

Rare Impact

2024

A look back on the year and how together we've made a real difference for people living with rare, less common and complex cancers in Australia.



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Acknowledgement of Country

Rare Cancers Australia acknowledges the 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 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.

A message from our Chair on behalf of the Founders

Since my wife Kate and I founded Rare Cancers Australia (RCA) in 2012, we have remained steadfast in our mission to improve the lives and health outcomes of all people living with rare, less common and complex (RLCC) cancers in Australia. We did this so that no one was left behind or felt alone in their cancer journey.

In that time, we have supported thousands of patients, along with their loved ones and carers, helping to navigate them through the maze of uncertainty and isolation that comes with a rare cancer diagnosis. Finding them specialist oncologists, access to treatments, clinical trials, peer support and services has and always will be our north star.

Over the past 12 years, our work has resulted in a dramatic increase in government investment for rare cancers. Our creation of the National Oncology Alliance and the subsequent production of our Vision 20–30 report was responsible for the Health Minister, the Hon Greg Hunt, mandating the development of the Australian Cancer Plan. Similarly, our work resulted in an allocation of over \$600 million to rare disease and rare cancer research. But there is still so much to be done.

At the end of 2023, Kate and I stepped back from day-to-day involvement with RCA and we have been delighted to see our incoming CEO, Christine Cockburn and her team maintaining if not accelerating the work of the organisation.

Highlights include financial support of \$4.36 million over four years from the Federal Government to allow us to enhance and expand our patient support services. This grant, together with the generous support we receive from public donations and partnerships we have developed with industry, allow us to provide meaningful support to our patients.

Part of that ongoing support is our Patient Treatment Fund (PTF). Over the years, we have raised vital funds and awareness for rare cancer patients, with more than \$5.5 million and counting donated to the PTF – where money donated goes directly to the patient, so that they can pay for their treatment, travel and the myriad other financial shocks that await our patients. Sadly, with the increasing array of proven therapies that remain unfunded by the Pharmaceutical Benefits Scheme (PBS) in Australia, its importance has never been greater.

Kate and I are so proud when we look back to our humble beginnings, working out of a home office with a patient support team of one, to where RCA is now and how much the organisation and our community has grown. The impact we have made is real and it is lasting.

However, whilst we've made great strides towards achieving true equity for rare over the years, there is a long way to go.

Rare and less common cancers continue to have unacceptably low survival rates and account for a disproportionately high number of total cancer deaths in Australia. This underscores the continued importance of research, treatment advances, strategic partnerships and invested support for those affected. Most importantly it highlights the need for a fairer, more responsive mechanism for the funding of therapies through the PBS for rare cancer patients.

Kate and I are confident in the legacy we've created and the team of dedicated people tasked with carrying it forward.

I acknowledge and thank the Directors of the Board for their strategic insights and guidance throughout the year. Their invaluable range of skills and experience has ensured a diverse representation of views and perspectives which has led to sound governance and accountability across all areas of the organisation.

Kate and I would also like to thank our extraordinary Chief Executive, Christine Cockburn, and the whole RCA team for their passion and commitment to the vision of the organisation. Their professionalism and dedication to the cause is reassuring and inspiring as Kate and I continue to step back from this wonderful organisation. There is still a great deal to do and with your support, we undoubtedly have the right team in place to get the job done.

Thank you,



Richard Vines
Chair, RCA



Richard & Kate Vines, Co-founders, RCA

A message from our CEO

In my first year as CEO at Rare Cancers Australia (RCA), it has been my focus to ensure that we never forget why we come to work and how important our Mission is. People with RLCC cancers deserve a dedicated and relentless team to make things better for them, and their families now and into the future.



Having spent several years as a Specialist Cancer Navigator at RCA, I am driven by the stories, experiences and the injustices I have heard, and our strategy takes a bold, multi-dimensional approach to achieving equity for everyone with cancer.

During the year, we have worked in lock-step with our community and partners to deliver on a number of important initiatives, some personal highlights being:

- Supporting a record number of families affected by RLCC cancers with our Specialist Navigation team. We know people have a better experience when they have a dedicated navigator by their side.
- Partnering with Cancer Australia for the delivery of the Australian Cancer Plan, to which RCA was a key contributor.
- Securing our first government grant, with a funding commitment of \$4.36 million over four years which will fund the expansion and delivery of our patient support telehealth service.
- Acquiring Mummy's Wish and integrating it into our patient support delivery model, to enhance its offering and ensure more mums diagnosed with cancer continue to be supported.

- Publishing our *Rare Cancer Moonshot: Equity for everyone with cancer* report and launching it at CanForum with the Minister for Health and Aged Care, The Hon. Mark Butler.
- Successful nomination of Professor David Thomas, Chief Science and Strategy Officer at Omico to address the National Press Club Address on Rare Cancers Awareness Day, shining a spotlight on rare cancer with his speech on 'Cancer – The Modern Day Plague'.

And that's just to name a few! With all that we do, we keep one thing in mind always – the community we serve. Our person-centred approach ensures that they are at the heart of our everything we do. I look forward to the coming year, with new and established supporters and collaborators all pulling in the same direction to improve lives and outcomes for those affected by RLCC cancers.

Warm regards,

A handwritten signature in black ink, appearing to read 'Christine Cockburn'. The signature is fluid and cursive.

Christine Cockburn
Chief Executive Officer, RCA



Members of RCA's Patient Support Team – Tenaya, Kirsten, Cathy and Jaime.

At RCA, the patient is at the centre of all that we do.

Our Patient Support Team comprises qualified navigators, allied health professionals and counsellors. They are in service to patient wellbeing and do whatever it takes to change the story of rare cancer, through improved diagnosis, limitless support and relentless advocacy.

Our mission

At Rare Cancers Australia (RCA), our mission is to improve the lives and health outcomes of people affected by rare, less common and complex cancers. We redefine cancer support, so no one is left behind or feels alone. Everyone is given the best possible chance to live beyond cancer.

We do whatever it takes to change the story of a rare cancer diagnosis through limitless support and advocacy. Our commitment extends to driving change in access, affordability, and quality of care, ensuring better outcomes for the patients of today and tomorrow.

We aim to be a beacon of hope, a force for change, and a steadfast ally for people living with rare, less common and complex cancers.

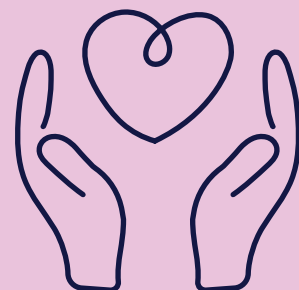
Vision

There is an equity in experience and outcomes for all people diagnosed with cancer.



Mission

Our mission is to improve the lives and health outcomes of all people living with rare, less common and complex cancers in Australia.



Strategic goals



Patient advocate

Empower and support rare cancer patients to effectively navigate and advocate their own healthcare journeys.



Meaningful impact

Amplify our brand and our impact to form partnerships for sustainability and growth.



A trusted voice

Become a trusted stakeholder in healthcare partnerships.



Outcome oriented

Deliver measurable change to policy that improves outcomes.



Workplace culture

Attract and retain competent professionals who follow best practice and put the patients first.

Values



Collaborative

We work in partnership with all stakeholders across the cancer care community toward common goals. We are grateful to those who contribute to our shared cause.



Patient-focused

We have an unwavering focus on the patient. We value and learn from the lived experience and prioritise the needs and voice of patients in all that we do.



Professional

We combine our expertise and experience with the latest research and evidence to provide sound advice.



Empathetic

We listen, take the time to understand, and are respectful and compassionate in our approach to each individual's unique circumstance and preferences.



Bold

We are not afraid to speak up, disrupt and start provocative conversations to drive meaningful change. We are ambitious, and relentless in our approach to make a positive difference.



Trustworthy

We deliver on what we promise and are honest in our approach.



Kate Vines receiving the 2024 Jeannie Ferris Award from The Hon Mark Butler MP.

Our history

One out of every four people diagnosed with cancer in Australia is told that their type of cancer is rare. That's one person every 13 minutes. Every 13 minutes, a daughter, a son, a mother or a father is told "we don't know the next steps for you".

One summer day in 1991, our founder Kate Vines was the person to receive this devastating news. Kate went through a long journey fuelled with courage, determination and optimism, only to be met with blank stares when she was looking for support.

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

Today, RCA is trusted to deliver a service to the rare cancer community that no one else does, in a way no one else does. Support as unique and individual as you are.

Our programs support over 1,000 patients and their families each year and from every angle; clinical, emotional, financial and practical. We understand a person's world has turned upside down. And we will do whatever it takes to navigate them through the chaos of rare cancer with empathy and compassion.

We equip our patients with courage, knowledge and motivation to advocate for themselves and demand to be heard. We stand side by side with them, to amplify the voices of the rare community and call out inequity in healthcare.

Better patient experiences and outcomes are our north star. And we won't stop reaching for them until the story and the system changes.

Approximately

40,000

Australians are diagnosed with a rare or less common cancer each year. Some **16,000 people** lose their lives – that's **43 people every day**.



While about one quarter of cancer diagnoses in Australia are rare or less common, they cause a third of all cancer deaths.

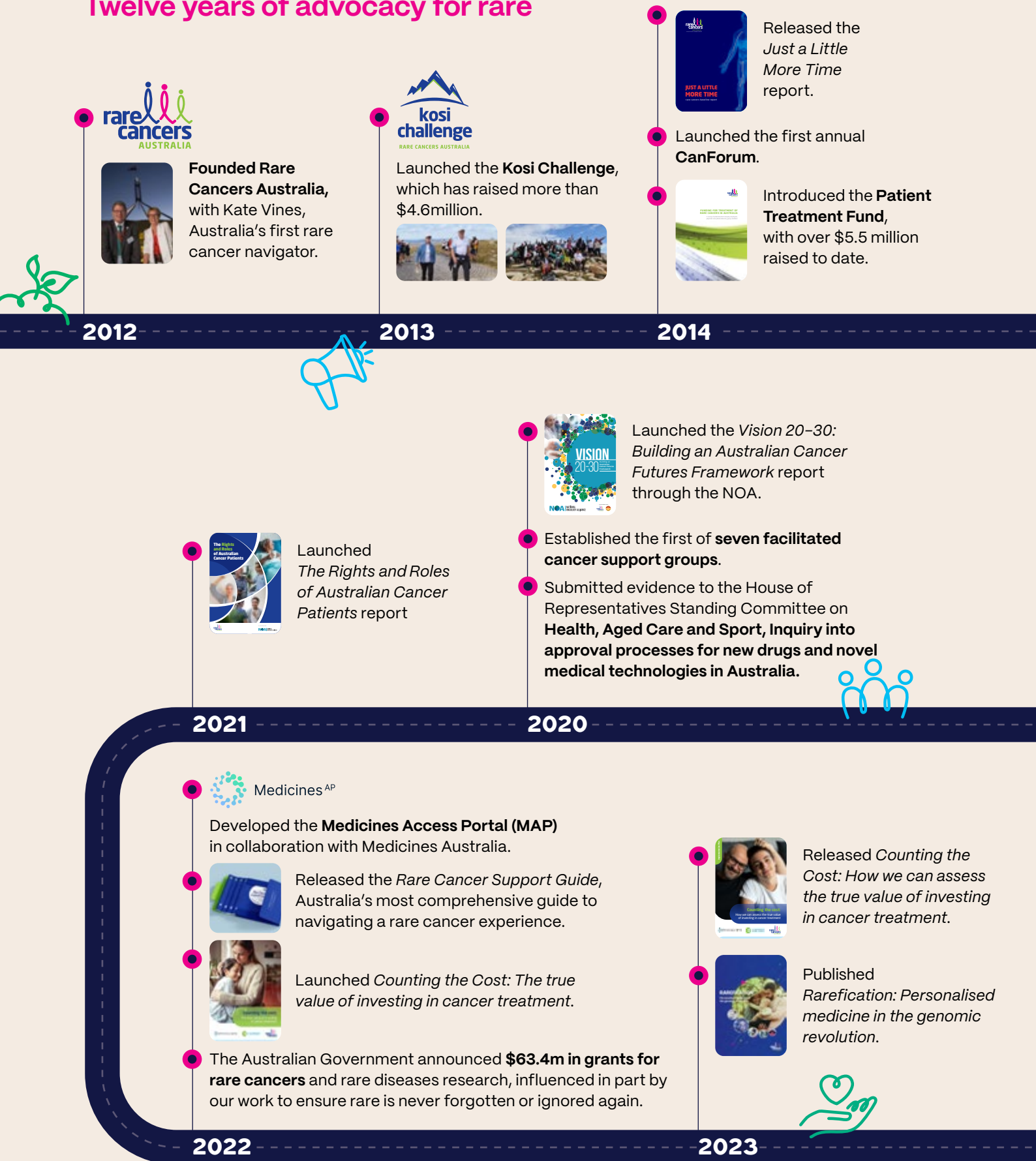
Although five-year survival rates are improving, there is greater progress in common cancers, which now have an overall five-year survival rate of 79%, compared to just 43% for less common cancers and 63% for rare cancers.



The RCA Team

Timeline

Twelve years of advocacy for rare



2012



Founded **Rare Cancers Australia**, with Kate Vines, Australia's first rare cancer navigator.

2013



Launched the **Kosi Challenge**, which has raised more than \$4.6million.

2014



Released the *Just a Little More Time* report.

Launched the first annual **CanForum**.



Introduced the **Patient Treatment Fund**, with over \$5.5 million raised to date.

2021



Launched *The Rights and Roles of Australian Cancer Patients* report

2020



Launched the *Vision 20-30: Building an Australian Cancer Futures Framework* report through the NOA.

Established the first of **seven facilitated cancer support groups**.

Submitted evidence to the House of Representatives Standing Committee on **Health, Aged Care and Sport, Inquiry into approval processes for new drugs and novel medical technologies in Australia**.

2022



Medicines^{AP}

Developed the **Medicines Access Portal (MAP)** in collaboration with Medicines Australia.



Released the *Rare Cancer Support Guide*, Australia's most comprehensive guide to navigating a rare cancer experience.

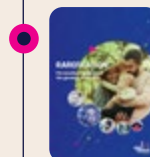


Launched *Counting the Cost: The true value of investing in cancer treatment*.

The Australian Government announced **\$63.4m in grants for rare cancers** and rare diseases research, influenced in part by our work to ensure rare is never forgotten or ignored again.

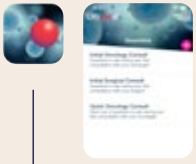


Released *Counting the Cost: How we can assess the true value of investing in cancer treatment*.



Published *Rarefaction: Personalised medicine in the genomic revolution*.

2023



- Launched the **CAN.recall app**.
- Submitted evidence to the **Senate Inquiry into Availability of new, innovative and specialist cancer drugs in Australia**.



2015

- Released *Just a Little More Time 2*.



2016




Released the *Rare Solutions: A Time to Act* report.

- Presented evidence at the **Senate Inquiry for funding research into cancers with low survival rates**.



2017


-  Omico.
- **Partnered with Omico** supporting the development of clinical trial options for all Australians living with cancer.



Released the *Genomic Testing Blueprint* report through the NOA Project.

2019



-  **NATIONAL ONCOLOGY ALLIANCE**
- Initiated the **National Oncology Alliance (NOA)**.

- Launched the **KnowledgeBase**.

-  Developed the **Pinnacle Program**.

- Announcement of a dramatic increase in Australian Government funding (\$248 million over five years) in **support of clinical trials** for rare cancers and rare diseases, influenced in part by our research reports and ongoing advocacy efforts.




2018

-  Acquired the **Mummy's Wish foundation**.
- Elevated the voice of Australians impacted by rare cancers through written and oral evidence to the **Senate Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancers**.



Secured a **National Press Club Address** for Prof. David Thomas on Rare Cancers Awareness Day (26 June) speaking on 'Cancer: The modern plague'.

2024

-  Published *A Rare Cancer Moonshot: Equity for everyone with cancer*.

- RCA received \$4.36m in government funding through the Australian Cancer Nursing and Navigation Program, to **expand and enhance its specialist telehealth service**.



NOEL'S STORY



Last February, 35-year-old Noel's world was turned upside down.

"I was working hard to chip away at my goals, raising my son to be the best version of himself that he can be, and making wedding plans with my new fiancée. And then I developed this cough that I just couldn't shake, and would cause me to pass out," Noel recalls.

After self-admitting to hospital and undergoing a CT scan, PET scan and biopsy, the unexpected cause was revealed: stage 4b Thymic Carcinoma.

"When I heard those three words – 'You have cancer,' – it was gut-wrenching. I felt like I had been hit by a freight train with no signs of it slowing down. I felt worried, shock, fear and overwhelmed, all at once. It's like my hopes, dreams and plans for the future were shattered within seconds."

Within a week Noel was in urgent surgery in an attempt to remove the 13cm mass from his chest. Doctors could only remove 15 per cent of the tumour due to its precarious location between the heart and left lung – which also rendered radiation too risky.

His next step was six rounds of chemotherapy followed by Keytruda, a type of immunotherapy. With 12 rounds costing around \$60,000, Noel had to crowdfund through RCA's Patient Treatment Fund to help afford it.

"The treatment is very expensive, and I can't believe that it's not listed on the PBS for rare cancers, but it's covered for people with a more common cancer. It just seems wrong," he reflects.

Noel says that before he was diagnosed, he had no idea of the challenges that rare cancer patients had to face.

"When I was diagnosed, we didn't know what to do, who to contact, who to ask for help, or where to look for research. It's like this awful diagnosis was just dropped in our lap and we were left to figure it out. It all happened so quickly, but with such limited information. We felt very overwhelmed and a bit lost."

A carer in a global thymoma cancer support group recommended Noel contact RCA for guidance.

"We reached out to RCA right away, and I would strongly advise anyone else with a rare cancer do the same. Having them as part of our support network has been amazing."

Noel is now a member of the online RCA Thymoma Cancer Support Group.



NOEL CARMONA
PATIENT ADVOCATE

“

When I was diagnosed, we didn't know what to do, who to contact, who to ask for help, or where to look for research. It's like this awful diagnosis was just dropped in our lap and we were left to figure it out. It all happened so quickly, but with such limited information. We felt very overwhelmed and a bit lost.”



Noel in hospital with his wife Cheyanne by his bedside

Our impact

We do whatever it takes to change the story of a rare cancer diagnosis through limitless support and advocacy. Here's a snapshot of our impact for rare in 2024.

Patient Support

Our Rare Cancer Support Guide has been **downloaded**

536

times, with **513 hardcopies** posted to people impacted by rare cancer, and a further **3,800 views** of the information online.



Our **Specialist Cancer Navigators** have provided personalised support to more than **1,000 patients and families** impacted by a rare or less common cancer so far this year.



Connected over **200 patients and their families** to appropriate services and support around the country.



Connected **2,575 people with cancer, and carers**, through our **7 support groups**.



Supported patients in need with more than **\$158,000 distributed in crisis funding** to help with things like out-of-pocket cancer expenses and medical bills.



Awards and acknowledgements



RCA co-founder, Kate Vines, was recognised for her contributions to the cancer community by being awarded the **2024 Jeannie Ferris Award** by Cancer Australia.



RCA was a finalist in the national **Health Industry Hub and PRIME Awards**.*

*Results to be determined.

Advocacy

Brought together **370 people**

across the patient community, government, healthcare, research, and industry at



CanForum24 to launch *A Rare Cancer Moonshot: Equity for everyone with cancer* with support from the Health Minister and Shadow Health Minister.



\$4.36 million

in government grant funding allocated.

Engaged in more than

120

meetings and speaking engagements with key stakeholders to raise awareness about RCA.



Delivery of a **televised National Press Club Address** on Rare Cancers Awareness Day by Professor David Thomas.

Address on Rare Cancers Awareness Day by Professor David Thomas.



Held

2

Thought Leader events with 28 Parliamentarians, Senators and advisors to raise awareness of the critical issues and facilitate conversation and knowledge sharing.

Invited to **provide oral evidence to the Senate Inquiry into rare and less common cancers**, shining a light on the issues and solutions for rare through the Committee's recommendations.



What sets them [Rare Cancers Australia] apart from other groups is that they identify the problems and really diligently work towards offering solutions to government.

"Many groups arrive with a problem and hand it to government to solve. Rare Cancers helps articulate the problems that even governments sometimes can't see, and then work towards offering solutions, mindful of the way government works, to find good outcomes for the Australian community."

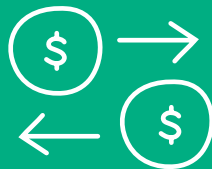
- Senator Deborah O'Neill

Funds raised

Our patient fundraising platform, the **Patient Treatment Fund**, helped patients raise over

\$350,000
in donations

this year alone to help afford non-subsidised therapies, travel to appointments and out-of-pocket costs.



Over

\$213,000

was **donated** by individuals and organisations to support RCA and Mummy's Wish.*



Almost

\$1.3 million

was raised through community **fundraising** and challenge events in support of RCA and Mummy's Wish.*



Raising the rare voice

A total of **20 media releases**, four podcast interviews and approximately

232

media mentions in major news and trade publication across print, online, radio and television.



Our **Inside Rare Newsletter** shared patient support and advocacy messages with over

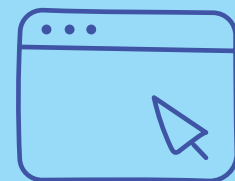
14,000
subscribers.



Our **website** provided over

97,000

unique visitors with trusted information and guidance (including the Patient Treatment Fund and KnowledgeBase).



More than

21,300

followers across RCA's social media platforms.



Mummy's Wish

Mummy's Wish supported

692 mums
with cancer.



Sent out **614 packs** to mums with cancer this year-to-date, which included

823 bears
for their little kids to cuddle.



“

I want to sincerely thank you for your incredible work and unwavering support. The care and compassion you've shown have provided me with great comfort, not only easing my mind but also significantly reducing the anxiety I've been experiencing.

"Your organisation has made me feel that I am not alone in this battle against illness. Knowing that you are there for me has brought immense relief and strength during this difficult time.

"Thank you once again, from the bottom of my heart, for everything you do. Your kindness means more than words can express."

- Nina, a Mummy's Wish mum

“

I just received the care package you thoughtfully posted to me with the card letting me know I am not alone, and I almost teared up with gratitude receiving your hand-written card.

"I don't know if you guys realise what such a seemingly simple act like yours in sending me that package can do to break through the sense of isolation and abandonment that we can sometimes feel out here in 'Cancerland' (particularly in rural context).

"It feels like the first act of genuine kindness and solidarity that I have received from an institution like yours since my cancer experience unfolded, so for that I am deeply grateful."

- Patient supported by RCA

Our patient services and programs



Patient Support

Personalised support, without limits

RCA provides support from every angle to people impacted by rare cancer.

A key component of our patient support is our free specialist cancer telehealth navigation service. Each patient has access to their own Specialist Cancer Navigator for personalised clinical, emotional, financial and practical support throughout their diagnosis, treatment and beyond. This year, RCA was announced as the recipient of \$4.36m over four years in grant funding from the Government's Australian Cancer Nursing and Navigation Program, to enhance and expand this service.

Our team of Specialist Cancer Navigators do whatever it takes to support people through the challenges and uncertainty that a rare cancer diagnosis can bring, with information, support and guidance that is personalised to each individual. Whatever matters to them, matters to us.

Our support has no limits, and can take many forms:



Clinical

We help to improve a person's health literacy for shared decision making and access to clinical trials as part of their navigation of the healthcare system.



Emotional

We are there to listen, answer questions, and help people access whatever they need.



Peer

We connect people with others who understand, such as through our safe and welcoming support groups.



Financial

We help people find appropriate services and option to help manage costs and support with fundraising.



Carers

We provide guidance to carers on how best to take care of others, as well as themselves.



We strive to continue strengthening our support programs and explore new initiatives for better patient experiences that hold less uncertainty."

**- Cathy Slattery,
Head of Patient Programs**

Medicines Access Portal (MAP)



Facilitating faster access to the latest treatments

In 2022, we teamed up with Medicines Australia (MA) to develop the Medicines Access Portal (MAP), an initiative designed to give clinicians faster access to new medicines for cancer patients.

The first of its kind in Australia, the secure online portal allows clinicians to view Access Programs that pharmaceutical companies have available for cancer patients in Australia, in one single location.

This year, we are grateful to have received \$60,000 in funding for the MAP from the Oncology Industry Taskforce (OIT), ensuring its future for another year.



I will definitely continue to use and recommend MAP. It is so easy to find possible programs for patients all in the one place."

- Cancer clinician



Medicines^{AP}

KnowledgeBase



Bridging the rare information gap

We created the KnowledgeBase to help connect people impacted by rare and less common cancers with the information, services, and support they need. The first-of-its-kind resource is designed to fill the significant gap in information that exists for people with rare cancer.

Accessible from the RCA website, the online platform houses information on almost 200 rare or less common cancers, including definitions, symptoms and treatment, as well as cancer syndrome types.

The resource also provides clinicians with a starting point if they are unfamiliar with their patient's rare cancer. From here they can search multi-disciplinary teams, specialists, treatment centres, and clinical trial information for patients.



Our hope is that the KnowledgeBase can help patients feel slightly less isolated and abandoned, particularly if they hear 'I've never heard of your cancer before' from their care team."

**- Jaime Macedo,
RCA Cancer Navigation
Program Lead**

61

Rare Cancer Health
Professionals listed

The KnowledgeBase
saw a total of over

31,900

unique users in the
past year

349

clinical trials
listed

Mummy's Wish

Practical support for mums with cancer



RCA acquired the former cancer support charity, Mummy's Wish, in early 2024 to ensure the continued provision of practical support to mums living with cancer.

The Mummy's Wish service helps manage the distressing burden of cancer on mums and their families by providing practical, tailored support during the treatment journey.

As part of the RCA Patient Support Team, Mummy's Wish coordinators offer families information and resources such as care packs, recordable comfort bears, educational books, counselling sessions, and financial support for cleaning, groceries and fuel.

This support gives the gift of time to mums with cancer so they can focus on what's most important – being a mum.



“

Having had my own personal experience with breast cancer when I was diagnosed 10 years ago and being a mother to two young children at the time, I understand the enormous challenge of trying to be a great mum when you are going through treatment. I also am acutely aware of what Mummy's Wish means to the 1,000-plus mums it supports each year and the value it can bring to a family.”

– Christine Cockburn, CEO of Rare Cancers Australia

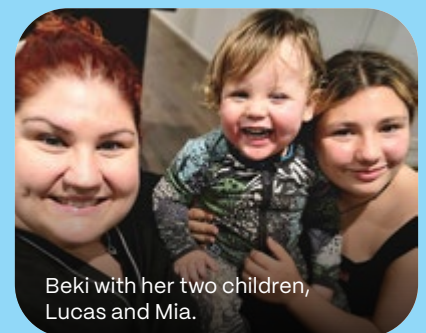
“

I connected with Mummy's Wish and joined their Facebook group of mums. There I have found a similar sense of reassurance from other mums going through their own cancer experience. They've told me that the feelings I have of fear, frustration and isolation are all very normal.

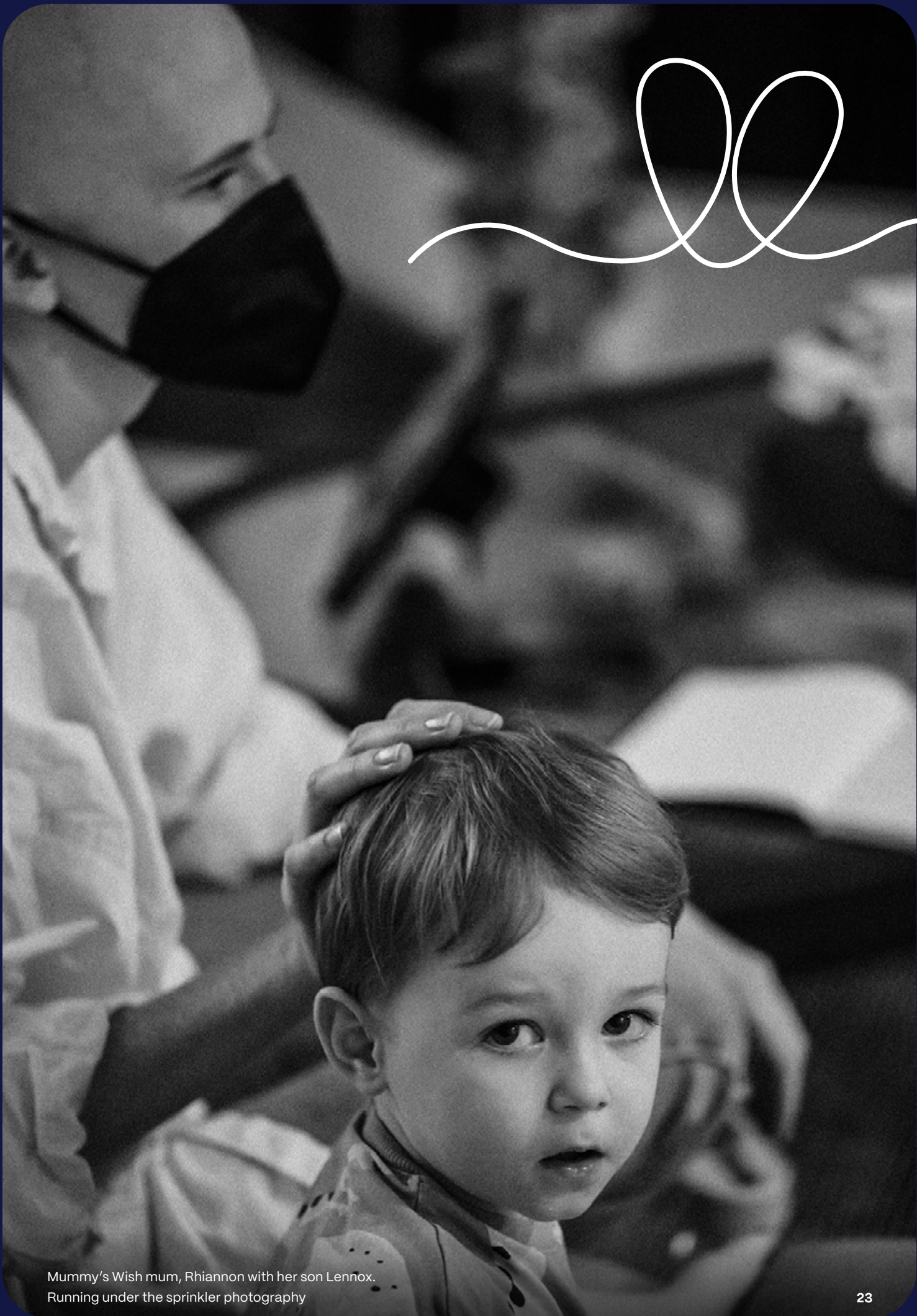
“The amazing Mummy's Wish team has been so supportive too. We have lovely long chats and they've been reassuring in letting me know that I'm not alone, I'm not going through this by myself and that there are others out there who can help.

“Mummy's Wish have also provided me with a beautiful care pack which included two gorgeous bears for my children. I'm going to record a message and give the bears to them when I go into hospital for my surgery. For the week that I'm not home, they'll have that comfort at least and hopefully feel like I'm that little bit closer. I'm so grateful for that.”

– Beki, a Mummy's Wish mum



Beki with her two children, Lucas and Mia.



Mummy's Wish mum, Rhiannon with her son Lennox.
Running under the sprinkler photography

Our advocacy in action

Senate Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer

In June 2023, a Senate Inquiry was launched into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer.

Rare Cancers Australia's submission highlighted a number of significant barriers, including:

- late, protracted diagnosis due to insidious symptoms
- absence of screening programs
- paucity of experts with knowledge about rare cancers
- geography
- high out-of-pocket costs.

RCA's CEO, Christine Cockburn, presented at the Inquiry in February 2024 and outlined reasonable and rational steps towards achieving equitable access for all Australians to cancer diagnostics, treatments and support.

In May 2024, we welcomed the release of the Senate report and its 41 recommendations. It recognised the inequity faced by rare cancer patients and incorporated our evidence and key advocacy asks we've been championing for years, including timely and affordable access to novel medicines, greater access to genomic screening and precision oncology, and addressing access to clinical trials.

The Inquiry and Report have shone a bright light on the inequity in our health and care system. We are advocating for a Government response and implementation and working with stakeholders across the sector to make this happen.

In September this year, the Government announced its intention to legislate for a complete ban on genetic discrimination in life insurance, a key recommendation from the Report and a critical step in realising the potential of genetic testing, particularly for the prevention of inherited cancers.



Whilst cancer outcomes in Australia are amongst the best in the world, this inquiry has made clear that these outcomes are not felt equally amongst all Australian cancer patients.

"Those diagnosed with rare or less common cancers do not always receive the same level of support, or have access to the same diagnosis and treatment options, as those with more common cancers, having, at times, deadly consequences."

– Senate Standing Committee on Community Affairs, *Equitable access to diagnosis and treatment for rare and less common cancers, including neuroendocrine cancer.*



(L-R) Prof. David Thomas, The Hon Mark Butler, Christine Cockburn.

Advancing genomic-led cancer care

Rare Cancers Australia remains a leading voice on genomics in cancer care and the transformative potential of precision oncology for people with rare cancers, following through on our recommendations in *Rarefication: Personalised Medicine in the Genomic Revolution*.

Partnering with Australian Genomics, we are bringing together patients, thought leaders, researchers, clinicians, policymakers, industry and other experts to debate the opportunities, barriers and challenges in implementing genomic-led care in Australia. Through a three-part roundtable series, with the final event in November, we are developing a way forward.

Through a partnership with Cancer Australia, we will ensure the roundtable series, and the voice of our patients shapes the new *Framework for Genomics in Cancer Control*, which recognises rare cancer patients as a priority group for genomic-led care.



Rare Cancers Australia is a vital partner to implement the goals and actions of the Australian Cancer Plan, and our partnership is a crucial step towards addressing the unique challenges faced by those affected by rare and less common cancers."

**– Prof. Dorothy Keefe, CEO,
Cancer Australia**



(L-R) Charlotte Noble, Christine Cockburn and Senator Louise Pratt.

Public affairs and Thought Leader events

Raising awareness of rare cancers and the policy changes that will improve people's lives is a core part of our advocacy.

Throughout the year, we have met with MPs and Senators from all sides of politics to discuss a broad range of policy issues and build support for a 'Rare Cancer Moonshot' and other important reforms.

We have connected several patients with their local members and supported patients to generously share their own experiences at Parliamentary events and meetings, to elevate their voices and ensure no one forgets rare.

Through our Thought Leader Dinners, hosted by the Parliamentary Friends of Cancer Care and Cure, we have briefed MPs and Senators on the Australian Rare Cancers Portal, the potential of genomics and precision oncology, the issues facing people with a rare cancer diagnosis and the hope and solutions that we have within our grasp. These personal events bring together patients, leading experts Senators and Parliamentarians to reflect on their own experiences and roles in creating a better world for rare.

Our sincere thanks to the Co-Chairs of the Parliamentary Friends of Cancer Care and Cure – Senator the Hon Michaelia Cash, Ms Kylea Tink MP and Senator Deborah O'Neill for their leadership and support for people with cancer in Australia.



(L-R) Christine Cockburn, Senator The Hon Michaelia Cash and Ms Kylea Tink MP.



Christine Cockburn and John Zalberg

Access to treatments

Equitable and affordable access to treatments remains a major issue for our patients.

Australia's Health Technology Assessment (HTA) processes were designed primarily for common diseases and large patient numbers, meaning many people diagnosed with rare cancers have been left behind and excluded from accessing innovative medicines and technologies.

In April this year, RCA CEO, Christine Cockburn, took a consensus statement to Parliament calling for life-saving cancer drugs to be made urgently available to more Australians. Rare Cancers Australia is supported in pursuit of this change by BEAT Bladder Cancer Australia, Breast Cancer Network Australia, Canteen Australia, Inherited Cancers Australia, Leukaemia Foundation, Lung Foundation Australia, Melanoma Patients Australia, Melanoma & Skin Cancer Advocacy Network (MSCAN), Omico, and Pancare Foundation.

After years of advocacy, there are cautious signs of a shift.

Developing guidance on methods for assessing tumour-agnostic therapies, genomic therapies and gene therapies was a key recommendation in the final report of the HTA Review, published by the Government in September 2024. This long-awaited Review, to which RCA submitted evidence and recommendations, recommends major reforms, many of which will tackle systemic issues we have been highlighting for the past decade.

“

We propose moving away from the outdated process of reviewing medicines for specific tumour types, for example those specifically for breast, or lung, or skin cancer. Instead, we need to be focusing on the specific genetic and biological make-up of the cancer itself.”

– Christine Cockburn, CEO, RCA

Campaigns and events

Kosi Challenge

The Kosi Challenge is RCA's major fundraising event, held in March each year since 2013. One of the most heartwarming events of the year for the rare cancer community, it sees people unite from across Australia – including patients, their families and friends – to hike the 21km round trip from Thredbo to our country's highest point, the summit of Mount Kosciuszko.

All funds raised go towards RCA's Patient Support Programs and our Crisis Fund, which provides patients with crisis support payments and financial assistance for costs associated with their diagnosis and many other out-of-pocket expenses associated with the impact of a RLCC cancer.

The demand on our crisis fund is higher than ever. Thanks to the support and successful fundraising efforts of Kosi Challengers, we can continue to be there for the rare community.



1 in 3

people who call Rare Cancers Australia's navigator support service report financial stress because of their rare cancer diagnosis in their first call. Most people report financial stress and hardship at some stage in their support journey.

After more than 10 years running, the Kosi Challenge has raised more than

\$4.6 million

to support vital patient support programs.



The 2024 Kosi Challenge:

Was supported by

694

in person participants.

123

virtual challengers.

Raised over

\$677,000

to help support Australians impacted by RLCC.

Prompted over

800

organisations and advocates to help raise awareness of rare.



“

It was my first year participating and I loved it! The event was so well organised and everyone was so grateful. It had a really great vibe.”

- 2024 Kosi participant



“

We had an amazing weekend completing the Kosi Challenge to raise money for Australians impacted by rare cancer. Huge shout out to Rare Cancers Australia and all their supporters for hosting this annual fundraising event... After the walk, listening to the stories from people with lived experience of a rare cancer was a powerful reminder of why we were there, and the importance of this event.”

- 2024 Kosi participant





Members of Parliament, Ross Vasta and Anne Webster.



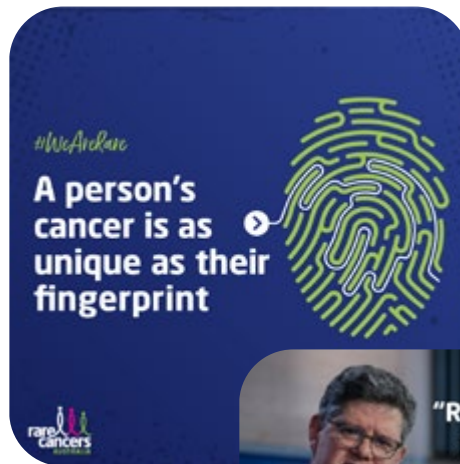
Rare Cancers Awareness Day

In 2021, RCA declared 26 June Australia's first Rare Cancers Awareness Day.

This year's campaign centred around how a person's cancer is as unique as their fingerprint, highlighting the reality of navigating the maze that is our complex health system with limited information, little support, and often huge financial burdens.

People were asked to pledge their support for rare by adding a virtual fingerprint to our online map of Australia. The 500+ pledges made throughout June were a powerful visual reminder that although patients may be rare, they are not alone.

RCA also participated in a National Press Club Address in Canberra on RCA Day featuring Omico's Professor David Thomas presenting on 'Cancer: the Modern Day Plague'.



Watch here: https://www.youtube.com/watch?v=9rciQb-_tUE&t=3s



In 2024:

510

Australians pledged their support for rare with a virtual fingerprint.

We reached over **232,000**

people through social media.

170

people attended the National Press Club Address.

215

organisations and advocates shared content about RCA Day on socials.

More than **8,700**

people visited our campaign landing page.

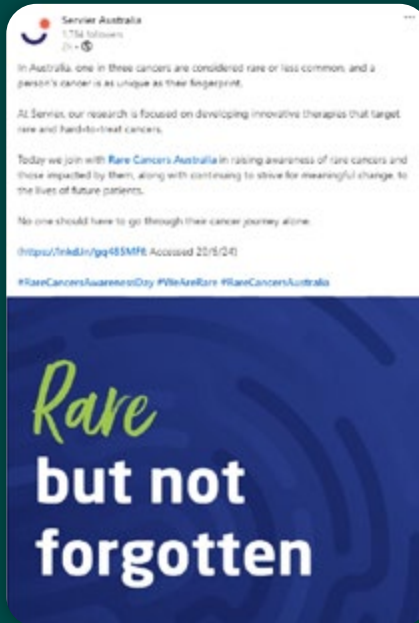
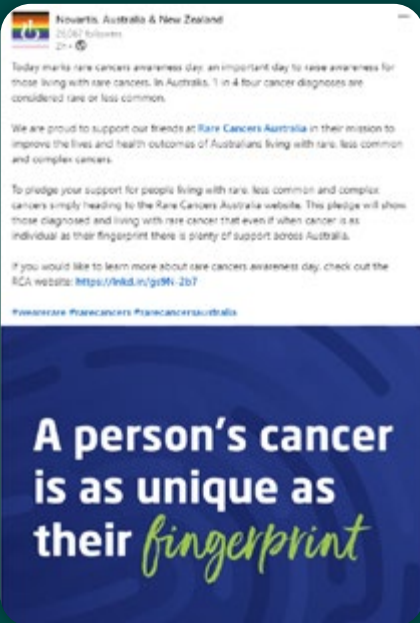
Inaugural

partnership with Icon Cancer Centre for RCA Day.

“

This was a truly extraordinary address by such an impressive scientist and leader, Professor David Thomas. I'd encourage everyone to watch it back on ABC iView for inspiration on how close we are getting to real hope combating rare cancers.”

– Natasha Robinson,
Health Editor, The Australian





Panelists from the 'Countdown is On' session (see illustration on opposite page).



(L-R) Josie Downey, Prof Georgina Long and Trent Zimmerman.

CanForum

CanForum is our annual advocacy conference, designed to challenge thinking, educate and inspire attendees, and advocate for change to improve care and outcomes for everyone affected by cancer.

It brings together leading experts in research, healthcare, biotech, policy and lived experience to talk about the latest developments, trends and issues in cancer care, with a focus on rare. At CanForum we discuss the big opportunities and challenges in providing the best care to people diagnosed with cancer, including hearing first-hand from patients about their experiences.

CanForum 2024 centred around a 'Rare Cancer Moonshot', which calls on all of us – government, health care providers, industry, researchers, and the community – to work together to achieve equity for everyone with cancer. **We proposed an ambitious target for Australia to achieve greater than 90% five-year survival for everyone diagnosed with cancer, and for true equity of experience by 2035.**



The immediate actions needed to bring us closer to achieving this bold vision are outlined in our latest report, *Rare Cancer Moonshot: Equity for everyone with cancer*, which was launched at CanForum by the Minister for Health and Aged Care the Hon. Mark Butler.

We believe no one should be left behind. Together, we can turn the tide against rare cancers and build a healthcare system that is fair, compassionate, and equitable for all.

370

delegates (online and in-person).



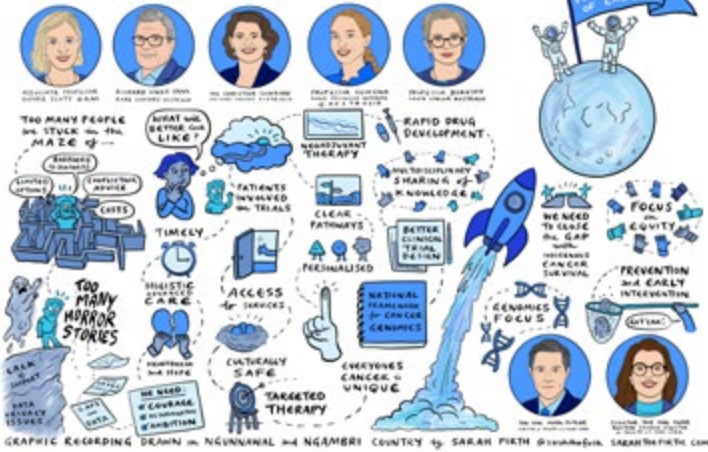
165

items of media coverage.



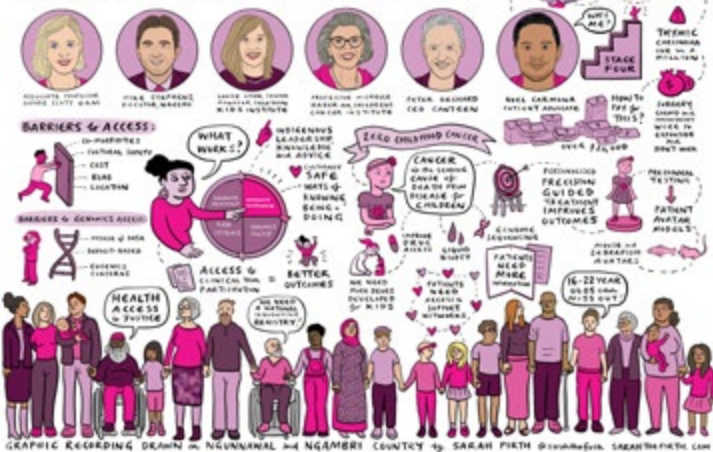
Christine Cockburn with The Hon Mark Butler MP.

A BETTER WORLD FOR RARE



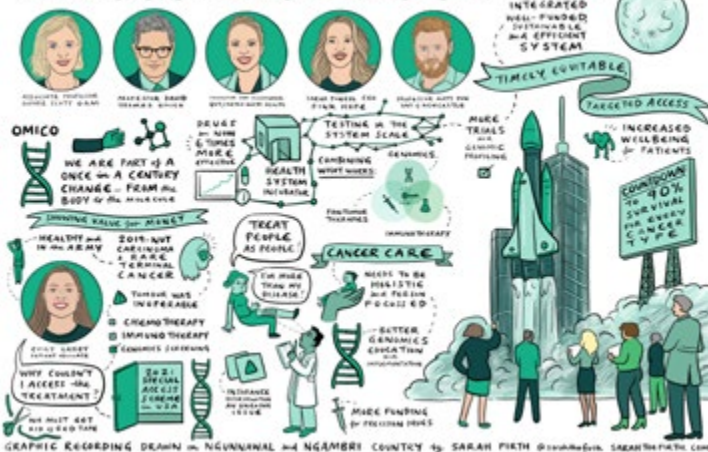
A better world for rare

NO ONE IS LEFT BEHIND



No one is left behind

THE COUNTDOWN IS ON



The countdown is on

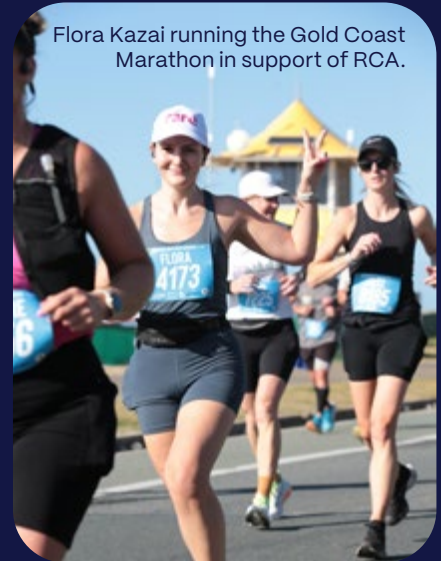
Community fundraising

We couldn't do what we do without our passionate supporters and the generosity of the Australian community. Their efforts and contribution show people impacted by rare cancer that they are not alone and allow our team to keep improving lives and health outcomes.

This year,

\$1.5 million

was raised from community groups and public donations.



Flora Kazai running the Gold Coast Marathon in support of RCA.



We received

237

donations from individuals and organisations.



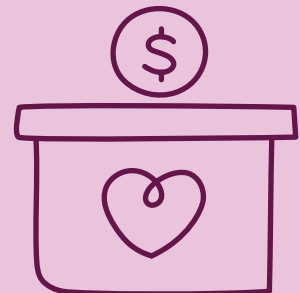
59

individual community fundraisers hosted or participated in challenge events to help raise vital funds for RCA and Mummy's Wish.

Almost **200** donations, totalling

\$351,867

were received through the Patient Treatment Fund to help Australians afford expensive treatment and cancer related costs.



Dani's Dynamos, taking on the Kosi Challenge for the third year in a row and with their biggest team yet.





Dry July

Dry July is a much-loved and well recognised national fundraiser, with funds going directly to local and national cancer support organisations across Australia.

For the first time, Rare Cancers Australia was selected as a beneficiary for the 2024 Dry July campaign. We had 274 supporters join Dry July fundraising for RCA, raising a total of \$87,506.99 throughout the campaign. This will go into our patient support programs, assisting people with managing the rising cost of living and their cancer-related expenses, continuing our support groups and distributing our Rare Cancer Support Guide and other information.

Mummy's Wish was also a beneficiary of Dry July once again in 2024. An amazing 416 supporters signed up to fundraise for Mummy's Wish, raising a total of \$91,338.48. Funds will contribute to the provision of our tailored care packs, including Comfort Bears, a curated selection of books, information and vouchers for practical assistance such as meals or cleaning.

We had **274 supporters** join Dry July fundraising for RCA, raising a total of

\$87,506.99

throughout the campaign.



An amazing **416 supporters** signed up to fundraise for Mummy's Wish, raising a total of

\$91,338.48.





The boxers in the 2024 Corporate Clash presenting a cheque to RCA representatives

The Corporate Clash in Macarthur

In August this year, 22 brave Sydney businesspeople stepped into the boxing ring. The Corporate Clash in Macarthur turned everyday business identities into amateur boxers, facing off in the name of charity.

In total, the event raised a mammoth \$330,000, with \$142,358 going towards funding RCA's much-needed patient support care packs we send out to every one of our new patients.

An enormous thank you to all the organisers, fighters, trainers, supporters and sponsors who made this incredible event and donation happen!

\$142,358

was raised for RCA's patient support care packs.





Motor Events Racing

Founded by Ben McGuire after his wife was diagnosed with an extremely rare type of cancer called adrenocortical carcinoma, Motor Events Racing raises funds to support rare and less common cancer patients, carers and families.

Motor Events Racing delivers Australia's largest cheap car racing events and with Ben at the wheel, he and his team hold events across the country where car enthusiasts of all skill levels can get together, build their own race cars and test their wheels in a fun, friendly, safe and affordable environment.

They do this all while raising funds for RCA, with a staggering \$49,000 and counting donated this year alone and a total of \$215,813 since the event started in 2019.

“

I was going to get involved in participating in some of the RCA fundraisers, but I felt like this wasn't enough, I wanted to do more and something that just wasn't a once off. So, Motor Events Racing was created."

– Ben, Founder of Motor Events Racing

Individual community fundraisers

City2Surf

RCA patient and advocate, Charlotte Noble, and her colleagues from the WiseTech Global Talent Team participated in City2Surf and raised \$12,527, which her employer WiseTech Global matched, resulting in a whopping \$25,054 being donated toward RCA's patient support services.

“

The atmosphere was electric with 90,000 runners of all ages and levels of fitness participating in the world's largest fun run, I could not be prouder of what we have achieved.”

- Charlotte



The Liv Sproule Memorial Round

Livinia (Liv) Sproule was a kind and loving woman who was taken too soon by a rare cancer. She was an amazing hockey player and always put the team first.

The Liv Sproule Memorial Round was founded in 2021 by her hockey community and provides a chance to remember Livinia and fundraise to help support Australians who have been diagnosed with rare or less common cancers.

This year they fundraised over \$6,500 through the sale of wristbands, ribbons and cookies, as well as accepting general donations. To date the community fundraising event has raised more than \$21,500 in honour of Liv.



Phillida in the middle with Liv on the right

“

This whole memorial round is a chance to remember Livinia and the comradery of the sport she loved to play.”

- Phillida, Liv's childhood friend



Mummy's Wish High Tea

A team of 14 organisers, led by cancer survivor and mum of two, Bogi, **raised almost \$9,000 for Mummy's Wish** at a high tea with 80 guests in North Ipswich in June. Funds were raised through ticket sales, raffles and auction items, while the organiser's children shared their own memories of their mum's experience with breast cancer in a heartfelt speech.

“

When mum was in hospital it really put a pause on our life. But thanks to the people at Mummy's Wish for helping and providing people that could clean the house. When mum got cleared of cancer after a long fight, we were grateful and thankful for our family and friends and the people at the hospital, but also for Mummy's Wish.”

– Noah, Bogi's son



Bogi with her children Maya and Noah



Volunteers from AztraZeneca stuffing Mummy's Wish bears

Volunteering

RCA has been running a Mummy's Wish Volunteer Program since April 2024.

The main task of our volunteers has been stuffing our Mummy's Wish bears, getting them ready to be sent to our wonderful mums and families. Each bear has been stuffed with love and care and has been given a little cuddle of support before being sent.

Since April 2024 we have had well over 40 hours of volunteer work and hundreds of bears stuffed.

This has allowed Mummy's Wish to continue sending care packs out to our mums in a timely manner, allowing them to provide their children with beautiful comfort bears and recordable messages while they are receiving treatment.

The continuation of the Mummy's Wish care packs would be hard to achieve without the wonderful help of our volunteers.



Oxley College students completing their Duke of Edinburgh hours



Since April 2024 we have had well over

40 hours

of volunteer work and hundreds of bears stuffed.



Pinnacle



Attendees of the APOA Hackathon held in Kuala Lumpur

The Pinnacle Program is a peer-to-peer mentoring program for patient organisations across the globe.

RCA initially created Pinnacle as a way to share the team's wins, challenges and experiences with other patient organisations in the APAC region – knowing the value of honesty and collaboration.

It is based on the principles of shared knowledge and aims to create a community for learning, connecting, collaborating and sharing across patient organisations internationally so that we can all learn, grow and better support our patients.

Since its inception in 2017, Pinnacle has grown to:

- Pinnacle members comprise of over **400 patient organisations** from **25 regions** across the globe.
- over **30 multi-day workshops** have been hosted face to face and online.
- resources are available in **10 languages**, including workshop workbooks, the Pinnacle website, and the Pinnacle Playbook.

In 2024 we:

Presented **multi-day workshops** in Singapore, Kuala Lumpur and Dubai.

Hosted **55 participants** from **32 patient organisations** in multiple languages across the globe.

Saw representation from over **14 countries**, including China, Japan, South Korea, Malaysia, Thailand, UAE, Ghana, Saudi Arabia and Qatar.

Covered a range of topics including **systems change, powerful communications, Health Technology Assessment and fundraising**.

Brought together **42 multidisciplinary leaders** from **12 countries** for the Asia Pacific Oncology Alliance (APOA) Hackathon to discuss key activities for implementation throughout the Asia Pacific region.

CLIMBING KOSI FOR DANI



Among the climbers at this year's Kosi Challenge were Dani's Dynamos, who returned for the third year in a row and with their biggest team yet.

Picnic Point family Rob (51), Lily (17) and Ella (16) Crossman, are team champions of 'Dani's Dynamos' and found motivation in doing the Kosi Challenge to remember their late wife and mother Danielle, who passed away from a rare cancer at age 46.

"Dani was diagnosed with Stage 4 Medullary Thyroid cancer in Easter of 2021, during the Covid-19 pandemic, when both of our girls were in their early teens. Her primary concern was for our children and how much time she had left with them," said Rob.

"After her diagnosis, which took a really long time get to the bottom of as is typical with rare cancers, we were lucky enough to find an oncologist who knew a bit about her condition and connected us with Kate Vines at Rare Cancers Australia (RCA).

"RCA was on the phone to me within two hours of my enquiry and immediately started to provide us with solutions, ideas and ultimately much needed hope.

"There were no drugs available for Dani's type of cancer on the PBS, and we simply could not afford the tens of thousands of dollars it would have cost to access that treatment. Through the support and advocacy of our oncologist and RCA we were able to get access to the drug Dani needed," reflects Rob.

Sadly, after a few months of exposure to gruelling treatments, Dani's condition deteriorated dramatically. She developed serious gastrointestinal problems and stopped eating. She passed away with Rob by her side a few days before Christmas in 2021, just eight short months after her diagnosis.

Rob conveyed why they return to Kosi each year to remember Dani and give back to RCA.



Rob Crossman with his wife Danielle and two daughters Lily and Ella.

"We want to give back to the charity that gave so much to us in our time of need, not to mention that Kosi Challenge is a great fit for our already stupidly competitive family," Rob said.

"It's also a great way to keep Dani's memory alive within the family and raise awareness about rare cancers to our friends. The more we talk about this, the more we normalise it, which is particularly important for younger people.

"We drove down to Thredbo with a minibus full of teenage girls, my daughter's friends, who all raised at least \$250 each for the cause. Dani had always wanted to do the Kosi Challenge herself, but never got the chance, so it was a special moment when we reached the summit as a team and celebrated her life together," he said.

Dani's Dynamo's took out the top community fundraiser award for Kosi, raising an enormous \$32,490 for RCA's patient support programs in honour of Dani.

Our partnerships

Corporate partners

Icon Cancer Centre – Australia & New Zealand provided \$10,000 in financial and additional in-kind support for Rare Cancers Awareness Day, helping us achieve greater awareness and support for people living with rare, less common or complex cancers.



Everyone deserves access to quality cancer care and support, yet despite one in four cancers diagnosed in Australia falling into the rare and less common categories, these patients don't have access to the same level of support as those diagnosed with more common cancers. We're proud to partner with Rare Cancers Australia to provide patients with additional support to help them navigate this difficult time in their lives."

– Paul Fenton, Icon Cancer Centre Australia and New Zealand CEO

Research partners

LaTrobe University for Project SPARC (Supporting People with Rare Cancers), which researches the unmet information needs for people living with rare cancers. The project is being led by PhD candidate Tamsin Farrugia and supported by her supervisors Saskia Duijts, a rare cancer research specialist from IKNL (Integraal Kankercentrum Nederland), and LaTrobe Professor Carlene Wilson and Professor Evelien Spelten and Christine Cockburn.

DYNAMALK: Dynamic ctDNA profiling in ALK+ NSCLC: RCA is proud to be a contributor to a study of tumour profiling using liquid biopsies.

Omico, enabling more people diagnosed with rare or less common cancers to access ProSPeCT, the largest and free comprehensive genomics profiling initiative in Australia.

Philanthropic partners

Macquarie Foundation

Chrysanthemum Foundation

Morgans Foundation

Cameron Family Foundation

Crommelin Family Foundation

The Croxley Foundation

Octagon Foundation

Tour de Cure – Woolies
Wheels and Walk

ily Foundation

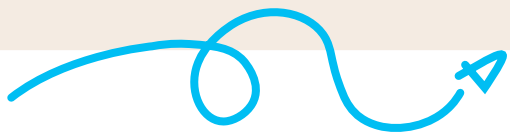
Key stakeholder partnerships



A. Menarini Australia Pty Ltd	Eli Lilly	Neuroendocrine Australia
AbbVie Pty Ltd	Gilead Sciences Pty Ltd	Novartis Pharmaceuticals Australia Pty Limited
Amgen	GSK Australia Pty Ltd	Ogilvy
Antengene (AUS) Pty Ltd	Head & Neck Cancer Australia	Otsuka Australia Pharmaceutical P/L
Astellas	Illumina	Ovarian Cancer Australia
AstraZeneca Pty Ltd	Inherited Cancers Australia	Pancare Foundation
Australian Genomics	Johnson & Johnson Innovative Medicine	patterntwo
Bayer	Leukaemia Foundation	Pfizer Australia Pty Limited
BEAT Bladder Cancer Australia	Liver Foundation	Private Cancer Physicians of Australia (PCPA)
BeiGene Aus Pty Ltd	Lung Foundation Australia	Prospection
Boehringer Ingelheim Pty Ltd	McGrath Foundation	Prostate Cancer Foundation of Australia
Bowel Cancer Australia	Medicines Australia	Roche Products Pty Ltd
Breast Cancer Network Australia	Medison Pharma	Sanofi
Bristol-Myers Squibb Australia Pty Ltd	Melanoma & Skin Cancer Advocacy Network (MSCAN)	Servier
Cancer Australia	Melanoma Patients Australia	Specialised Therapeutics Australia
Cancer Council Australia	Moderna	Takeda Pharmaceuticals Australia Pty Ltd
Cancer Nurses Society of Australia (CNSA)	MSD	Signature Law Bowral
Canteen Australia	National Press Club of Australia	
Daiichi Sankyo Australia Pty Ltd	Neuroblastoma Australia	

Patient advisory board

Alison Bolton	Alissa Jacobs	Sarah McGoram
Lisa Briggs	Nicholas Kelly	Anita McGrath
Caitlin Delaney	Lillian Leigh	Glen Ramos
Hosam Ehdeyhed	Jelena Magic	Nick Ribbe
Kerrilee Hall	Nigel Marks	Elizabeth Pickworth



Rare Legacy



Remembering those who left a gift in their Will

We would like to acknowledge those who so generously left a gift in their Will to Rare Cancers Australia. Your donation will help support the cancer patients of tomorrow.

Danielle Hickford

Jessica Zurcher

Maxwell Terence Denzi

Our Executive Team

We wouldn't be able to have the impact we do without our dedicated, purpose driven staff, who live and breathe our mission every day. We are united by our shared purpose of patient equity, and our collective ambition to change the story of rare cancer for all people living with a rare or less common cancer diagnosis and their loved ones.



Christine Cockburn
Chief Executive Officer



Alicia Ballesty
Head of Strategic Communications



Sarah Benger
Head of Policy & Public Affairs



Natalie Clancy
Head of Fundraising & Events



Sarah Clausen
Head of Operations



Nikki Kerr
Head of Partnerships



Cathy Slattery
Head of Patient Programs

Our Board



Richard Vines
Chair & Founder



Kate Vines
Director & Founder



Christine Cockburn
Director & CEO



Steve Baker
Director



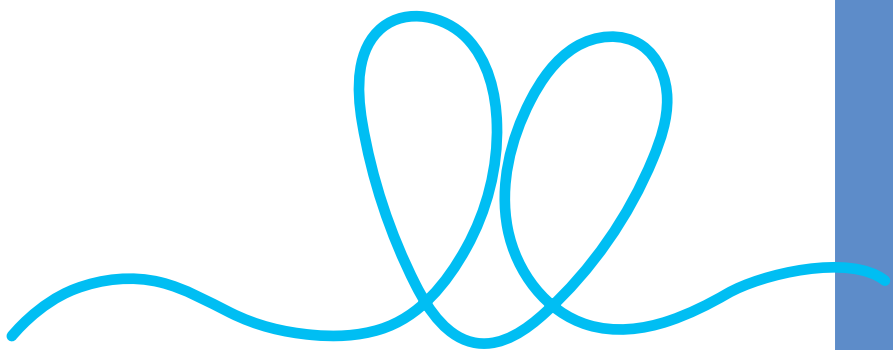
Trevor Burns
Director



Bruce Goodwin
Director



Kate McQuestin
Director



How you can help



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 1,000 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!

Visit rarecancers.org.au to get involved and learn more.

Contact us

Send an email:

Patient Support:

support@rarecancers.org.au

General enquiries:

contact@rarecancers.org.au

Give us a call:

Patient Support: 1800 257 600

General enquiries: (02) 4862 2768

Send a letter:

PO Box 440, Bowral,

New South Wales, 2576

(Care of Rare Cancers Australia, Secretariat)

