

**We Believe**  
every child  
deserves a chance  
at a healthy life

May 2017 E-Newsletter



Hello Everyone - Fantastic to meet so many of you in Hobart we sincerely appreciate all you do for us, I hope you enjoy this issue

**Our Star of Hope Wins the hearts of Conventioneers in Hobart, Tasmania**

### The Lions Kids Cancer Genome Project

A major fundraising program aimed at funding the \$800,000 needed to complete the sequencing of 400 children so that they may receive precision targeted medicine and the more data that is collected the sooner children all around the world will benefit. Lions Clubs International has now included Paediatric Cancer in its Global Service Network going forward following the Centennial Celebration and the work of Australian Lions is recognised on the LCI website by a link to our Website [alccrf.lions.org.au](http://alccrf.lions.org.au)

### We need Your Help!

Ways you can help: -

- Hold a Biggest BBQ or other Fundraiser
- Make a Club donation
- Recognise a member of your Club or community by purchasing awards



Ava Bell with Dad Tony on stage at Wrest Point

Story and more pics on page 2

**Many Clubs have expressed confusion on where to direct their donations this should help**

#### Club Donations FAQ

Funds from Biggest BBQ

Club to send to Peter Lamb with return slip

Funds Raised by Clubs at events  
- eg. Gift Wrap, Coins for Kids

Club to send by cheque to PO Box 777 Belconnen  
ACT 2616

By direct credit to ALCCRF account - note  
Treasurer must be emailed deposit receipt

Fund Raising event organised by  
Club involving sponsorship eg. Fun Run

Use Genome Power website set up for the Club

## Our "Star of Hope" in Hobart

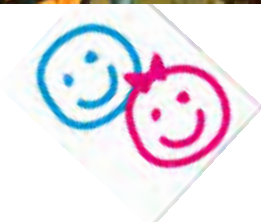
Ava Bell and her family were guests of the Foundation at the recent MD Convention in Hobart where Tony and Ava were on stage for a 20-minute presentation - Tony gave a very moving happy/sad speech of the traumatic experience they all three experienced as Ava underwent many rounds of surgery and chemotherapy.

Ava won the hearts of all Conventioneers when she thanked everyone for helping her and asked for help for sick children just like she was



Pictured above: Jen, Ava, Tony and Charlie

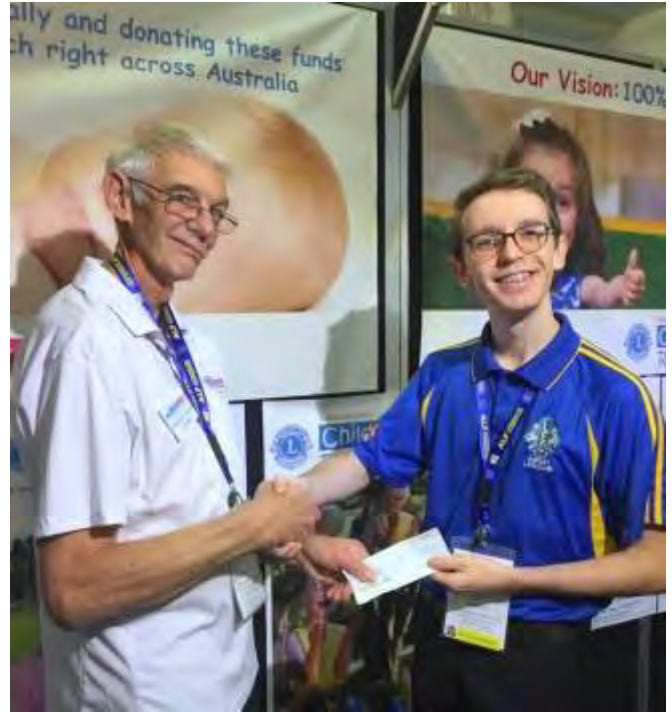
Ava loved going around all the display stands, especially the hearing dogs - picture below



## Leo Clubs continue Support

Apsley Leo Club (Q3) have been a regular supporter of the Foundation - a big thank you to all Club Members and especially Jesse Pascoe who presented a cheque for \$2,000.

A thank you also to Q Districts State Leo Coordinator Des Sawyer for his support



Pictured Leo Jesse Pascoe and ALCCRF Chairman John Thorpe

## ALCCRF Trustee Meeting

After a busy 4 days of Convention, a Trustees meeting followed on the Tuesday - a biannual face to face meeting, all others are by video link

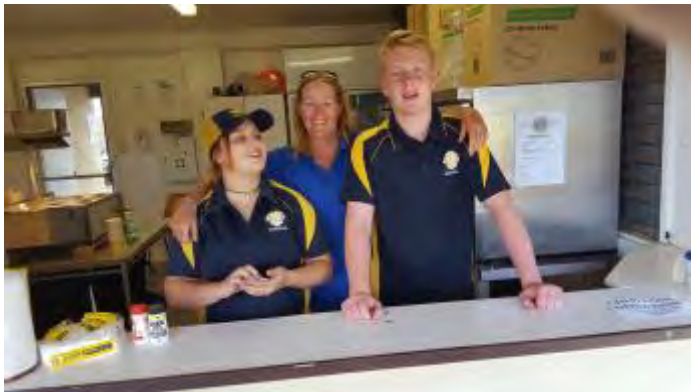


Pictured above, Trustees Ron Skeen, John McIntosh and Tony Roney

# Lions Biggest BBQ 2017

## Waroona Lions (W2)

"Great day at the Lion's Biggest BBQ moved this year from Centennial Park to Waroona Oval and it paid off as we had more people and were able to raise more money for the Australian Lions Children's Cancer Research Foundation. I'd like to thank the few Lions that did turn up to help, Mike Whitney, Dom Della - Franca, Dom Fiorenza, Ray Strachan, Louie Chiera, all ably led in the kitchen by Lynley Young, Phil "The Engine Driver" Turner and my partner in crime, who will now be known as Lisa "The Rock" Fry!! after having her head shaved at the event for The World's Biggest Shave for Leukaemia. BUT AN EVEN BIGGER "THANK YOU" GOES TO THE LEOS. Because there



were so few Lions, we honestly couldn't have done it without the Leos. The three Francos and Lincoln Hawke who helped us set up, Cashiers Extraordinaire, Ben McWilliams and Shiarna Ishiguchi (good to see the next Club Secretary and Vice President leading by example)



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

## The Lions Club of Mareeba (Q2)

has announced it will be holding the 2017 MSF Sugar Metrogaine to raise money for the Australian Lions Childhood Cancer Research Foundation.

The event to be held on Sunday the 18th June 2017 will allow people to get out, have some fun and get a bit of exercise. All money raised from registrations and the BBQ to be held will go to the Australian Lions Childhood Cancer Research Foundation. Tom Braes of Mareeba Lions said that it had been intended to join in the Lions Biggest BBQ with the Metrogaine so even if you don't go in the event you can support the Club's BBQ. As with last year the Metrogaine will have other activities including Graffiti Masterclass, Skate Park Comp, and Basketball competition.

Clubs, Associations, groups or individuals wishing to participate in the event should contact any Mareeba Lions Club member for further information. Visit the Facebook page or email lionsmba@gmail.com



<b>Progress Report:</b>	<b>Lions Kids Cancer Genome Project</b>
<b>Date:</b>	<b>30 April 2017</b>
<b>Prepared by:</b>	<b>Dr Marie Dziadek, Professor David Thomas, Dr Joe Collins</b>

## Background

The Lions Kids Cancer Genome Project (the Project) was formally initiated in September 2016.

The aims of the Project are to undertake whole genome sequencing (WGS) of tumour samples and matched normal DNA (germ-line) from 400 Australian children with high risk cancer over a three-year period. The genomic information will be utilised to assist clinicians in identifying targeted treatments for these children, as well as identifying genetic variants in their normal DNA that may have predisposed them to developing cancer at an early age.

The first Progress report was submitted to the Trustees of ALCCRF on 23 December 2016.

This second report provides an update of Project activities since 1 January 2017. The report covers updates on:

- genome sequence analysis of tumour samples to identify treatment strategies
- genome sequence analysis of children's blood samples for genetic risk analysis
- project governance
- national rollout of the Zero Childhood Cancer (ZCC) program
- media and marketing campaign

## Genome analysis of tumour samples

We have received tumour and blood samples from 35 children with high risk cancer from the Sydney Children's Hospital Network, for genome sequencing, and have used these samples to optimise all processes and procedures ahead of the national rollout of the program in mid-2017. The majority of patients recruited have had central nervous system (CNS) tumours (43%) followed by leukaemia/lymphoma and sarcoma. The LKCGP aims to achieve a 4-week turnaround time from receipt of sample to interpretation of the sequence data. Enabled by continued investment in personnel, automation and improved laboratory processes, the Kinghorn Centre for Clinical Genomics (KCCG) has introduced a high priority queue for clinically urgent samples such as those received for this program. Consequently, the turnaround time has reduced to an average of 7.5 days from sample to raw data, and 5.3 days from raw data to assessing data quality by the production bioinformatics team, and delivery to translational genomics team. A particular focus has been placed on the informatics analysis to identify genetic variants, to reduce this

from two additional weeks to a few days. The informatics team has developed a comprehensive germline and somatic cloud based analysis pipeline that can comprehensively interrogate the complexity of cancer genomes. A patient's genome can now be analysed in <3 days. Two of the major challenges with LKCGP are the integration with ZCC program, and communication with subject matter experts to interpret all the data. A popular business messaging application has been implemented that enables experts to collaboratively interpret WGS, RNA-Seq and Targeted-Seq data and prepare summaries for return of results to the Children's Cancer Institute (CCI). We have returned results to CCI for 7 cases from the first 35, which are summarised here:

- three patients with advanced leukaemia - in which the specific somatic mutations indicated potential treatment options
- one patient in which the genomic information indicated a different type of tumor that meant the current treatment was not effective and diagnosis and treatment needed to be re-assessed
- two patients with relapsed neuroblastoma where sequencing pointed to the enrolment of one patient onto an ALK inhibitor trial, and sensitivity to immunotherapy for the other.
- One patient with a glioma whose sequence suggested sensitivity to inhibitors developed to treat inherited ACVR1 mutations.

Thus, from the first 7 cases high-risk childhood cancer cases, we have identified new therapeutic targets or strategies in 5 patients, and supported the enrolment of a patient onto ALK inhibitor trial.

Genome analysis of germ-line DNA (blood) samples  
The germ-line of 22 of the 35 patients have been examined for deleterious variants in a target list of 157 genes linked to cancer risk and response to therapy. Across all cases, 65 rare missense, nonsense, or splice variants were found, of which six have been classed as having a severe effect on gene function. Five of 22 patients carried severe germ-line variants which should be considered by the Molecular Tumour Board or clinical geneticist for further consideration and potential return of results to the families. Three patients harboured variants with possible therapeutic relevance, and two patients carried dominant mutations associated with increased cancer risk.

## Project Governance

The first Steering Committee meeting of LKCGP, chaired by Dr Joe Collins, was held on 24 January 2017. Key actions from this meeting were to finalise a Collaboration Agreement between the Garvan Institute and the Children's Cancer Institute, and to develop a Data Access process for external researchers to gain access to LKCGP data for research purposes.

A Collaboration Agreement has been prepared that outlines the collaborative framework for the genome sequencing and other components of the Zero Childhood Cancer Program run through CCI. The draft agreement is currently being reviewed by the legal teams of the two institutes.

The Steering Committee determined that it would constitute the Data Access Committee for the project. An LKCGP Data Access application and Approval process has been established. Researchers from Roswell Park Cancer Institute, New York, have requested access to data for a specific study and this has been approved.

The second meeting of the Steering Committee is scheduled for 9 May.

## National Rollout

This Project is built on the infrastructure of the Zero Childhood Cancer Program (ZCCP), established at the Children's Cancer Institute. The ZCCP received A\$20M from the Australian Federal Government in November 2016, which will support the national rollout of the program eight children's hospitals across Australia. The rollout is now expected to be launched in July 2017.

The national rollout will be preceded by a roadshow to all the eight children's hospitals across to inform them of the ZCCP and the LKCGP and provide guidelines for clinicians and nursing staff.

## Media and marketing campaign to raise funds for LKCGP

The Garvan Research Foundation has teamed up with the ALCCRF to assist in the marketing of the Project and integrate fund-raising. Garvan engaged Public Relations consultants to develop specific branding for the Project, including a logo. This has led to the development of the Genome Power concept, with specific branding for the Lions project.



## Lions Biggest BBQ 2017

This year the 2017 Lions Biggest BBQ can take place any time between January and December – when it best suits your Club!



Once again, this year, we're running a competition where one lucky Australian Lions, Lioness or Leo Club will win a fabulous outdoor kitchen barbecue valued at around \$2,000. So, get your 'Intention to Participate' (ITP1) form back to us for a chance to win your club a brand new outdoor kitchen barbecue, including the kitchen sink!

Each club that participates gets a ticket. For every \$500 raised, your club will get an extra ticket in the nation-wide draw.

Also, don't forget to order this year's Biggest BBQ aprons for your team to wear at your big event!

**Good luck in the draw and for your Biggest BBQ 2017.**

Club Kits were mailed in February 2017 or you can download from [alccrf.lions.org.au/resources/Biggest BBQ](http://alccrf.lions.org.au/resources/Biggest%20BBQ)



The Lions Club of Gorokan Kanwal (N3) won the Lions Biggest BBQ Draw 2016

