pink hope

2021 — 2022

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

Pink Hope is 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.

Our Core Values

Compassion, Inclusivity, Agility, Transparency, Community first, Curiosity, Collaboration and Innovation.

Our Vision

Our vision is that every Australian is informed and supported to manage their risk of hereditary cancer. We do this by providing personal support, education and advocacy.

Our Mission

Here at Pink Hope, 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.

A message from the chair

As I write this year's Annual Report update, I am indeed grateful for our amazingly dedicated team at Pink Hope who have remained selflessly committed to our cause throughout a period of relentless and uncertain change for us all.

Life pre-Covid, now seems a distant memory and we have found ourselves needing to constantly readjust, amidst stop-start lockdown periods and natural disasters that have seen parts of our country endure conditions where much-needed hugs have been all too often kept to a distance. I am therefore exceptionally proud of the dedication shown by our Pink Hope team to ensure our community could remain connected throughout this time and awareness, support, and education programs could continue to flourish.

Amidst a time when, most alarmingly, regular preventative check-ups have also diminished, our team has been actively working with healthcare providers to ensure people are reminded to remain vigilant about their health. We have increased our activations to ensure routine conversations are being held about family history. We successfully campaigned for better understanding of tumour testing in ovarian cancer to help ensure Australian women have access to the best treatment options and the most up-to-date information and advice. We also increased our focus on providing support for the metastatic cancer community this year, recognising a need to listen and answer their voice for change. Finally, we overhauled our website, recognising a need to make it easier to navigate and find evidence-based information to support our high-risk families across Australia.

Delivering to each of these programs amidst this period has not been easy. Acknowledging this, on behalf of the Board, I want to sincerely say Thank You. Thank you, not only to Sarah and the team at Pink Hope but to our loyal, and our new, sponsoring Partners and of course to all of you in our wonderful Pink Hope community. Throughout this year, as with every year, you remain our inspiration. The unwavering strength and resilience of our community fills us with perpetual energy and hope for a brighter future.

Finally, I would like to acknowledge this year as marking our amazing 10th anniversary of Pink Hope being a stand-alone charity. Having been personally involved with Pink Hope since its inception, I am so grateful for being part of an organisation that has remained authentic to its cause and continues to evolve in response to the changing needs of our community. In marketing this anniversary, Thank You, to our beautiful Founder, Krystal, for your personal story, passion, and commitment in starting this journey and helping ensure a voice of advocacy for many. Thank You, also, to our Board, many of whom have served as volunteer members for many years and become treasured friends and extended family.

As we venture into the next 10 years, our Pink Hope mission to educate, advocate and support our community will remain the same so we can help ensure every family in Australia has the power to identify and prevent their risk of hereditary cancer.

And for that, I remain truly grateful.

Melissa Hayes-Smit.
Pink Hope Chair

Chief Executive Officer's Report

The Pink Hope team have been incredibly busy and productive this financial year. Once again, I'm reminded how lucky we are to have such a dedicated and passionate team who constantly strive to support, educate, and advocate for those living with a high risk for cancer.

As we moved into a COVID-19 normal, we were able to run some face-to-face events. These included an Expert Panel Evening in Melbourne, an Information and Support Day in Sydney and our 10-year anniversary as a stand-alone charity held at The Langham who have been a very generous partner of Pink Hope for many years. We also held a fundraising High Tea in Melbourne and of course our Bright Pink Lipstick Day campaign to help raise awareness of hereditary cancer and ensure all Australians are having that vital conversation about their family's health history! We proudly held focus groups with a metastatic cancer focus because our metastatic community voiced their concerns about being an under supported group. In the coming months and years, we hope to drive big improvements for this group.

As Pink Hope grows, we are always looking to improve upon our programs and campaigns to support our community. We will be seeking feedback from our community to get insights into where we can tailor what we deliver, better. We will also be focusing on education of healthcare professionals, particularly in the primary care setting as we know these health professionals are the most accessible and they are often the first people a patient will go to when they have questions around their risk of cancer. We want to ensure these healthcare professionals are routinely asking people about their family history and referring their high-risk patients to Pink Hope for education and support. For our community, we aim to further support them with new programs such as a peer support initiative and we intend to hold focus groups looking at the unique groups within our community to ensure our organisation is inclusive and safe for all.

Finally, I would like to take this opportunity to thank our sponsors, donators, supporters, and community. Every day I am blown away by the generosity and kindness of the people we work with. The future of Pink Hope is looking bright with our fantastic team, partners, board, and plans for the future!

Sarah Powell
CEO

Support Services & Programs

Information and Support Days

Designed for individuals with hereditary cancer risk, Pink Hope's Information and Support Days feature expert Speakers presenting evidence-based information relevant to those with hereditary cancer risk or cancer. Pink Hope community members sharing their personal stories, and the opportunity for families to connect in person.

Pink Hope Programs Manager, Robyn, facilitated the first **Information and Support Day** Pink Hope has held since coming out of the Covid-19 lock down period. This event was Sydney based and involved a fresh new 'panel style' approach where attendees were able to ask questions and hear from experts in a less formal way. Information and Support Days remain the most popular of our education activities and are a great avenue for our community to gather evidence-based information to support managing their risk of cancer.

Pictured: Sydney Information and Support Day

Online Support Groups

Pink Hope facilitates two online support groups where women can receive peer support or connect with other women in a similar situation. These closed and private groups are a great way to connect with women who are going through the same decisions, surgeries, or challenges as other high-risk women. People jump in to give support, provide reassurance, or share experiences. Members are required to follow the group guidelines which are published in each group. With over 2,000 women in the groups, it is clear that these groups provide great value to our community.

She Shares

Our She Shares events are a place for women to share laughs, thoughts, questions and advice. These events are held across the country and involve various activities and thoughtful interactions with others who truly "get it". We aim to create engaging and enjoyable events that spark meaningful conversations.

Pictured: Melbourne March She Shares

Programs and Advocacy

Pink Hope remains a leading patient voice and contributor to policy improvements and the health advocacy space for those at risk of hereditary cancer. We consistently contribute to relevant working groups, communities of practice, submissions to the health technology assessment process and evidence-based research. Through all of our work, we ensure the voices of those living with hereditary cancer risk are put forward in the hope of achieving better outcomes for our community.

After hearing from the community there was a need, Pink Hope facilitated focus groups for metastatic cancer patients. The goal was to better understand this group, the gaps in care and how these patients could be better supported to live better for longer. Across many months, we held three patient focus groups and one healthcare professional focus group. With a roundtable session planned to be held later in 2022 including a broader group of patients and healthcare professionals. We are grateful to the patients and healthcare professionals who contributed to our success sessions and will use what we learned during those sessions to inform our programs and campaigns moving forward.

Pink Hope contributed to an industry lead **roundtable discussion focused on Triple Negative Breast Cancer (TNBC)**. Noting that BRCA carriers are overrepresented in TNBC, we were able to organise attendance from Pink Hope community members and CEO Sarah was able to provide input from her personal experience. Contributing to industry lead activities relevant to the high-risk community ensures patient perspectives and experiences are heard.

Pictured: Triple Negative Breast Cancer roundtable

Campaigns & Events

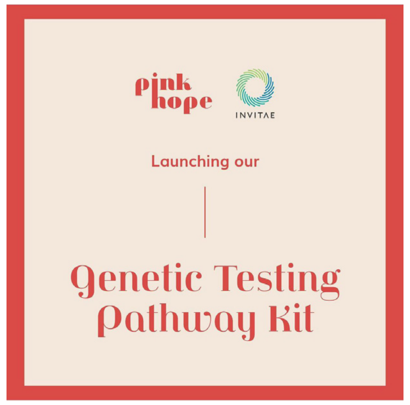
Bright Pink Lipstick Day 2021

Cancer doesn't wait for anyone. Due to the global pandemic, our health took a back seat in 2020. It was time to get into the driver's seat and take charge of our stories. Bright Pink Lipstick Day encouraged community to wear a Pink Hope lipstick to engage in conversations that revolve around hereditary health and understand their risk.

Sydney High Tea

In May 2022, we were so excited to finally have everyone back together to enjoy a delicious & indulgent selection of goodies at our Sydney High Tea. All funds raised allow Pink Hope to continue supporting, educating, and empowering high-risk individuals to manage their risk and make informed decisions about their health.

Pink Hope x Invitae Partnership



In June 2022, we launch an advocacy collaboration to help Australian families get the answers they need sooner, as new analysis highlights the consequences of potential barriers and delays to genetic testing across the nation.

Around two-thirds of Australian breast cancer patients with high risk, hereditary gene variants (such as BRCA) would not qualify for genetic testing due to the nation's eligibility criteria and would be unable to access what can be potentially life-changing knowledge.

Pink Hope advocates for early access to genetic testing where testing is warranted. Whether individuals are considering taking a test proactively to better understand their risk or if they have cancer themselves and are looking for answers or more personalised treatments.

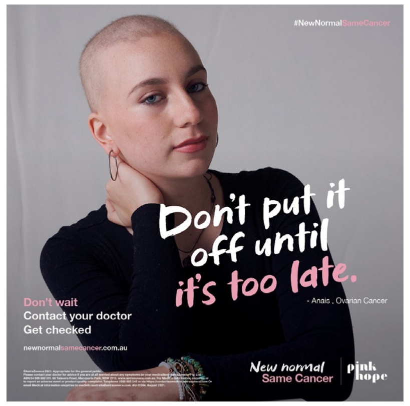
Testing Times Campaign

We launch our new campaign - Ovarian Cancer: Testing Times in November 2021. Being diagnosed with cancer is a highly stressful time for you and your loved ones. It is probably not the time you will be thinking about asking for genetic testing. That's why we created a checklist to take to your specialist, downloaded via our website. We hope with this campaign that all women are offered tumour testing at the time of their diagnosis.

Impact Dinner

In June, we held our Impact Dinner at The Langham Sydney celebrating ten years as a stand-alone organisation. It allowed our industry partners, collaborators, community, friends and family to come together and celebrate. Our fabulous MC Shelly Horton lead us through the night, introducing the Pink Hope CEO and Board and an extraordinary surprise performance by Samantha Jade. Our guests enjoyed a specially curated A-La-Carte fine dining experience throughout the evening. We were also lucky enough to hear from Corinne, who shared her personal story and lived experience of how Pink Hope impacted her life.

New Normal Same Cancer



Pink Hope was part of a national campaign, encouraging Australian's to return to their doctors amidst the ongoing COVID-19 pandemic. Because of the critical nature of this message, we were honoured to be part of a collective of organisations bringing this to the Australian public, joining forces with some of Australia's most powerful Patient Advocacy Groups. As a collective of patient organisations, we aimed to encourage people to contact their healthcare professionals, get checked, or re-book their missed medical appointments.

KATY'S STORY

"The medical community are very good at telling you how to be sick. But I had to educate myself on how to live"

Katy Morrison, 43, is married with three children, 7, 10, and 15. She was diagnosed with metastatic stage 4 cancer

> *"I was the person who never went to the doctor. I always swam, and walked everywhere. I enjoyed my life in my 20s like most people, then became the kale-eating, smoothing-making suburban mum. There's no history of breast cancer in my family, so when I was diagnosed, it came out of the blue.*

"I regularly checked my breasts. I found a small, pea-sized lump in my left breast in January 2020. I immediately went to my GP who dismissed it as a likely blocked milk duct from breast feeding my children. They weren't worried about it, and told me not to worry either.

"Over the next six weeks the lump grew until it was the size of a golf ball. I was finally sent for a mammogram in March 2020 where they saw the lump was 11 centimetres in diameter. My left breast looked like I'd had plastic surgery on it (while the right breast looked as though I'd breast fed three children!).

"I have a healthcare background. I knew what I saw on the screen. It was undoubtedly breast cancer. So I wasn't surprised when they told me to go immediately for a CT scan then a biopsy. By this time the world was starting to fall apart, with businesses and schools closing down. Doctors were being furloughed. So I wasn't surprised when the endocrine unit of the hospital called me on the Friday to tell me they were moving my appointment to the Monday. But then the receptionist told me that this was normal, 'when the patient has stage four breast cancer'. I went silent. She of course, realised her blunder and said: 'You didn't know what was wrong, did you?'. Well, now I did! I demanded to see the doctor and arranged to come in within the next 30 minutes.

"I found my husband and told him that the diagnosis was bad, really bad. Our appointment with the endocrinologist was terrible, the doctor could barely meet my eye. She told me I had stage four cancer, that it was in my breast, my lungs, liver and my pelvis. She told me to go home, tell my family and children my diagnosis.

"I was convinced I was going to be dead by Monday. I went into shock and cancelled everything – my work commitments, social dates, courses I was enrolled in. I couldn't think about anything other than that I'd be in the ground by Christmas.

"My Monday appointment with my surgeon did not go well. He told me 'I can't cure you.' All he told me was the treatment I'd be going through: full mastectomy followed by IV-fed chemo. He told me that if I was alive at the end of this, then we'd discuss my other options.

"Thankfully, he referred me to a medical oncologist. He was young, eager and knew that I needed a positive approach. He sent me to have all my scans and tests again before determining my course of treatment. He told me he would not give me a time line, otherwise I'd hang onto it. Instead, he told me that he was going to do everything he could to keep me alive.

"I agreed. Dealing with breast cancer is a mind game. If you give up, then you've lost. I knew I had to be my usual optimistic self and to meet the challenge head on. Having that mindset works for me.

"Rather than IV chemo, I had hormone therapy. I had a hormone blocker as my cancer is oestrogen-fed. Then I had a single mastectomy to remove my left breast and the lymph nodes on the left side. This was followed by five weeks of radiation. I wasn't offered reconstructive surgery, as that type of operation isn't considered necessary for people who have stage 4 cancer. The treatment is like having a permanent hangover – you feel exhausted, tired, nauseous.

"I've had to fight to have my other breast removed, and it's still being discussed.

> *"Having stage 4 cancer is like being at the top level of a game. You can't go back down the levels. You can't go backwards. The cancer in my lung, liver and pelvis has shrunk, but I will always have stage 4 cancer.*

"I have made some big changes to my way of life. I try to eat plant based as much as possible; I swim whenever the stress and anxiety gets too much; and I do drink tequila! I've also become a huge fan of Reiki as part of my healing journey. I'm now very picky about the people I bring into my life. And I fight every step of the way to be included in my medical information.

"I know some patients treat their doctors like God, but I demand to get every piece of information my medical team does. I approach life and my diagnosis with humour, but I'm also extremely dogged about being informed. I've always been this way, but I've had to toughen up.

"The first nurse I saw told me to go home, eat ice-cream and to get my affairs in order. Thankfully I ignored her. Instead, I reached out to people on social media for their help and advice .That's when I found Pink Hope. Their advice and support has helped carry me through some tough times. Because when you are given a cancer diagnosis it can become monotonous – for you, your family, your friends. After a while people get bored of it. So having an online community, where there's always someone to listen to you rant, or cry, or ask questions – even at 2am - has undoubtedly saved me.

> *"The medical community are very good at telling you how to be sick. But I had to educate myself on how to live."*

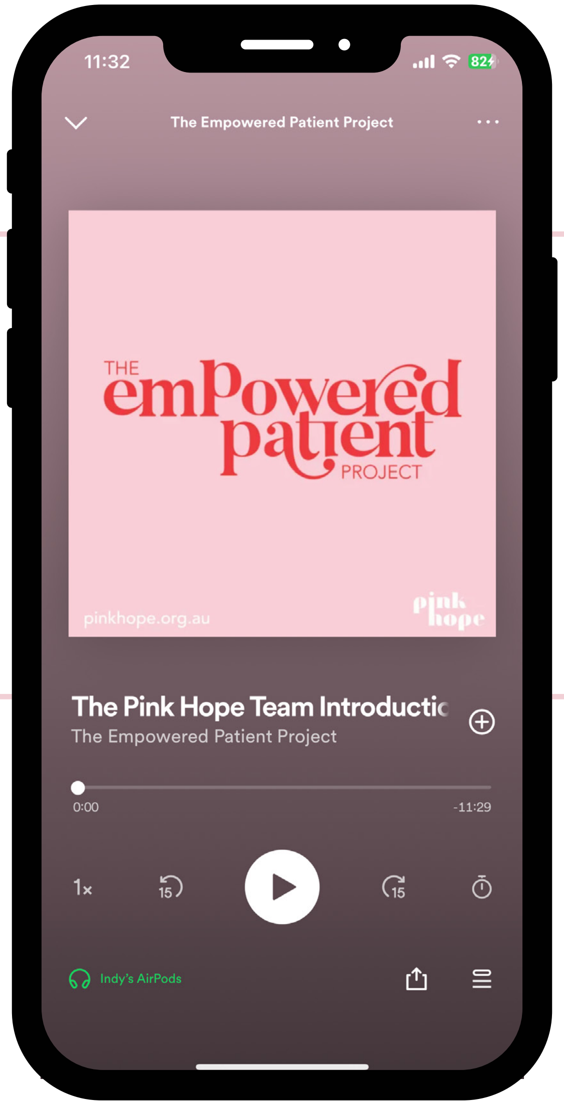
Digital Impact

Our Reach

INSTAGRAM
22.1K FOLLOWERS

FACEBOOK
31K FOLLOWERS

TWITTER
7.6K FOLLOWERS



Now Streaming

In 2021, we launched The Empowered Patient Project Podcast.

The Empowered Patient Project, hosted by Nikki Wishart, aims to educate, inform, and empower listeners to take control of their health and have the confidence to ask questions and push for answers.

SHU'S STORY

"Love got me through"

Shu was diagnosed with triple negative breast cancer at the age of 49. She has BRCA1 gene mutation, despite no history of the mutation in either side of her family.

"I've always been proactive with my breast health: I often had mammograms and self-checked my breasts regularly. In December last year (2021) I found a large lump during a routine self-check. I immediately made an appointment with my GP for further investigating. And that's when I was diagnosed with breast cancer.

> *"It was a scary time. But my team of doctors were amazing and my husband and friends were all incredibly supportive. I just took it all step by step: the first step was discovery; the second step was action.*

"I had surgery to remove the lump from my breast so that the doctor could assess it. They found that the lump was a hybrid: 50% was hormone driven and 50% was triple negative driven. Around 15% of women who have breast cancer have triple negative breast cancer. My diagnosis was that my breast cancer was aggressive stage two, due to the combination of hormone and triple negative cancers.

"At first, my head was full of questions. What about work, my future, long-term? My doctors told me that best treatment plan for me would be to have six months of intense chemotherapy, followed by radiation therapy. They gave me a lot of information about my diagnosis and treatment and were always available – over email or SMS – to answer my questions. I stayed off the internet and trusted the nurses and doctors to give me all the facts. There's so much information available from reliable medical sources, which is how I found Pink Hope. My oncologist and a friend who'd been through a double mastectomy recommended the site. At first I didn't want to join a group of strangers to talk about my diagnosis, but I soon changed my mind. The community here was a great help – it's where I formed new relationships and found sources of truth.

"My oncologist suspected that I, as with most triple negative patients, might have a history of genetic mutation and advised me to have a gene test. Again, he was extremely helpful in answering all my questions and laid out the various treatment plans available to me if the test returned positive. So I went into the test knowing all the options that would be available to me.

"Before I had the gene test I had to answer some family history questions – neither side of my family has had breast cancer. My gene doctor reassured me that it was unlikely then that my test would come back positive. But it did. I had the BRCA1 gene mutation.

"I didn't cry when I received the news : my doctor had prepared me for this possible outcome. I knew the treatment pathway I would need to follow. I actually felt relieved. Relieved that I could get started on the right treatment for me.

> *"I've never paid attention to my body in the way I do now. My body is my voice and I have to be sensitive and listen to it. During, and after the chemotherapy, and managing the side effects, my body trained me to listen to it, so that I knew when I had to stop and rest. Rest is just so important, not just when you're going through chemotherapy, but also for your mind, body and soul.*

"I had to find a way to deal with the worry, it never stopped during that entire 12 months of scans,

SHU'S STORY (CONT.)

tests and treatments. What I've learned to do is to be aware, to pinpoint and name just one worry. I'd ask myself: 'What can I do with this worry?' And I'd answer: 'I can throw it away.'

"There was no point worrying about some test results you'd get in two days' time. Healthy distractions, such as cooking a nice meal, or watching Netflix helped me relax and stay calm.

"Talking to other people in my support group on Pink Hope has also helped. People are so open about their experiences, the pain, the joy, the worries and their anxieties. It is a safe place for me to seek support. At first I just read other people's stories, but then I slowly began to contribute. Even now, after my treatment has finished, I still participate in the community to help others. I'm really open to meeting people who have gone through the same experience as me, so that I can pay it forward and share advice and my journey.

"When you've been diagnosed with breast cancer it's about finding your courage. We all have that courage inside of us and we can all get through this with a strong mind, body and spirit. It's important to use the support you are offered. Love, and accepting love, was part of my treatment plan and it definitely helped me. Remember that you're not alone. There's other people out there who have been through what you have and want to help you. It's okay to be vulnerable."

The team leading the charge

THE BOARD


Melissa Hayes-Smit


Deborah Clay


Cassandra Kelly


John Sheehy


Brione Smink


Elise Stanberg

THE TEAM ON THE GROUND


Sarah Powell
CEO


Lisa Caterina
Campaign and Community Manager

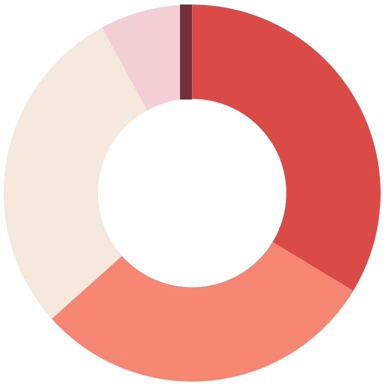

Robyn Smith
Programs Manager


Nikki Wishart
Social Media Manager

2021 – 2022

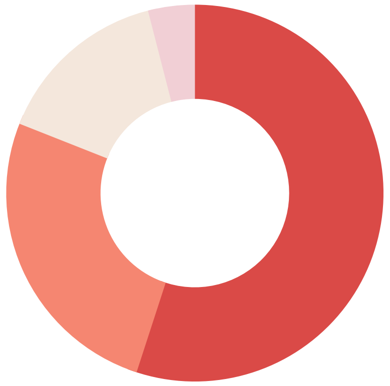
Financials

Income Sources



●	Corporate Sponsorships	$265,540.00	34%
●	Donations, Bequests & Fundraising	$234,522.00	30%
●	Grants	$ 223,304.00	29%
●	Merchandise Sales	$51,724.00	7%
●	Interest	$278.00	> 1%

Expenditure



●	Advocacy and Support Service Delivery	$326,587.00	55%
●	Programs and Educational Campaigns	$158,347.00	26%
●	Governance and Operations	$89,900.00	15%
●	Merchandise	$24,257.00	4%

Our Growth

Total comprehensive income for the year

Supporters

A thank you to some of our biggest supporters...

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MSD

NOVARTIS

AstraZeneca

GILEAD
Creating Possible

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GIRLS GETAWAYS
ESCAPE. INDULGE. RELAX.

gsk

HOLOGIC

INVITAE

kConFab
Kathleen Cuningham Foundation
Consortium for research into
Familial Breast cancer

Finally, our biggest thanks
go to our community.

pink
hope

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