

**WE BELIEVE
EVERY CHILD
DESERVES A CHANCE
AT A HEALTHY LIFE**



Australian Lions

**Childhood Cancer
Research Foundation**



**June 2018
Newsletter**

Hello to you all

A very big thank you to all for the support shown for our continued efforts raising funds to enable us to finalise our commitment to **The Lions Kids Cancer Genome project**. Our fund raising for the project is well on track, and a progress report is in this newsletter - we all know that we as Lions kick-started Whole Genome sequencing for high risk children with cancer resulting in more targeted and personalised treatment which is showing good signs of some success.

Also in the newsletter are pics from the MD Convention in Townsville which for the Foundation was a great success with all 9 Trustees putting in time at our display stands where they were kept very busy.

ALCCRF has finally gained DGR (Deductible Gift Recipient) status from the ATO which means we can finally offer tax deductible receipts for any personal donations at <https://alccrf.lions.org.au/> please help to spread the word

We can now also seek Corporate sponsorship and donations which has previously been offered but we have been unable to accept. At present Trustees are investigating a partnership with Cancer Australian (Federal Department of Health) in which they would match our donation dollar for dollar for approved high risk childhood cancer research

A committee of Mandurah Lions (W2) has commenced a new project to raise funds

"*JuLikeMyChops*" encourages men of all ages in Western Australia to grow 'Chops' throughout the month of June and receive sponsorship from family, friends, work mates and businesses they may work for. I wish every success to Lion Brook Arelette and his team for more information, what the project is all about check out the website at

<https://www.julikemychops.com.au/>



John Thorpe ALCCRF National

Chairman

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



Well-deserved reward for dedicated service



Lion Ron McLeod (Elmore Vale N3) 89 years of age celebrated 50 years of service on May 22nd - the exact date that he joined Newcastle Central in 1968. When the club closed in 2006 Ron transferred to Elmore Vale and commenced running the **Elmore Vale Coin Trail**. In that time, Ron and his team have raised and donated well over **\$60,000** for Childhood Cancer Research

Ron is pictured receiving a Palmer Fellow advanced pin from PIP Barry Palmer and a Palmer Fellow Platinum plaque from DG Glenn Byrne on behalf of Elmore Vale Lions. The pictures below show Ron and his team collecting spare coins



Report on Lions Kids Cancer Genome Project

(Genome Power) to Australian Lions Childhood Cancer

Research Foundation May 2018

By Dr Marie Dziadek, Dr Joe Collins



Background

The Lions Kids Cancer Genome Project (Genome Power), funded by the LCIF and ALCCRF, contributes whole genome sequencing (WGS) and analysis to the Zero Childhood Cancer (ZCC) program run by the Kids Cancer Centre, Sydney Children's Hospital, and Children's Cancer Institute (CCI). The WGS and informatics analysis are undertaken at the Garvan Institute of Medical Research, through the Kinghorn Centre for Clinical Genomics.

The WGS of a child's tumour aims to identify mutations and structural changes in the DNA (e.g. variants in genes, structural rearrangements) that are 'actionable', meaning there are drugs available that target such specific genetic alterations. Other laboratory assays are also performed at CCI and collaborating research centres in Melbourne which provide more information about the molecular changes in the tumours to help identify an appropriate treatment plan.

The WGS of DNA in the child's blood also aims to determine whether the child has inherent mutations that predispose them to developing cancer at an early age. This aspect contributes to a major research program at the Garvan Institute to identify the full range of inherited mutations associated with the development of childhood cancers.

Progress

Over the first year of the project (2016-2017) a pilot program was undertaken by ZCC and LKCGP to develop all the collection and processing of tumour and blood samples from children with high risk cancers in Sydney (Kids Cancer Centre, Sydney Children's Hospital, Randwick, and Children's Hospital, Westmead), and the methodologies to analyse these samples at Garvan and CCI. A process for assessing the clinical significance of genomic and other data was also developed as part of the pilot, with the establishment of a Multidisciplinary Tumour Board (MTB) that assesses the data from each child presented by the clinical and research teams and makes a recommendation to the clinician of possible treatment options based on the data. This pilot program, called TARGET, analysed samples from 59 patients and was instrumental in establishing high quality analysis in a time-frame suitable for decision-making by the paediatric oncologists. Some children in this pilot program received a new treatment plan that resulted from genomic and other information.

The pilot program has now ceased and the actual nation-wide precision medicine program, called PRISM (PRecISion) Medicine for Paediatric Oncology Patients), was launched towards the end of 2017 and now involves all 8 children's oncology centres across Australia. Seven of the sites have officially opened with Women's and Children's Hospital Adelaide to be opened soon (full local governance authorisation pending).

Since September 2017, 70 patients have been enrolled in PRISM, with an average of 9 new cases being enrolled each month. Approximately one third of enrolled children have a brain tumour, almost one third have sarcoma, and the remaining children have leukemia, lymphoma, neuroblastoma or other rare types of high risk aggressive cancers.

All patients have so far has WGS performed on their tumours and most have had other types of tests. To date 48 patients have been fully analysed and most of these have been presented to the MTB for recommendation on treatment options. Genetic changes were found in the majority of tumours and these changes led to a recommended alternative treatment of 21 patients to date. The PRISM program has been able to obtain access to a new drug from the USA for two of these patients, leading to a very significant slowdown in tumour growth for both children. Because the program has only been running for just over 6 months it is still too early to evaluate its impact, but the clinical and research staff are very excited by the early indications of good outcomes for some children considering these all had high risk cancers with poor prognosis.

In addition to the new treatment options resulting from PRISM, 12% of children in the pilot program (TARGET) were found to have known mutations in their blood DNA that have possibly predisposed them to developing the cancer in the first place. This type of information will be very important in the future for genetic screening of families at risk, enabling children and adults to be monitored frequently to pick up any developing tumours and remove and/or treat them at a very early stage when the chances of a full recovery are much higher.

Shave for Kid's Cancer!!



On the way to the MD Convention at Townsville, the Vanners Club decided that funds raised from nightly raffles, fines etc. would be donated to ALCCRF.

Mick Metcalf (Bathurst N4) made the bold statement that if the total reached \$1,500 he would have his beard shaved off!!

Pictured above at the ALCCRF display stand is **PDG Glenda McLeod (Tatura V5)** starting the Clip and at left beardless Mick a few minutes later.

With donations collected during the shave, the total well and truly exceeded the **\$1,500** - thank you Mick and all the members of the Vanners Club

The MD Lions Vanners Club is a mixed group of Lions who enjoy caravanning this great country. Every year the Australian Lions hold a Lions Convention in a capital city or large regional city. The Lions Vanners attend this Convention, but journey to it by a tour



Dear ALCCRF Trustees,

I have now commenced the third year of my PhD candidature and would like to thank you for your continuing support of our project "Genes underpinning predisposition to childhood cancer" and my PhD scholarship. This research study would not be possible without your funding.



My PhD project examines the DNA of childhood cancer patients that are suspected of a genetic contribution to their development of cancer. These include childhood cancer patients where there is a family history of malignancy or genetic disease, children who have developed cancer at least twice and/or siblings diagnosed with cancer. We have sequenced the germline DNA of over 70 childhood cancer patients, and have found over 20% of these children carry a variant in their DNA that may contribute to cancer development. We are continuing to analyse the data and prepare publications that will contribute to a greater understanding of the causes of childhood cancer. My results were presented at the International Symposium on Mutation in the Genome (Variant Detection) conference held in Spain in June 2017, and at the prestigious Grand Rounds at The Children's Hospital at Westmead in July 2017.

This study is challenging yet essential as genomic analysis is implemented into paediatric oncology clinics. I feel very fortunate to be able to dedicate my time to this work, and really believe the outcome will make a difference in the lives of those families tragically affected by childhood cancer.

Kind regards,

Dianne Sylvester

Lions Biggest BBQ 2018

Helping fight
kids cancer
for more than
ten years.



WIN! THIS OUTDOOR KITCHEN BBQ

Subject to availability at time of draw.
Otherwise, equivalent barbecue to be supplied.

St George Lions (N5) support significant community projects



St George Lions Club's Annual Charity Golf Day, with support from Club Rivers Riverwood, raised \$12,000 this month to support three Lions Projects. The projects are local and state, national and international in their focus showing the breadth of Lions projects, St George Lions president, John Craig said. The proceeds of the charity golf day, held at Beverley Park Golf Course on April 11, will see St George Lions donated \$4,000 to the Big Red Kidney Bus project, \$4000 to the Lions Kids Cancer Genome Project, and \$4000 to the Operation Smile project.

LC Brighton (C2) Sausage sizzle for ALCCRF Biggest BBQ



LC Launceston Riverside (T1)

\$15,000 Donation to Lions Kids Cancer Genome Project

T1 Trustee PCC
Tony Roney accepts
the cheque - one of
many generous
donations by the
Riverside Club



Leo Clubs Continue their support



Apsley Leos (Q3)
Club President Isaac
Parker hands over a
cheque for \$2,000 -
the proceeds of their
annual Trivia Night



Cathedral School Leos (Q2) held a sausage
sizzle recently for the Foundation

