pink hope
HEREDITARY CANCER

2023 — 2024

Annual Report

Australia's leading patient-focused organisation committed to supporting people to reduce their risk of hereditary cancer.

pinkhope.org.au

Pink Hope acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.

Pink Hope inspired Indigenous artwork developed by Ngunnawal sisters Jazz and Kristal @wilaydesigns

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OVERVIEW

About Pink Hope

We are a patient-focused organisation committed to supporting people to understand and reduce their risk of hereditary cancer. We provide evidence-based information to help break the cycle of cancer in Australian families and encourage conversations that save lives. We empower people to take charge of their own health by assessing, understanding, and reducing their risk of cancer. And we offer support every step of the way.

PERSONAL SUPPORT

We provide personalised support for your situation to help you better understand your risk of cancer.

EDUCATION

We are dedicated to providing you with expert-led and evidence-based resources for every stage of your hereditary cancer experience.

ADVOCACY

We're constantly striving for more awareness of and support for families at an increased risk of cancer.

Our Mission

We want to empower all Australians to understand and act upon hereditary cancer risk by educating them about their health history, providing them with evidence-based resources and connecting them to a supportive, nurturing community. We work collaboratively with healthcare providers to ensure a better transition for at-risk people as they move through each stage of their experience. We promote open discussion around family health history in Australia through targeted campaigns and education. We also advocate for those at risk of cancer and their families with the aim of earlier diagnoses, risk reduction, and better treatment options.

A MESSAGE FROM OUR CHAIR

Chairman's Report for the year ended 30 June 2024

It gives me great pleasure to write to you as the Chair of Pink Hope and to reflect on what has been another successful and busy year.

I would like to start by expressing my sincere gratitude to two long-term Board members, Cassandra Kelly and Elise Stanberg, who departed this year after many years of dedicated service. Serving as a Board member of a charity demands significant personal commitment, and we were fortunate to benefit from the insights and oversight of such high-calibre professionals.

Our team have continued to deliver on our purpose "to empower people with information and understanding of inherited cancer to help them manage their cancer risk".

This year, we have engaged in groundbreaking and significant research, with our CEO, Sarah Powell, co-authoring and presenting data from the inaugural patient-led study on the challenges women at risk of breast cancer face regarding access to genetic testing and genetic counselling.

We initiated a National Hereditary Cancer Risk survey to enhance advocacy and support for affected families and engaged in several additional research programs, all with the aim of improving outcomes for those in our community.

We continued our advocacy work, including hosting events at Parliament House, submissions to the HTA process to support cancer therapies and tests being listed on the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) and providing feedback during the Government consultation into the use of genetic testing in life insurance.

Our incredible team continues to meet with our community members "where they are" hosting valuable information and support days, high teas, much-needed getaways and community catchups across the country.

We don't do this alone.

I want to thank our wonderful supporters, the donors, medical collaborators, the charities that walk beside us, the companies that provide their expertise and most importantly our community who trust us with their stories.

All of you help us fight inherited cancer with knowledge, transparency and most importantly, hope.

Deborah Homewood
Board Chair

A MESSAGE FROM OUR CEO

Chief Executive Officer's Report for the year ended 30 June 2024

As we reflect on another year of significant achievements and growth, I am grateful for the unwavering commitment and dedication of our team, board, volunteers, and supporters. Together, we have continued to make a tangible impact on the lives of families affected by inherited cancer risk in Australia.

Our education events, fundraisers, support programs, and campaigns have enabled us to reach a broader audience, increase awareness, and provide crucial support to those who need it most. Highlights include facilitating sixteen in-person education events, online webinars, community catchups, and fundraisers that brought our community together - sharing the latest information and providing a safe space for our families to connect. Exhibiting at conferences and hosting events allowed us to share our expertise and learn from other leading organisations and experts in the field of hereditary cancer.

Our digital campaigns, such as Navigating Metastatic Cancer, Know Your Normal and mini-documentary series on triple-negative breast cancer have been widely accessed due to our impressive digital media reach. We also launched our first Hereditary Cancer Survey, collecting data to give a voice to the many thousands of Australians impacted by inherited cancer risk.

We are proud to have been involved in several research projects ensuring the patient is always front and centre. One of these is the MAGENTA study on which I was the lead author and honoured to present at the European Society for Medical Oncology (ESMO) meeting in October 2023. We have been invited to contribute to many other studies that are pushing the boundaries of inherited cancer research and paving the way for new treatments and therapies.

We have been honoured to be part of various working groups and committees including the kConFab Executive Committee, InGena Consumer Advisory Group, and supporting Cancer Australia on the implementation of the Australian Cancer Plan. We continue to contribute to the development of national frameworks, policies and consultations that focus on the needs of our community.

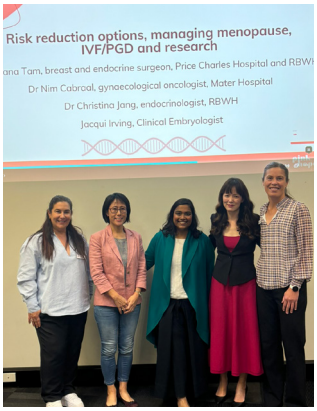
Our advocacy efforts continue with several events helping to raise awareness about the challenges our families face and the crucial need for support and evidence-based information. I am particularly proud of our event at Parliament House Canberra for Breast Cancer Awareness month, hosted in collaboration with Kylie Tink MP and Parliamentary Friends of Cancer Care and Cure. We also supported many submissions to PBAC in support of new therapies and tests giving more options to those diagnosed with cancer, as well as a 5,000-word response in support of changing the legislation on insurance discrimination.

As we look ahead to the next year, we are excited to continue our work in education, support and advocacy for families affected by inherited cancer risk. I am grateful for your ongoing support and look forward to sharing our future successes with you.

Together, we can make a difference in the lives of those affected by inherited cancer risk. No one should be disadvantaged by their genes.

Sarah Powell
Chief Executive Officer

KEY ACTIVITIES AND ACHIEVEMENTS



Information and Support Days

We continued our commitment to providing evidence-based education and support through our well-attended Information and Support Days held in Melbourne, Perth, Adelaide and Brisbane. These events bring together experts to share the latest information relevant to the hereditary cancer community.

Designed as panel-style discussions, these sessions allowed attendees to engage directly with experts. They also featured powerful personal stories from community members navigating an increased cancer risk. Beyond providing valuable insights, these events encouraging meaningful connections and support among attendees.

Community Catchups

Whenever we travel for events or conferences, our team hosts Community Catchups—casual gatherings where our community can connect, share experiences, and support one another.

In the 2023–24 financial year, we held five Community Catchups across Australia, bringing people together in Adelaide, Sydney, Perth, Canberra, and Brisbane.

Online Support Groups

Our two private groups provide a safe space for people assigned female at birth to connect, share experiences, and ask questions with others facing similar challenges. In June 2024, there were 2676 members, and they continue to offer a supportive and understanding community.

Online education and community outreach

Over the past year, we hosted a range of online education and information sessions, including Menopause and HRD Testing Webinars. We also held online Focus Groups for Men, Regional and Rural Communities, people with Ashkenazi Jewish ancestry, and LGBTQI+ people with inherited cancer risk.

Our focus groups aimed to gather in-depth, qualitative insights from diverse community groups. By encouraging open discussions, we gained a deeper understanding of the gaps in care and the unique challenges these people face.

Giveback Retreat - September 2023

In partnership with Girls Getaways, ICA hosted several community members for an all-inclusive pampering retreat in Torquay, Victoria. These deserving women enjoyed a luxurious weekend of meaningful conversations, shared experiences, delicious in-home meals, banquet seaside dinner, and plenty of special treats and pampering.

CAMPAIGNS, EVENTS AND FUNDRAISING

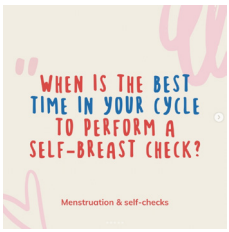
Over the past year, we have launched impactful campaigns, events, and fundraising activities to educate, engage, and empower our community.

Through these initiatives, we continue to raise awareness, amplify community voices, and push for real change—ensuring that those at risk of hereditary cancer receive the support, resources, and awareness they deserve.

October 2023

Know Your Normal

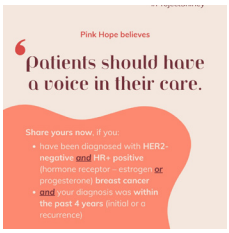
In recognition of Breast Cancer Awareness Month, we promoted our Know Your Normal campaign—a powerful initiative educating people on the importance of self-breast checks. Through engaging videos and social media content, we provided step-by-step guidance on how to perform self-exams, encouraging early detection and proactive health management.

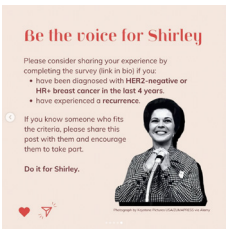


December 2023

Project Shirley Survey Launch

Project Shirley was a national research initiative led by Inherited Cancers Australia, inspired by breast cancer advocate Shirley Temple Black. The project gave over 100 Australians with early and advanced breast cancer the chance to share their experiences, highlighting key unmet needs. Their insights are helping to shape better patient-clinician conversations, guide support programs, and inform long-term improvements in breast cancer care.

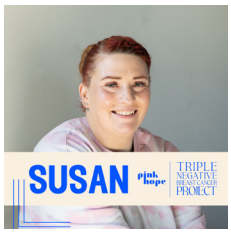




March 2024

TNBC Docuseries & Stories

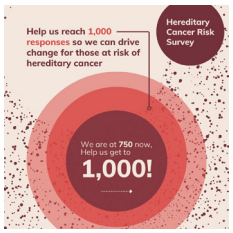
Triple-negative breast cancer (TNBC) presents unique challenges, and our TNBC docuseries provided a platform for powerful, real-life stories from those impacted. This campaign raised awareness and the urgent need for better treatments and support systems.



May 2024

National Hereditary Cancer Survey

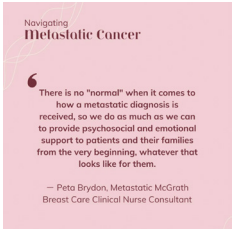
Our National Hereditary Cancer Survey was launched to gather critical data on the lived experiences of those affected by inherited cancer risk. The insights gained will be used to drive policy change, improve support services, and advocate for better and more affordable access to genetic testing, support services and risk management options.



April 2024

Navigating Metastatic Cancer

A metastatic cancer diagnosis comes with many challenges, which is why we created the Navigating Metastatic Cancer page—an evidence-based hub designed to support patients and their families. This resource provides trusted information, personal stories, and expert-reviewed guidance to help people make informed decisions about their care.



16 July 2023
Melbourne High Tea

13 August 2023
Sunshine Coast Marathon

2 March 2024
Canberra High Tea

13 August
City to surf – Running event

Signature High Tea events

Our exclusive High Tea events in Melbourne and Canberra brought together our team, community members, friends, family, and supporters. Guests enjoyed delicious food, great company, and exciting prizes while engaging in informative discussions on cancer risk management. Topics included breast checking and exploring family health history in a warm and welcoming atmosphere.

Running teams

This year, we officially entered teams into City2Surf and Run Melbourne, bringing our community together to raise awareness and fundraise. Thank you to all our supporters and team members for joining us and making a difference.

Other major events

Hosting these events has been essential in amplifying the voices of those living with an inherited cancer risk. Through the TNBC Docuseries Screened in Melbourne, the TNBC Event at Parliament House in Canberra, hosted in collaboration with Kylea Tink MP and the Parliamentary Friends of Cancer Cure and Prevention, and our Hereditary Cancer Awareness Event at Parliament House in Melbourne with MP Katie Hall, we have been able to highlight the urgent challenges faced by our community. These events have shed light on the financial burden, healthcare inequities, and obstacles our community experiences, as well as the critical need for better access to life-saving treatments and support.

Additionally, our Peer Support Mentor Program workshop in Sydney provided training to our dedicated mentors, equipping them with the skills to support those navigating hereditary cancer risk. Peer support remains a cornerstone of our work, ensuring that no one must face this path alone.

By bringing together policymakers, advocates, and the community, we continue to drive meaningful change, advocate for improved healthcare access, and push for better outcomes for those at high risk of cancer

7 September 2023
TNBC docuseries screening - Melbourne

8 March 2024
IWD event at Parliament House with MP Katie Hall - Melbourne

18 October 2023
TNBC event at Parliament House with MSD and Kylea Tink MP (Parliamentary Friends of Cancer Care and Cure) - Canberra

15 March 2024
Peer Support Mentor Program workshop

HAYLEY'S STORY

Hayley Clarke was 34 when she was told she had the BRCA2 gene mutation.

This meant that she is at a higher risk of developing breast and ovarian cancer.

"When my mother passed away from metastatic breast cancer in 2012, I decided it was time to find out my own health risks. I visited genetic counsellors in Bendigo and discussed the health history of my family tree with them. I was told that as my mother's type of breast cancer was not genetic then testing was not a priority. Although I had a gut instinct telling me to push the issue, I let it go for a while.

"Then in 2016 I received a letter from Lifepool, part of The Peter MacCallum Cancer Centre, asking me to take part in a genetic research project. I am unsure how I made it onto their mailing list – I must have ticked a box at some stage to give them permission to contact me. They requested a blood sample which was to be used for research into genetic mutations.

Initially I put it on my never-ending list of things to do. Then, about 18 months after receiving the request, I took the pathology slip and had a blood test.

"It was December, around six to nine months later, when I received a letter from Lifepool, inviting me to call them to discuss my results. When I called, the man on the other end of the phone asked me if I had ever heard of the BRCA gene mutation. When I told him that I had pushed for my own testing, he gave me the news. I was positive for the BRCA2 genetic mutation. I was in shock. My gut feeling had been right all along.

"Everything kicked up a gear. I had an appointment with the genetics team at the Austin Hospital in Melbourne, where they went over my results and what this meant for my future health. They were very thorough and clear about my options: I could keep having mammograms and ultrasounds of my breasts to watch for abnormalities or I could investigate preventative surgery.

"Watching my beautiful mum pass away from this horrible disease at such a young age made the decision easy for me. My family was complete, and I did not want my children or my husband, Julian, to have to go through what I did. Especially if there was a way I could prevent it. I decided to have preventative surgery to get the ticking time bombs off my chest.

"With the support and guidance from my surgeons, nurses, doctors, psychologists, breast care nurses, Julian, my family and close friends I was ready to have my double prophylactic mastectomy with reconstructive surgery. It was scheduled for Friday, 15th December 2017. My feelings were mixed and contradictory. I was scared and worried, but at the same time I knew it would be a huge relief. I had implants which will be reviewed in ten years for a possible replacement.

"Now, nearly six years on at the age of 40 years, I am about to undergo an oophorectomy to eliminate my chances of developing ovarian cancer. I continue to have an MRI every five years for continuing reviews following my mastectomy.

“My relationship with my body has changed. I have had to learn to love the breasts I have now, which was difficult for me - my previous breasts were such a sexual part of my intimacy with my husband. I now have very limited sensations.

“This journey has been hard and long. Thankfully, I have had the support of my family, some of whom are also BRCA2 gene positive. The Pink Hope Community has also allowed me to network amongst other members in a similar situation. My community has encouraged me and given me the strength to advocate for myself, as well as the amazing people whom I have sadly lost along the way. These people were also BRCA2 positive and gained their angel wings, so I am their voice now.

“The biggest lesson I have learnt is that each choice a person with the BRCA2 gene mutation makes is an individual one. Just because it was easy for me to make the decision for preventative surgeries does not mean it is as easy for other family members. I have also had to learn not to blame myself for the possibility of my children inheriting the BRCA2 gene.

When the time comes for them to be tested, I will support and guide them as much as they need.”

With this genetic knowledge, Angela felt empowered to take control of her health through early screening and breast checks. She shared, “It meant that I had the knowledge to start screening and breast checking early. Because of that, I could catch the breast cancer before it spread to my lymph nodes.”

PINK HOPE ADVOCACY

Advocacy and Research

We continue to make a meaningful impact through our programs and advocacy efforts.

We've taken every opportunity to present, participate in panels, and raise awareness about the 1 in 400 people who carry a gene mutation that increases their cancer risk. This has included ongoing feedback and submissions to support the inclusion of essential medications and tests on the Pharmaceutical Benefits Scheme (PBS) and the Medicare Benefits Schedule (MBS). This year alone, our team prepared five submissions to the Pharmaceutical Benefits Advisory Committee (PBAC) in support of new cancer therapies being listed on the PBS. Ensuring timely access to medicines and tests is critical, which is why we also contributed feedback to the Health Technology Assessment (HTA) review. Additionally, we continue to be actively involved in key working groups and research projects that impact the hereditary cancer community.

Our commitment to improving outcomes for those at high risk of inherited cancers remains at the heart of everything we do.

Conference attendance

Attending national and international conferences is an important part of our awareness work, ensuring that the voices of the inherited cancer community are heard in key discussions shaping healthcare policy, research, and patient support. By engaging with experts, policymakers, and industry leaders, we advocate for better access to genetic testing, improved care pathways, and greater awareness of hereditary cancer risks.

Over the past year, we've proudly represented our community at conferences across Australia

and globally, including Familial Aspects of Cancer (Kingscliff, August 2023) Medicines

Australia PharmAus (Canberra, September 2023) CanForum (Canberra, October 2023) Gilead Community Awards and Conference (Madrid, November 2023) Patient Voice Initiatives(PVI) Data Collection for Patient Organisations (Canberra, February 2024) Women's Health Summit (March 2024) Cancer Nurses Society of Australia Congress (Brisbane, European Society for Medical Oncology (ESMO) Madrid June 2024) Facing Our Risk of Cancer Empowered (FORCE) Conference (Philadelphia, June 2024). Each event strengthens our ability to drive change, build partnerships, and ensure that the inherited cancer community remains at the forefront of conversations about prevention, treatment, and support.

29 August – 1 September 2023
KconFab Kingscliff

6 September 2023
Medicines Australia PharmAus
Canberra

17 October 2023
CanForum Canberra

20 – 24 October 2023
ESMO Madrid

Nov 2023
Gilead Community Awards and Conference Madrid

13 – 15 June 2024 Philadelphia FORCE Conference

21 June 2024
Brisbane Cancer Nurses Society of Australia Congress

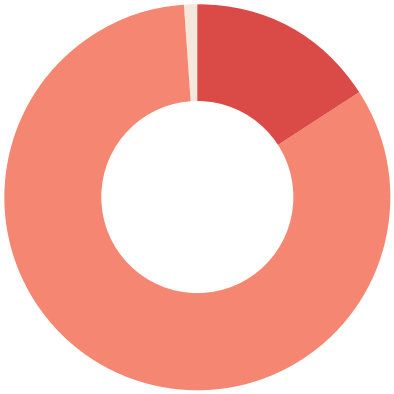
26 February 2024
PVI Data Collection for patient Organisations Canberra

4 March 2024
Women's Health Summit

FINANCIAL OVERVIEW

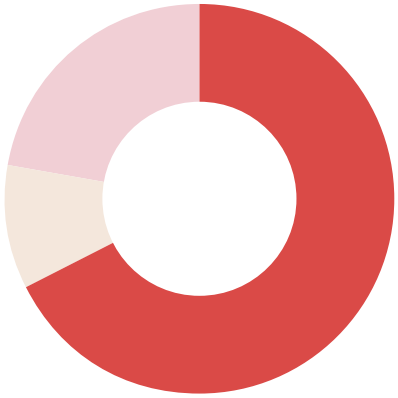
Income

Income Sources



Donations & Fundraising	$117,373.00	16%
Sponsorships & Grants	$607,171.00	83%
Interest	$10,448.00	1%
	$734,992.00	100%

Expenditure



Programs and Services - Support, Education & Advocacy	$638,986.00	67%
Fundraising & Events Expenses	$95,082.00	10%
Governance & Operations	$212,762.00	22%
	$946,830.00	100%
	$(211,838.00)	

pink hope
HEREDITARY CANCER

SUPPORTERS

AstraZeneca
gsk
ooh!
MSD
NOVARTIS
GILEAD Creating Possible
elm
kConFab Kathleen Cuningham Foundation Consortium for research into Familial Breast cancer
GIRLS GETAWAYS ESCAPE. INDULGE. RELAX.
Lilly
Ogilvy
MONASH University
DNA Screen POWERED BY MONASH UNIVERSITY
Peter Mac Peter MacCallum Cancer Centre Victoria Australia
ST JOHN OF GOD Subiaco Hospital
branded products® established 1999 Your Branding Partner
Creative Advocacy SOLUTIONS

Finally, our biggest thanks
go to our community.

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