

Gene support services up & running

A range of interested health professionals gathered at the Cancer Council Victoria recently to hear about the services available to people at risk of cancer because of genes or their family history. These services include Cancer Gene Connect and the “Cancer in my family” internet group.

Attendees at the meeting heard how people diagnosed with a cancer gene or given a high risk assessment may experience a high level of distress. Distress at the time of genetic testing is often managed very well by doctors and genetic counsellors working at the family cancer clinics. Further down the track, help may be needed with making decisions about surgery, sharing information with family and dealing with sadness.



Trish Waters and Kate Wakelin

Support from people who are in a similar situation can lessen the isolation felt by people at increased risk, said Trish Waters, Community Development Manager of Cancer Gene Connect. The program provides formal training for volunteers and ongoing support. As people phone up the service asking for help, they are matched with a volunteer with similar experiences.

Trish would welcome calls from those who have been diagnosed with a cancer gene, either interested in volunteering or seeking support themselves. At the moment volunteers are trained to help people with one of the breast and ovarian cancer BRCA genes, but Trish would love to expand the program to include Lynch Syndrome (HNPCC) and FAP (Familial Adenomatous Polyposis).

The facilitator of the “Cancer in my family” Internet Support Group, Kate Wakelin, told the gathering that membership is open to people with a high risk family history. It’s not necessary for a family gene to be identified to join the online

discussion. In many families, genetic testing cannot be carried out, or fails to identify a gene causing the family history of cancer. People in this situation may still be advised to carry out cancer screening or consider risk-reducing surgery. The internet group allows members to discuss the issues surrounding management of their cancer risk and relationships and offers a real sense of community and empathy from people who share similar experiences.

“Cancer in my family” is part of the www.cancerconnections.com.au online community. The website is owned and administered by Cancer Council staff. Most of the site can be viewed by the public, but to safeguard the privacy of members, only members of the group can access it and read the posts.



For more information you can email csg@cancervic.org.au. People can also be referred to the group by their family cancer clinic.



Story from Elaine

Elaine is a long-standing member of the Victorian Family Cancer Register (VFCR) and also volunteers for Cancer Connect and participates in the “Cancer in my family” internet support group.

Six years after actually being diagnosed with cancer I decided that it was time to assist others through their “journey”. I called the Cancer Council Victoria (CCV) to be a Cancer Connect volunteer. I have had a lot of satisfaction and enjoyment from calling other people who have either had the same cancer – bowel – or similar treatments, or the chance of ending up with a stoma. To be able to let others know that they are not alone and that someone else has been there and gone through it makes them feel a lot easier and more hopeful. It is all done via telephone with no cost to the volunteer.

Since then I have also been involved in a website run by the Cancer Council, which is set up for those touched by cancer. There has recently been developed a “Cancer in my family” group on this website specifically for those with familial cancer genes. This is a place where you can write down how your diagnosis affects you and others can respond with great empathy and maybe strategies of how to help. I have found it extremely helpful, especially when my 34-year-

old niece died 18 months ago due to FAP. To be able to put into words your deepest, darkest feelings and to get back great responses from people who truly understand is of unbelievable benefit. I was able to then acknowledge these feelings and accept what had happened. I can assure you that it is an extremely worthwhile website, we are all anonymous, but on the same path.

There are only a few of us in this group at the moment as it is still extremely new, but in time I am sure that we will manage to have “conversations” as with other groups that I am a member of.



Please join us, just hop on the site www.cancerconnections.com.au and have a little look in it. You won't be able to visit the Cancer in my family group until you register and join the group, but it will give you an idea of the type of things that others write.

Hope to “see” you there, Elaine.



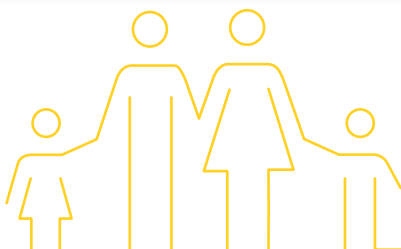
Meet our Genetic Counselling student Lynley



Lynley is pictured here (at left) with our Program Manager, Toulia McArdle

Our Register is pleased to be currently hosting a student who is gaining valuable experience of the many services provided by the Cancer Council Victoria (CCV). We wish Lynley well in her chosen career as a Genetic Counsellor and thank her for her contributions.

“My name is Lynley and I am spending eight weeks with the CCV for community placement as part of my Masters of Genetic Counselling. Since starting the course earlier this year my interest in cancer genetics has grown and has become an area I hope to be involved with in my future career. Being given the opportunity to be involved with the CCV was ideal for me, and the experience so far has been invaluable.



These last few weeks I have been involved with the Victorian Family Cancer Register (VFCR). Before starting with the CCV I knew nothing about the VFCR, but have since learnt what an incredible resource it is, especially from a clinical perspective. The information provided by the VFCR is vital in enabling health professionals to give individuals the most accurate advice about their potential cancer risk.

Every family is different, and some people know more about the incidence of cancer within their families than others. For different reasons people may not know the type of cancer a member of their family has had, or sometimes they may not even know they have had cancer at all. However, having this information may be vital for clinicians, as it could change a person's cancer risk. I am involved in a project looking at exactly this, the importance of the VFCR cancer verifications.

My placement here has also given me insight into some of the great work the CCV does to support both people with cancer and their families. This is definitely something I intend to make use of when I'm a genetic counsellor; to recommend the CCV to individuals and families both with cancer, and at risk of cancer, so that they can access the support they may need.

I am now half way through my placement and am thoroughly enjoying the experience. I feel that I have learnt so much in the short amount of time I have been here, and I can't wait to see what the next half brings!"

Benefits of checking family history

Review looks at the impact of the verification service on the risk assessment given to people attending a family cancer clinic

For the past decade, the Victorian Family Cancer Register (VFCR) has been working to help genetic counsellors provide genetic risk assessments to families. Information about the exact cancer found in each family is relayed back to the Family Cancer Clinic (FCC) via the verification service, so that an accurate assessment of risk can be made.

People attending a clinic are asked to complete a family history questionnaire and advise of any cancers in family members and where the cancer was found.

Sometimes there are cancers in family individuals that are not known to the person completing the questionnaire. In other cases, cancers are reported but are confirmed to be a different type of cancer.

Depending on the exact nature of the "new" or different cancer, there may

be no effect on the clinic's assessment of the family genetic risk. For example, melanoma is a common cancer in the Australian community and would usually have little impact on a risk assessment. On the other hand, if a "new" diagnosis of ovarian cancer in a family member is confirmed, the family risk of cancer may change significantly. The family's eligibility for genetic testing and important clinical management advice can change too.

The VFCR and the Royal Melbourne Hospital FCC are currently working together to review how often a risk assessment changes because of new information supplied by the verification service. The plan is to look at all RMH families verified during 2010 where new or different cancers were found and check a sample to see whether the risk assessment given would have changed.

The findings will be presented to family cancer specialists at an upcoming conference in New South Wales.

Study seeks volunteers

Volunteers are still needed for a study looking at the benefits of red wine in reducing the risk of bowel cancer.

Anyone with a family history of bowel cancer, or a personal history of bowel cancer or bowel adenomas can contact the study team to discuss participation in the study.

If you agree to take part, you will be given a small amount of (non-alcoholic) red wine or a placebo to drink each day for six weeks. You will also need to visit the research centre at the Royal Melbourne Hospital.



Please phone Virginia on **9342 8995** or email virginia.bird@mh.org.au to find out more.

Update your details

It's really important to us that you let us know if you move house. Keeping your address up to date with VFQR is a little easier now. Please tear off this strip and send it to us when you know your new address.

First name Mr/Ms/Mrs/Miss

Last name

Phone

Email

NEW ADDRESS

Suburb

State

Postcode

OLD ADDRESS

Suburb

State

Postcode

Mail to: VFQR, 1 Rathdowne Street
Carlton Vic 3053 OR email the details
to: VFQR@cancervic.org.au OR
phone the details to: 9635 5176

We welcome comments and feedback from our newsletter readers. Feel free to drop us a line or make a suggestion for a future article.

Victorian Family Cancer Centres

Austin Health Genetics Service

Phone (03) 9496 3027
www.austin.org.au

The Peter Mac Familial Cancer Centre

Phone (03) 9656 1199
www.petermac.org

The Royal Melbourne Hospital Familial Cancer Centre

Phone (03) 9342 7151
www.rmh.mh.org.au

The Southern Health Familial Cancer Centre

Phone (03) 9594 2009
www.southernhealth.org.au

Family Cancer Registers in Australia and New Zealand

Victorian Family Cancer Register

Phone: (03) 9635 5176
Email: VFQR@cancervic.org.au

Queensland Familial Bowel Cancer Registry

Phone: (07) 3636 5117
Email: ghq@health.qld.gov.au

NSW & ACT Hereditary Cancer Registry

Phone: 1800 505 644
Email: hcr@cancerinstitute.org.au

South Australia

Phone: (08) 8161 6995
Email:
cywhs.famcancer@cywhs.sa.gov.au

Tasmanian Familial Cancer Register

Phone: (03) 6222 8296
Email: jo.burke@dhhs.tas.gov.au

Western Australia Familial Cancer Register

Phone: (08) 9340 1603
Email: fcp@health.wa.gov.au

New Zealand Familial Bowel Cancer Registry

North Island: 0800 476 123
Email: gensec@adhb.govt.nz
South Island: Phone +643 378 6148
Email: fbcrcd@cdhb.govt.nz



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