rare cancers
AUSTRALIA

INNOVATION AGAINST INEQUALITY

2018/2019 Annual Review

A MESSAGE FROM RARE CANCERS AUSTRALIA'S FOUNDERS

Wow – this is amazing! That was our first reaction on 17th March 2018 when over 500 people registered and took part in the **RCA 2018 Mount Kosciuszko Challenge**. Our minds were cast back to the first Kosi Challenge in 2013 – the *Parliament to Peak*. Richard, frustrated by closed doors in Canberra, took it upon himself to walk from Parliament House to Kosciuszko. That year Richard and I were joined only by Steve Moyes and 35 friends and family from Thredbo to the Kosciuszko summit. What a stunning contrast this year: 500 eager climbers and in the case of the *Pharma Cup* climbers competing against one another. Five hundred Rare caps over Kosciuszko all raising funds for rare and less common cancer patients. The Kosi Challenge is our marquee fundraising event raising over $365,000 this year.

It has been a year of achievements all round for the Rare Cancers Australia (RCA) team. Those once closed doors of Canberra are slowly opening, culminating on Budget night 2018 when $248 million was announced in support of clinical trials for rare cancers and rare diseases. Our government and policy advocacy team has been relentless in making sure that RLC patients voices are heard in the corridors of Canberra. Our approach is bi-partisan and all inclusive.An indicator of our success is the over-subscription to our MP dinners.

It's not just our policy team that has delivered success. We have dedicated, hardworking teams across all disciplines. RCA is achieving outcomes for patients beyond our critical mass by building innovation into our DNA, embracing new technology to put patients in touch, and making sure our activity is based on data and evidence-driven research. Data and research underpin our activity. Through our research and policy reports like. *Rare Solutions, A Time to Act* we brought the cancer community together to influence real legislative change that will ultimately deliver meaningful improvement to patients' lives.

Innovation is a constant. In July we publicly launched Knowledgebase – a set of online resources and a rare cancer directory to provide patients with hope after the shock of diagnosis. And our fledgling mentoring program – Summit – will enter its second cycle – expanding the number of Asian countries where we provide advice and guidance, whilst building community.

Richard and I remain committed to our stated goal of informing better decision making connected to rare and less common cancers and opening up increased access to affordable treatment options for all Australians. We have mentioned the RCA team but the achievements of the past year would not have been possible without the ongoing support of the cancer community: the clinicians and specialist oncologists, our sponsors and donors, the RCA board and everyone who has opened a door or climbed a mountain in support of a rare cancer patient.

Thank you all. Together we are giving a voice to rare and less common cancer patients.

K Vines

Richard Vines
Chief Executive Officer
and Founder

Kate Vines
Head of Patient Care
and Founder

Rare Cancers Australia
Bowral, 26 March 2019

CONTENTS

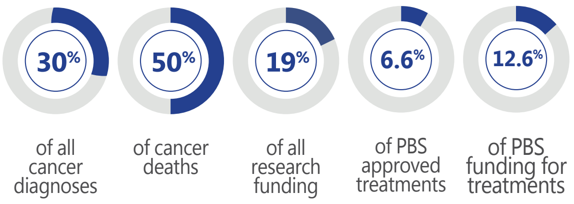
INDEX OF ABBREVIATIONS

Rare Cancer (RC) – Cancer affecting less than 6 people per 100,000 of the population annually
Less Common Cancer (LC) – Cancer affecting 6-12 people per 100,000 of the population annually
RLC – Rare and/or Less Common Cancers
PBS – (Australian) Pharmaceutical Benefits Scheme
PBAC – Pharmaceutical Benefits Advisory Council (A separate, independent agency from the PBS)
TGA – Therapeutic Goods Agency
AIHW – Australian Institute of Health & Welfare
AHPRA – Australian Health Practitioner Regulation Agency

BRINGING INNOVATION TO THE STRUGGLE AGAINST INEQUALITY

This is our story. Rare Cancers Australia was born out of inequality – the inescapable fact that 30% of all cancer diagnoses are of a rare or less common cancer, and account for 50% of all cancer deaths in Australia. And yet these cancers that have such a devastating impact on the Australian population receive less research funding, less PBS funding for treatments and account for a smaller percentage of PBS approved treatments. It was the imbalance in this equation that lead Richard and Kate Vines to co-founding RCA in 2012.

RLC cancers account for:



What is a Rare or Less Common Cancer?

A rare cancer is defined as a type of cancer that has less than 6 incidences per 100,000 Australians per year. A less common cancer is defined as one that has between 6 and 12 incidences per 100,000 Australians per year. That means that 52,000 Australians will be diagnosed with an RLC cancer every year. Research shows mortality rates of around 50% within 5 years. Life is made that little bit more difficult for rare and lesser common cancer patients because where there are treatments available, or clinical trials, the cost of medication is disproportionately high.

Rare cancers do not discriminate against age whilst they are the biggest killer amongst the 60-68 age group, rare cancers can be found in any age group:

RLC cancers affect all ages and claim the lives of:

one Australian child every four days;

one Gen Y every day;

10 Gen Xs every day;

and

more Australians, aged 60-69, than any other cause of death.

About Rare Cancers Australia

Rare Cancers Australia Ltd is a charity and patient advocacy group that sets out to redress the imbalance and improve the lives and health outcomes of Australians living with rare or less common (RLC) cancers. We give patients hope. We do that by growing awareness of rare cancers, providing support, information and assistance to patients and advocating for equal access to treatments. We connect patients with specialist oncologists and get them access to leading-edge clinical trials for the latest treatments. Where the cost of treatment is prohibitive we can sometimes offer assistance through our Patient Support Fund (PTF).

While our patient support team is working hard on behalf of patients other RCA team members work with government, clinicians, media, industry and the broader cancer community to ensure rare cancer patient voices are heard and represented. Our research and publications successfully highlight the plight of RLC patients and advocate for policy reform around research and treatment, and greater access to treatments via the PBS. RCA was the first patient organisation to successfully advocate to have a drug listed on the Australian PBS – in June 2017.

We are relentless in growing the awareness of the plight of rare cancer sufferers and a need for change in the way RLC patients are treated within the Australian health system. In 2012 rare cancers were largely ignored or in some cases they had been forgotten altogether. By 2017 when RCA launched its tipping-point research, ***Rare Solutions: A Time to Act*** which lead to a positive response from the Hon. Greg Hunt MP, Minister for Health and Sport.

INNOVATION

RCA was founded in 2012 – so we are a relatively young charity. We operate in the most not-for-profit sector in Australia. We bring innovative techniques to bear combined with a relentless pursuit of benefits for our patients. We use blends of traditional advocacy and new technology to take our campaigns to new audiences. Our Canberra based event, CanForum, is live-streamed via Facebook so that patients didn't have to travel to have their questions, concerns and input heard in Canberra.

All charities and patient organisations need to fundraise to remain sustainable but current economic trends set the bar higher for us all: flat or falling wage growth in Australia makes fundraising that little bit more difficult. That is why innovation is so critical to emerging charities.

Other examples of **RCA**'s innovative include:

- **Advocacy and Government** Experience has taught us that working in alliance with other patient organisations, industry and clinicians is an effective way to unite patient voices. In May 2018, RCA launched the National Oncology Alliance, a cancer industry alliance of patient groups, patients, clinicians and the pharmaceutical industry. NOA's purpose is the development of policy positions that both address issues of access to cancer treatments, and have broad cancer community support – ultimately improving outcomes for Australian patients.
- **Fundraising** Traditional fundraising techniques are rapidly being supplanted by online methods. All **RCA** campaigns are supplemented by social and digital media support. We consider ourselves exponents of best-practice online fundraising, recently raising $135,000 in 72 hours for a young patient in immediate need via media and social channels.
- **Patient Support** RCA focuses on individual patient stories and through relentless media and social media activity grow awareness of the patient's issues to help with fundraising. We help them to put together dedicated fundraising pages and provide them with the support of our industry-recognised media and relations team to give their fundraising the best possible chances of success.
- **Data, Research and Technology Usage** After the shock of diagnosis patients crave information about their cancer, where they should seek help, and the sources of best advice. RCA holds Australia's most comprehensive database of specialist of specialist oncologists, cancer centres and rare cancer definitions. Go to **www.Knowledgebase.rarecancers.org.au**

RCA has been quick to embrace new technologies. Patients who need help asking the right questions of their oncologists can find pre-prepared scripts on our CAN.recall app. Responses can be recorded and replayed to share the diagnosis and proposed treatment therapies with family and carers. This is particularly helpful to patients where English is not their first language.

Innovation is built into the DNA of RCA – it is how our small, but dedicated team consistently punches above its weight to deliver more and better patient outcomes to Australians.

How was RCA able to help James and his family?

- Effective fundraising to pay for treatment and travel to Germany, accommodation & living costs.
- Sourcing a specialist neurosurgeon.
- James was the first RCA patient to have a dedicated fundraising webpage created for him.

message from our patients

James Warrington-Love

This is James, our beautiful, kind compassionate son who enjoyed nothing more than making people smile.

Our lives didn't come crashing down in one momentous moment. It was more that it was stripped back one brick at a time. In October 2013 James came out of the bedroom holding his right hand with a vacant sadness in his eyes that lasted only a few moments. There was something wrong, but we didn't understand what it could be. The doctor explained James' had experienced a seizure and arranged an appointment with the hospital that diagnosed him with childhood epilepsy. After a serious seizure a few days later he was given CT & MRI scans and the radiologist confirmed there were no tumours or other structural abnormalities which was a huge relief.

Over the next few months James went from a seizure every couple of days to thirty seizures a day and on a routine follow-up MRI three months later they found a large 'inoperable' malignant tumour the size of a grapefruit and was directly placed into palliative care. We didn't even understand the word 'palliative' and certainly couldn't comprehend James was now part of it.

Treatment commenced and research was vigorous. We made plans but rare conditions are an expensive impediment. To give James' a chance our first aim was surgery to remove the tumour and one of Australia's world-renowned neurosurgeons was willing to do the operation but a large amount of money was needed for this to happen.

Paul spoke to people within the community and was put in contact with Richard & Kate from RCA. Within a miraculously short time Kate & Richard organised a fund-raising page and a local television crew to report on our story. Within 24hrs of the interview going to air the community that surrounded us raised the much-needed funds to allow the operation to go ahead.

James' recovered well and we continued researching and treatment overseas whilst enjoying the beauty of our family. We rolled down hills, made daisy chains, danced when there was no music and embraced every moment we had together but unfortunately in June 2015 James' lost his life. Paul and I still cannot come to terms that we will not see James' smile or hear his laughter again but we are eternally grateful for Kate & Richard's crowd funding action which was instrumental in giving us the gift of time. It enabled us to create beautiful memories that we will forever be thankful for.

James lost his fight with cancer but his struggle was not in vain. His bravery was an inspiration to Richard and Kate of what was possible to achieve for rare cancer patients and led to the founding of the ***RCA Patient Treatment Fund*** *(PTF). Through the PTF RCA helps Australian patients like James get access to the medicines they need– in particular those for rare and less common cancers.*

PATIENT SUPPORT AND CARE: WE UNDERSTAND RARE

The 'Why?' behind **Rare Cancers Australia** is never far away. Every day in the Bowral head office we are talking to Australians who have just been diagnosed with a rare cancer, going through a rare cancer treatment process or who have been looking for solutions to their condition for some time. At **RCA** our patients are always front-and-centre.

Historically rare or less common cancer patients in Australia have been offered very little in the way of support. At RCA our Rare Care Program provides support, information and treatment options to assist with the specific challenges that come with an RLC diagnosis. The help we provide includes:

- Navigating and finding clinical trials attached to your diagnosis
- Identifying compassionate access programs to give you affordable access to medicine
- Help with fundraising for treatments and medication not covered under the PBS
- Connecting you with the right people that can help (specialist oncologists, radiotherapists, surgeons, cancer centres)

Patient Support is led by Kate Vines, Founder and Head of Patient Care. A cancer survivor herself, Kate knows the isolation and confusion faced by rare cancer patients and she is laser-focused on keeping patients at the centre of everything that we do.

RARE CARE PROGRAM

Individual Phone Support

It's good to talk. Whether you need advice or information, or someone who will listen RCA is here for you.

We encourage patients and families to contact RCA direct by phone as we can offer direct access to qualified staff who will provide information and advice, as well as support. This support is made available at no cost and we pride ourselves on providing patient engagement of the highest quality. The aim behind this is to alleviate some of the stress that comes with a rare cancer diagnosis.

Database

Gives patients, families and carers the best information for navigating the Australian healthcare system.

Patient outcomes are greatly improved with access to specialist doctors, appropriate support services and awareness of treatment options. Over the past six years we have built a database to be the source of resources dedicated to the needs of RLC patients. The RCA database houses a rare cancers directory, lists of hospitals with specialist cancer centres, multi-disciplinary teams, clinical trials and individual clinicians. RCA's database brings information together in a single place for patients and their loved ones, carers and healthcare professionals.

Patient Treatment Fund

At RCA *we believe that cancer is cancer, and that affordable treatment options should be available to all Australians.*

Being diagnosed with an RLC cancer is a major financial challenge for tens of thousands of Australians every year. The shock of diagnosis is compounded by the uncertainty connected with rare and less common cancers, and the availability of affordable, government-provided treatment options. RCA has helped many patients through the resulting financial stress, and The Patient Treatment fund provides hope through a platform for raising money for treatment costs. We ask for a referral and some financial assessment measures to qualify a patient's eligibility to participate in the Fund.

CAN.recall App

Innovative technology assisting patients in times of need.

Patients diagnosed with cancer are confronted with vast quantities of life-changing information at a time of great stress. This is a harrowing experience that is often combined with the frustration of not recalling or clearly understanding a clinician's words during a consultation.

RCA's CAN.recall app allows patients to access pre-loaded questions to ask their clinician so that they can better understand both diagnosis and proposed treatment therapies. The app records both question and answer so that details can easily be shared with family and friends. Recordings are secured to protect both patient and clinician confidentiality, and our experience has found that this app is particularly beneficial for patients for whom English is not their first language, or who may face problems with medical terminology. Can.recall is available in Mandarin and will be translated into other languages.

Financial Advice

With the emotional stress of an RLC cancer diagnosis often comes financial stress. We are there to help alleviate the pressure.

For patients and carers an RLC cancer diagnosis may force you to take time off or stop working altogether. RCA can offer advice on how to approach financial institutions, utility companies, insurance agencies, government departments to build a case for compassionate consideration.

For further information on all of our patient support services, Knowledgebase, Patient Treatment Fund, CAN.recall,
go to www.rarecancers.org.au
or phone us on 1800 257 600.

PATIENT ADVOCACY AND INDUSTRY ENGAGEMENT

If patient support is the 'Why?' of RCA, then patient advocacy is definitively our 'How?' RCA's expertise has industry-wide recognition and Richard Vines is internationally in demand as a speaker around government advocacy. 2017/18 has seen a series of successful break-throughs as a result of years of RCA's ongoing advocacy efforts with government, clinicians and industry. We are proud of the fact that the policy changes we have been instrumental in influencing will make a real impact and improvement to patient's lives.

Never more so than during the 2017 CanForum event. when our team pulled together strong representation from across the cancer industry around our major policy piece, *Rare Solutions: A Time to Act*. Government ministers, patients and clinicians met to discuss the dilemma rare cancer patients face and ultimately call for change. We were successful in engendering Cabinet-level support from Health Minister Greg Hunt, securing a $13 million-dollar package for clinical trial funding, and support for a new PBAC process for pan-tumour therapies. (See detail in Campaigns for our Patients: CanForum 2017).

There is still inequity in the system – and whilst rare and less common cancers continue to be responsible for 50% of cancer deaths whilst only receiving 13% of government funding – our advocacy efforts will continue: across government, influential clinicians, industry and through industry bodies such as the National Oncology Alliance. RCA fights for the right for the patient voice to be heard during policy formation.

Government and Policy

RCA's advocacy work has a broad span of activity. Our government relations team can be found in meetings with politicians and their advisors; hosting dinners for MP's and their constituents; contributing to or helping Senate inquiries and hearings; or co-ordinating the Australian cancer community to work together and bring to bear the diverse voices of patients, influential clinicians and industry.

Our approach is bi-partisan and open. We pursue focused aims across the political spectrum including the encouragement of politicians for more flexible approaches to patient treatment, and to provide broader access to affordable cancer treatments. We never give up in our efforts for patients. At the end of 2018 15% of all parliamentarians had attended an "Educate and Advocate" dinner hosted by RCA.

Clinicians

Cancer research and oncology are complex areas and RCA seeks to be credible and accountable – as well as investing significantly in cancer research. We have long-standing relationships with senior and specialist oncologists nationally and internationally. We work closely with this community to ensure the solutions that we pursue for patients are achievable. We work with clinicians to find the treatments and specialists that are appropriate to a patient's condition, and clinicians in return help RCA to find the best clinical trials for our patients.

Six years of investment in these relationships is paying off for patients in many ways. We have a long-standing relationship with the The Kinghorn Cancer Centre, Australia's premier centre for genomic cancer research and major diseases. We have worked closely with Professor David Thomas on his MoST program (Molecular Screening and Therapies) helping fund the program and also referring eligible RCA patients.

Pharmaceutical Industry

When RCA launched the National Oncology Alliance (NOA) on 12th May 2018 to its industry pillar there was representation from every major multinational pharmaceutical company in the room. This is a measure not only of the depth of trust that the industry has for RCA but also the credibility of the programs that we run in conjunction with the pharmaceutical industry.

For a charity we are mindful of our relationship with the pharmaceutical industry. Experience has shown that through ongoing co-operation and interaction we generate the best possible outcomes for patients. We advise and train other organisations – in Australia and regionally – on best practice to maintain ethical and productive relationships with this critical industry partner.

CAMPAIGNS FOR OUR PATIENTS

RCA's strategic advocacy during CanForum 2017 with ***Rare Solutions: A Time to Act*** combined with our proactive media engagement resulted in immediate government action from the Minister for Health and Sport, the Hon. Greg Hunt MP:

1. A new **Pharmaceutical Benefits Advisory Committee (PBAC)/Therapeutic Goods Administration (TGA)** process for pan-tumour assessments to allow for faster access to treatments for rare cancers.
2. 20 per cent of the **Medical Research Future Fund (MRFF)** to be earmarked for research into rare conditions.
3. Calls for proposals for new clinical trials for rare cancers by the end of September 2017 as part of a $13 million budget package of benefits.

What has been achieved through the CanForum events for RLC cancer patients?

RCA's annual CanForum brings together influential people in the cancer community under the Parliament House's roof in Canberra - an excellent venue when you're looking to influence change for rare cancer patients. CanForum is a day of discussions highlighting the challenges that rare cancer patients face accessing medicines affordably. It involves cabinet ministers – government and opposition, their advisors, clinicians and clinical researchers, consultants, thought leaders and most importantly patients.

The thread of RCA innovation runs strongly through CanForum. It is run by charities and patient groups not industry groups or lobbyists; the forum is made accessible to patients via a Facebook livestream – so their voices can be heard; we introduce MPs to their constituents who are also rare cancer patients over lunch - education and advocacy take place simultaneously.

Why was the 2017 CanForum able to have such an impact?

- RCA successfully rallied the many influential stakeholders that have a role to play in improving the lives of RLC cancer patients - single-mindedly focusing them on the outcomes listed above.
- **CanForum** 'village' of support that we gathered included:
    - Government departments: Department of Health, PBS and TGA
    - Clinical experts including Professor Clare Scott, of the Walter & Eliza Hall Medical Research Institute, Professor David Thomas, Professor John Simes, of the National Health and Medical Research Centre Clinical Trials Centre and Professor John Zalcberg OAM, of Australian Clinical Trials Alliance
    - PWC our health industry advisors
    - Four extremely brave patients who were prepared to tell their stories, and our gold medallist ambassador, Kelly Cartwright, para-Olympian
- The policy centre piece, *Rare Solutions: A Time to Act,* did not seek to embarrass or shock but to act as a clarion call – highlighting solutions that could be readily embraced by all parties, and ultimately lead to actionable change.
- *Rare Solutions* had been validated by many of the stakeholders involved and its recommendations were endorsed as achievable by health economist. That's policy foundation carried out in consensus.
- The pharmaceutical industry was involved in a final review of the report's recommendations to collectively endorse the solutions in *Rare Solutions*. This made it a compelling proposition not only to the industry but also to the sitting government.
- Our strategic, coordinated media approach meant that the CanForum was not just a news item – it dominated the news agenda of the day. RCA leveraged a nationwide pool of talent including senior cancer clinicians, 14 patients providing media with spokespeople in every state. The media campaign was given a kick start with a focus piece on the 7:30 Report – taking it into a million Australian's homes. 452 media placements, and 31.7 million media impressions meant that the plight of rare and less common cancer sufferers was consistently being brought to the government's attention.

When we look back onthat year's CanForum we realise the unique position RCA has to deliver such a campaign and its outcome: our passion for change and our reputation give us the credibility and permission to pull such an all-encompassing community together.

That appetite for change continues unabated and this year Rare Cancers Australia delivered the update to Rare Solutions during the CanForum 2018, *"Rare Solutions, A Time to Act - Progress Update."*

COMMUNICATING THE RARE AND LESS COMMON CANCERS MESSAGE

Gemma Caprioli - Photo courtesy of SMH

When RCA was set up in 2012 the first things that we did were to establish a brand identity and a website – the basic elements essential for credibility. We have maintained a strong media and brand presence over six years and RCA is continually innovating through different vehicles and channels of communication. First and foremost, to make our patients' voice heard, and with increasing frequency to invite them to participate in the dialogue. We make our events, and forums available to patient participation using the channels that are most convenient for them to participate: mobile phone, social, digital channels and Facebook.

The distinctive RCA brand and effective communications are critical to our day-to-day operations – we use them to convey the needs of RLC patients to a wide array of stakeholders and we engage directly with patients too.

Aspects of RCA communication activity:

- To generate awareness for the cause of RLC cancers
- Communicate the need for change in attitudes to RLC cancers
- Our successful communication has and does influence government policy
- To deliver information to patients, the public, industry and government and make them aware of how we can help
- To fundraise and promote attendance & participation in our events

RCA is also a strong advocate of the Internet, and social media usage on behalf of patients. Once contacted by a patient we will have a fundraising page up and collecting donations within 24 hours. Our media team then accesses its full range of channels to direct traffic to that patient's cause. Fundraising can take-off in a very short timeframe indeed. In the case of one young patient in immediate need of treatment our online fundraising efforts changed the destiny of that particular patient completely and to the better.

Although traditional communication channels (television, print media) have become fragmented. Our approach is to integrate traditional and new channels to complement one another – maximising the impact of our campaigns.

Social media has turned patient advocacy on its head – so we have turned that to patient's advantage. At RCA social media provides the opportunity to let individual voices be heard and in 2018 we increased our number of Facebook 'Go Live' events including opportunities to join in debate, with Professor Andrew Wilson, Chair of the Pharmaceutical Benefits Advisory Committee to explain and educate around the Pharmaceutical Benefits Scheme (PBS) in Australia.

Awareness of a charity's cause is its life-blood and our engagement with media channels runs on a 24-hour cycle. Simultaneously we take a strategic approach – ensuring content is relevant to the media, and that we provide a wide range of voices from the cancer community to validate our story. How else during CanForum does RCA manage to keep itself top of the media agenda not just for the announcement but throughout the day? Our brand and media campaigns have taken rare and less common cancers from a largely ignored category to having a high-profile national presence, a profile that is known and respected and that has persuaded a government to act in favour of RLC patients.

Lejla Meduselac

Hi, my name is Lejla Meduselac and I'm 35 years old. In February 2016 I was diagnosed with Adrenal Corticol Cancer (ACC) – as a single mum of two beautiful children Mirella and Sanjin this was a devastating blow.

My daughter is 12 and suffers from cerebral palsy, my son is 9. Even when I had not been diagnosed life was hard enough – but being diagnosed with cancer just made things even tougher.

When I was first diagnosed I was treated with a chemotherapy drug. This kept me stable, but the side effects were absolutely debilitating – I struggled to be able to get up and look after my children.

Then somebody pointed me in the direction of Rare Cancers Australia and the wonderful Kate Vines. Kate helped me to realise that whilst the cancer journey is hard, that there are people there to help whenever they can – particularly the RCA team. My Gold-Coast based oncologist was understanding, but unfamiliar with my cancer because of its rarity. RCA helped connect my local oncologist with a specialist in Brisbane who had had experience with ACC. I had major surgery twice and then it was explained to me that there really weren't any other alternatives available to me at this point.

RCA came to the rescue again. It found me the right immunotherapy trial to get on for which I was so thankful. Through my PTF fundraising page RCA also helped me with the costs and expenses to travel from the Gold Coast to Sydney repeatedly for 6 months. I could never have afforded that as a single mother, RCA was so amazingly supportive.

I can't find the words to say how grateful I am to Kate and her team for everything they have done for me. Without their help it just would not have been possible.

With your generosity, our Patient Treatment Fund will help those Australians faced with high cost options, and gain access to the medicines that will ultimately help save or extend their lives. Through the Patient Treatment Fund in certain cases we are able to fund treatment, and some specific additional costs too. Please help us to continue this important work through your donations.

Go to www.rarecancers.org.au/donations

Lejla also appeared on ABC's 7:30 Report to highlight the plight of RLC patients.

How RCA's Patient Support Program services helped Lejla?

- Identification of the appropriate clinical trial
- Patient Treatment Fund (PTF)
  - Support for repeated travel, accommodation & other expenses
- PTF fundraising webpage
- Psycho-social support

message from our patients

CAMPAIGNS FOR OUR PATIENTS

Richard and Kate lead the first Kosi Challenge back in 2013 along with a group of friends and family. Not everything becomes a success overnight, and as they would be the first to admit, it took a couple of years for the concept to grow from its modest roots. From those early days the Kosi Challenge has now become one of RCA's marquee fundraising events – proceeds enable the funding of major projects such as support for clinical trials, research and treatment, generating real outcomes that will make a difference to rare and less common cancer patients.

About Kosi Challenge

For those that climb, the Kosi Challenge offers a unique fundraising experience – the opportunity to conquer Australia's highest peak whilst influencing the outcomes for Australians with RLC. At 2,228 metres above sea-level it is much more than just a walk-in-the-national-park; it is a physical challenge with the reward of a spectacular gala dinner in the evening that gives walkers an opportunity to come together, celebrate the day's achievements and compare blisters!

Consistent focus over the years on the differentiation of the event, and the donor experience meant that on 17 March 2018 the Kosi Challenge came of age – smashing fundraising and participation numbers: $365,000 raised and over 500 climbers ascending the mountain in distinctive 'rare' caps.

The introduction in 2017 of competitive elements such as the Pharma Cup has encouraged active participation and fundraising. RCA extends grateful thanks to Pharma Despatch for its generous support and sponsorship.

The success of the Kosi Challenge 2018 will extend our capabilities into foundation funding for new initiatives and we have introduced a new element to the Kosi Challenge already for all those sporting types: the Parliament2Peak cycle ride - a two day road-ride from the lawns of Parliament House in Canberra to the Alpine village in Thredbo.

How the Kosciuszko Challenge became a Marquee Fundraising Event

- Persistence, determination and continued investment

1349 unique participants since 2013

PARTICIPATION NUMBERS GROWTH SINCE 2012

OUR TECHNOLOGY STORY

Data

"Without data, you're just another person with an opinion"
W.Edwards Deming, Management Consultant

It took a data insight to help steer Richard and Kate in the direction they've taken. Early on in Rare Cancer Australia's history they identified the disproportionate amount of funding RLC cancers receive in support versus the profound impact they have on Australians (25,000 deaths annually). The data they were looking at highlighted a key issue for rare cancer patients: the financial implications of a rare cancer and the access to the right medication to prolong life.

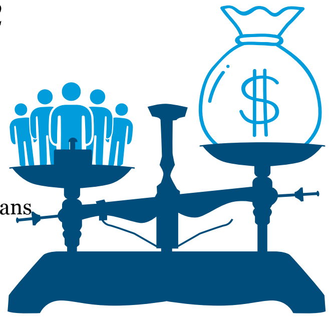
Four years after its foundation, RCA used data highly effectively in its policy paper *Rare Solutions: A Time to Act*. RCA was able to demonstrate to federal government the true impact of RLCs on Australians and the number cancer sufferers together with the lack of funding they receive. The data in the Rare Solutions report made our case compelling to government: in the budget following the reports release $284 million was allocated to three new RLC programs.

Rare is not rare

More than **200** different kinds of RCL cancers

Every year, **52,000** Australians are diagnosed with a RLC cancer

25,000 will die



Allocation of cancer research funding doesn't match the burden of RLC cancers.

Evidence and data-driven insights drive action at RCA. Statistics on rare cancers were originally lacking in detail for Australia so RCA worked with the cancer community to uncover them. Today we have the data that validates our work, but also delivers the insights to create change and better outcomes for patients. For example, the RCA Knowledgebase is a publicly-available database, unique to the Asia-Pacific region, covering over 214 types of cancer, 120 specialists and 200 plus specialised cancer centres.

Technology

At the patient-to-clinician level RCA has developed the CAN.recall app that enables patients to record oncologist sessions for easy recollection and sharing with carers and family. Conversations with our broader stakeholder groups (patients, clinicians, industry, government) are increasingly held online versus traditional channels. We make it convenient for rare cancer patients to engage digitally: Facebook feeds in our advocacy programs put patients in the corridors of Canberra, increasingly we deliver updates via online technology, and in the near future our website will provide first-point-of-contact advice through chat-bots.

Research

RCA initiates research and commissions it, as well as collaborating with some of Australia's best known cancer research establishments. The focus of cancer research is moving from a topological (lung, breast, brain) categorization to morphological (rate/type of change in cancer) using genomic signatures we have become involved in Australia's leading genomic cancer research. RCA has referred patients meeting the right criteria for the MoST (Molecular Screening and Therapeutics) program being conducted by Professor David Thomas. We have supported patients to help them get access to the program, and RCA has supported the research financially.

Internally at RCA we are constantly building on our existing data for our own research purposes. In 2018 we provided an update to the *Rare Solutions* report at CanForum18, together with exciting research programs including a study on the economic impact of rare cancers. RCA research carried out amongst 300 patient groups in Asia is now forming the basis for our Summit program, a mentoring and community building initiative that is building stronger patient advocacy in the region.

Technology, data and research walk hand-in-hand at RCA and in combination they help us to deliver a unique service: from the volumes of data that technology delivers we derive insight for action. At the same time technology allows us to deliver more outcomes for patients through efficiencies gained; we build data and evidence-based research into our policy papers, white papers and Senate Inquiry submissions – that in turn compels stakeholders into action and generates greater cut through for our campaigns. The overall outcome is meaningful and impactful change for our patients.

How is RCA helping Justin?

- RCA Patient Support connected Justin with a specialist oncologist in Perth.
- RCA has stuck with Justin at the time when he needed to negotiate the complex paths of getting treated with a currently non-available drug in Perth.

message from our patients

Justin Goodes

Hello. My name is Justin Goodes, I'm from Broome and I have metastatic Merkel-cell carcinoma (mCC).

Not many people know what mCC is here in Broome. The way I explain my condition is that it's a rare form of skin cancer – far more aggressive than the melanoma cancers that we are more familiar with in Australia. And it's very unusual to find in someone as young as myself. On average, patients are diagnosed at 75 – only 5% are diagnosed under 50. I'm currently 46.

Diagnosed at 38, I've had continual treatment for eight years. The constant rounds have exhausted me. After the carcinoma was first found in my leg I was treated with wide margin surgery, radiotherapy and then chemotherapy. We thought that had worked but in 2015 it was found that the tumour had metastasised and re-appeared in my thyroid without any form of lymph node activity. Thyroid removal was unsuccessful as the tumour was too advanced and attached to my windpipe and oesophagus and was growing down towards my heart. Thanks to more chemotherapy and radiotherapy we managed to kill off that tumour, only for it to reappear in February 2016 in my small intestine and a third site with two tumours sitting on top of one another within my bowel. My bowel had to be re-sectioned in three places but the tumour re-asserted itself once again, and even after further rounds of radiotherapy new and young tumours started to re-occur in the first diagnosis location: my lower right leg. It has been a long and painful journey for me with mCC.

I was beginning to give up hope when I rang Rare Cancers Australia earlier this year. RCA offered to help me find a clinical trial and contact a pharmaceutical company who had an immuno-therapy drug specifically for mCC on my behalf. The Patient Support team also helped introduce me to another oncologist in Perth who understood something about my condition, as he was already treating other patients with the same drug.

Finally, it seemed as if we were making progress – then one week before compassionate access to the drug closed a legal loophole created an obstacle. Both my oncologist and RCA fought my corner for me and in June this year we were able to break the deadlock. I am travelling to Perth for treatment as I write this story.

RCA has been a real help to me – it found new avenues of hope when doctors had written me off and put me in the just too hard basket. RCA has helped to get me compassionate access to the immuno-therapy drug, which is in trial and so expensive. That is another weight off my shoulders. RCA connected me with a specialist oncologist who understood mCC and could put me onto the right treatment for my condition.

There have been so many obstacles to get over. I want to thank RCA because at last I knew that there was someone who could help me, despite the distance between Bowral and Broome. Putting me in touch with an oncologist who understood the urgency connected with my condition was a major breakthrough, even though I have to travel to Perth every time I'm getting the treatment that I need.

Justin had a long journey to find the right oncologist and treatment for his condition. Once the right drug was found thanks to RCA Patient Support's engagement with the pharmaceutical industry and with the hospital we were able to turnaround access much quicker. Immuno-therapy is a highly complex area but Justin is currently in treatment and our very latest news is that he is responding well to the new immuno-therapy drug.

RCA LOOKING FORWARD

The past year has been one of amazing achievements for the whole RCA team – a year in which we went through a fulcrum point with many of our long-standing initiatives becoming significant contributors to the RCA mission. The year ahead is well mapped out with further exciting developments, our team is growing to provide support to a wider group of patients, and we are being called upon to deliver our own unique skillset to industry and patient groups beyond our immediate borders. We have outlined three innovative initiatives below that will take RCA on its upward trajectory into 2018/19.

Alliances – National Oncology Alliance (NOA)

RCA supports the foundation of industry alliances in the belief that united views across stakeholders are a powerful path to implementing change and making sure that the patient voice is heard across the spectrum. RCA co-chaired the Cancer Drugs Alliance until October 2017 putting the first Cancer Forum (2014) and the Rapid Resolution Process in place in its lifetime.

However, a more flexible structure allowing wider stakeholder participation was required and so in May 2018 CDA became the National Oncology Alliance (NOA) a not-for-profit alliance of patients, patient organisations, industry representatives and leading cancer clinicians. Its purpose is to develop policy positions that address the issues of access to cancer treatments and have broad cancer community support – ultimately improving outcomes for Australian patients.

- Within two months of formation NOA has provided a submission to the PBAC special meeting investigating pan-tumour subsidy frameworks: *'PD-1 and PD-L1 checkpoint inhibitor immunotherapies: options for subsidy consideration for multiple cancer types'.*
- The best demonstration of how collaboration between a wide group of relevant stakeholders can lead to quick benefits for cancer patients.

SUMMIT PROGRAM

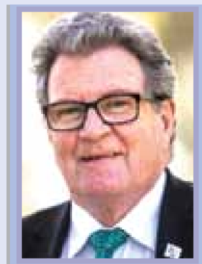
Summit Program – Asia

Research conducted in 2016 by RCA amongst 300 patient groups showed that the patient voice was not strong in Asia. However, our industry knowledge combined with data insights told us that there were ambitious groups that needed mentoring and help to get to the next level, to become effective and enhance patient outcomes in their countries.

Inspired by our success in Australia the Summit Program was set up as a mentoring service to advise and connect like-minded patient groups in the region. Our first 'Summit' held in Singapore in January 2018 was attended by groups from China, India, Malaysia, Taiwan and The Philippines. The program teaches them how to engage with government, clinicians, and key decisions makers as well as the pharmaceutical industry. The aim is for them to gain a more professional and sustainable footing in the process. In parallel, we have developed a set of guidelines to help these groups, and future Summit participants grow their capabilities. The Summit Playbook was released at UICC World Cancer Congress in October 2018, and we are now focused on turning this into a digitised, region-wide collaborative platform.

Summit program's long-term goal is the creation of a professional patient advocacy movement for Asia: during its first cycle Summit has created a unique, sharing and environment strengthening for patient groups. Our plan for year two of Summit is to grow the number of participating organisations and countries, and from the Summit Playbook develop a highly interactive tool for regional collaboration.

OUR TEAM

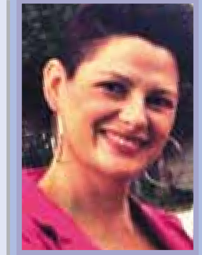


Richard Vines
Chief Executive and Founder

"I'm the CEO, but I'm also the CIO – the chief innovation officer. Through innovation I guide the RCA team to deliver better outcomes for more Australian rare cancer patients. I champion RCA's advocacy efforts - as the best way to deliver impactful change to patients."

Kate Vines
Head of Patient Care and Founder

"I've overseen the development of our patient care programs since the beginning of RCA. I see my role as keeping the patient front-and-centre of everything, fighting their corner for them when they're sick, and maintaining our own high standards of patient care."

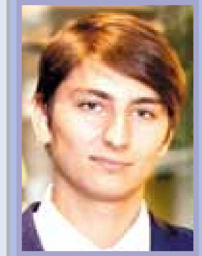


Christine Cockburn
Patient Care Team Lead

"Together, Kate and I are the first point of call for RCA patients. We give them hope and direction at a time when they may feel lost and confused. We help uncover solutions to the challenges Rare patients face and develop resources to meet the needs of patients with empathy, compassion and understanding."

Natalie Clancy
Fundraising & Event Co-ordinator

"Fundraising is the life-blood of every charity: I ensure that the dollars we raise through fundraising go directly towards patient support, research or advocacy. Also, that our donors are recognised for the important contribution that they make."

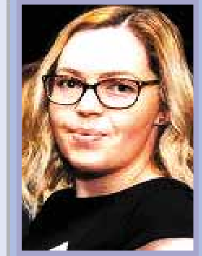


Nash Chance
Research & Data Manager

"At RCA we act on evidence and data-driven insights. Where previously statistics on rare cancers didn't exist, there is now significant data to validate the work of RCA. It's my job to break down the data, deliver the insights that point the way to action and ultimately better outcomes for RCA patients."

Zac Hulm
Community Engagement Manager

"If I have to cycle 1,000 kilometres to grow us the biggest, most supportive community in Australia – then I will. I'm building the RCA community that will support our patients into the future."

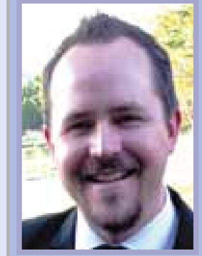


Jessica Brown
Finance and Patient Support Admin

"I manage all of our bookkeeping and support our Patient Care Team through my administration and accounting qualifications, and pursuit of a Master in Social Work. My skills complement our wider team and ensure the sustainability of RCA."

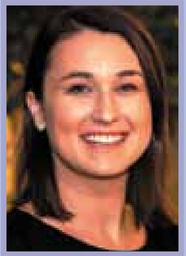
Nikki Kerr
Corporate & External Relations Manager

"I connect major organisations with the fantastic work that is done throughout RCA and engender the support that will allow us to continue the good work into the future."



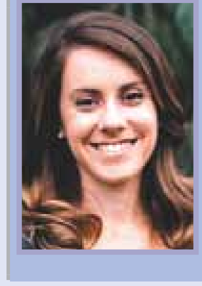
Bryan McDade
Patient Care Co-Ordinator

"With over 12 years experience in counselling and community services, as well as qualifications in biomedical science, I provide the patient care coordination team with person-centred, recovery focused insight to meet the unmet needs of patients."



Eliza Mitchell
Policy & Public Affairs Manager

"At RCA, we know it's essential to collaborate in developing good policy. I work with government, industry, clinicians and stakeholders who can make a real difference to our patients lives. I ensure they're aware of the issues at hand, and that they are 'guided' in the right direction!"



Lydia Willoughby
Executive Assistant to Richard Vines

"I look after the CEO's diary and help to ensure a smooth-running office. Being up-to-date with everything and everyone is vital to be able to keep our entire team coordinated so patients remain our main focus."

James Kissell
Director Summit Program (Asia)

"My role is to connect patient groups, build community & strengthen patient advocacy across Asia. We do this through RCA's mentoring program, Summit: capturing Australian best-practice, and sharing beyond our borders."

OUR BOARD

The RCA board is comprised of executives who have all been impacted by rare cancers during their lives in one way or another.

They bring great passion, and insight as well as good governance to the board. We are most grateful for the support and expert advice they have given throughout the year, and the stability RCA derives from board consistency.

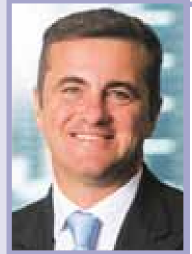
Richard Vines, Founder & Chairman (2012)

Richard and Kate established **Rare Cancers Australia** in 2012 as a patient advocacy group with the mission to improve the lives and outcomes for rare cancer patients. Richard is a relentless front-line campaigner on behalf of RLC patients.

Kate Vines, Founder & Head of Patient Care (2012)

Kate brings 25 years of business management and marketing experience to the **RCA** board.

Kate advocates tirelessly with government, clinicians and industry to ensure the voice of RLC patients is heard and their needs met.



Mathew McCrum, Director (2018)

RCA's newest board member brings strong financial credentials to **RCA**. He spent 27 years in financial markets with Vanguard, Treasury Corporation Victoria and Omega Global Investors, a $4.2 billion fund. Mathew founded Omega with partners George Vassos and Andrew Gruskin. George's premature passing from a rare cancer inspired Mathew to contribute to the work of **RCA**.

Trevor Burns, Director (2013)

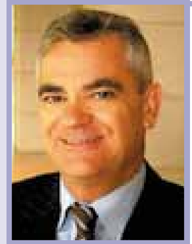
Trevor provides **RCA** with guidance on advocacy and government relations. His 25 years' experience in journalism, public service and most recently in government and public affairs for Macquarie Group and a number of other major institiutions is invaluable to **RCA**.

Mark Brennan, Director (2013)

A barrister and solicitor by training Mark's strong track record in government positions gives the **RCA** board unparalleled insight into the challenges facing government in health. Mark served as the Australian Small Business Commissioner between 2013-16. He is now a highly sought after speaker on the challenges of small business and government regulation.

Leah Graeve, Director (2014)

Leah brings a strong combination of legal and commercial skills to the **RCA** board. A graduate of Monash University and the Australian Institute of Directors, Leah specializes in commercial negotiation skills in both the corporate, and private-sector domains. Of her **RCA** board position Leah says that she is driven by her over-riding passion to right the inequality that exists for RLC patients – and to gain greater access to the medication that rare cancer patients deserve.



John Cannings OAM, Director (2015)

John has had an extensive career in consulting, corporate and commercial law for over 33 years. The depth of his knowledge and expertise in the Health and Pharmaceutical sectors is unparalleled. Until recently John was PWC's Health Consulting Leader for Australia and the Asia-Pacific region.

Just as critical as John's role on the board has been his patient advocacy since being diagnosed with NSCLC in 2014. He has campaigned tirelessly on behalf of fellow patients: presenting at forums, making submissions to Government and giving evidence at Senate Committee hearings.

Nina Parker, Director (2012)

A senior executive with Microsoft, Nina brings technical and commercial acumen to the **RCA** board. Nina has been crucial in guiding **RCA** in its innovative application of technology designed to assist rare cancer patients more easily navigate their cancer treatment and care.

Rare Cancers Australia Mission

The purpose of the Rare Cancers Australia team is to improve the lives and health outcomes of Australians living with rare or less common (RLC) cancers. In 2012 when Richard & Kate Vines founded Rare Cancers Australia rare and lesser common cancers were a largely ignored health category. In the 2018 health budget the Australian Federal Government provided $284 million in funding to support clinical trials for rare cancers and rare diseases.

Our campaigns support patients with rare cancers, seek increased funding for research and timely access to drugs for patients. RCA was the first patient organization to drive the listing of a drug on the Australian PBS (June 2017, Verinostat). We lead collaborative efforts and alliances including the NOA (National Oncology Alliance). We seek to perform at the level of a commercial business operating in the not-for-profit sector – to achieve this we recruit amazing staff who work tirelessly with government, clinicians and the industry to deliver better outcomes for RLC patients.

rare cancers AUSTRALIA

Rare Cancers Australia Ltd is governed by a board of directors and is classified as a Health Promotion Charity by the Federal Government. All contributions over $2 are fully tax deductible. Go to www.rarecancers.org.au/donations

ACKNOWLEDGEMENTS

On behalf of Rare Cancers Australia we would like to thank all of the people who have contributed to our success, and it's a long list! To our team whose indefatigable efforts make us the great organisation we are and our board who provide good counsel and guidance. To the extended Rare Cancers family who volunteer for events, participate in our initiatives and who are spread across a wide domain – you know who you are, we know who you are and recognise you here - thank you all. To our donors – we make sure every dollar counts and without your generosity the good work we do could not take place.

To the broader cancer community who have backed us and advised us: clinicians, doctors, administrators, patient groups, our patients themselves and our corporate partners in industry, the pharmaceutical industry and our ever-diligent suppliers. Thank you again. From the cancer community we would like to acknowledge Professor David Thomas (Kinghorn Cancer Centre), Clare Scott (Walter and Eliza Hall Institute) and Professor John Zalcberg OAM (Australian Clinical Trials Network) for your continuing support and counsel.

To the Australian Federal Government that has listened to our advocacy on behalf of RLC patients and is opening up support for a long-ignored category of patients, RCA and our patients are extremely grateful.

This annual review has been prepared by the Rare Cancers Australia team – all have contributed. Design and branding is masterminded by Belynda Simpson. The author and editor is James Kissell.

SUPPORTERS

Rare Cancers Australia would like to extend a big thank you to the following organisations who have supported us so generously. Without their support, our hurdles would be great and our aheivements less. Thank you for sharing the vision.

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AnthonyLahood MOTORS
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BCFA Brenda Colahan Fine Art
Blue Dinosaur
Bristol-Myers Squibb
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PO Box 440, Bowral NSW 2576
www.rarecancers.org.au
ABN 24 159 196 997 **P** +61 2 4862 2768 **E** contact@rarecancers.org.au