

Volume. #26  
November 2017

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## FROM THE CHAIRMAN

The end of 2017 is fast approaching and the Foundation is busy finalising its audit and preparing for the Annual General Meeting on Monday 4 December.

Since our last newsletter, the Foundation held its very first Quiz Night – which was a great success. Our thanks to all those that helped, organised and worked at this event and, in particular, to the Perth Demons Football Club for the use of their venue. We have already had lots of people ask when the next one is on! Our team is working on a date for 2018 and will keep you posted when it's confirmed.

At the end of September, Professor Ursula Kees officially retired from her position at the Telethon Kids Institute.

CLCRF has had a very close relationship with Professor Kees and was, in fact, the

organisation that brought her to Perth (back in 1984) to set up a laboratory for research into childhood cancers. We wish Professor Kees all the best for her retirement. The next Foundation Update will feature her legacy in detail.

May I take this opportunity to wish you and your families all the best for Christmas and a Happy New Year.

Geoff Cattach, AM



**CHAIRMAN**



## ABOVE AND BEYOND \$10,000!

For the month of August 2017, Children's Leukaemia & Cancer Research Foundation Inc. (CLCRF) was one of three charity organisations competing in the 'Vote for Good' Community Reward Grant Program held by Beyond Bank.

The organisation that had the greatest number of online votes on the Beyond Bank website by the end of August would be awarded a \$10,000 grant from the bank. While CLCRF were mostly in the lead, the race to gather votes from the community was tense as the other charities were not lagging far behind with their votes.

At the end of the month, we waited with anticipation to find out which organisation had won the \$10,000 grant. We were not told who the winner was in September, however, Andrea Alexander, CLCRF's Executive Officer, was advised to 'prepare a speech – just in case' for the Community Reward Grant Awards Night in October.

Beyond Bank held the award night on Tuesday 3 October, and revealed the winner of the grant. We were thrilled to learn that CLCRF had gathered the greatest number of votes from the community and won the \$10,000 grant!

"Firstly, thanks to the Beyond Bank staff – they were the ones that chose the charities to support in WA, secondly to our wonderful supporters for voting for us, and lastly but not least – to Beyond Bank for this amazing grant," Andrea stated.

CLCRF wants to thank Beyond Bank as well as each and every single person who voted for us in the program. We could not have won without your wonderful support! It is because of Beyond Bank and your vote that we now have \$10,000 to add to child cancer research funds. Rest assured that CLCRF will spend the \$10,000 wisely to help children with cancer.



# DR STIRNWEISS MAKES INROADS INTO FIGHTING RESISTANT CANCER

Last year Dr Anja Stirnweiss, Senior Researcher at the Telethon Kids Institute, received a Children's Leukaemia & Cancer Research Foundation (Inc.) (CLCRF) Project Grant that enabled her to evaluate pathways associated with drug resistance in NUT midline carcinoma, a type of aggressive cancer.

Further to this experimental work being conducted and analysed, Dr Stirnweiss submitted a Small Grant Application to CLCRF for support with the costs to finalise and publish the findings of this project.

In NUT midline carcinoma, the patient's genetic material is incorrectly repaired, which leads to the joining of two genes (called BRD4 and NUT) and creates a new hybrid gene that causes the cancer. A new class of cancer drugs called iBETs, designed to block the function of BRD4, are currently assessed worldwide in 21 clinical trials for patients with leukaemia, brain tumours, aggressive breast cancers and NUT midline carcinoma.

Dr Stirnweiss' findings indicate that the therapeutic benefits of these drugs are limited through the acquisition of resistance. This has important clinical ramifications.

For the study, she and her team used a unique collection of cell lines, obtained from NUT midline carcinoma patients, to identify drug-induced changes in

gene expression. Dr Stirnweiss then performed a correlation analysis to identify changes that are unique to iBET-resistant cells.

Network analysis, which assesses how those genes are functionally connected to each other, highlighted the oncogene FOS to be a central player of the gene network that is associated with drug resistance. Removal of this gene from the resistant cells showed that FOS is not a driver of resistance, but an ideal marker to predict whether the cancer cells will respond to iBET drug treatment. Ultimately, assessment of FOS could be used in the clinic to predict whether patients will benefit from iBET treatment.

It was agreed that the findings from this substantial body of work is highly relevant to patients with NUT midline carcinoma and other cancers with BRD4 involvement. Therefore, the findings should be made available to other researchers and clinicians. To publish these findings in the highly prestigious journal, *Molecular Cancer Research*, minor work needs to be done.

When completed, Ms Mahalia McEvoy, an outstanding young researcher who conducted experiments essential to the proposed manuscript as part of her



Honours studies, will assist Dr Stirnweiss with writing the manuscript.

The Foundation approved a budget of \$14,276 to cover these publication costs. Dr Stirnweiss passionately believes that this research presents a unique opportunity to make a difference for patients suffering from NUT midline carcinoma.

**Congratulations and thank you to Dr Stirnweiss for her outstanding scientific contribution to cancer research.**



# GARRY'S NEW YORK MARATHON



**"I couldn't possibly do justice in trying to explain the great work this amazing charity is doing in helping children and families."**

Garry Preston ran to raise money for Children's Leukaemia & Cancer Research Foundation Inc. (CLCRF) in this year's New York City Marathon on 5 November 2017.

He started training in March and won a place in the 42-km long New York Marathon (only a third of applicants are successful in gaining a place). Garry resolved to never take part in a major marathon after he ran the London Marathon 13 years ago. In spite of this, he changed his mind and committed himself to running in the New York Marathon this year.

"I have quickly realised my legs aren't as young as they used to be and that the only way I would get through it this time is through a great deal of hard work, dedication and mental toughness," Garry said as he started training.

"Your financial backing in the form of sponsorship ensured that I had a strong breeze pushing me along the way... or a chain around my ankle dragging me on!"

As to why he raised money for CLCRF, Garry explains, "I couldn't possibly do justice in trying to explain the great work this amazing charity is doing in helping children and families."

"I realise you may also be thinking that it would have been a lot easier to have entered the City to Surf Marathon here in Perth however, it would have been even easier for me to change my mind ... having booked and paid for my flights and accommodation in New York there was simply no going back!"

Garry covered all the costs of running the marathon and 100 per cent of the funds raised for the run went towards CLCRF. Well done Garry on your tremendous support for childhood cancer research!

**YOU ARE AN INSPIRATION AND CLCRF THANKS YOU FOR YOUR AMAZING CONTRIBUTION**

# A PIECE OF CAKE: CAKE DECORATING SEMINAR RAISES FUNDS FOR CLCRF



Making a difference can be a 'piece of cake'! On 17 August 2017, the Cake Decorators Association of WA organised the 19th National Cake Decorating Seminar that was held at Rendezvous Hotel Perth Scarborough. Antonio Argentieri from Italy, a well-known cake decorator and Foundation Friend, sought support from the organisers to raise funds for Children's Leukaemia & Cancer Research Foundation (Inc.) (CLCRF) via this event.

Gold coin donations for entry went towards the CLCRF and \$426.10 was raised by the Cake Decorators Association with the incredible help of Antonio. The cakes on display were absolutely stunning in artistry and detail. Congratulations to the winners and competitors of the cake competition who made jaws drop with their amazingly detailed designs!

CLCRF want to thank Antonio Argentieri and the Cake Decorators Association of WA for their generous efforts and passion for funding child cancer research.





## SHAKE A TIN FOR CHILD CANCER RESEARCH!



Justin Bruce has a Children's Leukaemia & Cancer Research Foundation Inc. (CLCRF) tin at his workplace, Statewide Bearings in Kewdale. Statewide Bearings specialises in the procurement, supply and support of bearing and power transmission products. Justin is the Financial Officer at the organisation.

When Justin, aged four, was diagnosed with leukaemia, his family became involved with the CLCRF. Justin wanted to help those children fight this disease, just as he had, and today he is one of our most dedicated volunteers and a board member for the CLCRF.

Do you know that a tin can collect up to \$300 to help better a child's life? Hundreds of businesses just like Statewide Bearings have CLCRF tins to collect money for child cancer research. Thank you to all of the businesses who have been diligently fundraising for the CLCRF through collection tins.



Want a simple and easy way to make a difference in the lives of children with cancer? Ask for a Children's Leukaemia & Cancer Research Foundation (Inc.) tin that can be placed in your school, workplace or club. If you would like to place a CLCRF tin at your workplace or organisation, please contact the office on (08) 9363 7400 or email [admin@childcancerresearch.com.au](mailto:admin@childcancerresearch.com.au).

## PERTH TRADIE EXPO 2017

The Perth Tradie Expo, which was sponsored by Toolmart, was held on the 16 - 18 June 2017 at the Ascot Racecourse. Every year the Foundation is proud to be chosen, along with 'Desperate for Love' Dog Pound Rescue, to collect the entry donations from patrons attending the expo.

A big thank you to the generous attendees who dug deep into their pockets in support of two great causes.

This year \$6,250.20 was raised for childhood cancer research!

We would like to give a massive shout out to all our supporters and friends who volunteered over the three days. The weather was perfect and we could not have done it without your help.



If you would like to become one of our valuable volunteers at our next event, contact the office on 9363 7400 or email Kate at [katelyn@childcancerresearch.com.au](mailto:katelyn@childcancerresearch.com.au) to request a 'Become a Volunteer' registration form or head to our website and enter your details online: [childcancerresearch.com.au](http://childcancerresearch.com.au)





## JOIN US ON SATURDAY 25 NOVEMBER FOR THE FRIENDS OF FINLAY CAMP OUT!



This Camp Out is for Finlay, it's for all the kids who have cancer and it's for you! By coming along to join us all on the 25th November you will be helping to fund research into childhood cancer and you will be sharing this incredibly fun event with Finlay and his friends. So, don't wait until the last minute make this huge and register today!

The Friends of Finlay Camp Out is an outdoor community event for families, adults and children to camp together overnight at Lathlain Park, in Lathlain to help raise awareness for the need to research further into Hepatoblastoma, a rare form of childhood cancer, and raise funds for the Children's Leukaemia & Cancer Research Foundation (Inc.).

There will be heaps of great activities for the kids, including footy kicking drills with the West Coast Eagles and Perth Demons players, a jumpy castle, bubble blowing, Face Painting sing-a-longs and much more! To find out more about the Camp Out, what camping gear to bring and of course buy your tickets, head to [www.friendsoffinlay.com.au](http://www.friendsoffinlay.com.au)



**BOOK NOW: [WWW.FRIENDSOFFINLAY.COM.AU](http://WWW.FRIENDSOFFINLAY.COM.AU)**

### WHY HOLD A CAMP OUT?

Four-year-old Finlay Higgs has undergone more than two years of chemotherapy treatments and spent much of his time in hospital. During treatment, he was not able to live a normal childhood enjoying the usual outdoor activities that he loved such as camping.

While in hospital, his mother, Katey Higgs, noticed that just like Finlay, the children who are treated for cancer spent most of their time indoors in front of screens to pass their time, and were unable to play outside like other children due to treatment. The Camp Out will be an opportunity for others to camp on behalf of children like Finlay, who are or were unable to.

### BE SPONSORED TO CAMP OUT!

To help us raise more funds for childhood cancer research, you can also be sponsored to Camp Out! Simply head to our Friends of Finlay Everyday Hero Fundraising Page: <http://fund.clcrfgiving.org/event/FriendsofFinlay> and click "start fundraising" to set up your own Fundraising page!

We'd love all the help you can give us to make this Camp Out a great success not just for Finlay, but for every little child and their family out there that need more research into their cancers! So go on, set up your page, get your friends, family and colleagues to sponsor you and help make a difference in the lives of so many!

### LIMITED EDITION FRIENDS OF FINLAY SLEEPING BAGS AVAILABLE!

We're so excited to offer a limited-edition Friends of Finlay children's Sleeping Bag for sale! We only have 100 Sleeping Bags available to purchase, so make sure you head to [friendsoffinlay.com.au/events/campout](http://friendsoffinlay.com.au/events/campout) and reserve yours now - ready to collect at the Camp Out! If you can't attend the Camp Out and still want to buy one, we can arrange postage costs with you.



# SOCKS FOR CHILDHOOD CANCER RESEARCH!

**CHILDREN'S LEUKAEMIA & CANCER RESEARCH FOUNDATION (INC.) (CLCRF) ARE PROUD TO ANNOUNCE A PARTNERSHIP WITH NEW PERTH BUSINESS, TOE THE LINE.**

On 7 September 2017, Toe the Line, launched and introduced an exciting new range of cotton-combed socks at The Old Laundry in North Perth. Zoe Manuel, Miss Teen Continents Australia National finalist and one of CLCRF's ambassadors, proudly modelled Toe the Line socks.

The very first pair of Toe the Line socks were auctioned off at an amazing \$1,500 at the launch, and all proceeds went to the CLCRF. That was just the first pair - the socks are priced at around \$14.95 each and can be purchased online at the Toe the Line website [www.toetheline.co](http://www.toetheline.co)

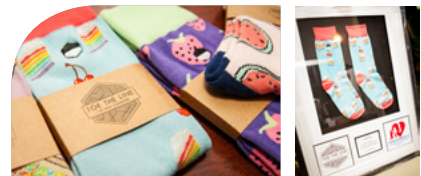
Toe the Line was formed when two men, Jack and Yean, came together with an idea to create the New Standard

in exciting sock wear made of soft combed cotton. Jack and Yean learned that children's feet become very cold when undergoing chemotherapy to treat cancer. As conventional wool and synthetic socks can irritate the skin, combed cotton is the best alternative. Toe the Line aims to make socks in children's sizes so that they can help keep little feet warm and bring a smile to children fighting cancer!

It was a wonderful night and CLCRF wish Jack, Yean and Toe the Line much success for the future. A donation of \$185 (being \$1 per pair of socks sold on launch night) was also made to CLCRF.

We also thank them for their generous contribution to child cancer research.

**[WWW.TOETHELINE.CO](http://WWW.TOETHELINE.CO)**



## SPOILT TO RAISE MONEY FOR CHILD CANCER RESEARCH

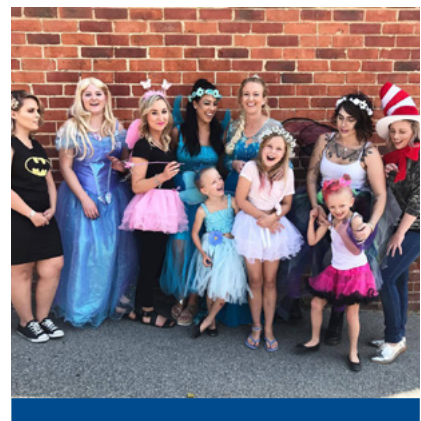


The Spoilt Hair Retreat in Wembley raised money for Children's Leukaemia & Cancer Research Foundation Inc. (CLCRF) by holding a 'Kids Cuts for Cancer' event on Sunday 17 September 2017. The event was held in honour of Spoilt Hair Retreat's owner, Elsa-Rene Mitchell's 5-year-old cousin, Grace, who is battling leukaemia.

"She has endured the harsh treatments that come with battling her disease and the ongoing effects these treatments have on her body," said Elsa-Rene.

There was a fantastic turnout of children and their parents on the day. The Spoilt hair team dressed in fancy dress (fairies, Princess Elsa, Batman, Star Wars characters and Dr. Seuss), while they styled crazy haircuts for children and coloured their hair in bright colours like pink and blue. There was also a cake stall, balloons, laughter and lots of glitter!

By the end of the day, \$2,250 was raised for the CLCRF to support child cancer research. What a fantastic result and the CLCRF want to thank Spoilt Hair Retreat for their passionate dedication to raising funds to help children with cancer.



**YOU CAN ALSO HOLD AN EVENT TO GIVE TO CHILDREN WITH CANCER, JUST START A FUNDRAISING PAGE ([WWW.FUND.CLCRFGIVING.ORG/EVENT/FUNDRAISING-EVENTS](http://WWW.FUND.CLCRFGIVING.ORG/EVENT/FUNDRAISING-EVENTS)) AND SHARE IT WITH FRIENDS AND FAMILY!**







## QUIZ NIGHT SUCCESS

It was a night of fun and sharpening our wits on Saturday 17 June 2017 for The Dance for a Cure Quiz Night. Mark Gibson was our MC and there were many challenging questions from categories like Movies, WA History and Sports that tested our IQ at Lathlain Function Centre.

Many attendees dressed up in amazing, and sometimes zany, costumes e.g. Emoticons, superheroes to name a few. Our Ambassador table, including Lisa Fernandez, Dr Ros Worthington OAM, Kerrin Hampson, Katey Higgs and Zoe Manuel, did their best to outwit the other tables.

The Raffle, Silent Auction and 'Heads N Tails' game were also a huge hit and an amazing time was had by everyone there. The

Quiz Night managed to raise almost \$11,000 for childhood cancer research! What an exceptional effort for our first quiz night.

Children's Leukaemia & Cancer Research Foundation (Inc.) would like to say a big thank you to the Perth Demons for providing us with their function centre and staff for the night. Also, we thank Mark Gibson for being a very engaging MC, our Ambassadors, the volunteers and all of the businesses who donated prizes for our Silent Auction, Raffles and giveaways. Thank you to everyone who participated and made the Quiz Night such a huge success!

**IF YOU WOULD LIKE TO HOLD AN EVENT LIKE A QUIZ NIGHT TO RAISE MONEY FOR CHILDHOOD CANCER RESEARCH, YOU CAN START A FUNDRAISING PAGE AT [WWW.FUND.CLCRFGIVING.ORG](http://WWW.FUND.CLCRFGIVING.ORG) AND SHARE IT WITH FRIENDS AND FAMILY.**

### THANK YOU TO OUR SPONSORS:



**+ MANY MORE**



# Friends of Finlay

## CAMP OUT



**REGISTER NOW!**  
**FRIENDSOFFINLAY.COM**

**SATURDAY**  
**25 NOVEMBER 2017**  
PERTH FOOTBALL CLUB, LATHLAIN OVAL

**PROUDLY SUPPORTING**



**CHILDREN'S**  
Leukaemia & Cancer Research  
Foundation (Inc.)





## HARRISON'S STORY

The effects of cancer on a family can be devastating. In the midst of the devastation, we sometimes hear stories that inspire and give us hope.

Andrew and Emma Williams are a brave couple from Mandurah who have battled with childhood cancer. Their four-year-old son, Harrison, developed neuroblastoma two years ago. They came close to financial ruin after losing their life savings and were forced to close their two butcher shops in the fight to save Harrison's life.

Now Harrison is cancer-free and the couple are rebuilding their lives, working together at 'The Butcher and his Wife' in the new Mandurah Forum.

"For the last two years, it's been absolutely horrendous but we've come out of it really good now," Emma said.

"Harrison was diagnosed in February 2015 with neuroblastoma and he had a year of pretty intense treatment, lots of surgeries, lots of chemotherapy."

"Andrew worked different places over the last couple of years, but I must admit it's been hard and the focus was on Harrison, it wasn't on anything else."

Andrew, Emma and Harrison are dedicated to helping fund childhood cancer research. The family raised money by selling packets of sunflower seeds and yellow ribbons through the 'Sowing the Seeds for Child Cancer Research' fundraiser to raise awareness for Childhood Cancer in September.

Currently, they raise funds for Children's Leukaemia & Cancer Research Foundation (Inc.) (CLCRF) by placing a CLCRF tin at their store.



**WHAT AN INSPIRING FAMILY AND THANK YOU TO ANDREW, EMMA AND HARRISON FOR THEIR FANTASTIC EFFORTS IN RAISING AWARENESS AND MONEY FOR THE CLCRF!**

## SOWING THE SEEDS FOR CHILDHOOD CANCER AWARENESS

September was not only the start of Spring, but also Childhood Cancer Awareness Month. Children's Leukaemia & Cancer Research Foundation (Inc.) (CLCRF) came up with a 'golden' way to raise awareness for childhood cancer.

Since September, CLCRF has been raising awareness for childhood cancer by selling sachets of sunflower seeds. Each sachet, supplied by Mr Fothergill's, contains 45 seeds and comes with a Gold Awareness Ribbon. Thank you to Mr Fothergill's for their support of CLCRF and childhood cancer awareness! So far we have raised \$1,400 with funds still coming in.

You can still help CLCRF raise awareness as we have packets and boxes still available for sale. Please give our office a call during business hours on 9363 7400 or email [katelyn@childcancerresearch.com.au](mailto:katelyn@childcancerresearch.com.au) to order your seeds today.

Sunflowers are a great idea to sell to your family, friends schools or clubs and they are easy to grow. Simply bury the seeds 30cm apart and 5mm deep in a sunny but sheltered position and keep moist.





# Foundation Update

Children's Leukaemia & Cancer Research Foundation Inc

## VOLUNTEER FOR CLCRF

Want to make a real difference for children and families struggling with cancer? Volunteer for Children's Leukaemia & Cancer Research Foundation (Inc.)! Many events and activities would not be possible without the incredible support of our dedicated volunteers.

There are lots of different jobs for volunteers like collecting donations, crowd control or help in exciting events. Gain great experience that you could use for your resume, have fun, feel great, meet amazing people and make a real difference in the lives of children and families fighting cancer!

To find out how you can volunteer and help children with cancer, just call (08) 9363 7400 or email [admin@childcancerresearch.com.au](mailto:admin@childcancerresearch.com.au).



## CONTACT US



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[www.childcancerresearch.com.au](http://www.childcancerresearch.com.au)



CLCRF



CLCRF

## Donate to Children's Leukaemia & Cancer Research Foundation Inc.

You can make a donation by visiting our website, phoning us or completing this form and faxing or mailing it to us (all details above).

### PLEASE COMPLETE FOR TAX RECEIPTING PURPOSES

Title:	First Name(s):
Surname:	
Company:	
Address:	
Suburb:	Postcode:
Phone:	DOB: ____/____/____
Mobile:	
Email:	

Thank you for your generosity!

### I would like to make a donation of:

☐ \$30 ☐ \$50 ☐ \$150 ☐ \$250 or (my own choice) \$

Please debit my ☐  VISA ☐  Mastercard

Card Number \_ \_ \_ \_ / \_ \_ \_ \_ / \_ \_ \_ \_ / \_ \_ \_ \_

Card Holder's Name \_\_\_\_\_ Expiry Date \_ \_ / \_ \_

Signature \_\_\_\_\_

OR ☐ I enclose my cheque / money order (payable to Children's Leukaemia & Cancer Research Foundation) - No Staples please.

OR ☐ I would like to make an ongoing credit card donation of \$

every: ☐ month ☐ 3 months ☐ 6 months ☐ 12 months

☐ I would prefer not to receive any further information from CLCRF.

Donations over \$2 are tax deductible and a receipt will be issued.

### Membership / Information Request

☐ I would like to become a member of the Children's Leukaemia & Cancer Research Foundation and am enclosing

☐ \$11 (individual membership) or ☐ \$22 (family membership)

☐ Please send me a bequest pamphlet.

Please send to: Children's Leukaemia & Cancer Research Foundation  
PO Box 1118, West Perth WA 6872

