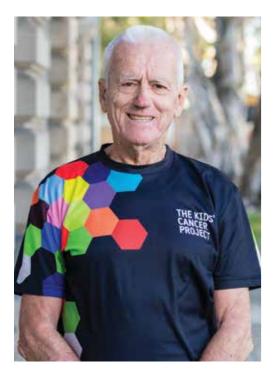


#### A MESSAGE FROM OUR FOUNDER



The Kids' Cancer Project officially turned 25 this past financial year. And on a night that I'll never forget, we gathered to celebrate the incredible community that has made this charity what it is today.

For years I had been taking children with cancer out on day trips. But then I was shown an empty research laboratory and was told if I really wanted to help them, I should work toward filling that lab with scientists to find better treatments and a cure.

And that's been my mission ever since. But I said from the outset I couldn't do it alone. I'm so pleased that I haven't had to and that every year I've had the help of some very special people.

Our 2018 Spring Appeal told the story of Josh who was diagnosed with a rare cancer when he was five. He defied incredibly slim odds to become the outgoing teenager he is today.

At Christmas, we shared the story of Pippa whose parents discovered she had leukaemia on Christmas Eve 2015. She was just three. Now Pippa is thriving, and she's been able to do full days at school.

Alec inspired us in our Easter Appeal along with his oncologist (and my great friend) Dr Luciano Dalla-Pozza. Right now, those two are appearing in brand advertising that was filmed at the end of 2018 with thanks to the Richards Rose agency and Nine Cares.

In the last appeal for this financial year we took Nicholas, a neuroblastoma survivor, to the lab where Associate Professor Alex Swarbrick and Dr Holly Holiday are working to help kids just like him.

Survival brings hope. But that's not the reality for every child diagnosed with cancer. This year we pay tribute to Ned Isham whose journey we followed for many years and who now will be forever six. Rest in peace Ned.

My sincerest thanks go to those children along with all the families who shared their stories with us, we are inspired by them daily.

My thanks also go to the countless others who worked hammer and tongs to fundraise on our behalf this past financial year; particularly those who channelled insurmountable grief into something good like Simon and Kim Kane whose son Declan gained his angel wings in May 2017; Sarah, Josh and Alicia Weir who lost their Evie Grace in December 2017; and Tim Hayes whose daughter Stephanie passed away in June 2018.

On 2 May 2018, I welcomed the new incoming Governor of NSW, Her Excellency the Honourable Margaret Beazley AO QC, and I want to thank her for her Vice Regal Patronage of our charity. I also thank the Governor-General and Mrs Hurley who continue to serve our charity as Patrons.

Finally, to every member of staff along with our committed volunteers, donors, corporate partners and supporters, thank you for choosing to help kids with cancer in the most meaningful way of all.

This isn't my charity, it's yours.

Col Reynolds OAM
FOUNDER AND DIRECTOR

## A MESSAGE FROM OUR CHAIRMAN AND CEO

We believe science is the solution to curing children's cancer and that is why we are committed to executing a long-term research investment strategy.

The Kids' Cancer Project allocated over \$2.83 million across 22 projects in the FY2019 financial year. In addition, we confirmed multi-year commitments including \$2.65 million to the Australian Brain Cancer Mission and more than \$10 million in funding future medical research.

We rationalised our funding priorities to three key areas: advocacy, bench, and clinic. Our advocacy platform gives us the opportunity to raise awareness of the issues faced by families, building support and providing real solutions for kids with cancer. To that end, in FY2019 we received a \$9 million commitment to childhood cancer research (2021 – 2023) from the Federal Government. We also continued collaborating with the Government across our joint priorities through Cancer Australia's Priority-driven Collaborative Cancer Research Scheme.

Scientific discovery through laboratory exploration works hand in glove with clinical research and we put significant emphasis on taking therapies from the bench to the bedside by increasing the number of clinical trials supported to help kids sooner.



Our fundraising strategy is focused on committing \$25 million over the next five years. By FY2023 our goal is to be at a stage where we can invest more than \$7.5 million annually. While we were impacted by a slowdown in spending during the past year, we continued to reset our fundraising mix and reduce reliance on telemarketing.

Extensive data analysis supports our push into more efficient and sustainable digital fundraising channels in order to drive greater funds into research, and we are proud to report our raffle program contributed only 25 per cent of total income this financial year versus 41 per cent the previous year.

We also report strong increases in our sustainable regular giving program, the successful launch of a major giving program and a 17 per cent increase in income generated through partnerships with the business community. We are greatly encouraged by these wins along with our donation margin which has improved from 71 per cent to 76 per cent.

Operationally, we have invested in our capacity with a \$150,000 increase in staff offset by reducing fundraising costs by \$740,000 compared to previous year. The increase in employee costs is aligned with our strategic focus to increase marketing and fundraising through digital and community channels.

We wish to recognise the expertise provided by every member of our Research Advisory Committee and Board of Directors, all of whom generously volunteer their time to ensure we accomplish our mission.

We're grateful for the ongoing support of our many stakeholders who stand with us against childhood cancer. Thank you to all the children and families who inspire us, along with our passionate corporate partners, foundations, donors, fundraisers, volunteers, interns and staff - you give both of us the greatest confidence in achieving our goals.

Owen Finegan CHIEF EXECUTIVE OFFICER

Adrian Fisk CHAIR OF THE BOARD



LEFT: A HANDFUL OF THE MANY MEMORIES WE'VE COLLECTED OVER THE PAST QUARTER CENTURY. HERE'S HOPING WE'RE NOT NEEDED IN ANOTHER 25.

#### **OUR BOARD**

Our Board of Directors is responsible for The Kids' Cancer Project overall performance and compliance, providing strategic direction, effective governance and leadership.



#### Adrian Fisk ACA, Mec (Chair)

Adrian is a partner at KPMG and has lead its Financial Services, Risk and Finance practices. He has extensive experience in the professional and financial services industries working with some of the largest companies on the ASX. Adrian is a member of the Institute of Chartered Accountants. He became involved with The Kids' Cancer Project after his son Aidan was diagnosed with a brain tumour at age five. Aidan is now in high school.



#### Nigel Everard CPA, BCom, Grad Cert (Mgmt), MBA (Deputy Chair)

Nigel is Director Operations Oceania at one of the largest inflight global catering companies. Prior to this he was the CFO of a leading Australian quick service restaurant business. Throughout his 20-year career, he has held senior positions in operations, general management, finance, strategy and business improvement. Nigel has been deployed in Asia and Europe working in various industries including automotive, aviation and the not-for-profit sector.



#### Col Reynolds OAM (Founder)

Col's contribution to the lives of children with cancer was officially recognised with an Order of Australia in 2000. Before founding the charity, Col was a tourist coach driver. He dedicated 30 years of his life to his profession, during which time he looked after many high profile clients including US Secret Service agents and members of the Papal visit of Pope John Paul II.



#### Simmone Reynolds BCom

Simmone is a founding member of The Kids' Cancer Project Board and is currently employed with the Australian Defence Force as a Communications Officer. Earlier in her career, Simmone spent nine years working in the fast moving consumer goods sector holding positions in marketing, national account management and category development for blue chip multinationals Unilever Australasia and Nestlé.



#### Richard Caldow BCom (Finance and Accounting)

Richard has worked as a stockbroker, corporate finance and funds management advisor since 1992. Prior to this he worked in chartered accounting with roles at Ernst & Young and Arthur Andersen. Richard's son Archie was diagnosed with high-risk neuroblastoma at just three years of age. Archie is now living with cancer and attending primary school.



#### Sue Anderson BBus, EBMA

Sue is Founder and Director of Retail Capabilities and Co Squared. Her specialty lies in designing service experience and innovation practices to support the retail property and broad business sectors in Australia as well as offshore. Sue discovered the importance of research into childhood cancer when her daughter Audrey was diagnosed with an inoperable brain tumour at age five. Audrey is now a confident 'tween' who loves school.



#### Doug Cunningham BCom, MBA

Doug is currently the Managing Director at Kimberley-Clark ANZ. Prior to this he enjoyed almost three decades at Johnson & Johnson in various roles across Asia Pacific, North America and Africa. He has extensive experience managing global retailers and building capability with large organisations. After losing his five-and-a-half-year-old son Murray to brain cancer, Doug became determined to donate his time and business experience to finding cures through scientific based research.



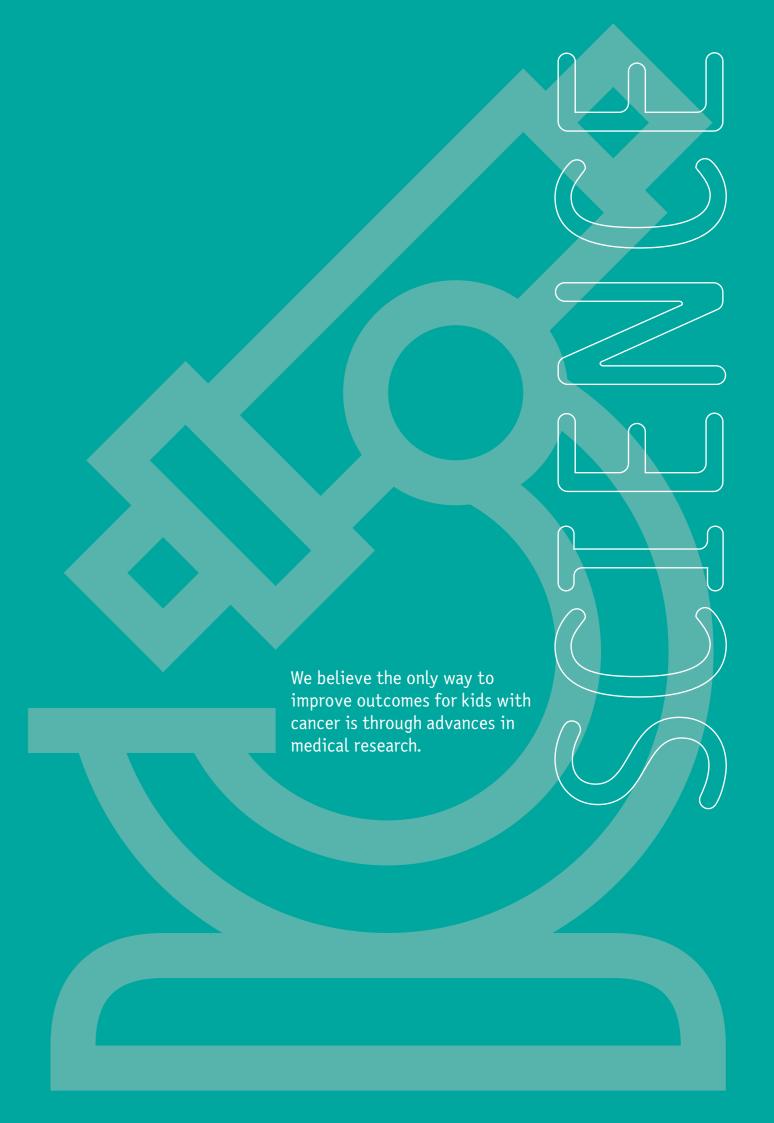
#### **Debra Singh**

Debra is the Group CEO Household Goods for Greenlit Brands overseeing Fantastic Furniture, Plush, OMF and Freedom, and is also an Executive Director on the Board. She has more than 30 years' experience in General Management Retail Operations, Organisational Design, Human Resources and Change Management. Prior to this, Debra had a career with Woolworths during which she was the first female to lead a trading division. Debra is also a member of Chief Executive Women (CEW).



#### Cathryn Prowse

Cathryn is a law partner at Colin Biggers & Paisley practising both insurance and employment law. She is in the 2018 and 2019 editions of The Best Lawyers in Australia in the field of insurance law for her work acting on behalf of professionals and entities facing negligence claims. While in the employment space, she acts for employers in unfair dismissal, general protection, discrimination, OH&S and other workplace-related claims.









studies funded



studies funded

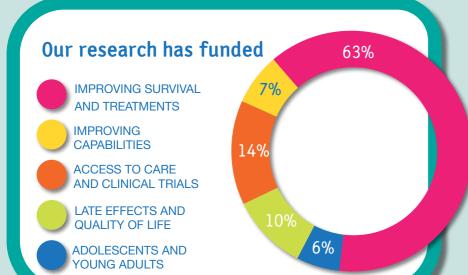
## Our projects investigated

- A VARIETY OF CANCERS
- **ACUTE LYMPHOBLASTIC** LEUKAEMIA (ALL)
- ACUTE MYELOID LEUKAEMIA

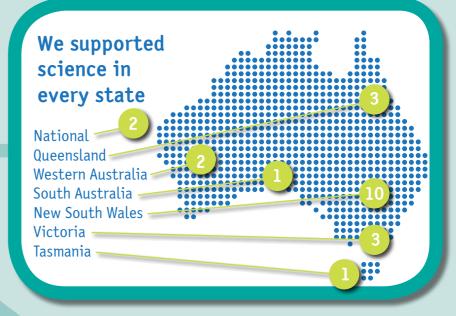
- NEUROBLASTOMA
- MEDULLOBLASTOMA
- OSTEOSARCOMA
- DIFFUSE INTRINSIC PONTINE GLIOMA (DIPG)

**TOTAL RESEARCH FUNDED** 

FY2019







**OVER THE PAST** 15 YEARS, WE **HAVE DONATED NEARLY** 

TO CHILDHOOD CANCER RESEARCH

We funded institutions

**UNSW** Australia

QIMR Berghofer Medical Research Institute

La Trobe University

The Children's Hospital at Westmead

Peter MacCallum Cancer Centre

Children's Cancer Institute

The Institute of Molecular Bioscience

Sydney Children's Hospital, Randwick

**ANZCHOG** 

Telethon Kids Institute

Royal Hobart Hospital

**UQ** Diamantina Institute

Kids Cancer Alliance

Murdoch Children's Research Institute

Women's and Children's Hospital, Adelaide

Garvan Institute of Medical Research









**BLOOD CANCER STUDIES** 

**BRAIN CANCER** 

**STUDIES** 

**CANCER** STUDY

**SOLID TUMOUR STUDIES** 

**CONCERNING ALL CANCERS** 





#### **NEW PROJECTS**

In FY2019, The Kids' Cancer Project continued funding 16 projects and in addition awarded grants to six new projects to help our most vulnerable children. Here we introduce those scientists.



"The Kids' Cancer Project is supporting a lot of vital, exciting, innovative work. They're helping researchers to move quickly and aggressively to pursue new ideas that we hope are going to make a real difference."



MicroRNA drugs for the treatment of neuroblastoma

Associate Professor Alex Swarbrick Garvan Institute of Medical Research "None of this research can take place without funding. It helps us to monitor the study, make sure we are doing it safely and confirm all the trial sites are compliant."





"Research funding from fundraising organisations provides an invaluable resource for both clinical and laboratory research. The Kids' Cancer Project does a great job providing crucial help to promote our work."



IntReAll-HR
Associate Professor Tamas Reversz
Women's and Children's Hospital, Adelaide





"Our aim is to take the findings from our lab into the clinic, and that's why this funding is so important. The work is highly sophisticated, and the ultimate goal is to improve the lives of children with cancer."



Using targeted chemotherapies to reduce intensity of radiotherapy in medulloblastoma Dr Nick Gottardo
Telethon Kids Institute



Ch in Di

Understanding the genetic basis of chemotherapy-induced cardiomyopathy in paediatric oncology survivors
Dr Rachel Conyers
Murdoch Children's Research Institute

"This work will enable the therapeutic targeting of every medulloblastoma, not just a subset, leading to more powerful clinical trials and ultimately more effective treatment options."



New therapies for incurable paediatric brain tumours

Professor Brandon Wainwright Institute of Molecular Bioscience, University of Queensland



THE KIDS' CANCER PROJECT

ANNUAL REPORT 2019 9



### **OUR FOCUS**

The Kids' Cancer Project supports bold scientific research that has the greatest chance of clinical success. A thorough peer review process is undertaken to ensure the best studies are funded.

but our funding policy is as easy as 🔼 🤭 🕻



## (A) is for advocacy

We want to make kids' cancer research a priority. We are committed to raising awareness of the issues faced by families, building support and providing real solutions for kids with cancer.



## is for bench

Laboratory research is the starting point to better understand childhood cancer. We support the type of pioneering thinking that will translate into new therapies to thwart this deadly disease.



is for clinic We are dedicated to ensuring discoveries at the lab bench are progressed into actual treatments as quickly as possible so that every child diagnosed has the best chance of living and living well.

## THE FUNDING APPLICATION PROCESS

Each March, The Kids' Cancer Project invites applications for research grants.

> Submissions detail the aim of the planned study specifying how it will assist in finding cures for childhood cancer. Plans, key performance ndicators and milestones are also provided.

An expert Research Advisory Committee (RAC) independently reviews all submissions in May and score them against nine key requirements.

> The RAC present their recommendations to The Kids' Cancer Project Board who make the final decision on which studies are to be funded each financial year.

## **OUR**

## **RESEARCH ADVISORY** COMMITTEE

#### Associate Professor David Ziegler, (Chair) MBBS UNSW, MD/PhD UNSW, Dip Paed, FRACP

Paediatric Oncologist with expertise in neuro-oncology and special early phase clinical trials.

#### Dr Justine Stehn, PhD

Research scientist with academic and industry experience in translational cancer research.

#### Dr Andrew Moore MBBS, FRACP, PhD Paediatric Oncologist and Director of the Queensland Children's Tumour Bank.

Professor Jonathan G Izant, PhD International experience in biomedical research, business and non-profit leadership.

#### Professor Murray Norris, AM BSc ANU, MAppSc NSWIT, PhD UNSW

Awarded scientist who has dedicated 30 years of his life to kids' cancer research.

#### Dr Brenda Weigel, MD, MSc

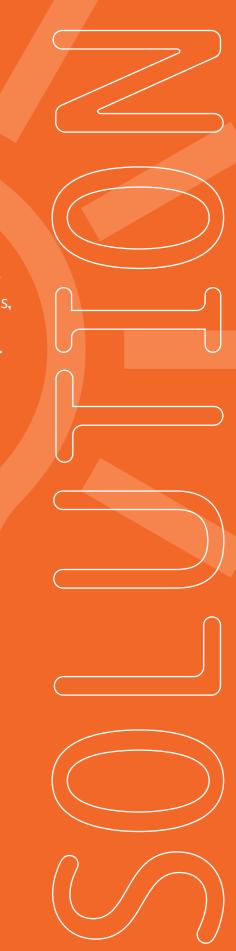
Director, Division of Pediatric Hematology/ Oncology, University of Minnesota.

#### Dr Timothy P Cripe, MD, PhD

Division Chief, Pediatric Hematology, Oncology and BMT, Nationwide Children's Hospital, Ohio.

THE RULES OF THE PEER REVIEW PROCESS STRICTLY STATE THAT RAC MEMBERS CANNOT REVIEW AND MAKE RECOMMENDATIONS ON THEIR OWN PROJECTS.

Our research priorities reflect our focus on finding better treatments, building research capabilities and supporting survivorship programs.







## **COMMUNITY FUNDRAISING** TOTAL RAISED: \$1.3 million



RUNNING



**SWIMMING** 

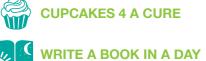




NETBALL



**SAILING** 





CRAZY HAIR + SOCK DAY



LOSE YOUR LOCKS



OTHER COMMUNITY

REGULAR GIVING TOTAL RAISED: \$1.2 million

**TOTAL NUMBER OF** REGULAR GIVERS

2,064 NEW REGULAR GIVERS FY2018 - 2019

\$22 AVERAGE MONTHLY GIFT

## **RAFFLES** TOTAL RAISED: \$2.1 million



736,081 TICKETS SOLD OVER 3 RAFFLES



**5 CARS GIVEN AWAY THANKS TO** SUTTONS CITY KIA



FY2019

**CLOSE TO 7,000 NEW SUPPORTERS** WITH INCREASING AVERAGE DOLLAR **VALUE OF TICKET PURCHASES** 

## TOTAL INCOME

FY2019

MILLION

16%

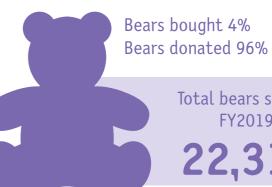
16%

12%

WHERE THE MONEY **COMES FROM** 

16%

**BEAR PROGRAM** TOTAL RAISED: \$1.4 million



Total bears sold in

FY2019 22,311

PARTNERSHIPS AND FOUNDATIONS TOTAL RAISED: \$957K





**GIFTS IN KIND** 

**ASSOCIATIONS** 

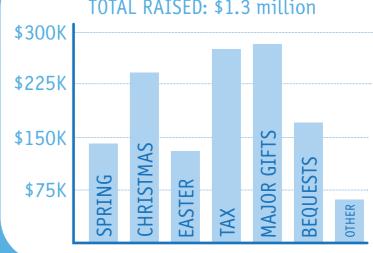


**SUPPORTERS** 

TRUSTS AND FOUNDATIONS



BEQUESTS, MAJOR GIFTS AND APPEALS TOTAL RAISED: \$1.3 million



25%













#### **PARTNERSHIPS**

The Kids' Cancer Project stands shoulder to shoulder with corporate citizens who choose to inspire hope in children diagnosed with cancer.

In FY2019, the charity extended gratitude to the commitment of long-term partners, all of whom demonstrate strong corporate social responsibility. Warm welcomes were extended to several new partners who assisted in supporting more childhood cancer research projects.

Aussie Industries, Sydney's most trusted skip bin provider, donated 50 cents for every kilometre travelled by a selection of their fleet and sponsored the charity's inaugural Golf Day.

In FY2019 The Kids' Cancer Project announced a partnership with RAMS Financial Group who provided an annual commitment to research and in-kind benefits.

Bromic Group were motivated to engage stakeholders to support science for kids with cancer in celebration of their 40-year anniversary. The company created a 'November to remember' with staff and customers alike involved in fundraising.

Smartways, a national medical logistics company, teamed up with The Kids' Cancer Project to deliver thousands of the charity's teddy bears to children in hospitals around the country saving significant operational costs and enabling even more funds to be invested in bold research.

Fast Automation announced their partnership by pledging an annual donation to support kids' cancer research with further fundraising support across events annually.

Lorraine Lea's month-long Party for Kids with Cancer® took place again around the nation. Independent stylists and party hosts came together with proceeds directed toward the ground-breaking Zero Childhood Cancer project.

To round out the year, Rondo Building Services, a global player in wall and ceiling systems, joined The Kids' Cancer Project family with a commitment to raise funds through a variety of activities across their Australian operations, which they did with outstanding success.

#### Associations in partnership

The Air Conditioning and Mechanical Contractors' Association (AMCA) was a proud supporter of The Kids' Cancer Project in FY2019 with money raised through their state offices, member donations and fundraisers held as part of golf days and an annual conference.

Meanwhile, the Facility Management Association (FMA) hosted golf days in each state, a Melbourne Cup Day luncheon in Sydney and an awards night in Melbourne.

#### **Trust and foundations**

Support from QBE Foundation continued for the seventh year with donations to research assisting to find better treatments specifically for children diagnosed with diffuse intrinsic pontine glioma and to provide access to clinical trials.

Thyne Reid Foundation embarked on a second year of aid to fund a staff member at The Kids' Cancer Project to manage campaigns and a new initiative, 'Project Kids'.

The Perpetual Foundation continued to support research into new therapies for incurable paediatric brain tumours conducted by Professor Brandon Wainwright at The University of Queensland Institute of Molecular Bioscience.

Throughout the financial year, the charity was also successful in receiving funding from PayPal Giving Fund, The McNally Foundation, AL & T Brorsen Family Foundation and Macquarie Group Foundation who generously matched the already impressive fundraising efforts of their staff.

IMAGES FROM TOP: AUSSIE INDUSTRIES SPONSORED THE CHARITY'S FIRST GOLF DAY, SMARTWAYS DELIVER BEARS TO KIDS IN HOSPITALS, LORRAINE LEA RAISED FUNDS THROUGH A MONTH-LONG PARTY, RONDO ARE COMMITTED TO SUPPORTING SCIENCE, FMA HELD GOLF DAYS IN EVERY STATE.

#### **THANK YOU**

Our valued partners share our vision of a future without childhood cancer.

#### **CORPORATE**

















#### **ASSOCIATIONS**







**MEDIA** 

**COMMUNITY** 

#### **SUPPORTERS**

















#### **GIFTS IN KIND**









#### TRUSTS AND FOUNDATIONS

























#### **GIVING THANKS**

The Kids' Cancer Project continued to demonstrate a commitment to organisational sustainability through targeted donation programs.

#### Regular giving

A major milestone for the regular giving program was achieved in FY2019. Income generated through various strategies and tactics totalled more than \$1.2 million – a year-on-year increase of 34 per cent. Consistent and reliable donor support enables the charity to make long-term commitments via this, the most efficient and sustainable form of giving.

#### Bear program

Sales and donations of The Kids' Cancer Project bears were up 48 per cent year-toyear. This growth is attributed to low-cost marketing tactics including discount offers, reactivating past customers and a new social media advertising strategy.

A delightful by-product of increased bear program activity on Facebook in FY2019 was the number of grateful recipients sharing their intimate stories. Whether heartwarming or heartbreaking, it was incredibly gratifying to learn the impact these furry friends have had, not only on children in hospital, but also their families.

In all, over 21,000 bears were donated to children in 67 hospitals around Australia. Income generated by this initiative totalled \$1.4 million of which more than \$220,000 was received in cash donations or rounding up on a purchase.

#### Quarterly appeals

In FY2019, The Kids' Cancer Project managed four seasonal appeals by executing traditional direct mail and digital marketing strategies that generated more than \$835,000 in donations.

The team refined data selection for campaigns to provide the greatest efficiencies and ensure relevant messaging was deployed to various donor segments.

A thorough review of mail house providers at the beginning of the financial year lead to a decision that not only enabled the charity to capitalise on greater economies but also more nimbly test new direct marketing plans.

The Kids' Cancer Project tested the use of SMS at the end of the 2019 Easter Appeal to non-respondents inviting donations. The trial of this low-cost high-yield marketing tactic was successful and has since been rolled out for all appeals.

#### Raffles

In partnership with telemarketer Apple Marketing Group, three raffle campaigns were carried out in FY2019 delivering income totalling \$2.1 million. A strategic change to the raffle program during this financial year was the transition from offering two midvalue major prizes to one high-value prize. That action meant an additional \$7,000 could go directly to scientific research.

#### Major gift

Donors to the charity were identified and personally invited by Owen Finegan to be one of a select group to join the Power Pledge, a program funding one research project over three-years. Major gifts brought in more than \$280,000 in donations representing a 470 per cent increase year-to-year.

LEFT, FROM TOP: OUR CUDDLY PALS DELIGHT KIDS AND PARENTS ALIKE, STARS OF OUR TAX APPEAL DR ALEX SWARBRICK AND NICHOLAS FORWOOD, RAFFLE WINNERS CELEBRATE, PROFESSOR BRANDON WAINWRIGHT AND TEAM WORKING ON THE POWER PLEDGE PROJECT.

#### **COMMUNITY SPIRIT**

A wide range of opportunities were coordinated in FY2019 to drive engagement and bring out the best in community groups and individuals.

#### Write a Book in a Day

This annual writing competition hit a new high in 2018. Just over \$330,000 was raised for research through entry fees and sponsorship representing a 49 per cent increase year-to-year. One thousand teams registered with the greatest growth coming from school groups (up 38 per cent on the year prior).

#### Cupcakes 4 a Cure

Arguably the most delicious fundraiser on The Kids' Cancer Project calendar, the participants in Cupcakes 4 a Cure cooked up more than \$60,000 in donations; a 16 per cent increase on the previous year.

#### Pirate Day in May

Right across the nation, children and office workers were encouraged to embrace their inner buccaneer and dress up like a pirate for Pirate Day in May in support of childhood brain cancer research. Previously known as Pirate Day Friday and held in June, The Kids' Cancer Project and The Pirate Ship Foundation aligned the filibuster fundraiser with Brain Cancer Action Month in 2019 and raised almost \$40,000, which was directed to the work of Dr Nick Gottardo at The Telethon Kids' Institute, WA.

#### Official charity partnerships

Billed as "Canberra's Toughest Cycling Event", Fitz's Challenge has chosen to support The Kids' Cancer Project for almost a decade. The event began in 1989 with just 37 riders but today welcomes over 1200 riders every October with many of them riding for a reason.

For the fifth year, Macquarie Bondi to Bronte Ocean Swim partnered with the charity. Swimmers braved the waves on Sunday 2 December raising thousands of dollars for childhood cancer research. Among their number was Nathan Rix, a childhood cancer survivor now in his thirties. He has participated in the event three times despite having had his right leg amputated above the knee after a relapse in 2005. To date, he has raised \$6,000 for his efforts.

Netball NSW and The Kids' Cancer Project joined forces for the ninth consecutive year in May and June colouring courts from Parkes in the state's central west to Norfolk Island in the Pacific Ocean to help children with cancer during Crazy Hair & Sock Days held right around the state.

Not to be outdone, NSW Rugby brought the colourful fundraiser to the field for the first time in FY2019 after officially being named a charity partner in FY2018 through the Positive Rugby Foundation.

#### Local legends

So many ordinary folk did extraordinary things during the last financial year. High teas and luncheons were popular with people baking a difference all around the country. The young and young at heart chose to lose their locks – sharing incredible before and after photos to raise enormous sums for science. People skimmed roads on scooters, traversed virtual terrain on treadmills and pushed and pulled themselves in Pilates classes all to make a difference for children diagnosed with cancer.

RIGHT, FROM TOP: WRITE A BOOK IN A DAY PARTICIPANTS, COMMUNITY GROUPS BAKE A DIFFERENCE, LITTLE PIRATES HELPING KIDS WITH BRAIN CANCER, SUNNY SKIES AT THE START OF THE BONDI TO BRONTE SWIM, NETBALLERS GO CRAZY FOR THE KIDS' CANCER PROJECT.













## **OUR IMPACT**

Since 2005, The Kids' Cancer Project has committed close to \$50 million in funding to reach the staunch goal of 100 per cent survival of every single child diagnosed.

In the last financial year, the charity stepped up the number of scientists and clinical trials supported in addition to making a significant pledge to the Morrison Government's Australian Brain Cancer Mission.





\$50 MILLION

Commitment to childhood cancer research

2005 - 2022



Government research collaboration



Zero

\$2.25 million contributed

2015 - 2022



Investment in biobanking projects

2011 - 2019



Our founder, Col Reynolds OAM, made a promise to never give up until a cure is found.

That is our ultimate aim.





# Josh's survival

THIS TIRELESS MUM HAS BEEN FIGHTING FOR HER 14-YEAR-OLD SON'S LIFE, AND WINNING, SINCE HE WAS FIVE WEEKS OLD.

"Josh showed

me that even

when there's only

a five per cent

chance, there is

always a positive

to be found."

How do you react when a respected doctor tells you your son only has a five per cent chance of survival? Alison remembers a lot of tears. Then her well-developed fight response kicked in.

"Dr Luciano Dalla-Pozza said the cancer had come back and had breached the blood and tissue barrier into Josh's brain," Alison recalls, her voice wracked with emotion.

"He said we could put Josh on medication to make him comfortable and he'll die in six to eight weeks. I said that until I'm told there's nothing at all that we can do, I will fight," said Alison.

Josh, now 14 years old, has been healthy for almost five years. It's the first period of his life that hasn't involved constant treatment and surgery.

#### WHERE IT BEGAN

When Josh was five weeks old, Alison was looking at photos and noticed a golden reflection coming from his left eye. Specialists discovered a tumour the size of a 50-cent piece and as thick as two coins. It was retinoblastoma, a rare form of cancer that forms, typically in infants, in the light-sensing area at the back of the eye.

Josh's left eye was removed when he was nine weeks old. Six months later tumours were found in his right eye. It took five years of chemotherapy, laser treatment, cryotherapy and radiation to save it. After two years of remission, a cancerous, golf-ball sized lump developed in his neck, and later a mass at the base of his skull which specialists eventually identified as another different rare cancer.

Seemingly endless years of intensive chemotherapy followed, with positivity and hope crushed along the way.

Finally came the conversation with Dr Dalla-Pozza.

"Five per cent was enough for us," Alison said. "Josh went straight into intensive chemotherapy then a stem cell transplant. He was so sick. I have photos of him that are just horrible. When he was asleep, he looked like he was dead. He had ulcers from his mouth and right through his digestive tract. One day he coughed up the lining of his oesophagus."

#### **DEFYING THE ODDS**

Josh took that slim chance of survival and ran with it. He's been free of cancer for almost half a decade and only needs testing twice a year.

"The sad thing is, it didn't have to be this way for him," Alison said.

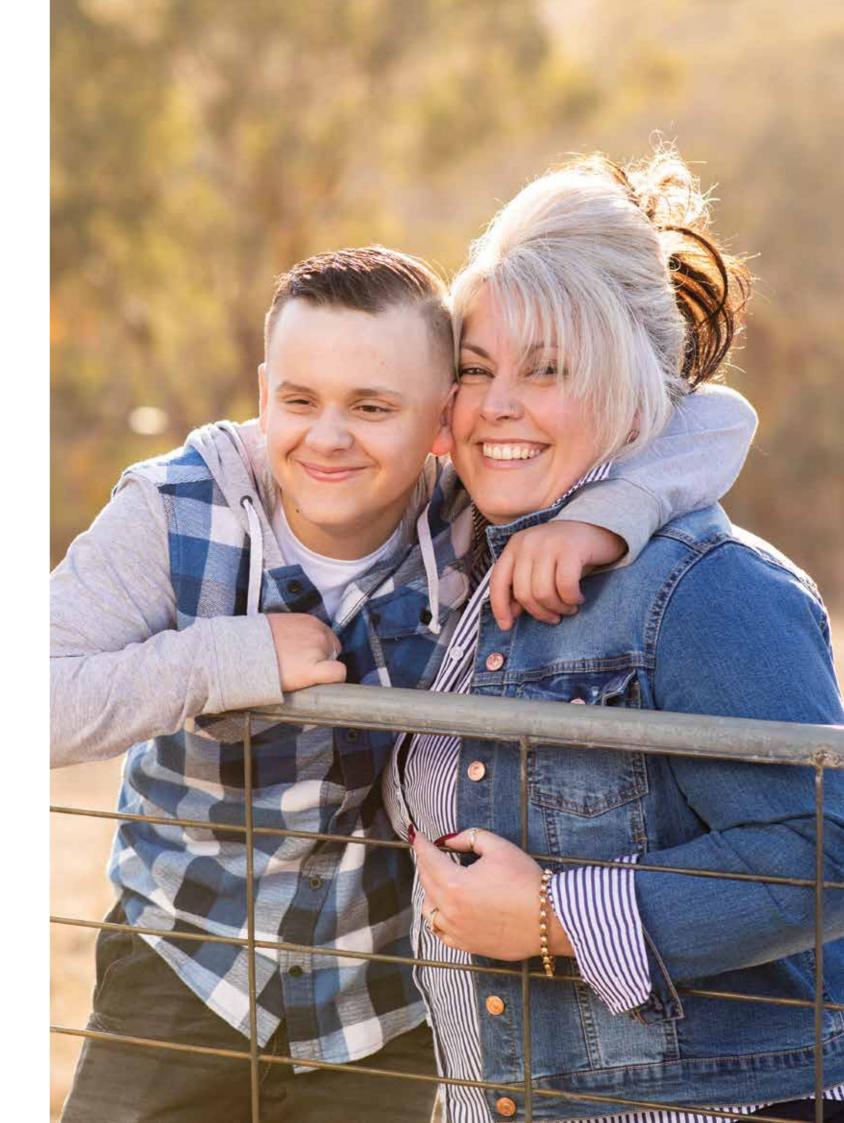
"With retinoblastoma they can now test in utero and can induce the baby earlier, meaning treatment can be started early so the eye can be saved."

Researchers are doing vital work to understand how and why cancers develop in children, including rare forms such as those that Josh has suffered. In fact, Josh's case has been discussed at major medical conferences and written in academic journals to educate specialists around the globe.

#### **ACCENT THE POSITIVES**

"Josh is only a teenager, but he has shown doctors that there are unique ways to treat rare cancers, and that is a positive from his long journey so far," said Alison.

"How did I get through it? Actually, I don't know. I never looked backwards and always stayed very positive. I ignored trivial things. Josh showed me that even when there's only a five per cent chance, there is always a positive to be found."













# Pippa's Christmas story

PIPPA WAS DIAGNOSED WITH ACUTE LYMPHOBLASTIC LEUKAEMIA ON 24 DECEMBER 2015, YET THE MEMORY IS STILL SO FRESH FOR HER MUM, YVETTE. "It all started with fatigue, really bad fatigue, and high temperatures," Yvette said. "I was actually so worried I took her to the hospital. But after looking her over, they sent us home thinking it was only a virus or urinary tract infection."

Like so many of us at the end of the year, the Launceston mum of three girls was racing to get through a massive to-do list. It was now Christmas Eve and the last chance to get a Santa photo. So, when Pippa woke up with a blood nose, it was just another thing they would need to work through.

"I remember getting the girls down to the shopping centre and putting Pip on Santa's knee," said Yvette. "I had to wipe the blood from her nose between shots - it just didn't stop all day."

"I knew it wasn't right, but the hospital had assured me she only had a virus, so I kept on pushing to get everything done so we could get to my in-laws that night for dinner."

#### THE DIAGNOSIS

After Christmas Eve dinner, which Pippa slept through, Dave and Yvette decided to try to get strong antibiotics from the hospital that would see her through the public holidays.

Yvette stayed at home to put seven-year-old Georgia and four-year-old Alexis to bed and stuff Santa sacks for the following morning. At 11.30pm, the phone rang. It was Dave. He was crying.

"You have to get here right now," he said. "They think she has leukaemia."

While Pippa was having the first of many blood transfusions, her anxious parents grappled with the logistics of travelling to Royal Hobart Hospital, a 30-minute flight away, for urgent treatment.

"At 8am the staff told me it was time to go to the airport," said Yvette. "Leaving so quickly meant I couldn't see my other girls on Christmas Day. I didn't end up seeing them for several days."

#### SIDE EFFECTS OF TREATMENT

Along with disfiguring bloating and frightening fits of anger, Pippa would lose her hair and be prone to diarrhea and vomiting as side effects of her treatment. Any high temperatures would necessitate an urgent dash to Emergency.

"The changes that took place in her body came on so dramatically, Pip didn't know how to support her own weight," recalled Yvette.

After a month of intensive treatment in Hobart, the family returned home where Pippa had

weekly intravenous chemotherapy that eventually went down to a monthly maintenance dose.

Life went on that way for 27 months until Pippa finished treatment in March 2018 when she had her port removed. For now, she only has monthly finger pricks. Regular oncology appointments will continue until she's 18.

#### LIVING IN THE PRESENT

"We had no choice but to sign her life away at the time to save her," Yvette said trying to recall the daunting list of long-term and late effects they were told Pippa might suffer as a result of her treatment. There is one she can't forget.

"I remember them saying that she'd have a big chance of getting a secondary cancer later in life," said Yvette. "I'm trying to live each day happily and not dwell on what we've been through. There's no point worrying about the what ifs."

"I just hope that in five to ten years' time, things will be different for another child. Ideally, childhood cancer will not even exist." "I just hope that in five to ten years' time, things will be different for another child. Ideally, childhood cancer will not even exist."

CLOCKWISE FROM TOP RIGHT:
THE HARMEY FAMILY ENJOY
SOME QUALITY TIME, THE
CHRISTMAS PHOTO TAKEN
HOURS BEFORE PIPPA'S
DIAGNOSIS, AND CUDDLES
FOR A FAVOURITE FRIEND.
IMAGE CREDIT: TRACY VAGG

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# Behind the cheeky smile

IN A VIDEO RECORDED IN AUGUST 2018, 10-YEAR-OLD **ALEC IS LAUGHING AND JOKING WITH HIS ONCOLOGIST, BUT JUST MONTHS EARLIER, THIS SWEET BOY TOLD HIS** PARENTS HE'D BE BETTER OFF DEAD.

It was March 2017. Alec and his identical twin Troy were getting very excited about going on their first big family holiday ever with mum Shirley

Shirley, keen to avoid any hiccups on the much-anticipated six-week trip to Shanghai and Seattle, took the brothers for a dental check-up as their adult front teeth were breaking through.

"After examining Alec, the dentist told me to cancel our holiday," said Shirley.
"He saw a lump on his soft palette that hadn't been there at the boys' last appointment a few months before."

"A barrage of tests showed some kind of a tumour behind his cheek bone between his jaw and skull," said dad, Peter. "But because of the location, doctors couldn't say for certain what it was."

A 13-hour surgery scheduled for the following May to get rid of "Larry the Lump", as Alec called it, revealed a rare childhood cancer known as Ewing's Sarcoma.

"The news was shocking," said Shirley, fighting back the tears. "All I could do

"It was heart wrenching," said Peter. "We had no idea what lay ahead of us. no understanding of what cancer really was and what toxic drugs were going to be pumped into our little boy's

#### **TOXICITY OF TREATMENT**

A couple of weeks after the operation, a grueling nine-month treatment program including chemotherapy and radiation was scheduled to ensure Alec was cancer free.

Pain, nausea from the chemo and complete ulceration of his mouth from the radiotherapy meant Alec lost almost five kilos despite being fed through a naso-gastric tube. His immunity was also incredibly low and at one point, he contracted life-

threatening Sepsis.

"It really affected his personality.
I'll never forget the day he told us, 'I'd be better off dead'," Peter said, his voice cracking with uncharacteristic emotion.

Today, the whole family are glad that all Alec needs is regular scans to ensure he remains cancer free, especially his twin brother Troy who missed their special friendship

of us, no understanding of what cancer really was and what toxic drugs were going to be pumped into our little boy's body."

"We had no idea what lay ahead



It was 1 September 2017 and the first day of Childhood Cancer Awareness Month. The Kids' Cancer Project founder, Col Reynolds was at The Children's Hospital at Westmead to see Alec's oncologist, Dr Luciano Dalla-Pozza and present him with thousands of pledges collected from people all over Australia.

"A nurse told us about Col and his bus, so I took Alec outside to check it out," said Peter.

As soon as Col saw Alec, he stopped all the formalities to personally give his solemn promise to never give up until kinder, more effective treatments were available for kids like him.

Later, when Alec was asked if he would like to be in a video with Dr Dalla-Pozza to help kids with cancer he didn't hesitate to say

"It was a positive outcome from what had been a dark. horrible period in his life," said Peter. "The research has to happen. Ten years ago, Alec wouldn't have survived. In another ten years, we hope his type of cancer won't even be an issue."











#### **FACTS ABOUT CHILDHOOD CANCER**

Each year, 300,000 families around the world hear the harrowing news, "Your child has cancer". Help us raise awareness by sharing these startling facts.

1. Childhood cancer is not the same as adult cancer.

Cancer in children is not strongly linked to lifestyle or environmental risk factors. The majority of childhood cancers remain poorly understood and the causes are unknown.

- 2. Childhood cancer is the numer one disease killer of Australian children. Cancer is the second leading cause of death overall (following injuries) in children aged 1-14.
- 3. Every two minutes a child is diagnosed with cancer somewhere in the world. That's 300,000 kids around the globe every year.
- 4. Cancer incidence among Australian children and adolescents is higher in boys. On average per year, 567 boys and 453 girls are diagnosed.
- 5. The average age of a child diagnosed with cancer is six.

But you don't have to be a child to be diagnosed with the disease; infants and pre-schoolers as well as adolescents and young adults (AYAs) can be affected by childhood cancer.

- 6. The most common kids' cancer in Australia is acute lymphoblastic leukaemia (ALL). ALL is followed by brain cancer and non-Hodgkin lymphomas diagnosed in children 0-14 years.
- 7. Three children and adolescents in Australia die of cancer each week.

The death of a child has a devastating effect on families and entire communities.

8. Forty per cent of deaths result from tumours of the central nervous system which include brain cancer.

Leukaemia accounts for 23 per cent of deaths and neuroblastoma eleven per cent.

9. In the 1950s, cancer was nearly always a death sentence for a child.

Today, eight out of ten kids diagnosed with cancer will survive. However, these improvements are not across all types. For instance, brain cancer survival has stagnated at 50 per cent.

10. In 80 per cent of children with cancer, the cancer has already spread to other areas of the body by the time it is diagnosed.

That's why so many children diagnosed with cancer need to begin treatment immediately.

11. Much of what we know about treating adult cancers has been learned from kids' cancer research.

Some aspects of cancer treatment today, such as combination therapy, are able to be traced to paediatric cancer research.

12. There are over a dozen types of childhood cancer and hundreds of subtypes.

The more rare types, when added together, account for about 30 per cent of cancers in children and adolescents. But because so few children are diagnosed with each type, it's very difficult to do research on these cancers.

13. Because of the treatments they had as kids, more than 99 per cent of childhood cancer survivors will have a chronic health problem and 96 per cent will have severe or life-threatening conditions.

By the time they are 50, survivors of childhood cancer experience about five severe or life-threatening chronic health conditions on average.



