

Australian Lions Childhood Cancer Research Foundation (ALCCRF) -

10 years of 'Serving & Success' to help give every child with cancer a chance at a healthy life.

At the 57th national convention in Melbourne in May 2009, the Multiple District Convention passed a notice of motion to establish a Lions category "A" Project to be known as Australian Lions Childhood Cancer Research Foundation (ALCCRF). Dr Joe Collins was appointed the Founding Chairman along with other appointed Trustees including PIP Barry Palmer AO, PCC Bob Buckley, PDG Jim Ede, PCC Lindsay Marsden, PDG Ross Wood and PDG John Thorpe, ALCCRF's current Chairman since 2016.

ALCCRF set about creating a clear vision, objectives and it forged a sustainable way of operating nationally with unwavering support from Lions, Lioness and Leo Cubs. Additionally, enormous effort was spent in developing strong and innovative relationships with the leading childhood cancer research institutions and their research leaders in Australia. This effort has seen much achieved in the past 10 years in Australia and beyond and unequivocally has saved the lives of many kids who otherwise would not be with us today.

The ALCCRF brand, as exemplified in the images below, has always been focused on Lions long history of supporting childhood cancer sufferers, the young boys and girls who despite their suffering remained full of joy and hope. We knew from day one that Lions working together could and will continue to play our part in one day achieving our vision of 100% survival for kids with cancer.



Our Vision: 100% survival for kids with cancer



ALCCRF is building its networks so we can assist Australian Lions help kids with cancer



"Every child deserves a chance at a healthy life"

Some of the outcomes that that ALCCF has achieved with the help of thousands of Lions include:

- **ALCCRF has become one of the largest regular donors to childhood cancer research in Australia.**



We have donated in excess of \$4.0million dollars to directly fund childhood cancer research with an additional \$2.7million provided by LCIF to ALCCRF's Genome Sequencing initiative with the Garvan Institute of Medical Research.

These seed funds of nearly \$7.0million have been a catalyst to enable research institutions to leverage donated funds to capture an additional \$30-40million value in traditionally funded research grants which otherwise would not have occurred.

- **ALCCRF funded the first ever national 'Phase 2' clinical trial in Neuroblastoma in 2011.**



ALCCRF Initially donated \$100,000 then immediately set out to raise a further \$200,000 which we did with the help of Lions clubs across Australia in less than 12 months to enable the trial to be completed. This money kicked off the clinical trial of two novel drugs, (Interferon & Valproate) in kids suffering from Neuroblastoma.

The clinical trial, was coordinated by Prof Glen Marshall and it involved Children's Hospitals in Australia and New Zealand. During the Gold Week conducted by Channel 9 in Sydney in June 2012 Dr David said "this trial offers real hope for patients who have and who otherwise would be on palliative care. Our goal is part of the standard treatment for children newly with neuroblastoma around the world".



Telethon Ziegler relapsed to make it diagnosed

- **In June 2012 ALCCRF agreed to become a funding partner with the Royal Children's Hospital Melbourne (RCH).**



The RCH had undertaken a worldwide recruitment process to find a new 'Head of Solid Tumours' research stream. The standard of candidates was very high with strong international interest because ALCCRF was able to ensure there would be dedicated research time, a research support package along with the reputation of the RCH to attract an outstanding clinician researcher who took up their posting in 2013.

ALCCRFs committed \$120,000 per annum for 3 years to fund the 'Head of 'Solid Tumours' research position.

- **In early 2013 ALCCRF formed an amazing relationship with Ava Bell who has become an ALCCRF ambassador and our "Little Start of Hope":**



Ava who was just six-months-old when her mum, Jenny, heard her screaming, and ran into her to find Ava struggling to breathe, her eyes rolling into the back of her head and her lips turning blue. Doctors originally thought Ava was choking on something, but after an examination failed to find any obstruction in her airway, she was put on a ventilator in the Intensive Care Unit. Ava was then sent for scans which, much to the shock of her

distraught parents revealed a five-and-a-half-centimetre cancerous tumour called a neuroblastoma in her chest and abdomen. The cancer had also spread to her bones.

Ava is now 8 years old and in 2017 spoke on the stage of the Chicago Centenary International Convention in front of 28,000 Lions to ask for their help for other kids

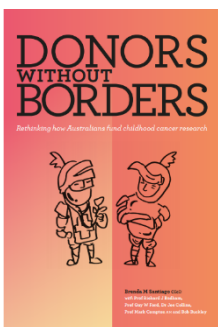


suffering from cancer by supporting ALCCRF's initiative to undertake Genome Sequencing of Kids with Cancer around the world.

- **ALCCRF is proud to have set up a sustainable Foundation for Lions** to undertake the following activities:
 - **'Ambassadors'** ALCCRF's Ambassadors, who are mostly Lions members, promote the foundations work within Districts, Clubs and the community at large.
 - **Information Kit.** Provided to each DGE and District Chairperson to help educate everyone on how Lions can help make a difference to the lives of kids with cancer.
 - **ALCCRF Promotional DVDs.** In the past 10 years ALCCRF had made 5 videos, the first of which was released in 2013 at the Canberra Convention, another was played to 28,000 Lions at the Centenary Convention in Chicago in 2017 and the last played at the Geelong Convention in 2019 to promote the work we do to help for kids suffering from Cancer.
 - **Lions Biggest BBQ** The Biggest BBQ continues to be a significant fundraiser for the Foundation, and we are committed to increasing Club participation in this area. ALCCRF writes to all clubs in Australia inviting them to participate. On average we have over 400 clubs registering for this iconic Lions tradition with 100% of monies donated going to research.
 - **ALCCRF / Lions Rose.** Following discussions and the signing of an agreement with Treloar Roses, ALCCRF launched the Lions Rose at the MD 201 Perth Convention in 2012.
 - **ALCCRF Awards schemes.** Including Neil William Awards, the Barry Palmer Fellowship and the ALCCRF Fellowship.
 - **ALCCRF Newsletters** continue to be distributed to all District Governors and Cabinet Secretaries to send to members. Newsletters are also posted on the ALCCRF website.
- **ALCCRF Research Projects:** In addition to the first ever three-year Neuroblastoma trial a further two trials were funded in 2013 and 2014. The first was further research into Neuroblastoma at Sydney Children's Hospital using a drug known as DFMO, not previously used in the treatment of childhood cancer. The second trial the NSW/QLD Rural Childhood Cancer Management Program. This vital pilot project used a select group of regional centres across New South Wales and Queensland to audit the current system of cancer management for patients with side effects of their treatment and devise a safer protocol for any treating doctor in a peripheral centre to provide the correct treatment program for patients. ALCCRF has also funded Scholarships and Fellowships for talented young researchers, because we believe these young people need to be supported to ensure they either stay here in Australia or can come back to here to help keep our national research effort at the forefront of global childhood cancer research.



- **In 2013 ALCCRF initiated a research project with the Macquarie University's Graduate School of Management titled: "Donors without Borders - Rethinking how Australians fund childhood cancer research".** This ground-breaking work was completed and released nationally in January 2015. The detailed report demystifies childhood cancers and cancer research. It explains the roles of a myriad of players who are involved in both childhood cancer research and philanthropy. It also promotes a philosophy which has become the hallmark of ALCCRF's success in building collaborative partnerships with Australia's leading research organisation around the country.



This work simplified the language, similarities and differences between research scientists and philanthropists and made it abundantly clear that, if we want to beat childhood cancers and give every child a chance at a healthy life, then we must:

- **Educate** ourselves about childhood cancers;
- **Collaborate** with other likeminded organisations; and
- **Donate** to the best high impact research, wherever it is being done.

It was this work that led Professor John Mattick, himself a world-renowned researcher, to lend his support and that of the Gavan Institute's world class Genome Sequencing resources to the campaign, to be the first country in the works to sequence the genome of kids with high risk cancers.

- **ALCCRF initiated a campaign in 2015 which was announced at the 2016 National Convention to commence the world's first Genome Sequencing project for Kids with high risk cancers.** Hundreds of Australian children with high-risk cancer



have had access to new genome sequencing technologies that has guided their treatment, following the project approval by LCI and LCIF in mid-2016. This was the first time in the history of Lions that it had funded a project of this kind. A total of \$4.0million was donated to this project including \$2.7million directly from LCIF and an additional \$1.3 million from ALCCRF working with Lions clubs around Australia. The Project,

which was first announced at the Lions Australia 2016 National Convention in Echuca, Victoria following more than 18 months of work and lobbying by ALCCRF. This project has already saved the lives of a number of kids who Clinicians had said would definitely otherwise have died.

- **ALCCRF has been a catalyst to showcase Lions Australia internationally.** In 2016 ALCCRF invited International President, Dr Yamada Jitsuhiro to visit Australia. This visit in September 2016 was the first visit to Australia by an International President, other than our own PIP Barry Palmer AO, in many years.



Since this first visit each successive President and a number of Vice Presidents, including the current Intentional President Gudrun Yngvadottir and Vice President, Jung Yul Choi have also come to Australia to visit the Lions Kids Cancer Genome Project.

PIP Barry Palmer AO attributes the reason that Childhood Cancer is one of the 5 Humanitarian Pillars that LCI and LCIF is focused on internationally through the work of Australian Lions. Highlights from Lions in Australia go as far back as 1975 when Lions founded the Leukaemia Foundation, followed by the Lions Cord Blood Banks and then the work outlined above which has been championed by ALCCRF.

Australian Lions have been passionate leaders in supporting childhood cancer sufferers and we will continue to advocate that *"Every child deserves the chance at a healthy life"*



The stage of the 2017 Centenary Convention in Chicago which had 28,000 Lions in attendance

