gene. Perhaps this work can provide a clue to finding BRCA3, and perhaps BRCA4, BRCA5 and other new genes.

Microarray or "Chip" analysis may also be able to provide valuable assistance in the search for BRCA3. This technology is capable of measuring the activity of all genes in specific tissues. Using this tool, genes have been identified whose activity is different in breast cancer tissue compared to normal breast tissue. These genes could also help lead us to *BRCA3*.

The successful end to the *BRCA3* hunt may lie with the careful combination of many different approaches. kConFab's collaborations with local and international efforts provide important additional power to help find other breast cancer genes.

Dr Melissa Southey, Senior Scientist, Peter MacCallum Cancer Institute

Below: Dr Kelly Phillips, Peter MacCallum Cancer Institute, Melbourne

Below: Dr Kathy Tucker (left), Prince of Wales Hospital, Sydney; Professor John Hopper (right), University of Melbourne

Below: Dr Melissa Southey Peter MacCallum Cancer Institute, Melbourne

Summary of new research projects

kConFab supplies researchers within Australia with biological samples and the life style questionnaires that you have filled in with the kConFab nurse. Below are some of the new research projects that use data and biological material collected by kConFab. All these projects have received ethical approval and funding in the past 12 months:

- **Analysis of families that do not appear to have a BRCA1 or BRCA2 mutation (fault). Researchers are looking for novel genes that may lead to the development of breast cancer. They are scanning all the chromosomes to find genetic markers that are linked to breast cancer** *(see page 5)*.

- **Analysis of families that do not appear to have a BRCA1 or BRCA2 mutation for faults in particular genes involved in repairing DNA damage, to see if they are responsible for the cancer in those families.**

- **Comparison of ovarian cancers arising in women carrying a mutation in BRCA1 or BRCA2 with ovarian cancers in the general population. It may be that ovarian cancers arising in mutation carriers may develop differently due to a combination of genetic and environmental influences.**

- **Analysis of families that carry a BRCA1 or BRCA2 mutation to estimate the risk of developing breast cancer by different ages in family members with a mutation (fault). This would allow genetic counsellors to advise women in kConFab families about the likelihood that they or their daughters might develop the disease should a mutation be found in their family.**

Breast Self ***Examination***

The earlier a breast cancer is diagnosed, the greater the likelihood that it is small and will not have spread beyond the breast, and the greater the chance of successful treatment. Women found to have a small breast cancer usually have the option of breast conserving treatment.

Mammographic screening is the most effective method of detecting small breast cancers among women aged 50-69.

Breast self examination, (regular, structured and systematic physical examination by women of their own breasts), is another possibility. The effectiveness, however, is not clear.

The **National Breast Cancer Centre** commissioned a review of the research about the effectiveness of breast self examination as a screening test for breast cancer.

On the one hand, it seems clear that finding breast cancer early has the potential to improve survival and treatment choice. It also appears that small cancers which have not yet spread from the breast could be found by a woman or her doctor. On the other hand, the results to date of the trials of breast self-examination do not appear to show that the technique means that women who find a breast cancer by using this technique will actually live longer.

The review concluded that:-

- Since women can potentially detect cancers that are still confined to the breast, at the least, women should be advised to be aware of any changes in their breasts and to have these promptly investigated.

- The evidence for the effectiveness of breast self examination is not sufficiently strong to justify continued public health campaigns to encourage its use.

- Public health initiatives would be better directed at encouraging participation in the national free mammographic screening for eligible women (BreastScreen) where the evidence of benefit is stronger.

It may be appropriate for women with a family history of breast or ovarian cancer to have regular mammographic screening starting from an earlier age than other women.

The Federal Minister for Health, Dr Michael Wooldridge, recently launched the National Breast Cancer Centre's new guidelines, "Advice about Famililial Aspects of Breast Cancer and Ovarian Cancer". These have been distributed to GPs and Family Cancer Centres throughout Australia.

For more information contact:-

National Breast Cancer Centre
PO Box 572,
Kings Cross NSW 1340,
or 153 Dowling Street,
Wooloomooloo, NSW, 2011
Tel: (02) 9334 1700
Fax: (02) 9326 9329
Email: directorate@nbcc.org.au

Dr Sally Redman and Dr Helen Zorbas, National Breast Cancer Centre, Sydney

Recently Published Literature

Booklet

"Information for Women Considering Preventive Mastectomy Because of a Strong Family History of Breast Cancer"

Video

"Genetics: Is Breast Cancer Inherited?"

The booklet and video were developed by the Hereditary Cancer Clinic, Prince of Wales Hospital, Sydney and the NSW Genetic Education Programme, Royal North Shore Hospital, May 2000.

Copies are available from:-

NSW Genetics Education Programme,
Tel: (02) 9926 7324, or

National Breast Cancer Centre,
Tel: (02) 9334 1700

Internet Sites

Cancer news on the net and other related newsgroups:

National Breast Cancer Centre
http://www.nbcc.org.au

Best Advice on Breast Cancer
http://hna.dhs.vic.gov.au/phb/hdev/genetics/append4.htm

Roswell Park Cancer Institute
http://rpci.med.buffalo.edu/departments/gynonc/grwp.html

University of Pennsylvania Cancer Centre
http://www.oncolink.upenn.edu:8083/

News from the Family Cancer Clinics

Victoria

The Victorian State Government has recently allocated dedicated funding ($1.5 million) to establish the Victorian Family Cancer Genetic Services. Five centres will share the funding:-

- Peter MacCallum Cancer Institute
- Royal Melbourne Hospital
- Monash Medical Centre
- Victorian Clinical Genetics Service
- Anti-Cancer Council of Victoria

These Family Cancer Genetics Centres offer genetic counselling, genetic testing, medical advice and psychological support to people concerned about their risk of developing cancer due to their family's cancer history. Individuals can be referred by General Practitioners or medical specialists.

The Peter MacCallum Family Cancer Centre now has extended working hours every Monday evening until 7pm. *(Contact details on back page)*

Dr Sue Anne McLachlan, Medical Oncologist
Ms Mary Anne Young, Genetic Counsellor.

New South Wales

Dr Sue Shanley has recently joined the Family Cancer Clinic at Westmead Hospital and also runs a clinic at the Nepean Hospital, Kingswood NSW either Tuesday morning or Tuesday afternoon weekly.

Ring the Family Cancer Clinic at Westmead Hospital for more details or to make an appointment.

Dr Judy Kirk, Westmead Hospital, Sydney

New Zealand

The Northern Region Genetics Service (NRGS), based in Auckland, offers risk assessment for breast, ovarian and colorectal cancers.

The referral numbers are increasing as the demand grows. The NRGS has been running for 5 years now, with the addition of a cancer division approximately 4 years ago.

These clinics are linked with kConFab and the Australian Colorectal Cancer Family Study. The familial breast cancer section is co-ordinated by Bronwyn Culling and the clinical geneticist is Dr Ingrid Winship. Referrals can be made through the clinics, doctors or by self-referral. *(Contact details are listed on back page)*

Dr Ingrid Winship, NRGS, Auckland

Message from the kConFab Team

Thank you for supporting the kConFab Research Project.

So as to keep kConFab running smoothly, we would greatly appreciate it if you could remember the following:-

- Please tell your research nurse if you change your address.
- Ring the cancer specialist at your Family Cancer Clinic to inform them of any new cases of cancer in your family.
- Let us know if you are going to have any surgery performed, either for the removal of a suspected cancer or for prophylactic reasons (breast or ovaries).

New Study

- Your kConFab research nurse may offer you the option of being involved in a new study titled, "Prospective psychoimmunological study of women from high-risk breast cancer families". This study is looking to see if there is a link between psychological state and susceptibility to breast cancer, and the outcome should a breast cancer occur.

  If you are interested in being involved in this study, the research nurse will provide you with a questionnaire for you to fill in at your convenience. For participants that see the research nurse *face to face*, you may be asked to have a simple skin test to determine your immune status. Details about the questionnaire and skin test will be explained to you by the project's research nurse, Ms Barbara Bennett, Hereditary Cancer Clinic, Prince of Wales Hospital, Sydney, Tel: (02) 9382 2592.

kConFab Contacts

If you have questions about kConFab, or would like to discuss eligibility to join, please phone your nearest Family Cancer Clinic listed below.

kConFab Coordinator
Heather Thorne
Peter MacCallum Cancer Institute
St Andrews Pl., East Melbourne, 3002
Research Division
Tel: (03) 9656 1542
Fax: (03) 9656 1457
Email: *h.thorne@pmci.unimelb.edu.au*

kConFab Family Cancer Clinics throughout Australia and New Zealand:-

Melbourne
Familial Cancer Centre
Peter MacCallum Cancer Institute
St Andrews Pl., East Melbourne, 3002
Contact: Dr Sue Anne MacLachlan or
Ms Mary Anne Young
Tel: (03) 9656 1064
Research Nurse: Ms Julie Kearney
Tel: (03) 9656 1903

Royal Melbourne Hospital
Familial Cancer Centre, Parkville, 3050
Contact: Dr Geoffrey Lindeman
Tel: (03) 9342 8845
Research Nurse: Ms Vicki Fennelly
Tel: (03) 9342 9347

Victorian Clinical Genetics Service
The Murdoch Institute
Royal Children's Hospital, Parkville, 3052
Contact:
Dr Mac Gardner, Tel: (03) 9345 5045, or
Dr Clara Gaff, Tel: (03) 8341 6316
Research Nurse: Ms Janine Furmedge
Tel: (03) 8341 6316

Victorian Clinical Genetics Service
Monash Medical Centre, Clayton, 3168
Contact: Ms Susan Fawcett
Tel: (03) 9594 2026
Research Nurse: Ms Janine Furmedge
Tel: (03) 8341 6316

Sydney
Familial Cancer Service
Department of Medicine
Westmead Hospital, Westmead, 2145
Contact: Dr Judy Kirk or Dr Sue Shanley
Tel: (02) 9845 6947
Research Nurse: Ms Karen Robinson
Tel: (02) 9845 6845

Prince of Wales Hospital
Hereditary Cancer Clinic
High Street, Randwick, 2031
Contact:Dr Kathy Tucker
Tel: (02) 9382 2577
Research Nurse: Ms Helen Conlon
Tel: (02) 9382 2607

Hunter Genetics
Hunter Area Health Service, NSW
Contact:
Dr Rodney Scott Tel: (02) 4921 4974 or
Dr Tracy Dudding, Tel: (02) 4985 3132

Brisbane
Queensland Clinical Genetics Service
Royal Children's Hospital
Bramston Terrace, Herston, 4029
Contact: Dr Mike Gattas
Tel: (07) 3636 1686
Research Nurse: Ms Vivianne Geldard
Tel: (07) 3636 5200

Adelaide
South Australian Clinical Genetics Services
Women's and Children's Hospital
North Adelaide, 5006
Contact: Dr Eric Haan or
Dr Graeme Suthers
Tel: (08) 8204 7375
Research Nurses: Ms Merryl Altree,
Ms Susan Schulz
Tel: (08) 8204 6821

Perth
Genetic Services of Western Australia
King Edward Memorial Hospital
374 Bagot Road, Subiaco, 6008
Contact: Dr Ian Walpole
Tel: (08) 9340 1525
Research Nurse: Ms Anna Nash
Tel: (08) 9340 1525

Auckland
Northern Regional Genetics Services
Auckland Hospital
Auckland, New Zealand
Contact: Ms Bronwyn Culling
Tel: +64 9 307 4949