

Please tick ✓

Yes I would like more information about the Familial Cancer Registry.

Name _____

Address _____

or

Phone _____

Please fax this form to:
Facsimile: (08) 9340 1725

or

Detach this form and mail it to:
Familial Cancer Registry
Familial Cancer Program
Genetic Services of Western Australia
374 Bagot Road, SUBIACO WA 6008



If you have a family history and have not been seen by Genetic Services of WA, an appointment can be arranged by phoning (08) 9340 1603 or asking your GP or specialist to send a referral to:

Genetic Services of WA
Familial Cancer Program
374 Bagot Road
Subiaco WA 6008

Or

Fax: (08) 9340 1725

Contact Details

Familial Cancer Registry
Familial Cancer Program
Genetic Services of Western Australia
374 Bagot Road, SUBIACO WA 6008
Telephone: (08) 9340 1603
Facsimile: (08) 9340 1725
Email: fcp@health.wa.gov.au



Department of Health
Genomics Directorate

Produced by the Familial Cancer Program
Genetic Services of Western Australia
and The Genomics Directorate, Department of Health
with assistance from The Cancer Council Western Australia
and The Anti-Cancer Foundation of South Australia

Familial Cancer Registry



Department of Health
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Approximately 5 – 10% of all cancers are due to a familial (inherited) form of cancer. Familial cancer may affect young adults and an increased risk of cancer can be inherited by their children. If a person is aware that they are at risk, there are measures that can be taken to reduce the chance of developing cancer or at least detect it at an early and potentially curable stage.

What is the Registry?

The Registry provides a service for people at increased risk of familial breast, bowel, ovarian and other cancer syndromes. It is an integrated part of the Familial Cancer Program at Genetic Services of Western Australia. The Registry provides the following services:

- Ensures that clients are aware of current surveillance recommendations specific to their situation or family history
- Provides a reminder service for the client or their doctor to ensure that surveillance check-ups are not forgotten
- Produces a bi-annual newsletter for Registry clients, updating them about topics of interest, new information, research findings and current local research projects
- Puts clients in touch with others who have had similar experiences or procedures
- Provides a contact point for information

The Registry does not take over the role of the doctors who already care for you.

Participation is voluntary and there is no obligation to join the Registry or sign the consent form. The consent form enables us to obtain relevant medical records to assist in providing you with accurate information and surveillance recommendations. Please note that the Registry only requires medical information relevant to the specific condition or cancer in your family.

Who can join the Registry

People who would benefit most from the Registry services are individuals from families where there is a significant history of cancer. That is, where there are a number of close blood relatives on the same side of the family (eg grandparents, parents, children, uncles or aunts, cousins), usually across several generations, who have developed related cancers, often at a young age (less than 50 years of age). There will always be exceptions to these guidelines and we advise, prior to joining the Registry, that you are seen by a Genetic Counsellor to discuss your specific situation and family history. A Genetic Counsellor will assess your risk, discuss surveillance recommendations and advise if there is genetic testing available. People who have a potentially increased risk of developing cancer and who may require frequent surveillance are eligible to join.

Confidentiality

Registry and Genetic Services staff are required to sign confidentiality agreements. The data collected by the Registry is stored in a secure database that is not linked to any other system.

If an independent ethics committee approves a research project that requests information held by the Registry, this may be released only if the information does not identify the client or their family members. If specific information is required the Registry Coordinator will write to you asking if you would like to participate in the particular project.

Removal of Information from the Registry

A person can at their request, have their name removed from the Registry at any time. Names may also be removed if it is found by gene testing, that they do not have an increased risk of developing cancer.

Management of the Registry

The Registry operates within the Familial Cancer Program (FCP), Genetic Services of WA. The head of the FCP is a medical specialist with expertise in familial cancer genetics. In addition, the Registry is overseen by a number of committees comprising of experts in specific fields of cancer. The Registry is subject to ethics and confidentiality clauses.

If you would like more information regarding joining the Registry, please complete the attached form and give it to your genetic counsellor or mail or fax to the contact address.