



Australian Lions

# Childhood Cancer Research Foundation



“We believe every child deserves  
a chance  
at a healthy life”

District Chairperson Guide  
2021 - 2022



Australian Lions

# Childhood Cancer Research Foundation



- **Our Vision**  
100 % survival for kids with cancer
- **Our Mission**  
Prevent kids with cancer dying by raising funds nationally and donating these funds to the best high impact childhood cancer research conducted right across Australia.

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## Who to Contact?

Click on the name to email – full contact details on [Trustee Contact Page](#)

Your Coordinator	<a href="#">Christine Duyvestyn</a>	<a href="mailto:acduyvestyn@gmail.com">acduyvestyn@gmail.com</a>
<a href="#">ALCCRF Awards</a>	<a href="#">Sandy Royal</a>	<a href="mailto:sandy.royal@adam.com.au">sandy.royal@adam.com.au</a>
<a href="#">Awards/Awards Credits</a>	<a href="#">Treasurer Ron Skeen</a>	<a href="mailto:rjskeen@optusnet.com.au">rjskeen@optusnet.com.au</a>
<a href="#">Biggest BBQ</a>	<a href="#">Peter Lamb</a>	<a href="mailto:peterlambman@gmail.com">peterlambman@gmail.com</a>
<a href="#">BBQ Aprons, Pens</a>	<a href="#">Vice Chair Tony Roney</a>	<a href="mailto:anthonyvincentroney@bigpond.com">anthonyvincentroney@bigpond.com</a>
<a href="#">Lions Longest Coin Line</a>	<a href="#">Appointee Kate Moore</a>	<a href="mailto:moz1965@hotmail.com">moz1965@hotmail.com</a>
<a href="#">Marketing (Brochures, Banners)</a>	<a href="#">Gary Parker</a>	<a href="mailto:gjparker@aapt.net.au">gjparker@aapt.net.au</a>
<a href="#">Newsletter</a>	<a href="#">Sandy Royal</a>	<a href="mailto:sandy.royal@adam.com.au">sandy.royal@adam.com.au</a>
<a href="#">Palmer Fellows</a>	<a href="#">Tony Roney</a>	<a href="mailto:anthonyvincentroney@bigpond.com">anthonyvincentroney@bigpond.com</a>
<a href="#">Website, Publicity</a>	<a href="#">Kerry Kilpatrick</a>	<a href="mailto:kerrykilpatrick@yahoo.com.au">kerrykilpatrick@yahoo.com.au</a>



## About Us



Every year in Australia more than 950 children and adolescents are diagnosed with cancer

Three Australian children die from cancer every week

Among childhood illnesses, cancer remains the most common cause of death in Australia.

Lions Australia wants to turn this around. We need your help so that:

- We can help give every child a chance at a healthy life; and
- 100% survival becomes a reality



## Our Goals

- Lions Australia through ALCCRF has become one of Australia's most important philanthropic donors to childhood cancer research.
- Fundraising by Lions will be directed to personalised medicine programs for children with high-risk or relapsed cancer.

ALCCRF will grow the number of Clubs that support the foundation research to at least 1000 clubs ALCCRF will grow and maintain its fundraising to \$1,000,000 per annum.

## Operating Principles

ALCCRF will;

- Operate always with the intent to add value to the overall work and brand of Lions Australia and within the Lions Clubs International Global Service
- Establish a national network of Lions clubs and administrative support that can meaningfully contribute and support its Vision, Mission and Goals;
- Have Deductible Gift Recipient Status (DGR) from the Australian Taxation Office so that we can issue tax deductible receipts to donors;
- Require accountability and reporting from recipients of ALCCRF funding;
- Seek out and utilise existing electronic and other sources of data, communication processes and business systems. We will work with and leverage from the extensive data, networks and systems already available in Lions Australia; and
- Minimise operating costs of the foundation to maximise the funds donated to
- achieve its Vision and Mission.

□

## Important Facts

- Over the last few decades global medical research efforts have seen survival rates from childhood cancer improve dramatically.
- Today, more than 8 out of 10 children in Australia survive their disease and the number of adults who are survivors of childhood cancer has increased to 1 in 900.
- Lions Australia has been supporting childhood cancer at least as far back as 1976.
- Lions formalised its support for childhood cancer research over 17 years ago establishing the Lions Cord Blood & Childhood Cancer Research Appeal.
- Since then Lions has raised more than \$10 million for childhood cancer research.
- The establishment of the Australian Lions Childhood Cancer Research Foundation (ALCCRF) has taken Lions commitment to focus on achieving 100% survival for kids with cancer to a new level.

## Why Focus Lions Support on Research?

- When ALCCRF was established as a Category A project of Lions Australia the intent was that the Foundation had as its prime focus to fund the best scientific and clinical research in Australia. This was embodied in the motion endorsed by Delegates at the 2009 MD Convention in Melbourne and in the Trust Deed that underpins the Foundations establishment and operations.
- Australian researchers are amongst the best in the world and are playing a significant role in the treatment of and research into childhood cancer.
- Networks are now established to share research both nationally and internationally.
- All funds raised by Lions, Lioness and LEO Clubs and donated to ALCCRF are directed to high impact scientific and clinical research available in Australia for personalised medicine programs for children with high-risk or relapsed cancer - Without ALCCRF much of this research simply would not happen.
- In the past, the Foundation has used several advisory bodies to assist Trustees to determine which research projects should be assisted and funded. Whilst advice received has enabled ALCCRF to fund very worthwhile and important studies it may not have considered research being conducted in all hospitals and independent medical research institutions in Australia.
- Trustees entered a partnership with Macquarie (University) Graduate School of Management (MGSM) who consulted with the top 20-30 Key Opinion Leaders in Paediatric Oncology across Australia to establish clear priorities for childhood cancer research. This ensures that Lions funding is directed to the highest priority childhood cancer research. The report from MGSM, released in late 2014, was also made available to other philanthropic groups, universities and government.
- ALL future submissions for research funding will be measured against the report to determine if it meets the priority for funding.

□

## Research currently funded

Currently ALCCRF is funding significant research trials in Australia

- **Supporting a Senior Biobank Specialist for the Hudson/Monash Paediatric Precision Medicine Program and Genomic Annotation of Rare Childhood Solid Tumours**  
**Funding Cost:** \$450,000 over 3 years commencing September 1<sup>st</sup> 2019
  
- **Telethon Kids Institute -**  
Paediatric Immunotherapy Program for high risk kids with cancer  
**Funding Cost;** \$1.05 million over 3 years commencing January 1<sup>st</sup> 2020
  
- **Cancer Australia** (Federal Govt. Dept. of Health) co-funding solid tumour research on \$ for \$ basis with other partners
  - Dr Andrew Care: Macquarie University  
Engineering a protein nanocage for targeted ionophoric-copper therapy
  - Dr Pouya Faridi Monash University  
Novel targets for paediatric brain tumour immunotherapy
  - Dr Jessica Buck Telethon Kids Institute  
Exploiting and enhancing brain-resident immune cells for the treatment of paediatric brain stem glioma (DIPG)
  
- All research projects are funded in agreed instalments and are subject to regular review and assessment by Trustees.
- Lions have supported childhood cancer research in one way or another for over 40 years and now with our efforts focused through ALCCRF we can be proud that we are truly making a difference in the fight towards our vision of 100% survival for all children with childhood cancer.

More information and reports can be found on our website –

<https://alccrf.lions.org.au/>



Australian Government

Cancer Australia





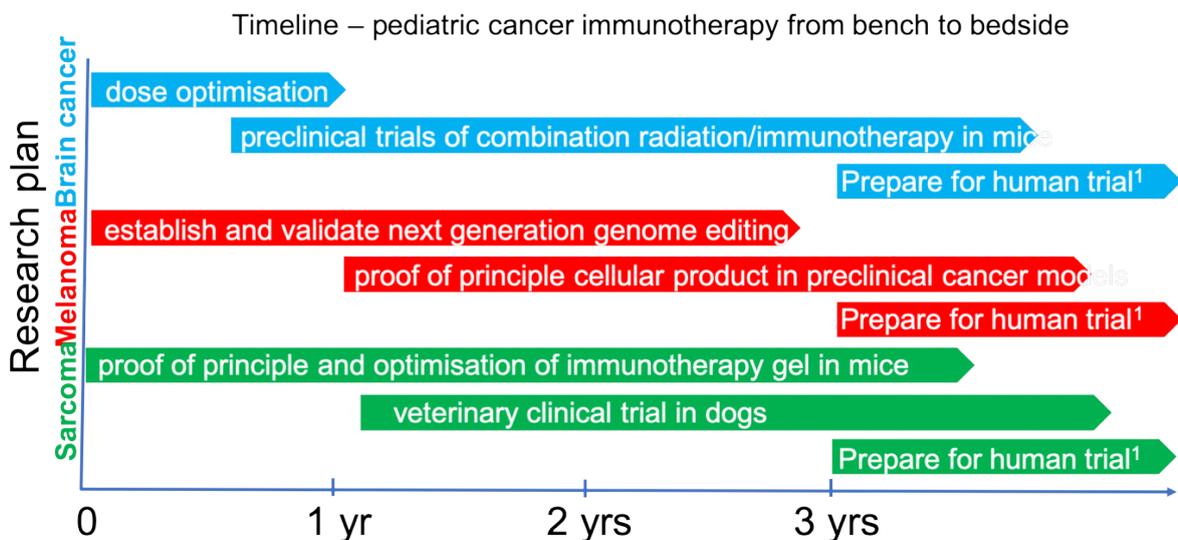
## PAEDIATRIC CANCER IMMUNOTHERAPY FOR AUSTRALIA

### The need for immunotherapy for children

As ALCCRF would be aware, although childhood cancer cure rates have significantly increased over the past few decades, cancer remains the leading cause of death by disease in children. For many children, current treatments simply cannot cure their cancer. Sadly, those children who manage to survive their disease are left with detrimental life-long side effects, an unavoidable consequence of the current dosages of radiotherapy and chemotherapy. These harsh treatments are not only toxic to cancer cells, but also to the developing bodies and brains of children. Too often, the cure is almost as terrible as the disease.

Financial support from the Australian Lions Childhood Cancer Research Foundation (ALCCRF) will significantly advance and accelerate Telethon Kids Cancer Centre research to develop new immunotherapy treatments for paediatric sarcoma, medulloblastoma, melanoma, leukemia and other childhood cancers. Our focus is not only on discovery and evaluation of new therapeutical approaches but the rapid translation of those findings into new treatments that can reach the clinic and cure children.

Our researchers at the Telethon Kids Cancer Centre are pioneering cancer immunotherapy for children in Australia and are undertaking the only comprehensive program of its type in Australia.



<sup>1</sup>File IP, liaise with CRO for clinical grade materials, partner with VC for commercialization of the product, start design clinical trial in humans.

## Hudson Monash Paediatric Precision Medicine (HMPPM) Program

Rajithri (Dilru) Habarakada is the Australian Lions Childhood Cancer Research Foundation (ALCCRF) Biobank Specialist for the Hudson Monash Paediatric Precision Medicine (HMPPM) Program, in a maternity leave appointment.



In the collaborative HMPPM Program, scientists at Hudson Institute have established a 'Living Biobank' of childhood brain/CNS and solid cancers - including living organoids or lab-grown 'mini-tumours' - to trial and develop targeted treatments and improve clinical outcomes, survival rates and quality of life (limiting side-effects) for childhood cancer patients. As the ALCCRF Biobank Specialist, Dilru brings technical and operational knowledge to the development of the 'Living Biobank' platform at Hudson Institute and oversees all biobanking activities for the HMPPM Program. She also coordinates the Monash Children's Cancer Biobank led by Dr Peter Downie at Monash Children's Hospital.

Dilru completed a Bachelor of Biomedical Science and Psychology at Victoria University, then joined the HMPPM Program in 2021. She is currently undertaking a Masters of Cancer Sciences at the University of Melbourne to expand her knowledge in the areas of quality of research, cancer care, prevention and education.

## Novel targets for paediatric brain tumour immunotherapy

Dr Pouya Faridi Monash University

### Project Synopsis and Aims

Every year more than 170 Australian children are diagnosed with brain cancer. Diffuse Intrinsic Pontine Glioma (DIPG) is the most aggressive childhood brainstem tumour with no cure and median survival of only nine months post-diagnosis. Cancer vaccination is an emerging approach for untreatable cancers. The fundamental mechanism of the immune system for combating cancer is recognition of peptides exclusively presented on the tumour surface in complex with Human Leukocyte Antigen (HLA) molecules. However, selecting the right antigen and corresponding peptide-HLA complex (p-HLA) is the most challenging part of any vaccination strategy.



Generation and presentation of p-HLAs is a dynamic process within the cell. Therefore, intra- and extracellular factors can affect the composition of the immunopeptidome (the array of peptides presented by a given HLA molecule). In the case of DIPG, two mechanisms can generate or potentiate DIPG tumour exclusive p-HLAs: 1) As the only, and first line of management of DIPG, radiotherapy not only causes tumour cell death, releasing antigen for subsequent presentation by professional antigen-presenting cells and the initiation of further immune responses; but can also increase the expression of p-HLA on the surface of resistant tumour cells rendering them more susceptible to immune attack. 2) Methylation/mutation of the Histone3 gene are epigenetic signatures of DIPG. Recently, it has been discovered that these two signatures turn on the expression of particular endogenous retroviruses (ERV) in DIPG tumours. These viral antigens can also form novel targets of immune responses.

This project received further support through Cancer Australia's [Priority-driven Collaborative Cancer Research Scheme](#).

## Exploiting and enhancing brain-resident immune cells for the treatment of paediatric brain stem glioma (DIPG)

Dr Jessica Buck Telethon Kids Institute



DIPG is a fatal brain cancer that affects children, with no effective treatments. This research project is proposing a new combination of treatments targeting the immune system in the brain to treat DIPG. First, the cancer cells will be labelled with a "flag" so the immune system can see them. The investigator will then use another treatment to block the "don't eat me" signals on the cancer cells, so the immune system can attack the cancer. This new treatment could help save the lives of children with DIPG, who currently have a 0% chance of survival.

### Project Synopsis and Aims

Diffuse intrinsic pontine glioma (DIPG, or diffuse midline glioma) is a fatal, highly aggressive brain tumour affecting children. Less than 10% of children diagnosed with DIPG are still alive 2 years later, highlighting an urgent need for improved treatments.

The problem: Due to the location of the tumour in a vital part of the brain, surgery is not an option in the treatment of DIPG. Currently, the only treatment shown to prolong survival is radiotherapy, however this only offers palliative relief of symptoms. No chemotherapy treatments for DIPG currently exist, and previous chemotherapy clinical trials using a single drug have also been unsuccessful. Novel combination treatments are desperately needed.

Major finding: Therapies targeting the immune system have shown remarkable clinical outcomes in other cancers, but not in brain tumours. This is in part because the brain has a specialised immune system less reliant on T cells, which are the target of most immunotherapy approaches. Instead, cells called microglia are the most common immune cell of the brain, comprising up to 50% of some brain tumours. Brain tumour cells, including DIPG cells, avoid microglial attack by expressing a "don't eat me" signal called CD47. Blocking CD47 with a therapeutic antibody (a-CD47) results in remarkable disease control by increasing the ability of microglia to recognise and kill brain cancer cells.

This project received further support through Cancer Australia's [Priority-driven Collaborative Cancer Research Scheme](#).

## Cage fighting" with neuroblastoma



Dr Andrew Care: Macquarie University  
Engineering a protein nanocage for targeted  
ionophoric-copper therapy

Neuroblastoma is the most common solid tumour in young children, yet no significant progress has been made over the last 10 years to improve survival, which for those diagnosed with high-risk neuroblastoma is less than 50 per cent. Unfortunately, current treatments also have severe lifelong side effects that diminish the emotional well-being and social integration of survivors.

There is hope. Recently, copper has been shown to drive neuroblastoma growth, proliferation and metastasis. Dr Care's project aims to engineer an innovative natural nanoparticle (called a 'Protein Nanocage') that can selectively target and disrupt copper levels inside neuroblastoma, causing tumour cell death. This nanotechnology is specifically designed to have high efficacy while minimising the harmful impacts treatment can have on healthy growing cells, improving patient outcomes.

This project received further support through Cancer Australia's [Priority-driven Collaborative Cancer Research Scheme](#).



**Australian Government**

**Cancer Australia**

**TELETHON  
KIDS  
INSTITUTE**

**HUDSON**  
INSTITUTE OF MEDICAL RESEARCH

**Murdoch  
Children's  
Hospital**

**Our New Children's  
Hospital**

# Australian Lions Longest Coin Line



Lay it on the Line for Childhood Cancer and help us break the Guinness World Record in 2022

Get your District Clubs motivated by encouraging them to organise a coin line with their Club, School, Sporting Group or workplace. Money raised will go towards funding projects of the Australian Lions Childhood Cancer Research Foundation



Group or workplace. Money raised will go towards funding projects of the Australian Lions Childhood Cancer Research Foundation

The Coin Line project will be organised by a committee of Lions in District N3 chaired by PDG Keith Stewart. Stay up to date on our Facebook Page and share events of participation [Australian lions longest coin line](#)



More information is available at [alccrf.lions.org.au/events](http://alccrf.lions.org.au/events)

Or Contact Board Appointee Katherine Moore

[moz1965@hotmail.com](mailto:moz1965@hotmail.com)



LAYING IT ON THE LINE FOR CHILDHOOD CANCER



Australian Lions Longest Coin Line



## Lions Biggest BBQ

Lions Biggest BBQ is an annual fundraising event undertaken by many of the 1,200 Clubs across the country. Each year the BBQ can take place at any time throughout the year when it best suits your Club. Competition for BBQ concludes June 30<sup>th</sup>) Funds raised will be used to help achieve ALCCRF's mission to prevent kids with cancer dying by raising funds nationally and donating these funds to the best scientific and clinical childhood cancer research conducted right across Australia.

"It never ceases to amaze me what Aussies can do when they work together" said Peter Lamb, Trustee of ALCCRF. Who would have thought the good old Aussie Barbie could have been used to help Lions raise over \$10 million for childhood cancer research? Well that's what we have done but the job's not over. More than 800 Australian kids are diagnosed every year with various forms of childhood cancer and unfortunately, we are still seeing around three kids dying every week.

Many of the 1,200 Lions Australia clubs will hold barbeques during the year to raise funds for medical research into the causes and prevention of, and to find a cure for, childhood cancer. Why Lions have been passionately supporting childhood cancer research since 1996 is very simple. "We believe every child deserves the chance at a healthy life" said Peter Lamb.



## Barry J Palmer Fellowship

The Australian Lions Childhood Cancer Research Foundation (ALCCRF) has established the Barry J Palmer Fellowship to recognise outstanding support for the Foundation's vision of 100% survival for kids with cancer.

Recipients of this fellowship will be recognised for being one of our ambassadors helping kids fulfill their right to a healthy life. The fellowship can be awarded to Lions and non-Lions who have dedicated time and effort on behalf of childhood cancer research.

In 2009 at MD201's Melbourne National Convention, current Lions International President (2013-2014) Barry Palmer of Berowra, NSW, Australia, was instrumental in approving the establishment of the ALCCRF. Barry was a founding trustee of the ALCCRF and remains an enthusiastic supporter of its work, which undertakes to fund impactful world class research into childhood cancers.

Applications for the Barry J Palmer fellowship can be found on the Foundation's website.

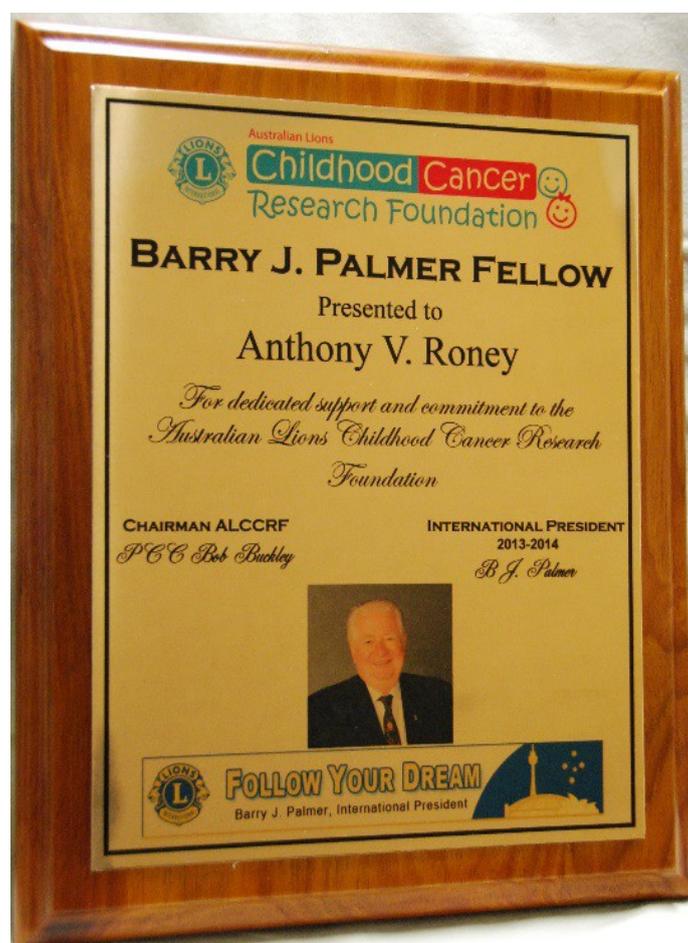
For further information contact:

Trustee PCC Toney Roney  
anthonyvincentronney@bigpond.com

Mob: 0409 829 511

<http://alccrf.lions.org.au>

The beautiful timber used to mount this fellowship is Acaciamelanoxyton, commonly known as the Australian Blackwood. The Acacia species is native in eastern Australia with this particular specimen coming from Tasmania. Tasmania is often referred to as the "Island of Inspiration", owing to its large and relatively unspoiled natural environment.



# ALCCRF Awards

## ALCCRF Awards

The Australian Lions Childhood Cancer Research Foundation (ALCCRF) Awards were established to recognise support for the Foundation's vision of 100% survival for kids with cancer



**Gold \$1,000**  
Gold Plate on Walnut Base  
225 x 300mm



**Silver \$500**  
Silver Plate on Walnut Base  
200 x 250mm



**Bronze \$250**  
Brass Plate on Walnut Base  
175 x 225mm

All awards come with an ALCCRF lapel pin in Gold, Silver or Bronze.

# Our Newsletters & Communications

Our Newsletters are published 4 times each year in August, November, February and May and have proven to be an excellent way to communicate to Lions Members and our supporter base outside Lions on the progress of the Foundation, forthcoming events and showcasing activities from Clubs and District Chairmen across the Country

Regular Direct Communications to District Chairmen via Video Conference and to Clubs should keep all members aware of all upcoming activities of the Foundation

Regular Contributions to the Australian Lion Magazine are also part of our overall plan



# Our Website & Facebook Page



Our Website has information on all our activities, including our Fundraisers such as the Lions Biggest BBQ, where our Funding grants go, Awareness program - The Lions Rose, our latest newsletters, awards programs - Barry Palmer Fellow, ALCCRF Fellowship and Neil Williams awards. Information on all these programs is available as a download, including order forms for all the awards

Also, included on the website is a "donate now" button to enable all individuals to make a direct donation via Credit Card if they wish but the facility is there mainly to encourage the public to support our Foundation - As we now have Deductible Gift Recipient (DGR Status) – any donation is a gift and any amount over \$2 is tax deductible

Our Facebook page is updated regularly with photos etc. that are made available to the editor

Our Web address is <http://alccrf.lions.org.au/>

Our Facebook page is at <https://www.facebook.com/> - enter ALCCRF in "search"

# Registered Charity

ALCCRF is a recognised a a registered charity and endorsed by ACNC and the ATO – the logo can now be seen on our publications



# Promotional Video



Video can be viewed on our website

Professor Terrance Johns, Head of the Telethon Kids Cancer Centre, said that as one of Australia's only comprehensive, paediatric cancer immunotherapy centre, the Telethon Kids Cancer Centre was making its mark on medical research.



Professor Terrance Johns  
Head, Telethon Kids Cancer Centre



Dr Raelene Endersby  
Co-Head, Brain Tumour Research

"The Centre is on a mission to prevent paediatric disease and improve the wellbeing of children with cancer. We bring together leading researchers and oncologists focused on developing therapies that destroy cancer cells, while minimising the side effects to children's short- and long-term health," Professor Johns said.

The \$1.05 millions of funding to Telethon Kids Institute builds on the Australian Lions Childhood Cancer Research Foundation's long history in supporting leading and innovative research into childhood cancer.



Dr Rishi Kotecha  
Consultant Paediatric Oncologist, Perth Children's Hospital

# District Conventions

Trustees have pledged support for District Chairmen at their Conventions by providing them with;

- Access to a pull up banner
- A set of Display Posters
- A Horizontal Banner
- An assortment of order forms
- Information brochures

This support will continue in future years



Lions Kids Cancer Genome Project

*"We believe every child deserves a chance at a healthy life"*



# MD Convention

Trustees are always available to discuss and answer any questions at the Multiple District Conventions - seen here is our stand at Geelong



# Merchandise

Although not a major part of our fundraising, we do have items available for Sale at MD and District Conventions and/or throughout the year from our District Chairmen - new items may be added from time to time while some disappear



**Stylish Pens which include the ALCCRF Logo \$5 each**

**all enquiries for pens or aprons contact Trustee Tony Roney**

[anthonyvincentroney@bigpond.com](mailto:anthonyvincentroney@bigpond.com)



**Lions Biggest BBQ Apron - just \$20 including postage**

**Released for Xmas 2013 this attractive Xmas Pin sold for \$5**

**A new design is released each year and they are sure to be valued by collectors  
The 2021 version will be available in October - all enquiries to PDG Austin Lanphier [ausandtoni@bigpond.com](mailto:ausandtoni@bigpond.com)**



# The Lions Rose



The original idea for a Lions Rose started in 2000 at the Lions club where Wilhem Kordes (Kordes Roses - Germany) is a member. The Club wanted to start an activity for the Friedensdorf Oberhausen (peace village Oberhausen) where heavily injured children from war torn countries are taken care of with the aim that they go back to their countries after successful recovery.

After receiving approval from LCI, the rose was officially named in a ceremony at the Kordes gardens in Sparrieshoop. It then went on to be released for sale in 2002. In the same year, it also received an award due to its great disease resistance.

Since its release in 2002, the Lions Rose has raised over AUD \$384,000 for Oberhausen and is one of Kordes most successful rose releases to date.

This rose has been hugely popular overseas and has raised a great deal of awareness of our Lions Organisation throughout the world.

Based in Portland Victoria, Treloar Roses (Australia's Leading Supplier of rose bushes) have been supplying bare root rose plants / bushes Australia-Wide for more than 45 years.

Following discussions and the signing of an agreement between the Foundation and Treloar Roses, ALCCRF will receive \$1 for each rose plant sold anywhere in Australia from 2012 on.

We ask Clubs and their members to support this initiative by purchasing the rose and / or promoting in your local community. They make a great guest speaker gift in place of flowers or wine.

Roses can be ordered online [on the Treloar Roses website](#) for your convenience. Or you can call them on 1300 044 85