



NEWSLETTER

Published by kConFab, The Peter MacCallum Cancer Centre, Grattan Street, Melbourne 3000. Tel: 03 8559 6526. Website: <http://www.kconfab.org>

Dear kConFab families

Since our last newsletter, there have been many advances made from our research work and we are keen to update you with some of this progress.

Firstly, in these difficult COVID times, we would like to thank the many kConFab participants who have continued to sign our consent forms, complete our lifestyle questionnaires and provide update about treatments we may not have known about. This has ensured that our day-to-day progress has continued unimpeded over recent months and we can provide the most up to date information to our researchers with active projects.

To make your contact with us easier, we have updated the kConFab home page over the past few months (www.kconfab.org). New features on the home page include a summary of recent kConFab publications that you may find to be informative and we have added a dedicated section where you can update any address changes or cancer treatments. Under the section "For the Families", we have added a general summary about our work, explaining why and how our research findings are advancing our understanding of familial cancer leading to improved cancer prevention and treatment. Our kConFab Clinical Follow Up team now have their own section, explaining their current research work; primarily based on the questionnaires our participants complete and return every 3 years. This information is supplying very important updates to us about your cancer surveillance routine and the barriers or enablers that shape the clinical service provided to you. We would be delighted to hear from you if you have suggestions on how to improve the home page even further.

We have three project updates in our research updates section of this edition that cover some of our new findings.

These include:

- Renea Taylor and Heather Thorne's important progress in identifying men at high-risk of developing prostate cancer if they carry a gene fault (mutation) in the *BRCA2* gene. They are building upon this work by 1) screening the blood DNA of men who have a diagnosis of prostate cancer who belong to multi-case prostate cancer families who have not had access to genetic testing to date and 2) men with a diagnosis of prostate cancer who belong to a multi-case breast cancer family where a gene fault has not been found. A large cancer gene panel will be used to identify faults (mutations) in genes not currently screened, as if a gene fault (mutation) is found it may have a major impact on prostate cancer incidence, progression and clinical management (page 6).
- Liz Christie's important discovery on how ovarian cancer cells become resistant or non-responsive to chemotherapy (drug treatment), which leads to poor survival. Given the clinical similarities between *BRCA*-gene faults related to prostate, breast and ovarian cancer, she is now testing if the gene faults (mutations) causing drug resistance in ovarian cancer are the same ones in breast and prostate cancer patients (page 6).

In our last edition, we outlined how in recent years there have been advances in the technology we use to detect gene faults (variants or mutations) that cause cancer. kConFab member Lesley Andrews has expanded upon this informative piece explaining how routine genetic testing on a germline (blood) DNA sample may now utilize a cancer gene panel, rather than test just one or two genes. Lesley has expanded the facts about a gene panel test to include new information about three rare cancer genes known as *BRIP1*, *RAD51C* and *RAD51D* in which mutations are associated with ovarian cancer (page 2).

An exciting area of our work is the translation of our kConFab research findings into clinical practice. One of these studies is being run by a clinical researcher, Kelly-Anne Phillips, who is looking for women who carry a *BRCA1* or *BRCA2* gene fault (mutation), and are planning to have risk-reducing removal of fallopian tubes (+/- ovaries) within 6 to 24 months for enrolment into the **STICs and STONES clinical trial**. It is hoped that this trial will show that aspirin can help prevent fallopian tube / ovarian cancer in women at high risk of developing this disease (page 3).

Another exciting study is led by Geoff Lindeman who is about to start recruiting to the **BRCA-P clinical trial**. This aims to test the effectiveness of a drug called Denosumab to decrease the risk or prevent breast cancer in women who carry a *BRCA1* gene mutation. It is important to highlight that this trial has come about due to the collaboration Geoff and his laboratory team have had with kConFab spanning 20 years in research using the normal breast tissue collected from kConFab women having surgery (page 2).

The National Breast Cancer Foundation (NBCF) have provided financial support to kConFab since we began our research work in 1997.

We are very appreciative of their support and the close day-to-day relationship with the NBCF team facilitates breast cancer research to improve clinical outcomes. You can read about the new excellent research projects that they will support starting this year on page 4.

In closing, because of the generosity and co-operation of our families, kConFab has become one of the world's best resources for research into familial aspects of breast, ovarian and, in recent times, prostate cancer. Your communications to us about new family members who become eligible to join kConFab, new diagnoses of cancer in your family

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and about impending surgery for the removal of both normal and cancer (breast, ovarian and prostate) tissue have enabled us to continue to support cutting edge world-wide research. On behalf of the entire kConFab team, I want to thank you most sincerely for your ongoing support. We hope that you find this newsletter informative and we welcome your feedback.

Professor Stephen Fox,
Chairperson,
kConFab Executive Committee.

What is Panel Testing?

Dr Lesley Andrews
Head of Department,
Hereditary Cancer Clinic,
Prince of Wales Hospital,
Sydney NSW



Testing for the breast cancer genes called *BRCA1* and *BRCA2* has now been available for over 20 years. Although this testing has explained why breast and ovarian cancer runs in some families, for many others who are negative for *BRCA1/2* mutation, the genetic link has remained unexplained.

A huge amount of research has been done to identify other genes in which mutations (faults) cause an increased risk of breast cancer. A relatively new method of genetic testing called Next Generation Sequencing (NGS) enables many genes to be tested at once. When several genes are tested simultaneously, this is called **panel testing**. Although many genes have been reported to be potentially linked to breast cancer, most clinics will only request results of the few genes where research has definitely proven the link, and enough information is known about the gene to use the result reliably in the clinic. Unfortunately, researchers and clinics are finding that these genes are responsible for only a small proportion of families that are not linked to *BRCA1* or *BRCA2*, so the search for more breast cancer genes continues.

Here are a few examples of genes that are tested in panels that are associated with increased risk of developing different tumours:

PALB2 is a gene that is similar to *BRCA2*. It is linked to breast cancer in men as well as women, and cancer of the pancreas in some families. Another is ***ATM***, which is associated with a severe neurological disorder in patients who have two faulty copies of the gene. However, it has also come to light that women who carry just one faulty copy may be at increased risk of breast cancer, depending on the particular fault in the *ATM* gene that they carry.

Inherited germline faults in a single copy of the ***TP53*** gene have been known to cause a condition called Li Fraumeni Syndrome. Fortunately, *TP53* mutations are a very rare cause of breast cancer, as these can also cause many other types of cancer, often occurring at young ages.

PTEN is another gene, which is a cause of Cowden's syndrome and is associated with increased risk of breast cancer, as well as cancer of the uterus and thyroid. Although these three cancers are quite often found in the same family, faults in the *PTEN* gene are rarely the cause.

Recent studies suggest that after *BRCA1* and *BRCA2*, mutations (faults) in the *BRIP1*, *RAD51C*, and *RAD51D* gene may be the next most important ovarian cancer predisposition genes. They are very rare gene faults and account for approximately 2% of ovarian cancer cases. The role of these gene faults in breast cancer, if any, is less defined and questionable so on-going research is important to clarify the impact of these genes.

Since November 2017, there has been a Medicare rebate for panel testing of individuals with breast and/or ovarian cancer who have at least a 10% chance of carrying a fault in some genes associated with breast and/or ovarian cancer. The referring doctor will decide which genes should be tested, depending on the cancers in the family.

If your family has participated in kConFab, blood from at least one member of your family who has had breast and/or ovarian cancer will have been tested for mutations in these genes. Often further panel testing is done. If you have consented to receive

results, you will have been informed if any relevant results have been found.

If you have seen a genetic counsellor in the past, you can contact the genetics clinic if you wish to know more about testing in your family.

Preventing Breast Cancer in Women with a faulty *BRCA1* Gene

By Professor Geoffrey Lindeman
Joint Head, Stem Cells and Cancer Division at the Walter and Eliza Hall Institute and Medical Oncologist, The Peter MacCallum Cancer Centre and Royal Melbourne Hospital, Melbourne.



Approximately one in 400 women in Australia are at the highest risk of breast cancer because they carry a *BRCA1* or *BRCA2* gene mutation. For these people, carrying a gene mutation is associated with an approximate 70% risk of developing breast cancer and a 40% risk of developing ovarian cancer, over the course of their lifetime.

Currently, many women with a *BRCA* gene mutation undertake measures to prevent breast and ovarian cancer, including the surgical removal of their breasts and ovaries. A new clinical trial hopes to offer these women another prevention option.

The *BRCA-P* clinical trial aims to test the effectiveness of a drug called Denosumab to decrease or prevent the risk of developing breast cancer in women who carry a *BRCA1* gene mutation. Denosumab is an antibody that neutralises a molecule called RANK ligand. It is already used in the clinic to reduce the risk of bone fracture in patients who have thin bones (osteoporosis) and to keep bones strong for patients who have cancer that has spread to bone. Its safety profile is therefore well understood. Recent laboratory studies suggest

that switching off RANK ligand with Denosumab could also target the culprit cell that gives rise to breast cancer in women with the *BRCA1* gene mutation.

Based on these pre-clinical data, the BRCA-P prevention study has been fast-tracked to the clinic. The BRCA-P study hopes to offer women a treatment option that could delay or even prevent the need for mastectomy. Women who participate in the BRCA-P trial will continue to receive close monitoring, scans through their own specialist, and will receive additional follow-up in partnership with the BRCA-P study team. Participants will be randomly assigned to receive denosumab or placebo as a small injection (under the skin) every 6 months for 5 years. Participants will be followed up every 12 months for a further five years. The study is 'double blinded'. This means that participants (and the team) will not know whether they are being treated with Denosumab or placebo. This is very important, as it is the only way to properly determine whether Denosumab has breast cancer prevention properties and to identify if there are any unwanted side effects or benefits (such as strengthened bones).

The study will be coordinated in Australia by Breast Cancer Trials – Australia's largest clinical trials research group, which has been conducting clinical trials research for more than 40 years.

Throughout Australia, 15 sites will be open to patient recruitment together with six other countries including Austria, Germany, Israel, Spain, the United Kingdom and the United States. The international recruitment target is 2,918 participants and Australia will recruit 300 participants over a two-year period.

The BRCA-P clinical trial is a prevention clinical trial, therefore potential participants include women who have not had breast cancer but who carry a *BRCA1* gene mutation.

The eligibility criteria for the BRCA-P study includes:

- Women who carry a *BRCA1* gene mutation.
- Age 25 - 55 years.
- Unaffected by breast or ovarian cancer.
- May be either pre or post-menopausal.
- Not pregnant or planning to get pregnant.

- Have not had preventative breast surgery.
- Not taking any breast cancer preventative agents such as Tamoxifen or an Aromatase Inhibitor.

To find out more about the BRCA-P clinical trial, visit the Breast Cancer Trials website at www.breastcancertrials.org.au.



STICs and STONEs – A Clinical Trial for Women with a *BRCA1* or *BRCA2* Mutation

By Professor
Kelly-Anne Phillips

Consultant Medical Oncologist,
National Breast Cancer
Foundation Practitioner Fellow,
The Peter MacCallum
Cancer Centre, Melbourne.



Researchers are looking for women who carry a *BRCA1* or *BRCA2* mutation, and are planning to have risk-reducing removal of fallopian tubes (+/- ovaries) within 6 to 24 months for enrolment into the STICs and STONEs clinical trial.

Aspirin has been available for over 100 years. Research suggests that taking aspirin reduces the probability

of getting many types of cancer because of its anti-inflammatory action. Inflammation during ovulation is thought to contribute to the development of ovarian cancer, and because aspirin is an anti-inflammatory medication, it may help to prevent it. Participants will have a 50:50 chance (randomly allocated) of receiving either aspirin or a placebo (inactive "sugar tablet"), and will be asked to take 1 pill a day for 6 months to a maximum of 2 years, prior to the planned surgery.

STICs and STONEs is led in Australia by the Australia New Zealand Gynaecological Oncology Group (ANZGOG) and the NHMRC Clinical Trials Centre, The University of Sydney as the Australian trial coordinating centre, in collaboration with the Canadian Cancer Trials Group (CCTG). It is hoped that this trial will show that aspirin can help prevent fallopian tube and ovarian cancer in women at high risk of developing this disease.

STICs and STONEs will enrol 414 patients in hospitals based in Australia and Canada, and the ANZGOG Study Chair of this trial is Professor Kelly-Anne Phillips. For more information about the STICs and STONEs trial, contact stics@ctc.usyd.edu.au/ 02 9562 5000, or speak to your treating clinician about whether you are eligible to participate. The study is available at the following locations in Australia:

NSW

Prince of Wales Hospital and Westmead Hospital, Sydney.

VICTORIA

Peter MacCallum Cancer Centre, Melbourne.



National Breast Cancer Foundation awards \$10 million worth of grants to usher in a new age of technology and innovation in breast cancer research

The National Breast Cancer Foundation (NBCF) has awarded 16 game-changing research projects worth over \$10M in funding to support its ambitious aim of zero breast cancer deaths by 2030.

The 16 research projects are based across the country and include looking at how new technologies such as Artificial Intelligence and Immunotherapy could help to save lives through early detection and new treatment options.

Breast cancer is the most commonly diagnosed cancer in the country, with 53 Australians diagnosed each day. Its incidence is rapidly rising, with breast cancer diagnosis rates almost doubling since 1994. Currently, eight women die each day from the disease. Investing in research is the only way to change the stats.

Professor Sarah Hosking, CEO of NBCF stated, “2020 has been a significant year for shining a light on the critical role of medical and scientific research for better health outcomes. That’s why I’m proud to be able to present 16 researchers with the support they need to push towards our goal of Zero Deaths from breast cancer by 2030.”

“To our supporters, we want to thank you, now more than ever, for your continued contributions which are making a real impact in breast cancer research. This year, many of the projects being funded are looking at how cutting-edge technology, and innovation, can bring us that step closer to meeting our aim and I’m excited to see the results that these projects will bring.”

Some of the projects funded this year include:

- **Dr Roberta Mazzieri (University of Queensland) - New Vaccinations for Triple-Negative and Brain Metastatic Breast Cancer** - The study will test new vaccines which could boost the body’s immune response against breast cancer

when used in combination with other immunotherapies. Ultimately, the goal is to identify potential vaccination-based strategies to help improve treatment outcomes of aggressive breast cancers.

- **Dr David Croucher (Garvan Institute of Medical Research) - Targeting the JNK protein to effectively treat Triple Negative Breast Cancer (TNBC)** - Using a novel technology platform, Dr Croucher and his team will be able to investigate the complex behaviour of the JNK protein in breast cancer. They believe a “scaffold protein”, which controls the activity of JNK, could be targeted with a drug to inhibit the growth of metastatic cancer cells. This could lead to a new medication option for women with TNBC breast cancer.
- **Professor Kelly-Anne Phillips (Peter MacCallum Cancer Centre) - iPreventNext - Helping women with breast cancer to make treatment decisions** - Rates of preventative double mastectomies following a breast cancer diagnosis are rising, but it is believed that many of these surgeries are not medically necessary. This study will develop ‘iPreventNEXT’, a new online tool that will estimate a women’s personal risk of a second breast cancer, to help her make a fully informed decision about whether to undergo a double mastectomy.
- **Professor John Hopper (University of Melbourne) - New risk factors for Breast Cancer based on Digital Mammograms** - Recent studies have shown that women with dense breast tissue are at a higher risk of breast cancer. This study will incorporate new mammography-based risk factors, including breast density, to improve screening processes in the clinic in Australia and globally.

NBCF Research Director Dr Chris Pettigrew said, “We’ve seen time and time again how breast cancer research

has shifted the needle forward in our aim to end deaths from the disease. This year’s talented researchers will investigate a number of initiatives to support prevention, early detection, improved quality of life and potential new treatment options for breast cancer.”

NBCF has made incredible achievements in Australian breast cancer research since its inception in 1994. Since then, the five-year survival rate for breast cancer has increased from 76% to 91% - showing that cutting-edge research is the key to stopping deaths from breast cancer. By identifying, funding and championing world-class research, NBCF will continue to work towards a goal of Zero Deaths from breast cancer by 2030.

Want to get involved and raise funds for vital breast cancer research this June? You can pledge to **WEAR IT, SHAVE IT or COLOUR IT** for GO PINK to raise funds and take decisive action towards a future without fear of breast cancer. To find out more go to <https://fundraise.nbcf.org.au/event/go-pink/home>



About the National Breast Cancer Foundation

The National Breast Cancer Foundation (NBCF) is the only national body that funds life-changing breast cancer research with money raised entirely by the Australian public. Breast cancer is the most common life-threatening cancer facing Australian women with eight women dying from the disease each day – mothers, sisters, wives, daughters and friends.

Research is the only way to prevent deaths and improve how breast cancer is diagnosed, managed and treated. By funding only world-class research, NBCF is working towards a goal of zero deaths from breast cancer by 2030.

NBCF research has helped fund the development of better therapies, led to greater understanding of possible ways to stop the spread of breast cancer

to other areas, and improved quality of life for patients and their families. Since its establishment in 1994, NBCF has awarded more than \$181 million to around 557 Australian-based research projects to improve the health and wellbeing of those affected by breast cancer. With no Government funding, this money has been raised entirely by the Australian public.

May 2020, Sydney

A message from



EDU EVENINGS

In partnership with experts, doctors and geneticists, Edu Evenings are an online weekday evening events held live for the community.

You will hear from an expert about a specific topic that directly impacts upon your high-risk journey.

Upcoming Edu Evenings include:

- Latest Science & Treatments In The Hereditary Cancer Space – Tuesday 28th July 2020
- An introduction to breast reconstruction options following mastectomy – Tuesday 25th August
- Managing Surgical Menopause Post Cancer or preventative surgery – Tuesday 29th September
- Breast Cancer Awareness: Understanding your breasts and risk factors – Tuesday 27th October

COVID RESOURCES FOR THE HIGH-RISK COMMUNITY

With news of Coronavirus dominating news cycles, Facebook feeds and coffee shop conversation, you might be worried about what Coronavirus means for you, especially if you have cancer or are a cancer survivor.

Pink Hope is keeping community up-to-date with information regarding the impact of COVID-19.

www.pinkhope.org.au

Breast
Cancer
Network
Australia



New fertility videos for young women with breast cancer

Breast Cancer Network Australia (BCNA) has released a series of videos to encourage and help young women diagnosed with breast cancer to have a discussion about fertility preservation before starting breast cancer treatment.

The videos, which can be viewed on BCNA's YouTube channel, feature young Australian women talking about the fertility decisions they made during their breast cancer journey. Fertility specialist Associate Professor Kate Stern explains why these discussions are important and that there is nearly always time to undertake fertility preservation measures before chemotherapy treatment starts.

The videos result from a survey conducted by BCNA, which showed that one in six young women diagnosed with breast cancer in Australia is not being informed of her fertility options. More than half of the women surveyed said they were not referred to a fertility specialist before their treatment started.

The findings also revealed that, in some cases, limited options were discussed and all the potential risks to fertility were not fully explained. More than half of respondents chose not to pursue any fertility options, with 29 per cent of those women saying they

found it 'overwhelming' at the time of their diagnosis.

Young women (20-39) account for around five per cent of all breast cancer diagnoses in Australia – this means that two young women are diagnosed with breast cancer every day. In the middle of a whirlwind of decisions they have to make around treatment, these young women also have to consider the risks to their fertility.

Associate Professor Kate Stern says it is important for young women to be informed about the risks of treatment to their fertility.

'There is almost always time to think about fertility preservation before starting treatment and there are options available, no matter where they live,' she told BCNA.

'A lot of young women diagnosed with breast cancer will have chemotherapy. It is very effective against cancer, but it can reduce the total number of eggs. That is why it is vital for these young women to consider fertility as part of their treatment regimen.

'Having a breast cancer diagnosis is really overwhelming. It is so important to have your oncology team, your treatment team and your fertility team working together.

'Even young women who think they don't want to have a baby should have the discussion to open their mind to thinking about it. This is all about looking after their future,' Prof Stern said.

Young women diagnosed with breast cancer wanting to know more about fertility preservation options, and breast cancer treatment and care, can sign up to BCNA's My Journey online tool. The tool was developed with assistance from breast cancer clinicians and women who have been diagnosed with breast cancer, and provides information tailored to people's individual needs at all stages of their breast cancer journey.

BCNA also has a booklet – Fertility-related choices – which can be downloaded free of charge from its website.

The fertility videos were developed with support from Cancer Australia through the Supporting Women in Rural Areas Diagnosed with Breast Cancer Program.

RESEARCH UPDATES

Improving genetic testing for men with familial prostate cancer

By Associate Professor Renea Taylor and Associate Professor Heather Thorne

Monash University Biomedicine Discovery Institute & The Peter MacCallum Cancer Centre.

Prostate cancer remains the most commonly diagnosed cancer in Australian men, with 3,500 prostate cancer-related deaths each year. The risk of developing prostate cancer is strongly influenced by family history, and dramatic progress has been made in the area of genetic profiling and analysis of prostate cancer tissue in the past decade.

In an exciting new project, Associate Professors Renea Taylor and Heather Thorne were successful in obtaining a grant for new research funded by Prostate Cancer Foundation of Australia (PCFA), the peak national body for prostate cancer in Australia.

This new project follows on from a series of fruitful studies by this team who discovered the link between familial *BRCA2* mutations (gene faults) and poor prognosis in men with prostate cancer. These men experience mortality rates that are much higher for men who have these mutations, and they are less likely to respond to standard hormonal treatments and chemotherapy, but may respond well to newer targeted cancer drugs. This has led to practice-changing advances in the way we approach treatment for men with *BRCA2* mutations.

However, there are other, yet unidentified germline mutations not yet screened for in high-risk cohorts of men where there are multiple cases of prostate cancer in the family. These other gene mutations may also have a major impact on prostate cancer incidence, progression and clinical

management. The discovery of newly associated germline mutations will be the focus of this project.

Renea and Heather will utilise the world-leading kConFab cohort, including prostate cancer patients from 82 multi-case families who are confirmed non-carriers of a *BRCA1/2* mutations; these are the families who will benefit directly from additional germline testing. These patients have been recruited to kConFab over the past 20 years through the Family Cancer Clinics (FCCs) of Australia and New Zealand. Multiple gene panel tests are proving to be an affordable and effective way to investigate the heritability of breast cancer, and we will test if this approach is also useful for men with prostate cancer. This is a world-leading project that could help us find better ways of detecting and treating deadly forms of prostate cancer. Our ultimate goal is to deliver a paradigm shift in genetic testing for prostate cancer patients by identifying new gene mutations that are clinically significant.

If you are interested in the study or being involved, please email or ring Heather on:

heather.thorne@petermac.org or toll-free number 1800 221 894

Understanding the mechanisms of acquired drug resistance in cancer

By Dr Liz Christie, research scientist, The Peter MacCallum Cancer Centre, Melbourne

The most common type of ovarian cancer is an aggressive disease that frequently becomes resistant to chemotherapy (drug treatment), leading to poor survival outcomes for many affected women.

We recently discovered a few gene faults (mutations), in some ovarian cancer samples that cause chemotherapy resistance. Given the clinical similarities between *BRCA*-related prostate, breast and ovarian cancer, with patients receiving similar treatment regimens including PARP inhibitors, we are testing if the gene faults causing resistance in ovarian

cancer also cause resistance in breast and prostate cancer patients. Specifically, we are testing samples collected as part of the CASCADE autopsy program. Further details about CASCADE, our rapid autopsy program is outlined in Laura Forrest's article.

The most common resistance mechanism to treatment we identified in ovarian cancer patients was a gene fault that led to a pump, which sits on the surface of the cancer cells, to be turned up. In cancer cells with the gene fault, the pump is able to push enough of the drug treatment (chemotherapy) out of the cancer cell so there is insufficient to kill the cancer cells. When we tested kConFab cancer tissue samples from breast cancer patients, we found the same gene fault (mutation) in 30% of patients.

Interestingly, we have found that individual patients can have more than one gene fault (mutation) that causes drug resistance. When we studied multiple advanced cancer tissue samples collected by CASCADE in breast and ovarian cancer patients, we found that the cancer cells could have none, some or all of these gene faults. The absence of these gene faults in some cancer tissue sites when the patient's cancer was resistant to drug chemotherapy suggests that other resistance mechanisms must be present that we have not found yet.

We are continuing to look for new gene faults that may cause drug chemotherapy resistance, as understanding the spectrum of drug resistance mechanisms is crucial for finding new and effective ways to treat cancer patients. We also hope to develop blood tests to use to identify which patients have the gene faults that could guide improved treatment and test these findings in clinical trials.



Dr Liz Christie.

kConFab Follow-Up Goes Online

The kConFab Clinical Follow-up Study has been sending out questionnaires to women recruited to kConFab between 1997 and 2008, to collect medical history, family history and lifestyle information.

These questionnaires have been in a booklet form and sent in the mail every 3 years. Increasingly women have been telling us that they would prefer to complete their questionnaire online, so we have been working hard to make this happen. In the next few months, our online questionnaire will go live and we hope this makes filling in our questionnaire a quicker and easier experience for our participants. We understand that not all of our participants have access to email or feel confident in completing online questionnaires so, for these women; we will continue to send the booklet to you in the mail as we have always done.

If we have an email address on our database for you then you will receive your questionnaire link in an email when your next questionnaire is due. If we do not have an email address for you then you will receive it in the mail as you have always done. If you would like to add or update your email address with us then please contact us on 1800 111 581 or email us at kconfabfup@petermac.org

Some women may also receive, or have already received, a phone call from us regarding collection of mammogram images. We are contacting a particular subset of women from our study and asking them if they have their mammogram films at home from their breast cancer diagnosis. Information from these mammograms are expected to be used by researchers for many important projects, including developing an accurate online tool to help women with breast cancer to determine their future cancer risks and therefore what type of surgery might suit them best. If women do have their mammograms, we will be organising a pre-paid envelope to be sent out to collect these mammogram films, which can be returned to women if desired.

We would like to thank women who have participated in the follow-up and hope you will continue to help us in the future.

The experiences of the CASCADE rapid autopsy program clinical and research team

Dr Laura Forrest, *Senior Research Fellow, Psychosocial Cancer Genomics Research Associate & Academic Genetic Counsellor, The Peter MacCallum Cancer Centre, Melbourne*

CASCADE is an Australian-first cancer rapid autopsy program, facilitating genetic analysis of advanced cancer tissue.

Patients from numerous cancer groups, including kConFab, are recruited once they have reached an understanding that there are no longer treatments available to them. CASCADE therefore places not only patients and their families, but also the clinical and research team, in a unique situation to advance our knowledge for new treatment options. Recognising this, we developed CASCADE Psychosocial, a research program to capture these unique experiences of our patients. Whilst our study with CASCADE patients is still open and recruiting, research with the CASCADE clinical and research team is now complete.

The roles of the CASCADE clinicians and researchers vary, but all are critically important in the success of the program. These roles include broaching the topic of rapid autopsy with a patient and gaining consent, being on-call to ensure the safe and respectful transfer

of decreased participants throughout the rapid autopsy and subsequent return to the family, and the analysis of cancer tissue samples in the laboratory.

We aimed to explore the experiences of the CASCADE team including: the impact of the program on their clinical and research work and personal wellbeing; how the clinical team functions in ensuring the successful recruitment of patients and; how the research team deal with challenges that have arisen through the conduct of CASCADE.

We interviewed nine clinicians and eleven researchers (n=20). We thematically analysed transcript data to produce an in-depth understanding of participant experiences. All expressed passion for CASCADE and derived psychosocial and professional benefits from being members of the CASCADE group. However, they simultaneously described the various challenges associated with their role. These included; careful patient selection and sensitive recruitment, the demands of being on-call and the confronting nature of autopsy research. Nevertheless, participants explained that the significance of the research, and the meaning it brings to end-of-life patients, outweighs any burdens.

Recently, we presented these findings to the CASCADE clinicians and researchers. This research has been presented at national and international conferences. We are currently working towards the publication of results and have one manuscript under review. We would also like to take the opportunity to thank the CASCADE clinicians and researchers who participated in this research for being so willing to share their experiences with us.



Dr Laura Forrest, 3rd right, and her team.

Collaborating Family Cancer Centres

Melbourne

**The Parkville Familial Cancer Centre
Peter MacCallum Cancer Centre &
The Royal Melbourne Hospital
Peter MacCallum Cancer Centre**

Level 1B 305 Grattan St, Melbourne, 3000
Contact: Ms Alexandra Lewis
Tel: 3 8559 5322

The Royal Melbourne Hospital

Level 2 Centre, Infill Building, Grattan
Street, Parkville, 3050
Contact: Mr Michael Bogwitz
Tel: 03 9342 7151

Monash Medical Centre

Clayton, 3168
Contact: Dr Marion Harris
Phone: 03 9594 2009

Austin Health Clinical Genetics Service

Level 8, Harold Stokes Building
Austin Hospital
HEDIELBERG VIC 3084
Tel: 9496 3027

Victorian Regional Family Cancer Clinics:

**Albury/ Ballarat/Wodonga/
Shepparton Austin Health
Family Cancer Clinic**
Tel: 03 9496 3027

**Bendigo/ Mildura
Peter MacCallum Cancer Centre
Family Cancer Clinic**
Tel: 03 8559 5322

**Geelong/Warrnambool
Royal Melbourne Hospital Family
Cancer Clinic**
Tel: 03 9342 7151

**Moe/Traralgon
Monash Medical Centre Family
Cancer Clinic**
Tel: 9594 2009

Sydney

**Familial Cancer Service
Westmead Hospital**
Westmead, 2145
Contact: A/Prof Judy Kirk
Phone: 02 8890 6947

**Prince of Wales Hospital
Hereditary Cancer Clinic**
High Street, Randwick, 2031
Contact: A/Prof Kathy Tucker
Phone: 02 93825107

St George Community Hospital Hereditary Cancer Clinic

Kogarah, 2217
Contact: A/Prof Kathy Tucker
Phone: 02 93825107

St Vincent's Cancer Genetics Clinic

Darlinghurst, 2010
Contact Professor Allan Spigelman
Phone: 02 9355 5647

The Hunter Family Cancer Service

Cnr Turton & Tinonee Roads
(PO Box 84) Waratah NSW 2298
Phone: 49853132 Fax: 49853133
Email: HNELHDFamilyCancerService
@health.nsw.gov.au

Sydney Cancer Genetics

P.O. Box 845 Broadway, 2007
Contact: Dr Hilda High
Phone 02 9304 0438
info@sydneycancergenetics.com.au
Contact: Dr Hilda High

Brisbane

Genetic Health Queensland Royal Women's and Children's Hospital

Bramston Terrace Herston, 4029
Contact: Dr Rachel Susman
Phone 07 3646 1686

Nicholson St Specialist Centre

Suite 107, Level 7
83 Nicholson Street
Greenslopes, QLD 4120
T: 07 3217 8244 F: 07 3217 8255
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Canberra

ACT Genetics Service

Level 5, Building 1
The Canberra Hospital
Yamba Drive, Garran 2605
Contact: Dr Linda Warwick
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Adelaide

**Adult Genetics Unit
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**Genetic Services of Western Australia
King Edward Memorial Hospital**
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Tasmania

Tasmanian Clinical Genetics Service Royal Hobart Hospital

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Auckland – New Zealand

Genetic Health Service NZ – Northern Hub

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Genetic Health Service NZ – Central Hub

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Christchurch – New Zealand

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