pink hope
HEREDITARY CANCER

2022 — 2023

Annual Report

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

pinkhope.org.au

CONTENTS

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

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.

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 journey. 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.

PERSONAL SUPPORT

We provide personalised support for your situation to help you better understand the risk of breast, ovarian and prostate cancer.

EDUCATION

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

ADVOCACY

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

A MESSAGE FROM THE CHAIR

Chairperson's Report for the year ended 30 June 2023

Dear Pink Hope Community,

As another year draws to a close, it prompts us to reflect on what truly matters: our unwavering commitment to our mission.

At Pink Hope, our aim might sound straightforward: to ensure Australians are well- informed and proactive about hereditary cancer risks. However, the depth of our work lies in educating individuals about their health history, offering reliable resources, and nurturing connections within a supportive community.

Our Board and management team's dedication to this cause remains steadfast. We firmly believe that serving our community is not just a responsibility, but a profound honour.

Central to our belief is that no individual should feel alone while grappling with emotions or while navigating the intricate journey that comes with understanding and confronting hereditary cancer challenges.

While our shared path continues, with its mix of challenges and opportunities, it's crucial that we pause to acknowledge our achievements. This past year, some of our proudest moments include:

- Organising over 20 educational, support, and fundraising events across nearly every State and Territory in Australia;
- Advocacy initiatives, such as the event we hosted at Canberra's Parliament House, where we spotlighted challenges faced by families dealing with hereditary cancer;
- Pink Hope's campaign and visibility during World Ovarian Cancer Day, which included more than 30 radio interviews; and
- Launching a self-breast check reminder during Breast Cancer Awareness month; and

To conclude, I wish to extend my heartfelt gratitude to our resilient community, the dedicated Pink Hope team, our medical collaborators, the experts guiding our steps, our generous sponsors. donors, and my esteemed fellow Board members. Each contribution, no matter its size, is invaluable. Each one of you truly makes a difference.

Thank you for partnering with us on this vital journey.
Together, we can continue pushing for and achieving better outcomes.

Warmest regards,

Cassandra Kelly
Acting Chairperson

CHIEF EXECUTIVE OFFICER'S REPORT

Chief Executive Officer's Report for the year ended 30 June 2023

As we come to the close of another successful year, I have enjoyed reflecting on all our experiences, successes and appreciating the impact we've had. As Australia's only organisation supporting families with hereditary cancer risk, we continue to learn, adapt, and grow. Once again, I could not be prouder of my team at Pink Hope, who continually go above and beyond to support our community.

We've had a busy year and there are so many highlights to mention:

- **EDUCATION EVENTS**
  We ran four face-to-face educational events across Australia bringing together experts to deliver evidence-based information on various aspects of being at high risk of cancer. We tailored these events to the needs of our community and the latest research. We enjoyed providing our less formal engagement and education across Instagram hosting different guests, speaking about topics relevant in the hereditary cancer space.

- **COMMUNITY CATCHUPS**
  We hosted 11 events in different parts of Australia, giving our community the opportunity to connect and support one and other.

- **FUNDRAISING EVENTS**
  Our events included four Pink Hope Signature High Teas and two running events, all an excellent opportunity for our community to get together for a good cause.

- **ADVOCACY**
  Our important work continued, hosting an event at Parliament House in Canberra, highlighting the challenges our community face to members of Parliament, including one of our community's biggest challenges around categorisation and wait times for prophylactic mastectomies. We drafted 10 HTA submissions, supporting access to vital medications and tests. In June, Alicia Payne MP spoke about Pink Hope in Federal Parliament. We held a roundtable discussion with patients and healthcare professionals focused on metastatic cancer. The valuable data from this activity will drive new information and resources for our community and will inform our future advocacy efforts.

- **HEALTHCARE PROFESSIONAL EDUCATION**
  We enjoyed engaging with healthcare professionals at several clinician focused conferences including exhibiting at HealthEd, Australian Primary Healthcare Nurses Association conferences and the Australian Pharmacy Professional conference.

- **HEALTH CAMPAIGNS**
  For Breast Cancer Awareness Month, we focused on self-breast checking with our Know Your Normal campaign. We set up a reminder service where people can sign up to receive a regular SMS and email, helping them to remember this important check. For World Ovarian Cancer Day, we did 27 radio interviews reaching an estimated 13.4m Australians, discussing the link between ovarian cancer and hereditary mutations and the signs and symptoms to look out for.

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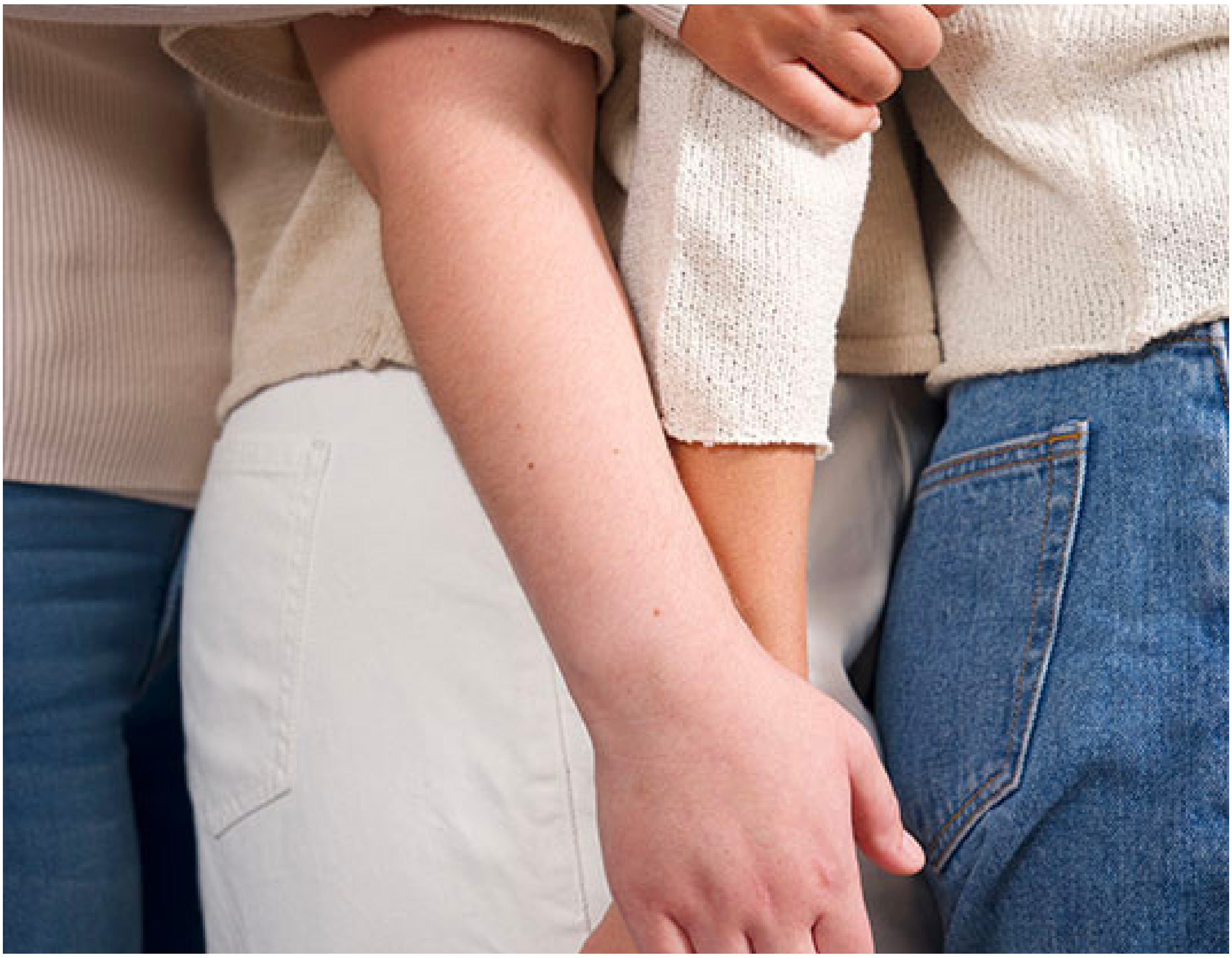
On the financial front, we invested some of the profits from the previous two financial years into the organisation. This included increasing our programs, building our capacity and capability in the team, and creating new and updated resources on our website.

None of this would be possible without our dedicated partners supporting Pink Hope and our mission of breaking the cycle of hereditary cancer in Australian families.

Every week, I have conversations with our community that reinforce the absolute need for the education programs and support services we provide. These are new people who are facing a higher risk of cancer due to a hereditary cancer gene variation or those who have known for some time but are now facing the unthinkable task of talking to their children or families about what it means for them, or deciding when the best time is to have surgery. Hereditary cancer is a condition that doesn't end with you; it's a constant cycle that often never ends. Pink Hope is here to support these families with their conversations and decisions, and we want to empower our community to manage their risk, informed.

My final words are to thank the many people and organisations who continue to support our vision, believe in us, and want to help us continue the vital work that we do. Thank you to every one of you. We are very fortunate to have such a supportive and dedicated community, sponsors, Board, and team, and I couldn't be more honoured to be leading the charge for Pink Hope now and into the future.

Sarah Powell
CEO



SUPPORT SERVICES
& PROGRAMS

Information and Support days

Continuing our strong track record of delivering evidence-based education and support, we again held our popular Information and Support Days. These are important events where we bring together experts to present up-to-date information relevant to the hereditary cancer community.

Robyn, our Programs Manager, facilitated our Information and Support days in Brisbane and Adelaide. These were panel-style events, making it easy for attendees to engage with the experts. These events always include community members sharing their stories and experiences of being at high risk for cancer. Not only are these events valuable for information gathering, they provide an excellent opportunity to engage with other community members.

Edu events

We held two face-to-face education events: one focused on *living well with metastatic cancer* and the other, *tumour testing in ovarian cancer*. These events included expert speakers, community speakers sharing their lived experiences, and time for community to network.

Online Support Groups

We are leading up to our 10th year managing our popular online support groups. These two groups allow women to connect, share experiences and ask questions within a community of people in a similar situation. Now, with over 2,400 members, these private groups continue to provide a safe place for women to support each other.

Metastatic Cancer Roundtable

One of our focuses over this year was investigating the experiences of those with metastatic cancer. After our valuable focus groups in early 2022, we held a roundtable workshop bringing together many patients, health professionals and other health organisations to delve into the intricacies of living with metastatic cancer. This was a great opportunity to bring together many different organisations and health professionals from all aspects of the cancer field. We look forward to launching our report in the future.

Community Catchups

Whenever we travel, the Pink Hope team host Community Catchups. These events always coincide with another event or conference we attend. Our community love these casual catchups to share and network with other high-risk cancer people. We had record numbers at our Adelaide event this year, which coincided with International Women's Day. We held seven Community Catchups across this financial year. In May 2023, we organised our inaugural Nip and Sip gathering. This occasion offered women from the Pink Hope community and beyond a chance to connect and contribute by creating and 'donating' a mould of their nipple. These moulds are utilised to produce silicone prosthetics for women who have undergone mastectomies.

Giveback Retreat

In partnership with Girls Getaway, Pink Hope hosted several community members for an all-inclusive pampering retreat in Byron Bay. These deserving women enjoyed a luxurious weekend filled with in-house pampering sessions, delectable banquet dinners, and other delightful treats.

Genetic Testing Grant

Thanks to sponsorship from SHEIN, we provided complimentary genetic testing and counselling to 50 individuals. Teaming up with Eugene, an Australian-founded company dedicated to offering accessible end-to-end care for all, we empowered these 50 selected applicants to make informed decisions about their health.

CAMPAIGNS, EVENTS AND FUNDRAISING

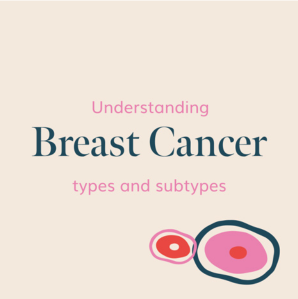
Understanding Breast Cancer

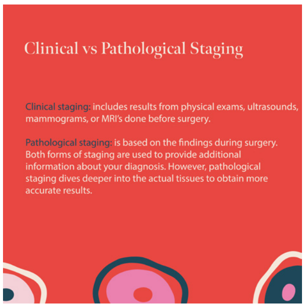
Understanding Breast Cancer campaign was designed to raise awareness about the different types, subtypes, stages, and grades of breast cancer while providing evidence-based resources that help support those experiencing the complexities of this disease and their carers.

This aim of this educational campaign was to promote easy-to-understand information and evidence-based resources from Pink Hope's website. These resources aim to educate patients and their caregivers (support individuals) about personalised treatment options and enhance their comprehension of the diverse nuances encompassed by the term "breast cancer."

"We're told that after cancer treatment we won't sweat the small stuff

but sometimes the seemingly small stuff is part of the long tail of the *Big Stuff*."





Clinical vs Pathological Staging

Clinical staging: includes results from physical exams, ultrasounds, mammograms, or MRI's done before surgery.

Pathological staging: is based on the findings during surgery. Both forms of staging are used to provide additional information about your diagnosis. However, pathological staging dives deeper into the actual tissues to obtain more accurate results.

"Some friends disappear when you're diagnosed with breast cancer, others step up"

Let us know your experiences in the comments

Generation PINK

Generation Pink is a campaign developed in partnership with SHEIN, with the goal of raising awareness and fostering positive transformations for women dealing with breast and ovarian cancers.

This project aimed to equip Australian women with the knowledge and motivation to perform breast examinations, assert their health needs, and initiate crucial discussions with their loved ones—raising inquiries such as, 'What types of cancer are prevalent in our family?' and 'What proactive steps can we take?' The campaign delves into various subjects, ranging from understanding health literacy to overcoming obstacles related to accessing genetic testing, addressing body image concerns, and managing sexual health post-cancer treatment.

Know your Normal

Our Breast Cancer Awareness Month campaign- ‘Know Your Normal’ encourages vital discussions regarding self-examinations, empowering women to conduct them regularly with confidence. This campaign introduced Pink Hope’s innovative automated self-check tool, created to educate women and their families about the significance of regular self-examinations and demonstrate thorough techniques for performing these checks. This helps to establish a baseline for their breasts and foster a sense of ease and confidence among women when self-breast checking.

Signature High Tea events

Our exclusive High Tea events took place in Melbourne, Gold Coast, Canberra, and Melbourne, bringing together our team, the Pink Hope community, friends, family, and supporters. Each gathering featured delicious food, wonderful company, and exciting prizes, along with informative sessions on cancer risk management. We delved into topics like breast checking, exploring family health history, and the mission of Pink Hope, mixing in a touch of seriousness amidst the fun.

Bright Pink Lipstick Day #DareToShare

In September 2022, we commemorated the 10th anniversary of our Bright Pink Lipstick Day campaign. This year, our emphasis was on the idea that cancer doesn't wait for anyone. We urged our community and followers to join us in acting by wearing their Bright Pink lipstick on September 16 and engaging in discussions about their family health history. We called upon our community to show support through donations, fundraising efforts, or by purchasing a Pink Hope Lipstick.

Running teams

We formally entered teams into the Sydney Running Festival and Run Melbourne this year. This was a great opportunity to get community members together and raise awareness and funds for Pink Hope. We started small and look forward to growing this in the future. Thanks to all our supporters and team members for putting on a Pink Hope t-shirt and joining our teams.

ANGELA'S STORY

"I feel like a Pink Hope Success story… they have been instrumental in encouraging me to be proactive in my health"

At just twenty-seven years old, Angela was diagnosed with ductal carcinoma in situ (DCIS), an early-stage breast cancer. Her family history deeply influenced her experience, with Angela's grandmother, grandfather, and great-grandmother grappling with early-onset breast and ovarian cancers.

The pivotal role of family history became evident when Angela's aunt and mother prompted her to undergo BRCA genetic testing, revealing that she, along with her brother, carried the BRCA 2 genetic mutation at the age of twenty-three.

> *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."*

Angela stated that she also had a regular self-breast check routine between her yearly GP visits and checks, but the most crucial element was staying on top of her risk and getting her screening done.

Angela's vigilance in breast health was driven by the impact of her family's history. Despite initial recommendations against early screening, Angela's belief in the power of self-advocacy pushed her to challenge advice.

> *She mentions, "When I found out I had the BRCA gene mutation, I was advised not to start screening until I was thirty because the risk of getting cancer at a young agewas really low. My question was then…well, am I going to be in the 99% that it won't happen or in the 1% that it could happen? And I think knowing that there was always a chance, I really advocated for myself and pushed back."*

After receiving a referral from her GP, Angela underwent a series of screenings, including a mammogram, MRI, and ultrasound. She said, "The process was really straightforward for me. I got the screening done, then the biopsy, followed by a bilateral mastectomy and sentinel lymph node biopsy three weeks after my DCIS diagnosis."

"I was already familiar with Pink Hope and had engaged in discussions within the community about bilateral mastectomy, which made it clear to me that it was the path I wanted to take. The diagnosis itself made the surgery a no-brainer for me."

"Once I got my results from the node biopsy, I found out the staging was high-grade DCIS, and my medical team decided I didn't need any further treatment in terms of suppressing the hormones since I was young and still wanted to have children."

Despite the straightforward nature of the treatment process, Angela navigated physical and emotional challenges.

"After surgery, it took about six weeks until it got to a point where I could function like before and then another few months until I felt like I could get back to normal and start exercising and moving my body. The healing process takes time, and you have to be really gentle with yourself."

"Emotionally, it was a shock for me, but trying to look at the positive side of it all helped me manage. It's easy to let your mind wander into dark places because of the negative associations with the word 'cancer'. My advice

is to stay off the internet and not go down that research rabbit hole. Listen to what your doctors have to say."

> *"I also think it helped that I was proactive in making decisions, knowing that I had options and a great team of doctors around me that I could trust."*

When asked about her self-image and relationship with her body throughout her experience, she said, "It was really confronting, but I now have a deep respect for my body and what it's been through. It's translated to how I look after myself by eating well and exercising. I always tried to look after myself, but I take it much more seriously now."

"Physically, it's a work in progress every day in terms of what I look like, the scars I have, and what that means to me emotionally. Every day, I get better at seeing them as a symbol of strength, resilience and courage instead of the negative connotation of what it means to have had cancer."

"Having a tight-knit support group of close friends and family was also really important for navigating the experience. When creating that network, I found that not everyone will understand the weight of a cancer diagnosis and what you'll go through physically and emotionally. It's important not to dwell on that; instead, connect with people who can support you no matter what and who you feel comfortable to be open with because you can't do it alone."

"And, being open with my friends meant I had some influence over their breast health, prompting them to be aware that it can happen in your 20s and they could get checked."

Angela emphasised that she also found an invaluable source of support in the Pink Hope community.

> *"Pink Hope for me has been instrumental in encouraging me to be proactive in my health. They supported me from the beginning of my BRCA 2 diagnosis through surgery and beyond. I found the events informative and their blogs with personal stories so empowering. Those stories provided so much comfort for me, knowing that I wasn't alone."*

"I feel like a Pink Hope success story – I got informed early on through their resources, connected with the right doctors, was supported the entire way through and came out on the other side."

Angela's experience is a testament to the power of proactive breast health management, self-advocacy, and community support. She leaves this crucial advice, "Take charge of your health. If you know you have the BRCA gene, take it seriously. Advocate for yourself. Self-breast check and get screened – even if your doctor doesn't think you need it. If you feel in your body that you need it, then do it."

Discover Empowering Resources:

Are you facing a breast cancer diagnosis or want to support a loved one? Explore Pink Hope's breast cancer support resources for more guidance.

Self-Breast Check Automated Reminder:

To make self-breast checks part of your regular self-care routine, check out Pink Hope's automated reminder tool here.

SAM'S STORY

"I didn't have a regular self-check routine. I thought I was invincible"

At the end of 2022, after moving from Sydney to Melbourne, 33-year-old Sam noticed an unusual discomfort in her breast – her nipple appeared to be sticking to her bra. Sam's discomfort persisted, and she dismissed it initially as friction from her sports bra during workouts, escalating into a raw and sore sensation. By February 2023, she discovered an unfamiliar lump on the right side of her breast.

With a family history of breast cancer, Sam's concern prompted her to act quickly. She sought medical attention and underwent an ultrasound after her GP recognised the potential risk.

"At first, I asked how much the ultrasound would cost and then had to look at my calendar and work schedule to see when I could fit the appointment in – which happened to be three weeks later. After I told Mum, she suggested I get it checked sooner than that, so I moved the appointment forward a week."

"Once I got to the appointment, I knew that when I was in the ultrasound longer than fifteen or twenty minutes, and there were many moments of long silence from the technicians, something definitely wasn't right."

"Another doctor was brought in for a second opinion, which led to an immediate contrast mammogram and a biopsy. I thought the mammogram would be the worst part. I didn't even give the biopsy a second thought. They biopsied my breast and the lymph nodes in my underarm and needed three samples from each area, but I was in so much pain they couldn't get all of them from my underarm."

> *The biopsy results showed that Sam had HER2+ breast cancer. This diagnosis set the stage for a gruelling experience – chemotherapy, mastectomy, and potentially radiation. Her cancer was Grade 3 HER2+, having spread to three lymph nodes. Though her biopsy indicated Stage 2, surgery would confirm her exact staging later.*

Sam faced a whirlwind of medical consultations and scans while exploring fertility preservation options. "After being referred to a breast surgeon and having blood tests and an ECG, I was referred to an oncologist. From that point, everything was go, go, go!"

When asked about her treatment plan, Sam said, "They gave me the option to take chemotherapy and immunotherapy together – TCHP chemotherapy with Herceptin and Perjeta, which are HER2+ targeted immunotherapies."

"PBS doesn't cover Perjeta, so it was an additional $6,000. But knowing that it would decrease the amount of chemotherapy I needed – which would now be eighteen weeks of chemo on a three-week cycle – I said yes and went ahead with it."

At the time of the interview, Sam was still waiting to undergo surgery.

"I also opted to have the double mastectomy – I don't want to continue to wonder, and I never want to go through this again if I can avoid it. They gave me the option to have the DIEP flap or implants. I've opted to have the implants. I thought, why add stomach surgery, another scar and a longer recovery when I don't need to."

When asked about her relationship with her body during this experience, Sam said, “I was really worried about looking like a cancer patient. When told I would lose my hair, that was tough for me. There’s been weight loss and gain. My skin is pale, eyes are sunken – it’s really confronting looking in the mirror.”

“I’m yet to have surgery, so I’m nervous about what that will do to my self-image. I’m going from having these natural breasts my whole life to implants, which I never considered would happen. I’m not looking forward to that part, but hopefully, after recovery, I can look at myself and be happy with what’s there.”

When asked about a regular self-breast check before diagnosis, Sam mentioned,

> *“I didn’t have a regular self-check routine. I thought I was invincible. I was exercising five or six days a week, leading a pretty healthy, active lifestyle, and I’m young, so I didn’t think it would happen to me. But now I know cancer doesn’t discriminate. And although I have a family history with my aunty’s diagnosis eighteen years ago, it hasn’t been in my awareness since I was young, so I didn’t think about it.”*

Sam mentioned that she found unwavering support from her family, friends, and colleagues during her experience. “I’m close with my two female leaders at work and never have to hide any appointments from them. After my diagnosis, I called them to let them know what was happening, and we all cried together. I can imagine that conversation would be quite difficult if you don’t have a good relationship with your boss or people around you.”

When asked about the advice she would like to leave for anyone going through breast cancer, Sam said:

> *“Go and see the GP as soon as you feel something’s wrong. I know there are questions about the cost of things, and there’s less bulk billing around now, but in the grand scheme of things, it actually doesn’t matter. Your health is so important. The lesson for me was if you think something feels wrong, chances are, there probably is. Your gut will always be right.”*

“It’s your own experience, so you can try to take the advice from everyone else, but just remember that everyone’s journey is different, so don’t get too caught up in the details of everyone else’s story.”

Discover Empowering Resources:

Are you facing a breast cancer diagnosis or want to support a loved one? Explore Pink Hope’s breast cancer support resources for more guidance.

Self-Breast Check Automated Reminder:

To make self-breast checks part of your regular self-care routine, check out Pink Hope’s automated reminder tool here.

Pictured:
Sarah, Pink Hope CEO
Nikki, Pink Hope Community Member
Kylea Tink, Federal MP for North Sydney

PINK HOPE ADVOCACY

Pink Hope continues to have an impact through our programs and advocacy work. We held our first Parliamentary event focusing on the challenges those with hereditary cancer face – such as long wait times for prophylactic surgery. This event included members of parliament, health-focused organisations, industry members and, most importantly, our community. We also supported other events focused on triple-negative breast cancer and attended many health professional events where we could provide information about hereditary cancer and the services we provide. These included GPCE, APNA, APP, ASBD, HealthED and other smaller conferences.

We had opportunities to present, be part of panels and shine a light on the 1 in 400 people who carry a gene mutation, putting them at risk of cancer. We continue to provide feedback and submissions to support the inclusion of medications and tests on the Pharmaceutical Benefits Scheme (PBS) and the Medicare Benefits Schedule (MBS). We know that getting medicine and tests to patients quickly is essential, which is why we also provided feedback for the review of the HTA process. We continue to contribute to working groups relevant to the hereditary cancer community, and we continually seek opportunities in the media to raise awareness for the community of people we support. During Ovarian Cancer Awareness month, Pink Hope CEO Sarah Powell and Programs Manager Robyn Smith completed 27 radio interviews speaking about the hereditary aspect of ovarian cancer.

DIGITAL IMPACT

Our Reach

INSTAGRAM
22.1K FOLLOWERS

FACEBOOK
31K FOLLOWERS

TWITTER (X)
7.4K FOLLOWERS

LINKEDIN
1.1K FOLLOWERS

NEWSLETTER
5,000 + SUBSCRIBERS

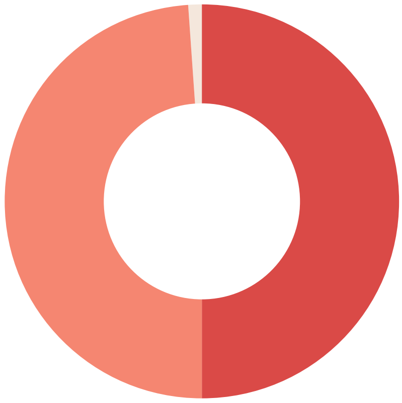
ONLINE SUPPORT GROUP
2.5K MEMBERS (AVERAGING OVER 220 DAILY ACTIVE MEMBERS)

WEBSITE
101K PAGES VIEWED

FINANCIAL OVERVIEW

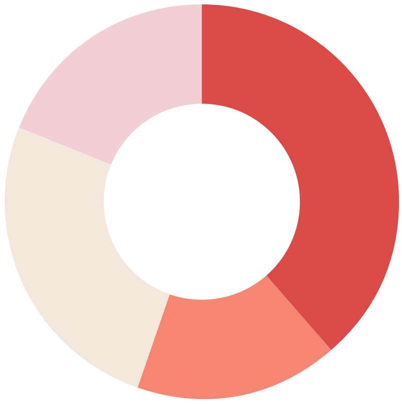
Income Growth

Income Sources



●	Donations and Fundraising	$386,301.00	50%
●	Corporate Grants and Sponsorships	$381,250.00	49%
●	Interest	$9,193.00	1%
		$776,744.00	100%

Expenditure



●	Programs, Education & Advocacy	$341,276.80	39%
●	Community Support Services	$146,414.80	17%
●	Fundraising & Event Expenses	$232,876.40	26%
●	Governance and Operations	$163,592.00	19%
		$884,160.00	100%
		$(107,416.00)	

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.

eugene
Lilly
Ogilvy
SHEIN

MONASH
University
DNA Screen
POWERED BY MONASH UNIVERSITY
Peter Mac
Peter MacCallum Cancer Centre
Victoria Australia

Finally, our biggest thanks
go to our community.

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