Rare Impact 2025

How together we've made a real difference for people living with rare and less common cancers in Australia.

rare cancers Australia

Acknowledgement of Country

Rare Cancers Australia acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands and waters on which we all work, live, and learn. We pay our respects to Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.

We honour the deep connection that Aboriginal and Torres Strait Islander peoples have to Country — to land, waters, skies, and community — and the enduring strength of the world's oldest continuing cultures.

We recognise the wisdom, resilience, and leadership of Aboriginal and Torres Strait Islander peoples, whose knowledge systems have sustained communities, cared for Country, and nurtured wellbeing for tens of thousands of years. Their ways of knowing, being and doing continue to guide us toward a more just, sustainable, and connected future.

We also acknowledge the significant disparities in cancer outcomes experienced by Aboriginal and Torres Strait Islander peoples, who are more likely to be diagnosed at an advanced stage, face multiple co-morbidities, and experience delays in starting treatment.

We are committed to working in genuine partnership with Aboriginal and Torres Strait Islander organisations and communities to focus on improving cancer prevention, treatment and care.

Contents

A Rare Champion: Caitlin's Story

For Caitlin Delaney, improving patient experience and outcomes has always been her guiding principle.

As a clinical scientist and IVF clinic manager, she dedicated her career to compassionate care. But after losing her mother-in-law to medical negligence and later being diagnosed with stage 4 clear cell ovarian cancer at just 39—with two young daughters—her mission became deeply personal.

Facing a grim prognosis, Caitlin chose not just to survive but to advocate. Her experience in a leading oncology hospital opened her eyes to the stark inequities in care—access to support, testing, and treatment was not equal for all. Determined to change that, she founded CareFully in 2019, an education and advocacy organisation that now works with hospitals and charities to improve patient care nationwide.

Caitlin's advocacy extends well beyond education. She collaborates with international researchers, pharmaceutical companies, and advocacy organisations to fast-track promising therapies—particularly for ovarian cancer. She was instrumental in gaining access to an off-label combination immunotherapy that is now in late-stage clinical trials, offering new hope for thousands of patients.

Caitlin with her husband Kevin and daughters Lilith and Willow.

"Cancer care is a postcode and tumour type lottery... it is grossly unethical."

Her reach is both local and global. Caitlin mentors cancer patients, helps them access global experts, and provides information on potential clinical trials and treatment pathways. Her personal story has been shared at international cancer conferences, inspiring others to seek innovative therapies. Her work with Rare Cancers Australia and other groups continues to push for equitable treatment access, regardless of postcode or cancer type.

Her voice carries into the halls of power. Caitlin has addressed audiences at Parliament House in both Sydney and Canberra, speaking directly to the Prime Minister about the urgent need for better cancer care. She has appeared on national television, in high-profile media campaigns, and in publications such as The Weekend Australian, where she discussed CAR-T-cell therapy—an emerging treatment that re-engineers the body's own immune cells to fight cancer.

While she began as a gynaecological cancer advocate, Caitlin now champions a tumour-agnostic approach—ensuring innovation, funding, and early detection benefit all cancers equally.

Her volunteer and leadership work spans numerous national committees and co-design projects. She has helped shape cancer policy, contributed to research initiatives, and partnered on awareness campaigns for rare and less common cancers. Her influence has touched thousands—patients, clinicians, researchers, and policymakers alike.

Her own survival is a testament to the power of precision medicine. Genetic testing and targeted therapies have allowed Caitlin to far outlive her prognosis. Yet, she never loses sight of those who cannot access the same opportunities. "If these treatments can keep me alive," she says, "they should be available to everyone who needs them."

Her belief is clear: access to life-saving treatment is a right, not a privilege. Through mentorship, education, and policy advocacy, Caitlin uses her personal story to inspire action and dismantle barriers in healthcare.

The past year has brought significant challenges—an unsuccessful clinical trial, emergency radiation, blood clots, and an expensive antibody drug conjugate (ADC) regimen costing $10,000 per cycle for ovarian cancer (while the same drug is free for advanced breast cancer). The side effects are harsh, and the outcome uncertain, but she remains focused on creating systemic change.

Despite chronic pain, fatigue, and the emotional toll of ongoing treatment, Caitlin spends her most precious resource—her time—helping others. She mentors newly diagnosed patients, advises policymakers, and trains health professionals. Her presence in the cancer community is both practical and deeply human: a source of knowledge, connection, inspiration and hope.

Caitlin's contribution to cancer advocacy is extraordinary not only because of her achievements, but because of her approach. She blends lived experience with strategic influence, using her personal journey to challenge systemic inequities and create lasting change. **Caitlin Delaney is not only surviving against the odds—she is changing the face of cancer care in Australia. A true rare champion.**

A MESSAGE FROM OUR CEO

"We stand at an inflection point — where awareness is turning into action, and action into systemic change."

This year's Impact Report stands as a testament to what can be achieved when purpose and partnership unite.

It reflects a community determined not only to change outcomes, but to transform the very experience of living with a rare or less common cancer.

Every figure, every story, every achievement captured in these pages represents far more than activity — it represents progress towards equity, dignity, and hope. Behind each number is a person: someone who felt less alone, a clinician empowered with knowledge, a carer supported in their role, a parent able to focus on family rather than fear. These are the outcomes that matter.

In 2025, we deepened our impact and expanded our reach. Our navigation team and support programs provided tailored assistance to more patients and families than ever before — connecting thousands through peer networks, delivering critical crisis support, and helping almost 1,000 mothers balance treatment with motherhood through Mummy's Wish.

Our advocacy gained new ground, shaping the national conversation on equitable access and genomic-led care. Among this year's milestones:

- Our **first national Cancer Lived Experience Survey**, amplifying the voices of nearly 2,500 Australians.
- The **launch of our landmark report *Now it's personal: access and equity for all*** in Parliament House alongside 29 patient advocates.
- Being **commissioned to develop Australia's first Optimal Care Pathway** for rare and less common cancers.
- Successfully collaborating on **securing $6.7 million in government investment** for the Australian Rare Cancer Portal.

This was also a year of renewal and recognition. Our refreshed brand embodies who we are today — bold, compassionate, and fearless in our pursuit of better outcomes. And being named one of Australia's Top 100 Best Places to Work reflects the culture of integrity, care, and collaboration that fuels our mission.

From the summit of the Kosi Challenge to the halls of Parliament, from pioneering research partnerships to the stories of resilience shared by patients, our collective efforts are reshaping what's possible.

We stand at an inflection point — where awareness is turning into action, and action into systemic change. None of this could happen without the trust of the people we serve, the generosity of our supporters, and the unwavering commitment of our team and Board.

Together, we are redefining what it means to live with a rare cancer — creating a system that sees, values, and responds to every individual. Our mission continues, guided by a single, unshakeable purpose: to ensure that no one is left behind.

Warm regards,
Christine Cockburn
Chief Executive Officer, RCA

A MESSAGE FROM OUR CHAIR

"Together, we will continue to ensure that our support has real, lasting impact – measured not just in statistics, but in lives changed."

It is a great privilege to write this message as the newly appointed Chair of Rare Cancers Australia.

Having served on the Board for several years, I've seen first-hand the extraordinary compassion, commitment, and integrity that defines this organisation. Stepping into this role is both an honour and a responsibility — to continue the legacy of limitless care and bold, brave advocacy that has guided RCA since its founding.

At RCA, our work is deeply human. Every conversation, every program, every advocacy effort is grounded in one simple question: what impact will this have on the people we serve?

Impact is not just about numbers — though the growth in our reach and programs this year is something we can all be proud of. Impact is about meaning. It's about a mum who can focus on her children instead of her cancer costs. A patient who finally finds the right treatment or a supportive ear. A family who feels seen and understood in the most isolating of times.

For people living with rare and less common cancers, impact means hope — hope made real through action, connection, and change. It means navigating a health system that too often overlooks them and finding someone who will not only walk beside them but also fight for them. That's what the team at RCA does every day.

In the past year, we have expanded our navigation and support services, amplified the rare cancer voice in Parliament and policy, and forged new partnerships that are changing what's possible in cancer care. Each milestone is a testament to the power of a dedicated community — our team, our supporters, and the many brave individuals who share their stories to drive reform.

As I commence my first term as Chair, I am inspired by the determination of our founders, Kate and Richard Vines, and by the tireless work of our CEO, Christine Cockburn, and the RCA team. Together, we will continue to ensure that our support has real, lasting impact — measured not just in statistics, but in lives changed.

Because for every person facing a rare cancer, impact means everything.

Warm regards,
Bruce Goodwin
RCA Chair

"My work begins with listening. I want to understand what is most important to the person and how to tailor my support to best meet their needs. My goal is to make sure my patients feel heard, supported and never alone. My hope is that, in every interaction, they feel not just cared for but truly cared about."

Tenaya Wright, RCA Specialist Cancer Support Navigator

Our Vision & Mission

At Rare Cancers Australia, we're changing the story of a rare cancer diagnosis.

Our purpose is to redefine cancer support, so no one is left behind or feels alone. Everyone is given the best possible chance to live beyond cancer.

We are a steadfast ally for people living with rare and less common cancers. We stand side by side with patients and their families with knowledge, energy and an unwavering determination to create a better world for rare.

Our limitless support leaves no stone unturned in the search for ways to ease some of the challenges that come with rare cancer. And our relentless advocacy continues to drive change in access, affordability, and quality of care, ensuring better outcomes for the patients of today and tomorrow.

Kate and Richard Vines founded Rare Cancers Australia in 2012 to ensure that no one receiving a cancer diagnosis would feel isolated, left behind, or without any options.

Vision

Every person impacted by rare cancer is supported from every angle, from the very beginning.

Mission

We do whatever it takes to change the story of rare cancer through improved diagnosis, limitless support, and relentless advocacy.

Our Philosophy

The patient guides all that we do. Rare Cancers Australia wouldn't exist without them. We are in service to their wellbeing.

Kate Vines: Australia's First Rare Cancer Navigator

In 1991, at just 33, Kate was told she had an incurable and extremely rare cancer – Medullary Thyroid Carcinoma – and was advised to get her affairs in order.

But Kate chose a different path. Refusing to accept the limits of her diagnosis, she became her own advocate, navigating complex treatments, enduring multiple surgeries, and seeking alternative therapies.

"Kate Vines has demonstrated unparalleled dedication to advocating for those affected by rare cancers. Her efforts in providing essential resources and raising public awareness have made a significant impact on the lives of many Australians."

– Minister for Health and Aged Care, The Hon Mark Butler MP

Kate Vines, speaking at Cancer Australia's 2024 Jeannie Ferris Awards.

Her lived experience—marked by isolation, pain, and a lack of information—fuelled a bold vision: **no one should have to face rare cancer alone.**

In 2012, alongside her husband Richard, Kate co-founded Rare Cancers Australia (RCA), a charity on a mission to transform the rare cancer landscape across the country. From her home office and trusty blue notebook, Kate helped build a national movement—one person, one story, one breakthrough at a time.

What started as a humble idea has today changed outcomes for tens of thousands of people.

Known as Australia's first rare cancer navigator, Kate offered personalised support to thousands of patients, advocating fiercely for those left behind by the health system. She pioneered the Patient Treatment Fund—Australia's first crowdfunding platform dedicated to helping patients access life-extending treatments not listed on the PBS which has raised more than $6 million for patients.

Kate and Richard walked from Canberra to the summit of Mt. Kosciuszko in 2013, launching the first Kosi Challenge, now an annual event uniting over 700 participants in solidarity and support. Their reports—Rare Solutions and Vision 20-30—were instrumental in shaping the Australian Cancer Plan, ensuring rare cancer patients were finally seen, heard, and supported at the national level.

Kate's work laid the foundation for RCA's patient navigation model, which today provides tailored, one-on-one support to Australians with rare and less common cancers—regardless of age, location, or background. This level of personalised care would have been unthinkable just a decade ago.

In August 2024, Kate was awarded the prestigious Jeannie Ferris Cancer Australia Recognition Award, honouring her tireless advocacy and enduring impact on the cancer sector.

Thirty-four years after her diagnosis, Kate continues to live with cancer. Still navigating new treatments—none of them available on the PBS—she remains a symbol of strength, compassion, and determination.

Because of Kate, hope is no longer rare.

A MESSAGE FROM OUR PATRON

"RCA exemplifies this spirit, combining compassion with determination to make a real difference."

In March 2025, Rare Cancers Australia appointed its first official Patron – The Hon Tony Smith, former Speaker of the House of Representatives.

It is both a privilege and an honour to serve as the inaugural Patron of Rare Cancers Australia.

During my time as a Member of the House of Representatives and as Speaker, I saw first-hand the remarkable work this organisation does—supporting Australians facing the immense challenges of a rare or less common cancer diagnosis, and advocating tirelessly for better treatments, fairer access, and a stronger voice for those too often overlooked.

Throughout my parliamentary career, I came to deeply appreciate the value of informed, constructive advocacy—especially when it represents people whose needs are urgent, complex, and sometimes invisible in broader health discussions. **RCA exemplifies this spirit, combining compassion with determination to make a real difference.**

All of us have had or have a family member, friend or loved affected by cancer. Every year we see advances which, with support, offer hopes for better treatment, longer lives and cures.

As Patron, I look forward to working alongside Christine Cockburn, the RCA team, and the broader rare cancer community to help shine a brighter light on the inequities that persist, and to push for the changes we know are possible.

This Impact Report is more than a reflection on the year that has been, it is a testament to what can be achieved when dedicated people, patients, families, clinicians, researchers, and advocates work together. It is also a reminder that this work is crucial and there is more to be done to give every person the best possible chance at life beyond cancer.

I am proud to take on this role and to contribute, in whatever way I can, to ensuring that every Australian with a rare or less common cancer has the opportunity for the best possible care, treatment, and quality of life.

The Hon Tony Smith
Patron, Rare Cancers Australia

Our Impact

We do whatever it takes to change the story of a rare cancer diagnosis through limitless support and relentless advocacy.

Here's a snapshot of our impact for rare in 2025.

Patient support

Personalised support for 1,920

This year, our team of Specialist Cancer Navigators have provided personalised support to 1,920 patients and families affected by rare and less common cancers.

460 families connected

Over 460 patients and their families were connected to appropriate services and support across the country.

Connected 3,125 people through support groups

3,125 patients and their carers were connected through our eight support groups, running a total of 80 group sessions in the past year.

$158,000 in crisis funding for patients in need

Our crisis fund provided support for patients in need, helping cover things like out-of-pocket cancer expenses and medical bills.

Supported patients with travel and accommodation

In the past year this program has provided wrap around support to an average of 20 patients per month.

968 mums of young children supported

Thanks to our Mummy's Wish program, we provided practical support to almost 1,000 mums living with cancer who have young children.

Advocacy

344
CanForum25 participants

We brought together **344** patients, carers, parliamentarians, industry leaders, and advocacy groups for CanForum25 and the launch of 'Now it's personal: access and equity for all'.

4,085
Report & Policy Downloads

Over **4,000 downloads** of RCA's five core policy reports and papers.

2,500
Cancer Lived Experience Survey responses

We delivered the **first Cancer Lived Experience Survey, capturing the experience of nearly 2,500 adults** with cancer and carers across Australia.

120
Representations

We participated in over **120 conferences, expos, advisory committees and speaking engagements** with key stakeholders to raise awareness of RCA.

$6.7M
Government investment

We advocated with the Australian Rare Cancer Portal team to secure a **$6.7 million** Federal Government investment for them to run the Portal over the next four years.

$143.4M
Precision oncology investment

We supported efforts for an additional **$143.4 million** in Federal Government funding for precision oncology programs led by Omico and the Zero Childhood Cancer Program.

10
Patient advocates met with Federal MPs

10 federal members met with rare community constituents in one-on-one engagements.

54
Consumer comment submissions

54 submissions made to the Pharmaceutical Benefits Advisory Committee representing the rare community's experiences.

First
Optimal Care Pathway

We were commissioned to develop the **first national Optimal Care Pathway for People with Rare and Less Common Cancers.**

120
Roundtable participants

A **three-part Policy Roundtable Series on improving access to genomic led-cancer care** involved over 120 participants.

Two
Thought Leader dinners

28
Parliamentarians and advisors

Two Thought Leader dinners were held with 28 MPs and advisors to raise awareness of critical issues including RCA's election priorities, with patient advocates sharing their experiences directly with decision makers.

Funds raised

Kosi Challenge raised $678,000. Read more about this event on page 43.

$857,000

Through our fundraising platform, the **Patient Treatment Fund**, people gave **over $857,000** to help cover non-subsidised therapies, travel for treatment, and out-of-pocket costs.

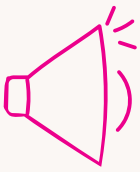
$675,782

Individuals and organisations **gave over $675,000 in general donations** to support RCA and Mummy's Wish, enabling us to deliver practical support programs to patients and their families when they need it most.

$1.17M

Over $1.17 million was raised through **community fundraising** and challenge events in support of RCA and Mummy's Wish, helping to raise voices, raise spirits and raise awareness.

Raising the rare voice



We issued **25 media releases** and received **545 media mentions** in major news and trade print, online, radio, and television outlets.

Our **two monthly newsletters** delivered patient support, Mummy's Wish and important advocacy updates to over **26,000 subscribers.**

Over **35,000** people follow RCA and Mummy's Wish across our social media channels.

Our website offered trusted information and guidance to over **178,445 unique visitors.**

Mummy's Wish

We supported 968 mums with cancer and their families.

We sent 900 care packs to mums with cancer including 1,850 recordable cuddly bears for their little ones.

Over $20,000 was raised thanks to the generosity of donors in our 2024 Mummy's Wish Christmas Appeal.

Refreshing our Brand

"With our new brand strategy, visual identity and website, we have future-proofed our ability to grow and stand alongside industry leaders, while still honouring the legacy Richard and Kate have built over the past 13 years."

– James Mathews, Marketing Manager, RCA

In February 2025, we launched a refreshed look and feel that reflects our unwavering commitment to redefine cancer support in Australia.

This included a new logo and brand guidelines as well as a new website, designed to help people easily access the information, support, and guidance they need.

Our refreshed brand reflects the work we're doing at RCA today and into the future, while paying homage to our heritage logo and colours.

We also opened a new local office for the community in Wollongong, NSW, expanding our on-the-ground presence beyond our head office in Bowral.

Thank you to the team at Three Blocks Left for their strategic and creative guidance, working in lock step with the RCA team and stakeholders and ultimately bringing our refreshed brand to life.

A MESSAGE FROM RCA'S HEAD OF OPERATIONS

Building a *great* place to work

At Rare Cancers Australia, we believe that delivering life-changing outcomes for patients starts with nurturing a workplace where our people can thrive. This year, we were proud to be formally certified as a Great Place to Work, with results that clearly reflect the unique culture we have built and protected.

With a 99% participation rate in the Great Place to Work survey, and an extraordinary 100% of employees agreeing that RCA is a great place to work, we stood out not just in the charity sector, but among the highest-performing workplaces in Australia, across all industries. These results are a reflection of our people-first approach, and the unwavering commitment we have to building a workplace where everyone feels valued, supported, and connected to purpose.

Our people and culture journey this year has gone hand-in-hand with the evolution of RCA as an organisation. Through our brand refresh, we've redefined and realigned our vision, mission, and values, ensuring that everyone in our team understands the bigger picture they are contributing to.

This year, we've seen these values lived in action—through the empathy in how we care for one another, the passion we bring to patient outcomes, and the flexibility we offer so people can balance meaningful careers with meaningful lives.

From a People and Culture perspective, our focus has been on embedding these values through every stage of the employee experience:

- Building flexible, supportive workplaces that empower people to do their best work, wherever they are.
- Prioritising mental health and wellbeing, especially for roles that support vulnerable patient communities;
- Investing in diversity, equity, and inclusion, ensuring every team member can bring their authentic self to work;
- Developing strong onboarding and professional growth pathways, so that every person joining RCA feels connected to our mission from day one;
- Creating genuine feedback and recognition loops, ensuring people feel appreciated, seen, and heard.

Our culture doesn't stand still—it moves with us as we grow. As we introduced our bold strategic goals, we aligned our people initiatives directly with these organisational priorities. Every person at RCA knows how their role contributes to achieving these goals, ensuring that clarity, accountability, and purpose flow from strategy through to individual contribution.

Being a Great Place to Work is not just a badge for us—it's a commitment. It's a reflection of who we are and who we aspire to be: an organisation that leads with heart, operates with integrity, and empowers its people to be part of something bigger than themselves.

As RCA continues to grow and evolve, I am incredibly proud of the culture we have built—one that ensures our people are in the strongest possible position to deliver on our mission and change the story of rare cancer in Australia.

Sarah Clausen CPHR
Head of Operations, RCA

Employee Engagement

Top areas of performance

98% Engagement

High overall engagement, with staff describing RCA as a workplace that "aligns with my values and gives me a sense of fulfilment that no other job ever has."

100% Leadership support

Positive ratings on manager approachability, compassion, and wellbeing support.

Wellbeing and flexibility

Strong agreement that RCA supports staff wellbeing and enables flexible working. One employee shared, "I really appreciate the flexibility and work/life balance offered at RCA – it's so well understood and respected here."

Retention and tenure

Low voluntary turnover (9%) compared to sector averages, with many staff choosing to stay long-term due to supportive culture and meaningful work.

Professional development

186 active enrolments in 2025 for our Learning Management System – 65% assigned compliance and required courses while 35% were voluntary enrolments for professional development training.

Earlier this year, RCA conducted an Employee Engagement survey, with 99% participation, using the Great Place to Work program to measure the levels of employee engagement, wellness and satisfaction. These pillars ensure we retain and attract the best people within our organisation and uphold our established and valued culture.

We are a Great Place to Work certified organisation with 100% staff endorsement, reflecting our strong values-driven culture focused on compassion, innovation, and impact for patients and staff, placing us in the top tier of organisations nationally.

"The people, the work we do and the passion everyone has is infectious. Everyone respects one another, has flexibility to live their lives, and makes a difference in their work."

– Staff survey respondent

Best Workplaces™
Great Place To Work.
AUSTRALIA 2025

In August 2025, RCA made the Top 100 list of Best Places to Work in Australia for 2025 – coming in at #25 in the small not-for-profit category and #3 in Healthcare & Social Assistance, Micro & Small category.

Our Values

Whatever It Takes

We embody a spirit of excellence in everything we do. We believe good is the enemy of great. When we say we'll do something, we do it.

Our passion and dedication sees us looking for opportunities to go above and beyond in every action and encounter, creating lasting impact for the patients we serve.

In Your Corner

We are dependable allies and advocates, standing steadfastly by the side of anyone who needs us.

Understanding what you really need and what really matters to each individual is how we best support our people.

Our deep compassion connects us to our cause so that no one faces the complexities of rare cancer alone.

Pulling In The Same Direction

Our shared purpose of patient equity is at the heart of our success. By aligning our efforts, we harness the collective strengths and talents of our team. It means we prioritise camaraderie and mutual respect within a culture of constant feedback and improvement, ensuring we move forward together.

Trailblazing Change

We aren't afraid to lead the charge. We make sure we are in the right rooms, with the right people, having the right conversations.

We think big and outside the box, innovate solutions and strive for lasting change and progress in the healthcare system.

Strategic Pillars


Patient Advocate


Meaningful Impact


A Trusted Voice


Outcome Oriented


Workplace Culture

Keep an eye out for these symbols on the following pages to see how we're ensuring our work always aligns with our strategic pillars.

"Cancer turned my life upside down, but the support Rare Cancers gave me changed everything. They organised travel so I could reach the treatment I needed and introduced me to others who had been through similar challenges. Knowing I wasn't facing this alone gave me strength and comfort."

– RCA community member

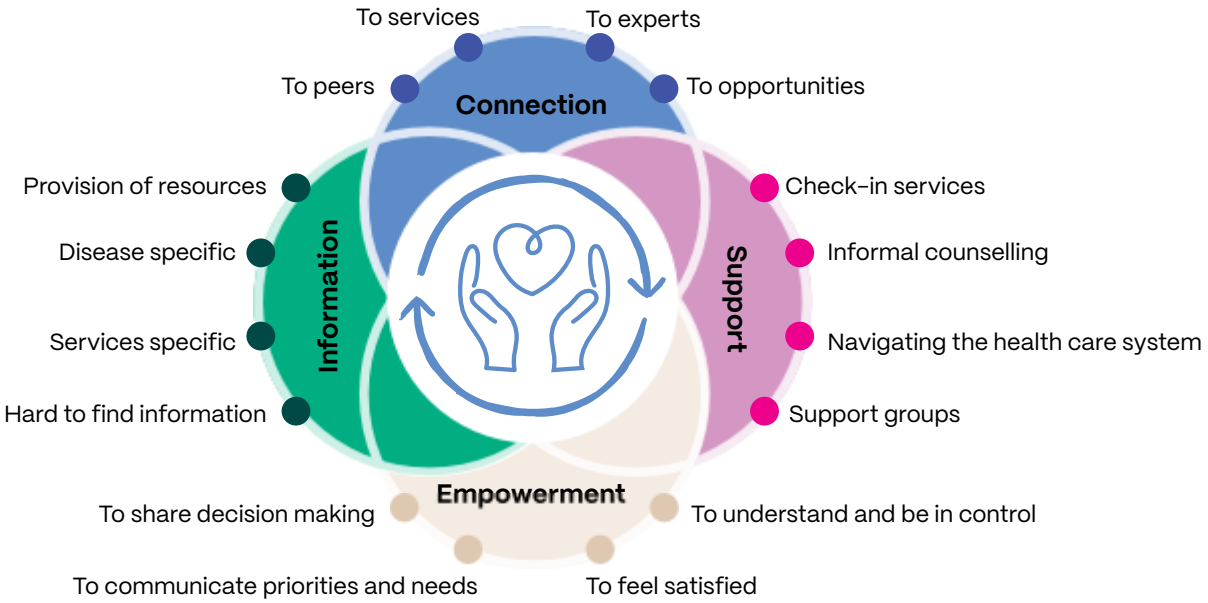
Support *without limits*

Our patients guide all that we do; their wellbeing is prioritised in every decision, program, and policy. Here's how we put that commitment into action over the past year.

RCA's Specialist Cancer Navigation Team

Specialist cancer navigation support

Our support knows no limits, which means we do whatever it takes to be there for all you need. Our team of specialist cancer navigators provide individualised, 360 degree person centred support that meets the person wherever they are and whatever their needs may be, whether it be emotional, financial, clinical, carer or peer support – the team leaves no stone unturned in their search for support that will make a real difference.



The top support requests our team received in 2024–2025 include resourcing and practical assistance, financial support and connection to support groups.

"Working as an RCA Specialist Cancer Navigator brings me immense pride and a deep sense of privilege. The support we're able to provide to patients and their families during such vulnerable and heartbreaking times is truly unmatched. I am constantly moved by the strength, resilience, and determination of the patients and families we support and equally inspired by the compassion and dedication within our patient support team."

– Abby Calley, Specialist Cancer Navigator

We are a partner in the Australian Cancer Nursing and Navigation Program (ACNNP), a key component of the Australian Cancer Plan. This is designed to link patients across Australia, regardless of who they are or where they live, with the best available cancer care as close to home as safely possible.

Through this Government funding, we have been able to **expand our services with additional Specialist Cancer Navigators, helping to meet the growing demand in supporting Australians living with rare and less common cancers.**

We continue to upskill our staff to provide appropriate and culturally safe support, particularly to patients from priority population communities. We also continue to expand our reach through our outreach efforts, **connecting with over 500 healthcare professionals and service providers over the last six months,** educating them about how we help and forming referral pathways.

Education *& Outreach*

At RCA, we believe in holistic, patient-focused support. That means we must also support healthcare professionals to better understand rare cancers and ease the educational burden that too often falls on the patient.

Arlie Novy BHSc/MN GCertChildNurs, Outreach & Education Manager, RCA

Education

RCA runs monthly patient education sessions, covering topics such as lymphatic massage, nutrition, tumour-specific information, and exercise physiology. These sessions are recorded, shared with patients, and delivered in partnership with expert stakeholders, ensuring smaller tumour groups feel represented.

6 Six sessions with

45 people from the patient community

255 viewings of the recordings.

Through the Australian Cancer Nursing and Navigation Program, work has begun a series of tumour-specific learning modules developed specifically for healthcare professionals and those supporting people living with rare and less common cancers.

The first module, for gynaecological cancers, launched in September this year, and was developed through an information partnership with Australia New Zealand Gynaecological Oncology Group (ANZGOG), literature review, a patient focus group, and the integration of Jane's story, who is living with vulvar cancer. Four more modules are also scheduled for development.

In GP education, RCA is collaborating with the VCCC Alliance to **develop a series of learning modules**, the first of which focuses on early diagnosis. The course aims to increase knowledge and skills of primary health care professionals in the importance of timely diagnosis, treatment and supportive care of people living with rare and less common cancers.

Through **$1 million in funding** received from the Government, RCA continues to progress the important development of appropriate and sensitive co-designed materials targeting culturally and linguistically diverse (CALD). This includes the integration of a newly established Reconciliation Action Plan, improved outreach and referral access for rural and remote communities, and the development of tailored resources and updated materials in languages Mandarin, Cantonese, and Greek.

Outreach

Between February and July 2025, our Education and Outreach Program distributed:

1,360 Brochures

150 Posters

We also built connections:

600+ Healthcare professionals reached

783 New referral pathways strengthened

Our Outreach presentations incorporate powerful photo-based stories, visually highlighting the Cancer Plan's objective for an integrated, multi-channel, multidisciplinary navigation model of care.

"Our partnership with Rare Cancers Australia promotes equity in cancer care through the Rare Cancer Community of Practice – a space for nurses to connect, share knowledge, and ensure people with rare cancers receive the best possible support wherever they are."

– Jemma Still, CEO, Cancer Nurses Society of Australia (CNSA)

Key professional engagements included:

- leading a Community of Practice through the CNSA, delivering five sessions annually to 48 active members within a wider network of more than 300 nurses who have registered their interest in rare cancers.
- representation on the VCCC Regional Steering Committee contributing both clinical and navigational experience.
- development of nurse referral packs for the CNSA Congress, with ten packs distributed since June to strengthen referral pathways and collaborative relationships.

"My outreach approach focuses on sustainability and identifying gaps, understanding who we are missing and where we can expand. The most rewarding part of my role has been working alongside patients and carers, amplifying their voices, embedding lived experience into outreach and education, and building systems and partnerships that make rare cancer navigation more responsive, inclusive, and effective."

– Arlie Novy, Outreach & Education Manager

Brave & bold navigation: Supporting *Luna*

Written by Kirsten Sherry, RCA Specialist Cancer Navigator, In memory of Luna Kemmery.

"At RCA, we remember Luna's story to help improve outcomes and supports for others. And moving forward, every 18 September – Luna's birthday – we will light a candle in the office and honour her."

Luna was diagnosed with Stage IV Neuroblastoma – a rare, aggressive cancer that had spread to her lymph nodes, bone marrow, bones, and pancreas. From my first meeting with her mum, Samantha, I was struck by the family's strength. Luna endured high-dose chemotherapy, radiation, surgeries, bone marrow transplants, and more. On top of that, she faced severe complications like respiratory failure and a major pulmonary haemorrhage.

At the same time, I had just discovered I was pregnant. While dreaming of the joys ahead in my own motherhood journey, I was overwhelmed with empathy for what Samantha and Luna were suffering through. Toddlerhood should be full of finger painting, making a mess, giggles, playgrounds, joy and love. While the Kemmery family had love in abundance, this rare cancer was robbing of the rest. **I made a quiet promise to do everything I could as their Navigator to support this brave little girl and her family.**

The odds were grim: only half of children with Neuroblastoma survive, and relapse drops survival chances to 5%. But there was hope – a promising treatment called DFMO. The problem? It wasn't available in Australia and cost over $500,000 overseas.

We discussed every possible option – even the desperate ones – and even selling everything they owned wouldn't get Samantha and her partner close.

The pain of a sum of money standing in the way of saving this child's life was almost unbearable, and I couldn't even begin to imagine how they were feeling.

I got straight to work, launching an RCA Patient Treatment Fund and sharing Luna's story through the media, and coordinated crisis support. Meanwhile, behind the scenes, RCA worked to bring DFMO to Australia. And finally – the breakthrough came. DFMO arrived, and Luna became the first RCA patient to access it locally. It worked: she showed no evidence of disease.

For a precious few months, Luna was doing well. Then in June 2025, I received one of the hardest calls of my working life – Luna had passed away.

As Patient Navigators, we live by the mantra "whatever it takes, limitless support". But in that moment, I felt utterly powerless.

In the face of grief, I remembered her incredible bravery. During fundraising, we used the phrase "Be brave like Luna." So I asked RCA staff to share their fears and pledge to face them with Luna's courage. Over half of the organisation responded, and I created a tribute video for her family.

Luna's impact lives on. She inspires how I work, parent, and live. We continue to tell her story to push for better support and research, and on 18 September – her birthday – we light a candle in her memory.

KnowledgeBase

Cancer information *at your fingertips*

The RCA KnowledgeBase helps patients and clinicians find information on the cancer types, specialists, services and clinical trials they're searching for.

Our KnowledgeBase has expanded to now include support and cancer service directories, making this resource even more comprehensive for a person looking for information specific to their cancer type.

In the past 12 months the KnowledgeBase has been visited by:

More than
55,250
users

Increased
23,000
from the year prior

Received
125,880
total views

Information that matters to you:

"We're rewriting the story for rare cancer patients – leading with compassion, advocacy, and care that meets people wherever they are. This year, we've reached more patients, deepened our support, and strengthened our impact. We remain focussed on our mission: to empower every person to be their own strongest advocate and to help create a healthcare system that listens."

– Cathy Slattery, Head of Patient Programs, RCA


mummy's wish
Practical support for mums with cancer
Mummy's wish
Practical support for mums with cancer
WARRIOR

We sent 900 care packs to mums with cancer including 1,850 recordable cuddly bears for their little ones.

Mummy's Wish has been a program of RCA's for more than a year now and in that time, we have seen the demand for support for mums increase exponentially.

The Mummy's Wish service helps manage the distressing burden of cancer on mums and their families by providing practical, tailored support during and after the treatment journey. Our Specialist Cancer Navigators offer mums information and resources such as care packs, recordable comfort bears, educational books, counselling sessions, and financial support wherever it is needed. This support gives the gift of time to mums with cancer so they can focus on what's most important – being a mum.

Almost
1,000 Mums
supported in
the past year.

Mummy's Wish Volunteers

"My kids are so little. Having the cute teddy bears in bed with them is really nice; they love pressing them to hear my voice! The books are so sweet too, we love reading together. They're beautiful memories that my kids will have forever."

– Erin, mum of two, living with brain cancer.

Volunteering

The second year of the Mummy's Wish Volunteer Program saw even more organisations jump on board to help lovingly prepare our signature recordable comfort bears for mums undergoing cancer treatment.

Thanks to over
500 hours of volunteer support
in the past year, hundreds of bears have been stuffed and sent as part of our care packs.
10 x more than the year prior

Each bear offers comfort to children and helps families stay connected through recordable messages while mum is away for treatment.

This vital work ensures care packs are delivered on time and with heart. The program's success simply wouldn't be possible without dedicated volunteers.

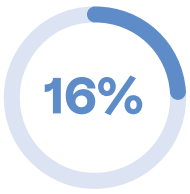
Medicines Access Portal

The Medicines Access Portal (MAP) is a single, secure online portal where clinicians and oncology pharmacists can view the special compassionate access programs that are available for cancer patients in Australia.

The benefits of this are twofold. Busy clinicians can have improved awareness of – and easy access to –access programs that are not publicly advertised and time consuming to uncover individually. But most importantly, it means patients can access potentially lifesaving medications, which at the very least, may help to buy them just a little more time.

Thanks to funding this year from the Oncology Industry Taskforce and endorsement from Medicines Australia, it has become widely regarded as the only centralised, comprehensive platform for access programs. It is therefore regarded as a critical and useful tool, especially in a rapidly changing oncology landscape.

In the past 12 months:



735 to 875 continued growth in the number of healthcare professionals utilising MAP.

of healthcare professionals who responded to a survey said they have used the MAP to successfully find a program for their patients.

96% said they would continue to use it.

Travel & Accommodation Program

The RCA Travel and Accommodation Program continues to play a vital role in ensuring equitable access to this life-changing treatment for Australians diagnosed with certain blood cancers.

Patients are supported end-to-end by our team who coordinate logistics, liaise with treatment centres, and provide personalised support throughout the journey.

The program helps bridge the gap for patients and carers who must travel significant distances by coordinating and funding travel and accommodation, allowing them to focus on treatment and recovery rather than financial stress.

In the past 12 months, the program has supported almost 200 patients. This represents a notable increase compared with previous years.

Impact on patients and families:

- Equity of access: Rural and regional patients are able to access specialised, potentially life-saving therapies without financial disadvantage.
- Wrap-around support: RCA's team reduces the administrative burden on patients and carers, ensuring logistical arrangements align with treatment schedules.
- Adaptability: The program has grown to meet increased patient demand.

"The calls from RCA gave me reassurance and peace of mind. My navigator understood what I was going through, answered my questions, and helped me get back on track. I don't know what I would have done without him."

– A participant in the Travel & Accommodation Program

Patient Treatment Fund

To help address the high and often unachievable expenses patients face in accessing the treatments they need, RCA established the first and only crowd funding platform for individual rare cancer patients in 2014.

The Patient Treatment Fund (PTF) allows patients to raise money for their expensive treatments. Since its establishment in 2014 it has seen an enormous $6 million raised towards directly supporting access to a patient's cancer treatment and potentially saving their life.

This past financial year, the PTF raised

$857,119

for patients.

"Asking for money was uncomfortable, but the support from family, friends, the rare cancer community, and others was incredible. We reached our fundraising goal, and after a few months on targeted therapy, I'm feeling good."

– Jacques Mathot, living with Ewing Sarcoma

Peer Connection

You may be rare, but you are not alone.

Living with a rare or less common cancer can feel isolating but connecting with others who truly understand can make a world of difference. Our Peer Support Groups help patients and carers learn, share, and find support from people walking a similar path.

Each group offers a safe, comfortable space to share your highs and lows, exchange information, and build genuine connections – or simply listen. These confidential forums allow people to:

- share insights about treatments, trials, and clinicians
- learn how others manage symptoms and challenges
- talk about things you may not want to share with friends or family
- reduce feelings of isolation and hopelessness
- improve emotional wellbeing and quality of life.

This year, we've also introduced in-person 'coffee & cake' catch ups in RCA's Bowral and Wollongong offices, where our community can meet with each other in an intimate and safe environment supported by members of our Specialist Cancer Navigation team.

We aim to ensure that no matter how you choose to connect, you'll find understanding, encouragement, and a reminder that you are not facing this alone.

Driving Change

Since launching our *'Rare Cancer Moonshot'* in August 2024, we have worked publicly and behind-the-scenes to drive change, so that Australia can meet the bold ambition: **five-year survival over 90% for every cancer type and true equity of experience by 2035.**

We do whatever it takes to raise the tide for better outcomes.

Over the past year, Rare Cancers Australia has played a leading role in policy conversations and development, fixing a firm spotlight on rare cancers and the solutions that will deliver equity.

Rare but not forgotten: ending the cancer lottery

Throughout 2025, we ensured that rare cancer awareness and reform stayed on the agenda, engaging with MPs, Senators and decision-makers across the political spectrum.

"If my cancer was in the breast or lung, I would have been able to access it on the PBS. But because it's rare, it's not covered, and I've had to pay out of my own pocket."

– Natalie, living with adrenocortical carcinoma, speaking at an RCA Thought Leader Dinner

At the end of 2024, we launched Rare Cancers Australia's Election Manifesto, calling for an end to Australia's 'cancer lottery'. It raised public and political awareness of the gross inequities in access and outcomes – no one's survival should be determined by their cancer type, postcode or bank balance.

We sought commitment to bold reforms that will save lives, end inequity and make Australia a global leader in cancer care:

- genomic testing for all rare, less common and advanced cancers
- faster, fairer, affordable **access to medicines** and treatments
- highly **specialised expertise** and treatment, regardless of where you live, through the Australian Rare Cancer Portal and increased financial support.

Following the election, we welcomed new and returning MPs and Senators to the 48th Parliament, with information about rare cancers and meetings. Throughout the year we supported patients to share their powerful stories at Parliamentary events and meetings – ensuring the voices of those living with rare cancers are heard loud and clear.

Longstanding Parliamentary engagement contributed strongly towards the 2023 Senate Inquiry into Equitable access to diagnosis and treatment for people with rare and less common cancers, which RCA provided written and oral evidence for. The Senate Inquiry was a landmark moment in elevating the challenges facing people with rare and less common cancers and urgency of change.

Nearly two years later in August 2025, with advocacy from RCA and many other patient organisations, the Government responded, recognising the challenges facing people with rare cancers and supporting – in part or in full – **31 of the Committee's 41 recommendations.**

We continue to work with government and policy makers to implement long-overdue systemic reform needed for faster, fairer, and more equitable access to cancer medicines.

Amplifying the Patient Voice

RCA's first national Cancer Lived Experience Survey.

Our Cancer Lived Experience Survey was designed to unearth the data and insights that are too often overlooked – the experience of people with cancer and their carers, from pre-diagnosis through to survivorship and end-of-life care.

Nearly 2,500 adults diagnosed with cancer and carers responded to the survey. Notably, three-quarters of respondents were affected by a rare or less common cancer.

Early findings from the survey revealed that for those with a rare or less common cancer:

Half said their mental health could have been better supported and **one quarter** wanted to be referred to mental health services but were not.

More than **one quarter** of carers said the person they cared for did not have appropriate end-of-life care.

felt their symptoms were overlooked or dismissed.

wanted access to a supportive care navigator – but only **one quarter** were referred and connected with one.

One in three
had to attend four or more appointments about their symptoms before receiving a diagnosis.

One in three
carers were not referred to a carer support service but wanted to be.

One in four
were diagnosed with a different condition before they got their cancer diagnosis.

One in five
waited more than six months from their first medical appointment to cancer testing; for 1 in 14, that wait stretched to over three years.

The insights from this survey are already shaping our own services and support programs and will play a significant role in our policy and advocacy over the coming years. The early findings were launched in 'Now it's Personal: access and equity for all' at Parliament House in early September.

Now it's personal: access and equity for all

In September this year, RCA released a landmark report, 'Now it's personal: Access and equity for all', exposing the deep inequities in experience and outcomes for people with rare and less common cancers – inequities that begin even before a diagnosis is made.

The report grounded current policy realities and opportunities in the lived experience of people affected by rare and less common cancers, with six recommendations to accelerate progress towards the Rare Cancer Moonshot and stamp out the inequities in Australia's health and care systems.

Equity will not happen by chance. It requires new ways of thinking, tailored policy, deep collaboration, and unwavering national and local commitment. The report set out practical ways to do that so that rare cancers benefit from the same shifts in policy, funding and focus that have delivered improved services, pathways and outcomes for other cancers.

"We need a better, more compassionate system – one that values lives, not numbers. We're not statistics – we're people, with families. It makes you feel expendable."

– Celestino, living with adrenocortical carcinoma

Photos from the policy report launch 'Now it's personal: access and equity for all' at Parliament House

Advancing genomic-led care

"It's fantastic to be here and participate in what is such a fantastic roundtable. There is so much energy in the room as we talk about genomics and precision medicine. Now is the time to find a way forward."

– Vicki Durston,
Director of Policy & Advocacy,
Breast Cancer Network Australia

"Coming to an event like this is so important because we're collaborating and by working together we have more chance of influencing the government and getting them on board."

– Meredith Cummins,
CEO Neuroendocrine Australia

We remain a leading voice on the need for equitable and affordable access to genomic testing and precision oncology, working with patients and partners. Access to genomics has been a cornerstone of our advocacy and policy recommendations over the past several years and momentum is building.

In late 2024, we delivered our first **Policy Roundtable Series** in partnership with Australian Genomics. Through three sessions in Canberra, Sydney and Melbourne, over 120 delegates shared their experiences, ideas and commitments to increase access to genomic-led care in Australia. The summary report, Advancing genomic-led cancer care in Australia, sets out the case for change and five key steps for shifting genomic-led care from research to standard practice. We are grateful to Evo Health for their support in writing the summary report from this important series.

$143 million investment to expand access to precision oncology.

RCA proudly supported Omico and the Zero Childhood Cancer Program to secure vital funding, recognising their critical role in improving outcomes through precision medicine and bridging the gap between research and standard of care.

In March 2025, the Government announced major investments in the two leading precision oncology programs. **$112.6 million** over three years was committed to continue the **Zero Childhood Cancer (ZERO) program,** enabling nationwide genomic analysis for enrolled children to guide treatment and an expansion of the program to people aged 18 – 25. Every child diagnosed with cancer in Australia now has access to ZERO.

An additional $30.8 million was announced to expand **Omico's PrOSPeCT program,** Australia's largest cancer genomics initiative that provides genomic testing to match patients with rare or advanced cancers to treatments and clinical trials. Through RCA's **partnership with Omico,** we have **supported hundreds of patients to access genomic testing** and ensure patient voices and experiences shape the program's development and delivery.

Vital recognition of rare and strengthened national leadership.

Through our partnership with Cancer Australia and the Policy Roundtable Series, we have contributed to the Framework for Genomics in Cancer Control, a new framework developed to accelerate the use of genetic and genomic medicine in cancer care. The Framework recognises people with rare cancers as a priority population given their high unmet needs and the transformative potential of genomic medicine in their diagnosis and treatment.

Genomics Australia, launched in July 2025 to provide national leadership, coordination and expertise to support the better integration of genomics into the Australian health system, also recognises the importance of genomics for people with rare cancers, with an early priority to support the delivery of personalised cancer care.

Fairer, faster access for all

"The momentum is building to change the story for rare cancers. For the tens of thousands of Australians impacted by rare and less common cancers, equity is not an aspiration – it is what we expect. And it's time for policy to enable that."

– Christine Cockburn, CEO, RCA

In Australia, patients with rare cancers are often denied access to life-saving treatments due to longstanding, systemic challenges. Despite using the same drug, one patient may pay $31.60 per round (and $25 from 2026) while another pays over $8,000, simply because of where their cancer is located.

The current Health Technology Assessment (HTA) system is outdated, slow, and not designed for rare diseases, leading to long delays and inaccessible treatments. As a result, patients with rare cancers are often left behind, forced to fundraise to travel overseas for treatment.

Over the past year, RCA has submitted consumer evidence to support ***54 applications to the Pharmaceutical Benefits Advisory Committee (PBAC) and responded to numerous Medical Services Advisory Committee (MSAC),*** ensuring patient experiences are considered in decisions about medicines access.

Bold reform is needed and RCA continues to lead the way in advocating for equitable access for people with rare and less common cancers, including a fairer approach to medicines assessment through 'pan-tumour' applications.

After eight years of advocacy, back-and-forth between Government and PBAC and successive reviews recommending such a change, **we welcomed a positive recommendation from PBAC to subsidise a pan-tumour listing** – a move that could mark a major shift in how cancer medicines are assessed and funded in Australia.

This recommendation shows an appetite for change, an imperative for equity and a readiness to rethink how access to medicines works in Australia creating faster, fairer access for thousands of people. We remain steadfast in our efforts to have pan-tumour widely adopted.

Right care at the right time

The ARC Portal: A lifeline for rare cancer patients

In February 2025, the Federal Government announced a $6.7 million investment in the Australian Rare Cancer (ARC) Portal over four years. This unique online platform connects patients with rare cancer specialists, clinical trials, and treatments, ensuring equal access to expert care and support no matter where they live. People in regional and rural Australia will benefit most, gaining fast, seamless access to specialist cancer services without the need for extensive travel.

The announcement came after 18 months of advocacy from RCA and the ARC Portal team, including a joint pre-budget submission and Thought Leadership event.

"The ARC Portal is a practice-changing resource, providing me with access to detailed genetic and molecular analysis and offers expert guidance on treatment options for rare cancer patients. It also bridges an equity gap for our regional Aboriginal and Torres Strait Islander patients by providing them with access, information and new treatment options."

– Dr Michelle Harris,
Gynaecological Oncologist, Darwin, NT

Australia's first Optimal Care Pathway for people with rare and less common cancers.

At the start of 2025, Cancer Australia commissioned RCA to lead development of **Australia's first Optimal Care Pathway** for people with rare and less common cancers. This is an important recognition of the significant gap in best practice guidance for rare and less common cancers and the unique circumstances and challenges that patients and carers face.

RCA has established a rich and diverse Expert Working Group (EWG) with healthcare professionals and people with lived experience of rare and less common cancer to ensure the unique needs and experiences of patients are at the centre of the process. The EWG is co-chaired by Lillian Leigh, an advocate, lawyer and non-executive director living with a rare lung cancer, and Professor Clare Scott, a distinguished medical oncologist and cancer researcher.

The EWG has produced three draft resources: an Optimal Care Pathway, a Consumer Guide and Quick Reference Guide. They will be shared for public consultation later this year and published in ten languages in 2026.

"I want to see that at the end of the day, no matter where you are, who you are, every patient who is diagnosed with rare and less common cancer gets the best possible care in Australia. Ultimately, I want people to have improved survival and the best quality of life that they can have."

– Lillian Leigh,
Co-Chair, OCP Expert Working Group

Signature *Campaigns*

Uniting a community to raise awareness, vital funds and a groundswell of support. Individually we may be rare, but together we are many.

Kosi Challenge

A challenge that connects

The Kosi Challenge isn't just about reaching the summit of Australia's highest peak – it's an experience where supporters can come together to meet, share stories, and walk side-by-side with rare cancer patients and their families.

Every story, every step, every dollar shows people with rare cancer that they have not been forgotten, and that they are not alone.

It's more than just a physical challenge. It's a weekend that celebrates life, honours those people we've lost, and drives real change for the patients of today and tomorrow.

That's the magic of Kosi.

Surrounds
patients with people who care

Unites
supporters to create change

Celebrates
the rare cancer community

Elevates
the unique challenges patients face

Conquers
isolation, so patients don't feel so alone

This year, the Kosi Challenge, was held over two days in March with **more than 1,000 people** participating both in person and virtually. Together the highest fundraising total to date was achieved with an incredible **$678,000** going directly towards RCA's patient support programs, including the crisis support fund.

729 in person
271 virtual

For those in Thredbo taking on the 21km climb, it was a weekend of sunshine and wonderful community connection. We also loved hearing from our virtual teams about how and where they were taking on the challenge!

Thank you to the sponsors of the 2025 Kosi Challenge, your support makes this event possible and is deeply appreciated:

- Creative Advocacy Solutions
- Heng & Hurst
- Medicines Australia
- Biopharma Dispatch
- Cube PR

Thank you also to the organisations who made generous donations, showing company wide support for the rare cancer community:

- Cencora World Courier
- AstraZeneca
- BMS
- Boehringer Ingelheim
- Ipsen
- IQVIA
- Johnson & Johnson
- Merck Healthcare
- MSD
- Novartis
- Roche

Climbing for a cause *close to her heart*

"When I was diagnosed there were no support groups, I couldn't find any information about my disease, I didn't know anyone else with my disease or have any prospect of support. I was 18 years old and completely lost."

– Sarah McGoram OAM

Canberra mother and Order of Australia recipient, Sarah McGoram OAM, climbed Australia's highest peak in the 2025 Kosi Challenge, to raise awareness for people living with rare and less common cancers, of which she is one.

She conquered the 21km climb with her husband Tom by her side, along with 700 others from Thredbo Village to the mountain's peak and back, all in the name of rare.

At just 18, Sarah was diagnosed with Gastro Intestinal Stromal Tumours (GIST) and has lived with the rare cancer for her entire adult life. It wasn't until 20 years after her diagnosis that she met another person who truly understood her situation and could offer real support and hope; that person was RCA Co-Founder Kate Vines.

"When I was diagnosed there were no support groups, I couldn't find any information about my disease, I didn't know anyone else with my disease or have any prospect of support. I was 18 years old and completely lost," Sarah recalls.

"I remember one day, I finally called the RCA support line in a state of panic, and it was Kate who answered. Kate listened to all my questions, helped me understand why I was falling through the cracks in the system, and facing extraordinary treatment expenses, she assured me that I was not alone, and she was there the help.

"My conversation with her in that one phone call was the first time since I was diagnosed that I had felt someone else understood what I was going through and was a turning point for me as a person living with a rare cancer.

"Ten years on, I am still being supported by the amazing navigators at RCA, and I am so excited to be feeling well enough to be able to give back and show my support for this wonderful organisation by taking on the Kosi Challenge.

"What I love about this event is that it brings together a community of people who otherwise feel quite isolated in their cancer experience. To be able to hike up this mountain and raise a huge amount of money and awareness is so uplifting and it shows that there are people out there who care, and that change is possible.

"My story is just one of many. I know many patients who are not well enough to walk up Mount Kosi right now, so I did it for them. Individually we are rare, but collectively there are a lot of us. I'd encourage everyone to support Rare Cancers Australia, so they can continue to be a light for all patients in their darkest moments," Sarah concluded.

Rare Cancers Awareness Day

Rare Cancers Awareness Day is held on the 26 June each year. It is a day for our rare community to unite in a show of support and strength for those affected by rare cancers and raise awareness so we can all help change the story of a rare cancer diagnosis.

We know rare cancers can bring challenges including less information, knowledge and support, huge financial burdens and limited treatment options. That's why people diagnosed with rare cancers, and their loved ones, need our support.

This year's campaign was digitally led, with a strong presence across social media channels, featuring four personal videos on the importance of being aware of rare.

The campaign achieved more than:

1,000
Pledges on our online pledge map.

800
Downloads of our 'I'm Aware of Rare' Information Kit.

250
Orders for 'rare pairs' of socks.

32,000
Views of our videos on YouTube.

We also developed a free Information Kit for people to download by subscribing to our newsletter. The Kit featured important awareness information on:

- what it means when a cancer is "rare"
- the reality of a rare cancer diagnosis and the challenges people can experience
- stories from people who have been diagnosed with rare cancers; and
- signs and symptoms to look out for so you can advocate for yourself.

Thank you to our returning campaign partner, ICON Cancer Centre, for your continued support of Rare Cancers Awareness Day and helping us raise awareness of rare across your 40+ cancer centres.

Breaking the Stigma: *Jane's Story*

After losing her mother at a young age to breast cancer, and even going through her own experience with it, Jane had always been vigilant in screening and checking her own breasts for abnormalities but never thought to check anywhere else.

It wasn't until one day in July 2022, when Jane started to experience discomfort and soreness "down there". Initially she ignored it, but the pain intensified to the sensation of broken glass being smashed in between her legs and she knew she had to do something about it.

"I experienced fevers and pain while urinating, during intercourse and sometimes randomly for no reason at all," Jane recalls.

"While feeling somewhat embarrassed, I decided I had to see my doctor about it, so I booked an appointment. She listened to my symptoms and determined that I was perimenopausal, she didn't even look down there.

"I knew it wasn't just perimenopause, so I bit the bullet, took out the mirror and looked down there myself. I remember looking and thinking 'Oh my God'.

"It took six months for me to get a diagnosis; it was just before Christmas in December of 2022. They took a biopsy and the results came back with a diagnosis of Stage 3 Vulvar cancer.

"What's a vulva? was my first thought. I had never heard of it before. My thoughts then went to the other word 'cancer' which I knew about all too well."

The next few months saw Jane undergo two surgeries to remove the lesions and surrounding tissue. Unfortunately, further testing showed the cancer had also spread to her lymph nodes, so she also had to go through six weeks of radiation and chemotherapy.

"Thankfully I have recovered well, I started seeing a psychologist who has been wonderful, and now nearly 18 months later I am happy to say I am still doing well.

"My experience was awful, I really had to fight to be taken seriously and advocate for myself. I want people, especially women, to know my story and learn from my experience. We have a vulva and it can get cancer, cancer that spreads!

"If I had one message to leave with people, it would be to get to know your own body and to listen to it. If you feel like something's wrong, go get it checked, because it could save your life."

Jane's story and video featured across RCA socials for the 2025 Rare Cancer Awareness Day campaign.

Rare Long Lunch

The inaugural Rare Long Lunch was held in November 2024 at the Museum of Contemporary Art in The Rocks, Sydney, bringing together **190 key stakeholders from the rare cancer community**, including industry and corporate partners, top fundraisers, patients, carers and RCA Board directors.

The day consisted of meaningful videos and presentations, showing the **positive impact** that the generous support of RCA's partners and advocates enables the organisation to have on the rare cancer community.

Guests were inspired by powerful speakers Michael Crossland and Caitlin Delaney, who shared their remarkable, respective cancer journeys of resilience and hope. Thanks to a silent auction of Georg Jensen vases and generously donated raffle prizes, the event **raised over $105,000** to support our ongoing work to improve the lives and health outcomes of people affected by rare cancer.

"[CanForum] is one of the best cancer advocacy programmes that I have come across."

– Associate Professor Judith Lacey, Chris O'Brien Lifehouse

CanForum25

In September 2025, we hosted our tenth annual CanForum in the Great Hall of Parliament House, Canberra. The largest patient-centred advocacy event was attended by nearly **300 patients**, carers, government, patient organisations, health professionals and industry, CanForum25: Now it's personal – access and equity for all focussing on the lived experiences of Australians with rare and less common cancers, powered by the insights from our recently launched policy report of the same name.

The event featured three powerful sessions:

The answers within: Unleashing the power of personalised care explored the promise of personalised care through genomic-led treatments. Professor Matt Brown (Genomics England) and Tiffany Boughtwood (Genomics Australia) offered a compelling vision of what's achievable in Australia, and patient advocate Natalie Willacy highlighted the urgent need – and opportunity – to make genomic profiling standard in cancer care. The session closed with a fireside chat unpacking the challenges of implementing genomics-led care.

Ready or not, the cancer care revolution is here unveiled findings from the Cancer Lived Experience Survey, sparking conversation on whether systems are truly delivering patient-centred care. Keynotes from Professor Tracey O'Brien AM (Cancer Institute NSW) and carer Kevin MacIsaac, alongside a thought-provoking panel, explored the rapid innovation in cancer treatments and the system changes needed to create a better world for rare.

When we know better, we do better reinforced the power of supportive care and truly listening to patients. Highlights included patient advocate Tenielle Jordan and expert insights from Associate Professor Judith Lacey (Chris O'Brien Lifehouse) and Professor Mei Krishnasamy (University of Melbourne) on how supportive care and nurse-led research are driving more equitable cancer care. A panel discussion closed the session, focusing on embedding the patient voice from the ward to the Board.

"That's the reality of living with a rare cancer. Your treatment, your future, your survival, it all comes down to chance."

– Natalie Willacy

"Families like mine, we do not want special treatment – we want fair treatment."

– Kevin MacIsaac

"That mutation had been there all along. It was in the tumour they had taken out two years before. Surely that is something that should inform my treatment options from the start."

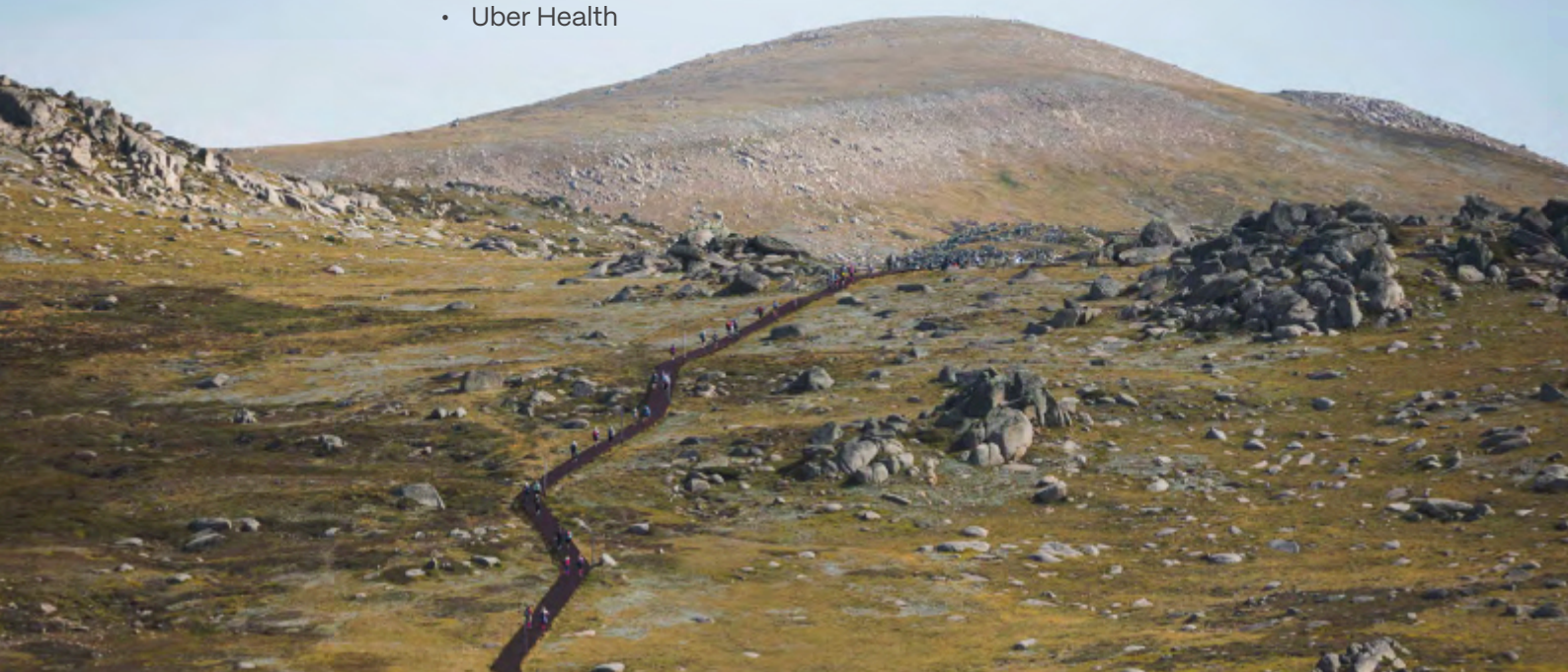
– Tenielle Jordan

With strong bipartisan support expressed during the addresses by Minister The Hon Mark Butler and Senator The Hon Anne Ruston, the event served as a call to action for how Australia can deliver more equitable, personalised care for people with rare cancers.

Grants & Philanthropy

We gratefully acknowledge the trusts, foundations, partners and entities below that have made a generous financial gift this year. We also thank those who wish to remain anonymous. We are humbled by your generosity.

- Cameron Family Foundation
- Croxley Foundation
- Illawarra Convoy Community Grant
- IMC Foundation
- McNally Foundation
- Morgans Foundation
- Neumann Benevolent Foundation
- Shaw & Partners
- The Book Shop Bowral & Kiama
- Uber Health



Community *Giving*

We couldn't do what we do without the support and generosity of individuals, communities, and partners across Australia. Every contribution – big or small – sends a powerful message to those affected by rare cancer: *you are not alone.*

$1,117,000 funds

raised this year by community groups and individual fundraisers, driving vital progress in rare cancer through unwavering support and relentless advocacy.

360 generous donations

received from individuals and organisations, each one helping to make a meaningful difference for people affected by rare cancer.

34 community fundraisers

took part in challenge events, raising vital funds and awareness in support of RCA and Mummy's Wish.

$857,119 donations

were made to the Patient Treatment Fund – providing crucial financial support to people managing the high costs of cancer treatment and related expenses.

Community fundraising *superstars*

Back to Back Wool Challenge:

This event attracted people from all over the world to a tiny town in Victoria's south west, where teams worked together in a race to shear a sheep, spin its wool then knit a full-size jumper to a set pattern. Every jumper knitted in record time helps bring hope and support to families facing the toughest of diagnoses.

This year marks their third year supporting RCA.

Over $7,600 raised

Hall Bushrangers Rugby Club:

The club chose to support RCA due to the invaluable assistance provided to one of their members, Anthony (Box) Hayes, who was diagnosed with terminal oesophageal cancer in August last year. This diagnosis has profoundly affected the entire club, which values family above all else and serves as a second home to many of its members. As a passionate and dedicated club, the Bushrangers are committed to supporting not only Anthony but also others affected by cancer.

$10,000 raised

NSW Doctors Orchestra:

The NSW Doctors Orchestra is a classical orchestra of doctors and medical students from all areas of NSW who come together annually to play in aid of charities in both the arts and medicine. This year they raised $12,500 for Mummy's Wish through their Stars and Planets performance for a sold out crowd at the Sydney Conservatorium of Music.

$12,500 raised

Dry July

Dry July is one of Australia's leading fundraising campaigns, supporting cancer organisations nationwide. In 2025, a total of 504 supporters took part in Dry July, giving up alcohol for the month in support of RCA and Mummy's Wish.

The vital funds raised went directly to supporting our patient programs – helping people manage cancer-related expenses, participate in support groups, and receive resources like our Rare Cancer Support Guide. They also helped to provide care packs for mums with cancer and include things like comfort bears, children's books, cancer information, and vouchers for practical assistance.

191 incredible supporters took on the Dry July challenge for RCA, raising **$86,196.62** to support people impacted by rare cancer.

313 fundraisers rallied behind Mummy's Wish, raising **$100,858.20** to help ease the burden on mums undergoing cancer treatment.

The Corporate Clash in Macarthur

In August, **22** courageous businesspeople from Sydney stepped into the boxing ring for the Corporate Clash in Macarthur. Transforming from everyday professionals into amateur fighters, they battled it out for important causes close to their hearts, including our own Head of Strategic Communications, Alicia 'Wrecking Ball' Ballesty.

An incredible **$308,000** was raised, **$138,000** of which went to RCA to help fund our essential patient support care packs, sent to every new patient.

A heartfelt thank you to all the organisers, fighters, trainers, supporters, and sponsors who made this unforgettable event and generous donation possible!

$138,000 raised

Motor Events Racing

Motor Events Racing was founded by Ben McGuire following his wife's diagnosis of an extremely rare form of cancer. Driven by personal experience, Ben and his team are committed to supporting Australians affected by rare and less common cancers.

Hosting Australia's largest cheap car racing events, Motor Events Racing invites car enthusiasts to build their own race cars and compete in a fun, inclusive, and affordable environment.

In 2025, Motor Events Racing raised **$85,737** for the rare cancer community!

We're incredibly honored to receive this ongoing support and the difference they continue to make for patients, carers, and families across the rare cancer community.

$85,737 raised

Honouring those who left a gift in their Will

We would like to acknowledge the compassionate individuals who chose to leave a lasting gift to Rare Cancers Australia.

We are deeply grateful for your generosity, which will help to support and improve the lives of patients and their families for years to come.

Jemma's *Legacy*

"We're so proud of the legacy Jemma has left and couldn't think of anyone better than Rare Cancers Australia to carry it forward. Their compassion and unwavering support gave Jem and our family strength and hope. We're forever grateful and hope this program brings the same comfort and courage to others."

– Elise, Jemma's sister

Jemma was 32 years old, married to the love of her life, Lang, a proud step-mother to Riley and fur-mum to her beloved dog George when she was diagnosed with stage 4 non-small cell lung cancer with an EGFR exon20 mutation.

What began as sciatica pain led to the discovery of tumours on her spine, and ultimately, her full diagnosis. Jemma faced this battle head-on, enduring multiple rounds of chemotherapy, immunotherapy, radiation, and even participating in a trial drug program.

Jemma was then offered access to a targeted therapy for her rare mutation. However, accessing this treatment came at an overwhelming cost at $10,000 per session, with sessions required every fortnight.

She fundraised effectively with her community, rallying behind her and taking her story to the media. This led to a feature on A Current Affair, which bolstered her donations and helped her to access the expensive treatment she needed.

During her cancer journey, wellness practices became a true sanctuary for Jemma. Through breathwork, reflection, movement, mindfulness, and nourishment she found strength not only for the body but for her mind and spirit. What began as a personal refuge grew into a deep passion that Jemma enjoyed sharing with others.

Jemma was stoic and determined not to let her cancer get in the way of her zest for life. She loved adventure, nature, and the great outdoors. She cherished every moment spent with family, enjoying good food, and had a passion for travel. Known for her caring and compassionate nature, Jemma was a much-loved member of her community, bringing warmth and light to everyone she met.

Sadly, Jemma passed away in December 2024, just before Christmas. The groundswell of support she received from her local community, and broader Australian public, while she was alive was incredible. She touched the hearts of so many and will be sorely missed.

Tenaya Wright, RCA Specialist Cancer Navigator, directly supported Jemma throughout her cancer experience and remembers her as "someone who reminded us all of the beauty in life's small moments".

Following Jemma's celebration of life ceremony, her family approached RCA with a generous gift in memory of Jemma, which will now be going towards the establishment of the Jemma Juckes Wellness Program, to honour her legacy and have a lasting impact for others diagnosed with cancer.

The Jemma Juckes Wellness Program is a heartfelt initiative that extends Jemma's passion for holistic cancer care, complementing your medical journey.

Rare Cancers Australia is honoured to be entrusted with Jemma's legacy and is continuing to work closely with her family on the development of the Jemma Juckes Wellness Program, which will launch in 2026.

Partnering *for purpose*

Our partners play a vital role in helping us drive better outcomes and improve lives every day.

Collaboration is at the heart of everything we do. With the unwavering support of our dedicated partners, we're improving access to treatment, amplifying the voices of those affected by rare cancer, and delivering practical support to patients and families when it matters most.

We want to thank and acknowledge everyone for their continued and invaluable support.

Government Partners

- Cancer Australia
- Australian Government Department of Health, Disability and Ageing

Health Sector Partners

- Prospection
- BioPharma Dispatch
- Creative Advocacy Solutions
- Cube PR
- GenesisCare
- Heng & Hurst
- ICON Cancer Centre
- Medical Oncology Group of Australia (MOGA)
- Cancer Nurses Society of Australia (CNSA)
- Omico
- Private Cancer Physicians of Australia (PCPA)
- Ramsay Health

Cancer Patient Organisation Partners:

- Breast Cancer Network Australia
- Cancer Council Australia
- Canteen
- Camp Quality
- Head and Neck Cancer Australia
- Leukaemia Foundation
- Lung Foundation Australia
- Liver Foundation
- Lymphoma Australia
- McGrath Foundation
- Melanoma Patients Australia
- Myeloma Australia
- Neuroendocrine Cancer Australia
- Ovarian Cancer Australia
- Prostate Cancer Foundation of Australia
- Pancare
- Patient Voice Initiative
- RedKite
- RUNDIPG
- The Asbestos and Dust Diseases Research Institute

Industry Partners

- AbbVie
- Amgen
- Astellas
- AstraZeneca
- Bayer
- BeOne Medicines
- Bristol Myers Squibb
- Boehringer Ingelheim
- Cencora World Courier
- Cyclotek
- Daiichi Sankyo
- Dr Reddy's
- Gilead
- GSK
- Ipsen
- IQVIA
- Johnson & Johnson
- Lilly
- Medicines Australia
- Medison Pharma
- Menarini
- Merck Healthcare
- Montu
- MSD
- Norgine
- Novartis
- Oncology Industry Taskforce
- Pfizer
- Roche
- Servier
- Specialised Therapeutics
- Takeda

A Rare Partnership - Omico

"Rare Cancers Australia and Omico share a commitment to ensuring no one is left behind. RCA's relentless advocacy and daily support for patients with rare and less common cancers is inspiring, strengthening our shared efforts to urgently deliver equitable access and mainstream precision oncology. While we work in different ways, our roles are complementary — together we amplify each other's impact. We deeply value RCA's voice in championing fairness and are proud to stand alongside them in building a national approach that delivers the best options and outcomes for Australians affected by cancer."

– Prof. David Thomas, Chief of Science and Strategy and Mr Ian Black, CEO Omico (pictured L – R)

Omico.

We're proud of our long-standing partnership with Omico, grounded in shared values of equity, fairness, and compassion. Advances in genomic profiling and precision oncology are transforming cancer care — especially for those with rare and less common cancers — offering more targeted treatments, fewer side effects, and ultimately improving quality of life and survival.

RCA's collaboration with Omico is guided by a shared commitment to ensure that the design and delivery of genomic cancer programs are shaped by the lived experiences of patients and carers.

Through the Patient Advocacy Advisory Group (PAAG), RCA brings together around 20 oncology advocacy organisations each quarter, creating a unified platform for patient perspectives to inform Omico's program development and strategic priorities. This model fosters genuine co-design -embedding equity, accessibility, and patient-centred outcomes into genomic care.

RCA's Patient Support Team plays a critical role in bridging the gap between complex science and patient understanding. By guiding patients and carers through the genomic profiling process- raising awareness, building confidence in healthcare discussions, and providing tailored support - they help make advanced testing more approachable and meaningful for those affected by rare and less common cancers.

At a systems level, RCA's sustained advocacy with government partners has been instrumental in securing ongoing public investment in genomic testing. This funding has enabled hundreds of Australians to access potentially life-changing insights from genomic profiling -advancing the national precision medicine agenda.

Research partners

DYNAMALK clinical trial

DYNAMALK is a clinical trial investigating the potential of comprehensive genomic profiling to revolutionise the treatment of ALK+ Non-Small Cell Lung Cancer (NSCLC).

As explained by Dr. Malinda Itchins, "when someone has a type of lung cancer that is ALK-positive, they often take inhibitor drugs directed to the ALK target to help treat it. But over time, the cancer can become resistant to this medicine. Right now, doctors don't have a reliable way to predict when this might happen or how to adjust treatment based on each person's specific situation".

Through liquid biopsies from obtained blood samples, researchers hope to predict resistance, guide treatment decisions, and improve outcomes.

RCA has supported this groundbreaking clinical trial to fully recruit over 60 participants, with initial final results from the trial due at the end of 2026.

TRACKER by Biobank

TRACKER is the first Australian tissue and data repository for longitudinally collected metastatic lung cancer samples.

It is transforming the landscape of lung cancer research by challenging traditional processes. RCA is proud to partner with researchers across Australia and internationally, accelerating the translation of research into real-world clinical outcomes that offer tangible hope for patients and their families affected by lung cancer.

La Trobe University

RCA engaged La Trobe University to conduct a literature review to inform the Expert Working Group in its advice for the draft Optimal Care Pathway, summarising existing evidence and evidence gaps in clinical guidelines and best practice for people with rare and less common cancers.

Supporting People with A Rare Cancer (SPARC) Living in Rural and Remote Communities

Rurality exacerbates the complex trajectory rare cancers patients are already in, because of difficulties accessing treatment and tailored supportive care.

In close collaboration with the Cancer Council Victoria, RCA partnered on the Rural 'SPARC' study.

The study aims to address unmet information needs and reduce psychological morbidities such as isolation, loneliness, depression, and anxiety, as well as increase the quality of life of rural patients diagnosed with a rare cancer.

Its purpose is to co-design and co-develop the first-ever peer-support psychosocial intervention program for people living in rural communities who have a rare type of cancer.

The final report is due to be delivered at the end of 2025.

So What? Research

So What? partnered with RCA on the first national Cancer Lived Experience Survey, which resulted in almost 2,500 participants and helped to inform our policy report Now it's personal: access and equity for all.

Tamsin Farrugia,
PhD Scholarship candidate

PhD Scholarship for Tamsin Farrugia

Tamsin's PhD research, conducted with Rare Cancers Australia, aims to improve the quality, accessibility, and delivery of information for people diagnosed with a rare cancer. Despite the vital role of information in guiding understanding, decisions, and emotional coping, many patients still face gaps and unmet needs.

Her work includes a systematic review of interventions to reduce information gaps and a qualitative study exploring patient and healthcare professional perspectives. Both published studies deepen understanding of how people navigate complex and emotionally charged information environments.

National Press Club of Australia partnership

Rare Cancers Australia is the preferred charity partner of the National Press Club of Australia.

We've been proud to sponsor the Excellence in Health Journalism Awards, which recognise the work of our country's top journalists from the sector – those who have brought complex, often confronting health issues into the spotlight. Their work gives a voice to those who might otherwise go unheard.

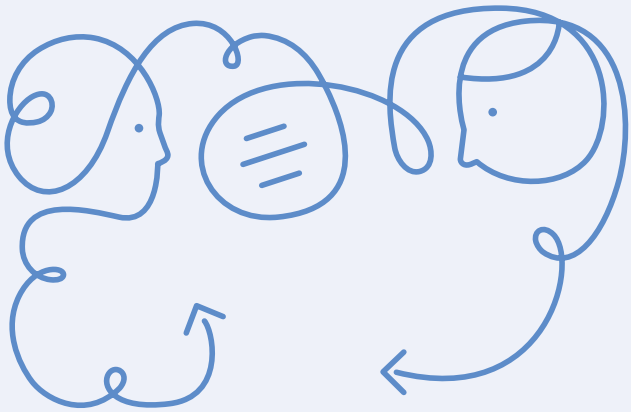
NATIONAL PRESS CLUB OF AUSTRALIA

Christine Cockburn with 2025 Health Journalism Awards Winner, Natasha Robinson (Health Editor, The Australian) and The Hon Mark Butler.

Community Advisory Board

The RCA Community Advisory Board (CAB) plays an important role at Rare Cancers Australia, ensuring the patient experience is at the heart of everything we do.

It provides incredibly valuable input from our patients, carers, and family members who apply their lived experiences and help shape RCA's policy development, resources, and projects. By bringing authentic, real-world insights, CAB members play a critical role in ensuring the perspectives of the rare cancer community are understood.



We would like to thank the following people for providing their expertise and precious time on the CAB this year:

- Lisa Briggs
- Noel Carmona
- Caitlin Delaney
- Hosam Ehdeyhed
- Kerrilee Hall
- Ashlynn Heaton
- Nick Kelly
- Lillian Leigh
- Jelena Magic
- Nigel Marks
- Sarah McGoram
- Anita McGrath
- Elizabeth Pickworth
- Glen Ramos
- Nicolas Ribbe

Our Leadership Team

Christine Cockburn
Chief Executive Officer

Our impact is made possible by our dedicated, purpose-driven staff who are determined to create a better world for rare. United by a shared commitment to patient equity, our leadership team is driven by the collective goal to change the story of rare and less common cancers.

Alicia Ballesty
Head of Strategic Communications

Sarah Benger
Head of Policy & Public Affairs

Natalie Clancy
Head of Fundraising

Sarah Clausen
Head of Operations

Nikki Kerr
Head of Partnerships

Cathy Slattery
Head of Patient Programs

Our Board

Bruce Goodwin
Director & Chair

Richard Vines
Director & Founder

Kate Vines
Director & Founder

Kate McQuestin
Director

Ben Taylor
Director

Steve Baker
Director

Christine Cockburn
CEO & Director

How you can help create impact:

Donate

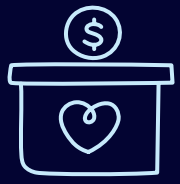
Whether it's a one-off or regular donation, or gift in your Will, every dollar helps us in delivering real impact for rare. Your donation goes directly towards our patient support services, which assist the thousands of new patients we support each year navigate their rare cancer diagnosis. Your help ensures no one feels alone and that everyone is given the best possible chance to survive cancer.

Fundraise

Join in on our annual Kosi Challenge fundraiser or create your own challenge event! Host a high tea or BBQ. Whatever you choose, your efforts will be making a real difference for a person living with a rare or less common cancer.

Partner with us

There are many ways we can work together to help reach even more people living with rare or less common cancers. Join us in being a voice for the voiceless and in making impactful change for all cancer patients in Australia, regardless of their diagnosis.



Volunteer

We can always do with more hands on deck! Whether it's stuffing our Mummy's Wish bears, helping out at the Kosi Challenge, tackling administrative tasks, or making thank you phone calls – there are plenty of ways for you, or your workplace, to offer in-kind help. Just reach out!

Our impact is made possible thanks to the support, collaboration, strength and commitment of the people that make up our rare community. Together we are stronger and we can make a real difference for those who truly need it.

Thank you!

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rare cancers Australia