

NSW & ACT Hereditary Cancer Registry

Registration form

Registration with the Hereditary Cancer Registry (HCR) is for people at risk of hereditary cancer syndromes.

Registration is voluntary but is strongly encouraged.

Please use this form for the first notification of your patient to the HCR.

Please complete all the requested information in BLOCK LETTERS and attach copies of family pedigree information, relevant histopathology reports and clinic letters.

The inclusion of an individual on the HCR requires a SIGNED CONSENT FORM. This can be found on the second page of the registration form.

Please send completed registration forms to:

**NSW & ACT Hereditary Cancer Registry
Cancer Institute NSW
PO Box 825
Alexandria NSW 1435**

If you have any questions about these forms or the HCR, please contact us:

**Tel: 1800 505 644
Fax: (02) 8374 3644
Email: CINSW-HCR@cancer.nsw.gov.au
Web: cancer.nsw.gov.au**

Thank you for your assistance.

Person being registered			
Title	<input type="checkbox"/> Male <input type="checkbox"/> Female	Maiden name	
Surname		Mother's maiden name	
Given names		Phone:	
Date of birth			
Address:		Email:	
Reason for registration			
(Please circle this individual's current status)			
FAP	Proven	Suspected	At risk due to family history
Lynch Syndrome	Proven	Suspected	At risk due to family history
Juvenile polyposis	Proven	Suspected	At risk due to family history
Peutz-Jeghers	Proven	Suspected	At risk due to family history
Other polyposis syndrome (give details)	Proven	Suspected	At risk due to family history
Genetic testing			
Has the <u>family</u> gene mutation been identified?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	If so, where?
Has <u>this person</u> had blood collected for genetic testing?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	If so, where?
If 'Yes' to the above, is this person:	<input type="checkbox"/> Mutation positive <input type="checkbox"/> No mutation found <input type="checkbox"/> Mutation negative <input type="checkbox"/> Results pending		
If a causative mutation is known, please provide details:			
Surveillance plans			
We will be offering our screening reminder service unless requested otherwise. If you are not the treating clinician, please give details of the clinician to whom screening reminders should be sent.			
Doctor:		Address:	
Next screening due:			
Details of registering clinician			
Title		Name	
Address			
Signature		Date	

In order to complete registration for the above person, please attach copies of:

- **Family pedigree**
- **Pathology and genetic test reports**
- **Clinic letter with screening recommendations**

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Consent form

If you (or your child/dependant) would like to be included on the Hereditary Cancer Registry, you will need to read through this form with your doctor or treating clinician. If you agree with its contents, please sign it and send it to:

**NSW & ACT Hereditary Cancer Registry
Cancer Institute NSW, PO Box 825, Alexandria 1435**

I consent to be included on the Hereditary Cancer Registry (HCR) on the understanding that:

1. The HCR will only obtain information about me (or my child/dependant) and my family that is necessary to:
 - verify relevant health details from my doctor
 - record an accurate family history
 - identify other family members who have a high risk of developing cancer, and assist me or my doctor to inform them of their increased risk and their treatment options
 - accurately record the details of my regular screening check-ups and gene test results (if applicable)
 - keep the information recorded about me on the HCR up to date.
2. I (or my child/dependant) understand the HCR Screening Reminder Service involves:
 - receiving a letter reminding me that I am (or my child/dependant is) due for a follow-up examination
 - allows the HCR to obtain relevant follow-up information from my doctor regarding my (or my child/dependant's) hereditary cancer condition.
3. I understand I can opt off the screening reminder service at any time.
4. I (or my child/dependant) may be asked to assist with research into hereditary cancer which would require a separate consent. I have the right to decline to participate in any research studies, and this decision will not in any way affect the services my family and I receive from the HCR.
5. My (or my child/dependant's) information will be kept confidential and will not be released in a form that could identify me (or my child/dependant), except when needed by a doctor, accredited genetic testing laboratory, family cancer clinic or another hereditary cancer register to assist in my care or the care of other members of my family. Any information identified with me (or my child/dependant) will not be passed on to any members of my family without my consent.

I, (*PRINT your full name*) _____, have read and understood the above information and agree to be included on the NSW & ACT Hereditary Cancer Registry.

Your signature: _____ Date: _____

Date of birth: _____ Address: _____

OR, if signing on behalf of your child or dependant who is under 16 years of age:

I, (*PRINT your full name*) _____, have read and understood the above information and agree for my child/dependant (*PRINT his/her full name*) _____

to be included on the NSW & ACT Hereditary Cancer Registry.

Your signature: _____ Date: _____

Date of birth: _____ Address: _____