

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



November Newsletter

Hello to you all

A very big thank you to all for the support shown for our Lions' biggest BBQ, if your Club is yet to send us the donation please make sure that it arrives in time to qualify for tickets in the draw for the BBQ Kitchen.

As Conventions are over in most Districts, it is pleasing to see that delegates responded well to presentations on behalf of the Foundation by Prof David Thomas and Dr Marie Dziadek (Garvan Institute), Trustees and District Chairs - we are all passionate about our cause and are available to Clubs at any time, just get in contact with any of the District Chairs or Trustees.

As we fast approach Christmas and the January Holidays please give thought to those many young children that will not be able to be at home with their family across Australia and around the world - not only the children themselves but their families who will be unable to spend their time joyously at home.

Our fund raising for the Genome project is well on track, but I appeal to you all and your Clubs to dig a bit deeper in support of the project so that we can continue our quest to ensure that we meet our **vision of 100% survival for kids with cancer**. Your Club can send their cheque to PO Box 770, Belconnen ACT 2616

If you would like to make a personal donation, this can be done at the following link
<https://www.mycause.com.au/payment/charity/2047>

John Thorpe ALCCRF National Chairman

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

LIONS KIDS CANCER GENOME PROJECT



**DEAR SANTA
ALL I WANT FOR
XMAS IS A CURE!**

Open letter to the ALCCRF and members

Dr Sara Khan

ALCCRF Clinical Research Fellow

Dear Australian Lion's Childhood Cancer Research Foundation and members,

In 2016 I was fortunate to be awarded the ALCCRF Clinical Research Fellowship to undertake work at the Monash Children's Hospital and Hudson Institute of Medical Research. A Paediatric Oncology Fellow, this fellowship has enabled me to establish lab-based research programs into two of the most prevalent and aggressive childhood brain tumours, Medulloblastoma and Diffuse Intrinsic Pontine Glioma.

A principle aim of my project is to develop and validate a rapid and cost-effective clinical pipeline to determine Medulloblastoma patient tumour molecular subtypes by analyzing archived patient samples from the Monash Children's Hospital and Royal Children's Hospital. I am very pleased to report that I have already processed and analyzed all available fresh frozen tumour samples from both hospitals using a state-of-the-art methylation-based assay and demonstrated that my results completely match with the patient outcomes, international central reviews and comparative international data where available. I am currently acquiring and processing additional formalin-fixed patient samples (a more common specimen storage technique) from both sites for analysis.

The establishment of this platform will rapidly translate into the clinical setting with change in clinical practices according to current international standards of treatment. This means that some patients will be identified as being suitable for de-escalation of therapy whilst others will have the opportunity to potentially access targeted inhibitors, both leading to improved outcomes and fewer long-term side effects.

Another major goal of my research program is to identify novel treatments for the universally fatal childhood brain tumour, Diffuse Intrinsic Pontine Glioma (DIPG). To date, I have comprehensively screened several patient tumour cell lines using a panel of drug compounds and identified top targets that will be further validated. It is hoped that the outcomes of these experiments will lead to a potentially new therapeutic option for these patients. Given that there is currently no effective treatment for DIPG this would represent a significant step forward in the treatment of this disease.

In addition to my research, the ALCCRF Clinical Research Fellowship also provides me with the opportunity to continue to provide clinical services to patients and families at Monash Children's Hospital and as an Honorary Fellow at The Royal Children's Hospital, where I can participate and attend the state wide tumour board meetings. This is an important part in my continued clinical education and development and allows me to identify gaps in our current clinical understandings that I can begin to explore in the laboratory with my research colleagues.

I am extremely grateful for the opportunity this fellowship has provided me in being able to undertake important translation research whilst also continuing my clinical engagement and development. I look forward to sharing more of my research progress and outcomes in the near future.

Yours sincerely,
Sara Khan



N2 District Convention - Queanbeyan



ALCCRF well represented by Trustee Ron Skeen OAM and Trustee David McKenna, District Chairman Ken McLeish (Centre) pictured with DG N2 Chris Howard and DG N4 Anne Jones OAM. to the right conventioners listen attentively to a well delivered presentation by District Chairman Ken McLeish

V1-4 Convention - Fed Uni Ballarat



Above: District Chairman Bec Day with Mary Day at her display stand. Bec gave an excellent presentation to Conventioners

V6 Convention Barham



Right: Lion Lee Walkington presents 2nd prize in annual Quilt Raffle to lucky Lockington Lion, below is the beautiful quilt that was first prize. donation to ALCCRF this year was \$5,000

Warren's Story



For most kids, the Christmas holidays are an exciting and memorable time. For Warren and his family, the end of the year would be memorable for a different reason. As the school term wound down, Warren's mum, Tara, noticed that he was becoming more and more lethargic, and that he had hardly any appetite. Despite staying home from school for a few days his energy levels, mood and appetite continued to deteriorate. Warren began having nose bleeds and Tara started to worry.

Doctors suggested it was a chest infection and put Warren on antibiotics straight away. When Warren had another nose bleed two days later, Tara decided to take him to the medical centre for a second opinion. They had not even pulled out of the street when Warren said he felt sick and threw up. Tara took him straight to the Emergency Department at their local hospital where Warren underwent a series of blood tests. These tests confirmed that Warren had Acute Lymphoblastic Leukaemia.



"For the next hour, the world stood still," Tara said. "I heard every word, including cancer, yet it felt like it went in one ear and out the other," Tara said. Warren's condition meant that he needed to start treatment straight away and within a matter of days he was admitted to Sydney Children's Hospital, Randwick for the first of several rounds of chemotherapy. In preparation for treatment, nurses put in a central venous line which would be used to deliver chemotherapy directly to his bloodstream - bringing with it potential side effects ranging from nausea to exhaustion to hair loss. Warren's first round of treatment lasted eight weeks and following this he could make the hour and a half trip home before returning to the Hospital just weeks later for a second round. During the time he spent in Hospital, his mood would sometimes drop and he would feel irritated but Hospital staff and

volunteers helped make his time there easier for both Warren and Tara.

"The Hospital is amazing," Tara said. "You have people there for you that really do care. I don't reach out much, but knowing they are there helps a lot." Warren is now in remission and has returned to school. There are still some challenges and for the next 18 months he will require 'home maintenance,' which includes taking chemotherapy tablets daily and Tara and Warren attend monthly follow-ups with Warren's doctor.

"This has been the biggest emotional rollercoaster ride I've ever been on," she says.

"I'll never be able to thank the awesome people around us, especially Warren's team of doctors and nurses."

Glen Innes Teenagers recycle to raise funds

They're a tiny part of every can of drink you buy - but they can earn money for good causes.

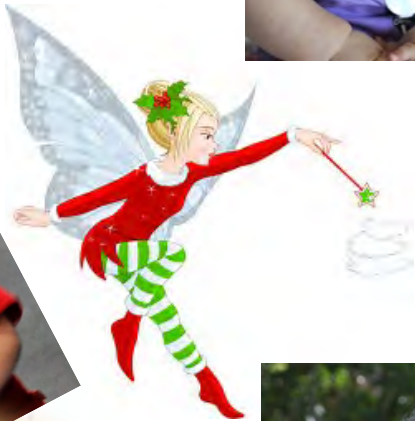
A bunch of teenagers in Glen Innes has been collecting ring-pulls from beer and soft-drink cans for more than two years. They then sell them for recycling at the Maclean Recycling Centre and give the money to the [Australian Lions Childhood Cancer Research Foundation](#).



The teenagers who go to various schools have a catering caravan which sells soft-drinks at fetes and festivals and every aluminium ring pull contributes.



LIONS KIDS CANCER GENOME PROJECT



DEAR SANTA
ALL I WANT FOR
XMAS IS A CURE!



We need Your Help!

Thank you



Australian Lions

Childhood Cancer Research Foundation





Samford Leo Club
presents their annual
**English Rose
High Tea**

In support of Genome Power

BOONAH LIONS
BIGGEST B-B-Q 8AM to 2PM
11th FEB - CORONATION PARK
**MARKETS, LIVE MUSIC,
ENTERTAINMENT, DISPLAYS**
PROCEEDS TO
LIONS CHILDHOOD CANCER RESEARCH FOUNDATION
SPONSORED BY: SCENIC RIM COUNCIL & BOONAH'S BENDIGO BANK

VIRTUAL SAUSAGE \$2.50



**COMMUNITY
BREAKFAST
BACON & EGGS
& COFFEE!**

This Saturday 21st October 2017
From 7:30am until 11am
@ Colaura Gardens
All donations collected for
The Lions Big

PROUDLY SUPPORTS
Lions Club
**Childhood Cancer
Research Foundation**
WARNING:
THE SAUSAGE IS OFFERED FOR VEGETARIANS, VEGETARIANS, AND ANY OTHER DIET OR ALLERGY.
THIS SAUSAGE WILL NOT MAKE YOU FEEL HOPE!
IT WILL ONLY MAKE YOU FEEL HOPE!
IT WILL MAKE YOU A SUPERHERO IN A CHILD WITH CANCER!



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