

Inherited Cancers Australia – Pilot Inherited Cancer Support Service

March–August 2025 (1 day per week)

Funded until August – no ongoing funding secured

At a Glance

- 35 individuals supported in 6 months
- Delivered via video, phone, and email based on patient preference
- 18 service days total (approximately 2 new consultations per week plus follow-up support)
- Support included both initial consultations (45–60 min) and follow-up advice

Who We've Helped

- 15 gene-positive individuals without cancer
- 16 with personal cancer history
- Remaining: partners, siblings, and parents seeking support for family members
- 2 males, majority female, most BRCA1 or BRCA2
- Unique, high-complexity cases:
 - Individuals with dual pathogenic variants (e.g. BRCA2 + RET, BRCA1 + BARD1)
 - Rare syndromes: Lynch (MLH1), FAP (APC), MEN2

What They're Asking

- How to talk to children about cancer and testing
- Interpreting Medicare items and financial hardship support
- Reproductive options and decision-making about risk-reducing surgery
- Guidance on surgical menopause, public vs private care, and risk management
- Help understanding and interpreting CanRisk and clinical guidelines

What They're Saying

"Without ICA you wouldn't get the human side of things – everything else is really clinical"

"It was exactly the additional information I needed to make an informed choice... and to be honest, saved me from unnecessary surgery."

"Without ICA I would feel alone in this journey. ICA made a real difference."

Why This Matters

Genetic testing without support is incomplete care.

This pilot has proven that even one day per week of access to specialised, trauma-informed genetic counselling can fill a critical gap for people living with inherited cancer risk.

Funding Ends in August

This service is low-cost, high-impact, and in high demand. Without government support, we risk leaving these individuals to navigate cancer risk and complex decision-making alone.

What's Needed

- Sustainable funding to continue and expand this service
- Recognition of ICA's role in bridging the post-testing gap
- Partnership with government to embed this model into preventive care pathways