

## Foundation Update

Children's Leukaemia & Cancer Research Foundation





The first half of 2017 has certainly flown by and winter is upon us.

If you are thinking of donating to a charity this year, please consider supporting CLCRF. The Foundation does not receive any funding from state or federal government – we rely on the generosity of the Australian (and in some cases international) community. There is a

#### FROM THE CHAIRMAN

donation form at the end of the newsletter and a reply paid envelope for your use.

So what's happened so far?

Family Night Out – a big thank you to the Perth Zoo for again hosting our Family Night Out and to our entertainment and Pinked for putting on such an impressive show. It was really wonderful to see so many families enjoying themselves on the night.

It's heart-warming to see all the events that are being organised to raise awareness and funds for childhood cancer research. We are truly indebted to many generous people and organisations for their support.

The Foundation recently provided funding of \$5,600 to Dr Laurence Cheung to attend the Keystone Symposia on Molecular and

Cellular Biology: Hematopoiesis in Banff Canada early in 2017.

This meeting was to bring together basic, translational and clinical researchers to discuss the key issues in leukaemia and blood cell development and Dr Cheung presented his recent findings at the symposia.

If you would like to know what your donations are supporting, you can head to our website **childcancerresearch.com**. **au** to view our recent Annual Report OR should you like a hard copy, please contact the office and we will gladly post one out to you.

**Geoff Cattach** Chairman



#### CLIMB FOR A SMILE

Rotary WA is once again organising a Climb for a Smile in 2017 at 108 St Georges Terrace, Perth on the Sunday morning of 10 September.

Participants are encouraged to register as individuals or teams to raise funds for three important charities, of which CLCRF is one. They can walk, jog or run up the 50 floors (that's 1,042 steps) via one of the tower stairwells on the Sunday morning.

Previous climbs have raised over \$300,000 for Rotary causes.

For more information see page 13 or head to climbforasmile.org.au to register!





## KUNUNURRA CAKES LEAD TO CASH FOR THE FOUNDATION

There was no shortage of cupcakes in Kununurra when Taylor, Jack and Amira decided to turn their home into a patisserie to support CLCRF. They wanted to make and sell as many cupcakes as possible to raise funds to help other kids.

They cooked up a storm, making more than 750 cupcakes. Boxes were piled high across the dining table and a long production line commenced to pipe delicious icing and

decorative delights to top off the yummy cakes.

Their truly amazing efforts raised \$2,000. With their cupcakes' popularity, could this be a future career path for these young chefs?

Thank you to Taylor, Jack and Amira, and mum, Cherise, for sharing this story and photos.



## CRACKING THE CANCER CODE FOR KIDS

'Excitement' and 'cancer' are two words that shouldn't really go together, until you add the word 'hope' to the sentence. Those are the words flowing out of the mouths of researchers from the Telethon Kids Institute in Perth as they edge closer to answering what causes pediatric cancer, thanks to funding by the Children's Leukaemia & Cancer Research Foundation (Inc.).

Dr Mark Cruickshank, who leads the Cancer Genomics and Epigenetics team, said it has been a long road to reach the pointy end of years of research and is excited to be on the verge of cracking the cancer code for kids.

"This is one project where we have no idea what causes leukaemia in infants and that's a really big focus of mine at present, because I'm very close to finding what we think are the answers to that conundrum," Dr Cruickshank said.

"It has taken more than four years to reach this stage, by studying the gene sequencing mutations in cells. This in turn has now escalated the drug therapy studies that are built on that gene research."

Dr Cruickshank revealed that the research team has been analysing data from cancer cells of infants to identify mutations that are not present in patients' healthy cells. As infants are

'brand new' to life they have had little time for their cells to mutate outside the womb, so there is something genetic causing them to have cancer.

"We've found some extremely exciting signals from the data, statistical signals, and now we need to test these out in the laboratory. This could be a huge advancement and it could open up a lot of different avenues, for example we could look at cohorts of patients to see if a mutation is associated with treatment outcomes," he said.

The genetic research and understanding has been crucial to take the team to this next stage as the make-up of the leukaemia affects whether the treatments will work or not. Having a genetic understanding can cut out the guessing games so patients can receive doses of drugs that are effective and also minimise the side effects to their bodies.

"We already know some drugs fail in some patients and we think this is due to the genetics," Dr Cruickshank said.

While researchers may have found the causes of the diseases, the next step is to develop the best treatment protocols to deliver to patients and their families.

"I don't really think that gaining short amounts of extensions of life is where we need to end up, we really need to cure these diseases. I want to reach a point where the therapies aren't putting the families through a year's worth of pain and then a lifetime of uncertainty," he said.

"I believe in finding absolute cures – and that is the goal of the research, to do that we need help. To accelerate the research we need to be able to test the drugs in all different ways and we need the best technologies. We have the capacity to do this, but it takes money to do it."

If you would like to contribute support to Dr Cruickshank and his team's research to help make a difference you can email CLCRF or call +61 8 9363 7400.

# "I believe in finding absolute cures"

Read a recent paper on infant leukaemia cell lines and drug screening published in Volume 31 of *Leukemia Journal* by Dr Mark Cruickshank to find out more:

www.nature.com/leu/journal/ v31/n1/full/leu2016165a.html



The Children's Leukaemia & Cancer Research Foundation (Inc.) has been incredibly fortunate to be a long-time beneficiary of the Wellard Group. Through this long-standing relationship, they have become a vital part of the CLCRF family and this relationship continues to strengthen.

In December last year, the Foundation's Chairman, Geoff Cattach and Executive Officer, Andrea Alexander (pictured with husband Gordon in photo above), were

invited to the Wellard annual Christmas party at Fraser's Restaurant to celebrate another year of working together to make a difference for children with leukaemia.

Wellard Group is one of Australia's largest producers and distributors of livestock and grain. They use their capabilities and relationships to raise funds to contribute to foundations like CLCRF.

Early in January 2017, Wellard Group continued to support the Foundation by

presenting a donation of \$25,000. CLCRF are truly indebted to the amazing support from Wellard and its management.

THANK YOU TO THE WELLARD GROUP FOR THEIR CONTINUED SUPPORT!

### **hbf** run For a **reason**



#### **HBF RUN FOR A REASON**

Congratulations to ALL the individuals and teams that participated in the 2017 HBF Run For A Reason held on Sunday 28 May! In total \$1,181,361 was raised for WA charities through the Run, of which over \$3,746 was raised for CLCRF.

There was a record turnout of 35,000 people who braved the cold to take part in the Run. As the first batch of runners stood behind the start line at 6.45am it was only a chilling 5 degrees Celsius. A big thank you and well done to the individuals and teams who ran on behalf of CLCRF!

**Teams**: Friends of Finlay, Magellan Power. Statewide Bearings and Team Kai.

**Individuals:** Ashley Damerell, Casey Walters, Roya Ansari Ian 'Seb' Cole, Kat Newton, Shana-Kura Derench and Taryn Carslake.



#### **Next Run Event**

This year's **Chevron City2Surf** which will be held on **Sunday 27**th **August** is the next fun run. It's not too late to register, you can sign up today and support Child Cancer Research.

Visit www.clcrfgiving.org to get started. Contact Kate in the office if you would like a KTFA Motive to Move Singlet to run in.

## **ZAVIER'S BIG HAIR CHOP**

Zavier's mission was to share his hair with those without it. When his plans hit a hurdle he was undeterred, he simply changed tact to lead him from a big chop to a great shave.

It was back in 2015 that Zavier originally decided he wanted to grow his hair to donate it to a foundation that made wigs for kids with Leukaemia. He was inspired by a mate who had done just that.

"I realised that kids with leukaemia don't get to go home every night like I do, they don't get to wake up in their own bed in the morning, they don't get to go school or the park to play like I get too. A lot of them spend so much time in hospital that the hospital is their home," Zavier explained.

"So I figured by donating my hair, wigs could be made for those kids, so that when they do get to go out they have a wig to wear and people don't stare at them because they look different."

For human hair to be used for a wig it is required to be at least 35cms in length. Unfortunately, Zavier's ambition to reach the length he needed would literally be cut short. At 11 years old he was about to start high school, his hair was 20 cm long: too long for high school regulations and too short to be used to make a wig.

Disappointed, he had to trim his locks before he could donate them

Zavier realised he could still make a difference. Instead of cutting his hair, he could shave his whole head and raise money for the Children's Leukaemia & Cancer Research Foundation. In the end, Zavier raised more than \$880 to contribute towards vital research to help kids with leukaemia. Thank you Zavier for your determination to help kids with Leukaemia!





#### CBA THANKS CLCRF TREASURER

Congratulations to our wonderful Treasurer, Kim Williamson, who was awarded a Certificate of Appreciation from the Commonwealth Bank of Australia in 2016.

Kim has been the Secretary of the Foundation since its inception 30 years ago and Treasurer since late 2002. Prior to this he was the Administrator of the former Princess Margaret Children's Medical Research Foundation (Inc.)

This is a well-deserved recognition of Kim's long and dedicated service to the CLCRF.

**WELL DONE KIM!** 







### ONCE AGAIN, THE FAMILIES OF PERTH TURNED OUT FOR THE CHILDREN'S LEUKAEMIA AND CANCER RESEARCH FOUNDATION'S ANNUAL DANCE FOR A CURE EVENT - HELD IN FORREST PLACE, PERTH, ON SUNDAY 30 OCTOBER 2016

The Dance was supported by Channel Nine with event Ambassador, Lisa Fernandez, encouraging the community to get involved. Combined with our Patron, Justin Langer, in the official TV commercial, it proved to be a wonderful way for the community to hear about how they could join the Dance for a Cure.

Louise Momber, also from Channel Nine, was able to attend the official day and was very excited by the dancing and the energy the families brought to the event. "Being involved in Dance for a Cure was such a highlight for me. I loved seeing the happiness on the faces of the participants – knowing they were making a difference to such an important cause and having so much fun at the same time!", said Louise.

Each year we try to offer the people of Perth something new and fun for families to participate in with a very important message to highlight the need for more research into childhood cancer. This of course takes lots of dollars and it's with events like these that we can help fund more research. So the next time you hear about a CLCRF event, get involved and tell your friends because everyone who supports our events supports our research. Stay tuned for the next Dance for A Cure because it will definitely be different and fun!



## BLAZING PADDLES ON THE MURRAY RIVER

#### By Greg Robertson - President, Mo55sCC Inc

It was a canoeist's dream day for a great cause when 26 paddlers took to the Murray River on a beautiful autumn day on Monday 24 April.

The annual fundraiser paddle event for 'Mandurah over 55's Canoe Club' (or Mo55sCC) brought together members and friends taking on their choice of several paddle options and donating funds to support CLCRF.

Based at Murray Bend on the Murray River, near Ravenswood, various groups of paddlers tackled different courses across the day. Some set out early to paddle upstream to Pinjarra and back (30kms), some did one-way downstream from Pinjarra (15kms), and other canoeists took shorter options both up and downstream.

But let's not forget the many others who stayed off the water, but gave their support.

Paddlers and supporters all contributed to the 'kitty' and enjoyed socialising around the BBQ with guest of honour, CLCRF's Kim Williamson.

Kim gave the crowd an overview of the Foundation's work, and thanked the paddlers for their donations and ongoing support. Coupled with members' associated craft and book club fundraisings the total funds raised this year came to \$1,733. A great result from a generous few.

Club President, Greg Robertson explained the Mandurah over 55's Canoe Club members' event has been held for about 18 years.



"From little things, big things have grown. So, cumulatively, Mo55sCC and friends, like many other valued groups, are quietly achieving great support for the CLCRF," Greg said.

"Mandurah's keen kayakers are eager to paddle for CLCRF again next year."

The CLCRF would like to sincerely thank the Mandurah Over 55's Canoe Club for their support over many years



## WE NEED YOUR EMAIL ADDRESS

How important is your email address to us? The answer to that is "Very Important".

With your email we can contact you quickly and cost effectively, while saving on paper. This allows us to keep you up-to-date with events and offers from the Foundation as they occur.

If you think you haven't yet supplied us with your email address, please contact the office so we can update our records.

After all, we would hate for you to miss out on something fabulous while supporting our great cause J.

Thank you!































### 2017 FAMILY NIGHT OUT GETS PINKED

Families and friends came together again to rock out under the stars to the sound of PINKED at this year's Family Night Out Concert held at the Perth Zoo.

It was a popular way for parents to have their kids entertained on March 18 as families gained entry to explore the zoo ahead of the concert kicking off as the sun set. It was a fantastic show – thanks to Sabrina, her band and dancers. We could just imagine the animals having a dance along in their enclosures! But it wasn't just covers of Pink's greatest hits and an abundance of animals for people to enjoy. There was so much more.

The entertainment rolled out all evening as Mal and Judi, from Awesome Balloon Creations joined us again to help keep the children (and adults) occupied with temporary tattoos and an amazing bubble machine. For the budding artists in the crowd, Sony Productions supplied an array of colouring-in sheets to keep them busy, and prizes for people to walk away with.

If you were lucky enough, you were picked out from the crowd with family passes to the latest Smurf movie. We hope the winning families enjoyed the movie.

While rain did threaten to dampen the vibes for the evening it held off for the night, which was greatly appreciated by the event organisers. Just when an injection of energy was needed, a gourmet barbecue was served up by Mustard Catering. It was a perfect evening, and great fun was had by everyone.

Events like these don't happen without volunteers, so a BIG thank you to:

- Kristy, Jonelle & Chris Carlsson
- Georgia Lowry
- Michele & Pat Seymour
- Kylie Dalton and her staff from Absolute Edge Media
- Gary Kearns
- Sarah Felmingham

The date for our 2018 Family Concert is yet to be confirmed, however keep your eyes peeled because it will be an event you don't want to miss!

You can sign up for our E-News by sending us your email address, like us on Facebook or add **www.childcancerresearch.com.au** to your favourites list online so you can keep an eye out for any upcoming events.







#### The ride kicks off:

**Day 1** – Monday 9 October Mandurah to Pinjarra (Fairbridge)

**Day 2** – Tuesday 10 October Pinjarra (Fairbridge) to Harvey

**Day 3** – Wednesday 11 October Harvey to Bunbury

**Day 4** – Thursday 12 October Bunbury to Busselton

Day 5 – Friday 13 October Busselton to Margaret River

Day 6 – Saturday 14 October Margaret River to Augusta **Costs:** There is a daily cost of \$25 per day which covers most meals, accommodation, fuel etc. This is a total of \$150 if you wish to participate in the entire Trek.

**Sponsorship:** The sponsorship minimum that is required but not limited to is \$300 if you wish to take part in the entire Trek or \$100 for one section or day.

**Riding Options:** You do not have to participate in the entire ride to take part in this Trek. You are able to arrange to ride certain days and legs to suit you.

**Criteria:** For the safety and benefit of all participants riders are expected to be able to maintain a speed of at least 20 kilometers per hour for a reasonable period. Each segment of the Trek is 25 to 30 km. Each day is approximately an 80 km ride.

You must have a reasonable level of fitness and maintain a pace of at least 20km per hour. There is a minimum age of 18 years unless a parent or guardian signs a disclosure for you to be able to participate in this fundraiser.

**What you need:** Road worthy bike, helmet, water bottle, sleeping bag, pillow, toiletries, towel, riding clothes, casual clothes and pyjamas. We have escort cars and a trailer which your belongings can travel in but please pack sparingly. It is also recommended to bring a spare tube or tyre for your bike in case of a puncture.



For more details, please contact Eric Maddock on 0433 905 703 or email swbiketrek@gmail.com.





PLEASE REMEMBER: THIS TREK IS A CHARITY RIDE, NOT A RACE IN ANY SHAPE OR FORM AND WILL THEREFORE BE CONDUCTED AT A LEISURELY PACE. THE GROUP WILL WORK TOGETHER TO ENSURE EACH OTHER'S WELLBEING.

## 2016 WELLARD STAR OF THE WEST CAMPDRAFT







The spectacle of a sport synonymous with outback Australia in suburban Perth is always a certainty to draw a crowd. The ninth annual Wellard 'Star of the West' Campdraft delivered for spectators and competitors all in the aid of raising funds for CLCRF.

The event drew together some of the State's and country's finest stockmen and women on horseback showcasing their skills from 25th to 27th November last year at the Boar Swamp Campdraft Club Grounds. With such a high calibre of riders, judges also travelled from interstate.

Campdrafting is a unique Australian sport dating back to the late 1800s and involves a horse and rider working cattle for the coveted title of the best stockhorse and rider. Points are awarded to the horse and rider for cut out, horse work and

course completion from a possible 100 points. A good campdrafter is not just a fine horseman/woman, but has the skill to select a suitable beast from a mob that will run well in the arena

Following the main event on the Saturday, the evening was about catching up with friends, meeting people and having fun in a safe and friendly environment. In addition to a delicious free BBQ dinner, live music and a licensed bar, the awards of the day's events were presented.

Donations of \$3,300 were received from this event.

We would like to give a special thank you to the McLarty family for their generous hospitality, the Boar Swamp Campdraft Club and Wellard Group for their continued support.

#### Sponsors:

- Blythewood Pastoral
- Haines Surveys
- Hi-Tech Ag Solutions
- Imperial Glass
- J&TSanders
- JR Performance
- Mitchell's Transport
- Morgan Feed Supplies
- Ravenswood Hotel
- Ross & Angela Hall Breakaway Stud
- Rozbys Gear
- Wellard Group
- West Coast Wool & Livestock

## CLCRF FUNDING TO DR A. BEESLEY

A landmark study that lifts the lid on key features of one of the most hostile cancers will soon be published with funding from the CLCRF. One of the Foundation's Fellowship recipients, Dr Alex Beesley with Dr Anja Stirnweiss have comprehensively described, for the first time, the genetics behind NUT Carcinoma.

NUT Carcinoma is one of the most aggressive human cancers, and there is a desperate need for effective therapies for patients with this illness. It is a rare genetically defined disease not specific to any tissue type or organ and common sites include the head and neck. So far the cancer has been very resistant to standard chemotherapy treatments. Specialists have found that tumours may initially respond to therapy, but then rapid recurrence is experienced. Treatment must be tailored to the individual patient.



The study is a culmination of the research program that the Foundation has funded over the last several years, both in the form of project grants and Dr Beesley's CLCRF Fellowship. This latest award of \$12,000 will assist in the publication of the highly important document.

It is hoped that the manuscript will be submitted to the journal Oncotarget and it represents a milestone publication that will help inform therapy choices for this aggressive cancer.



Expressing sympathy for cancer victims and what they go through was not enough for Carter Dunn. He wanted to do more and he did: shaving his head in the name of raising money for cancer research.

It was a sudden commitment that Carter was determined to see through when he came home from school one Monday to ask his parents if he could shave his head for charity.

"One of Carter's friends had a family member who was battling leukaemia and he just came home and said he felt like he wanted to show his support and asked if he could shave off his hair," Jacqueline Dunn explained.

"Carter literally decided on the Monday that he was going to do it on the Friday of the same week, so we set up his fundraising account and shared it via social media."

When Friday came, a small amount of nerves kicked in, but Carter had no doubt that he was going to do it. He had the full support of his school friends who still couldn't quite believe he was going through with it.

Once all his hair was reduced to tiny stubble his first reaction was – "Wow, it's cold!" Then Carter smiled and said he was proud of himself, as were all his friends who cheered him on.

For Carter's parents it was one of many proud parent moments they have had, acknowledging that he never hesitates to think of others despite his own personal trials. Carter recently had to undergo surgery to remove his gallbladder.

"We felt mega proud that Carter who has his own personal battles daily, just felt the need to do something for others, acted on it and followed through," Jacqueline said.

Within five days Carter exceeded the target of \$250 that he hoped to raise, instead he reached \$440. He has no hesitation in repeating the shave once he has regrown his hair.

"Within five days Carter exceeded the target of \$250 that he hoped to raise, instead he reached \$440."

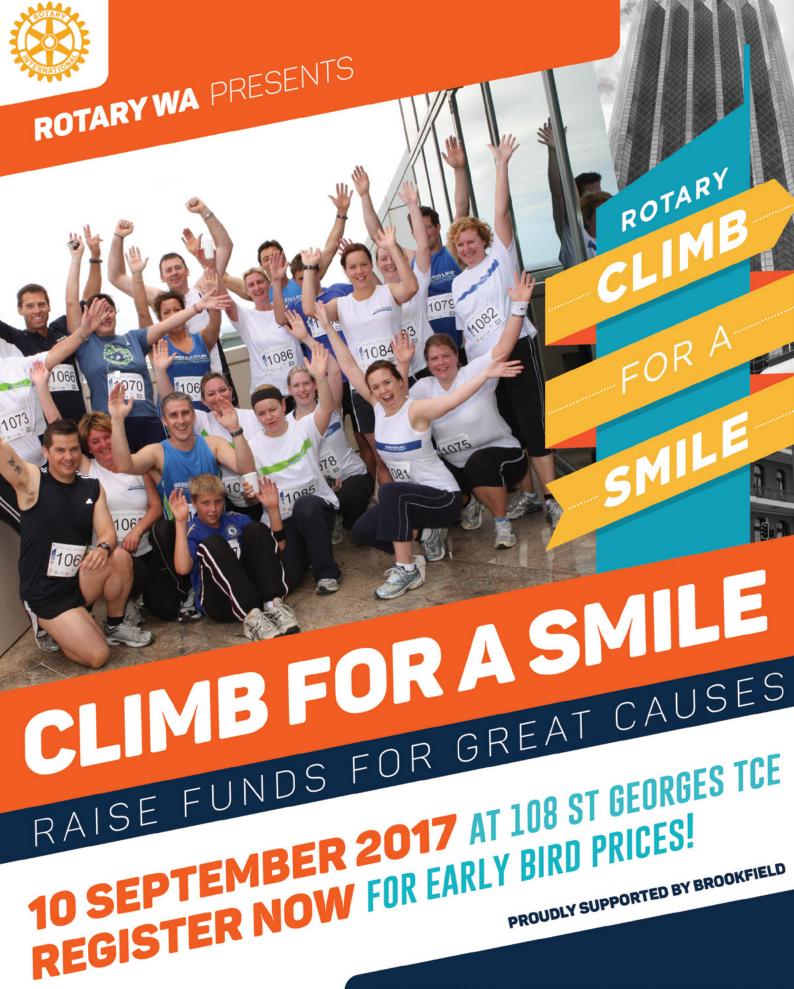
#### **LANDSDALE FORUM NEWS**

It has been seven years of fabulous support from Landsdale Forum News and their customers. What began in 2010 has in total amounted to \$10,917 donated to the CLCRF to fund childhood cancer research.

As they sadly have to close their doors we at the CLCRF want to wish owner, Paul Slattery, all the best for his future endeavours as he has played a big part in what CLCRF has been able to achieve under the Lansdale Forum News banner.

A huge THANK YOU to Paul and Landsdale Forum News for their incredible support towards child cancer research over the years as a valued member of the Foundation.





### PROUDLY SUPPORTING



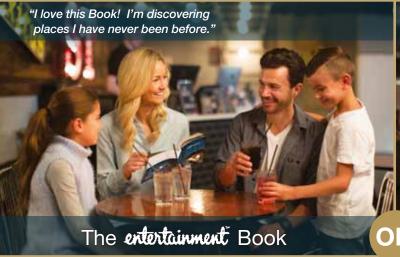




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#### Children's Leukaemia & Cancer Research Foundation

Contact: Andrea Alexander Phone: (08) 9363 7400 Email: admin@childcancerresearch.com.au Address: Suite 3/100 'Century Court' Hay Street, Subiaco WA 6008

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14Thanks for your support! 20% from each Membership sold contributes to vital research into childhood cancers!



(Photo L - R Professor Ursula Kees, Vicki Prastidis and Pat Taminga)

#### Charity Golf Day Royal Perth Golf Club

They may be more accustomed to green turf and and getting out of sand traps, but representatives from Royal Perth Golf Club embraced the chance to step into scientific surrounds on a visit to the CLCRF Research Lab.

Under the wing of tour guide Professor Ursula Kees, the golfers learned about very different challenges the researchers came up against each day as they strive to find answers to how they can help children with cancer.

It was an eye opening visit to see just what is taking place in the lab funded by CLCRF. They witnessed where and how the 'cell lines' taken from tumours of infants who are fighting or have survived cancer are being used to develop more effective treatment protocols for children around the world.

It was an 'ace' shot for the Foundation to make a great impression on the captivated audience. CLCRF has now been chosen as the 2017 beneficiary of the Royal Perth Golf Club's annual charity day.

Thank you to the Royal Perth Golf Club for their generous support. Further details about the day will follow.

#### **LEAVING A LEGACY**

While times are tough and Australian's feel the ripples of the economic downturn, many are forced to make the difficult decision that charity begins at home ...

Fortunately, finding yourself with less cash than normal does not mean that you cannot generously help causes close to your heart in the future.

Leaving a legacy (bequest), in your Will, allows you to give support to your favourite charities beyond your lifetime and ensures that there is a legal document outlining your wishes.

You can leave money, property or a percentage of your estate after your passing; and with it your legacy for the future.

The gift provides crucial funding to allow the likes of the Children's Leukaemia & Cancer Research Foundation (Inc.) to continue its vital work.

When you leave a Legacy you can have peace of mind that you will, one day, be supporting the charity whose work you believe in. This way, not only can you save the dollars now, you can also take steps to give a charity the gift that keeps on giving, after you pass.

Anyone can leave a Legacy, however small or large. If you have considered joining the many Australian's who have already exercised their free 'Will' and chosen to leave a Legacy, the good news is that the process is relatively quick and easy. Your solicitor can advise you on this.

Legacies can be anonymous but, letting your charity know of your kindness allows them to make plans for the future, assist you with wording the Legacy and thank you personally.

We always suggest that you discuss what you propose with your family so

they know of your wishes. Family should always come first.

For more information please contact:

#### Mrs Andrea Alexander Executive Officer

Children's Leukaemia & Cancer Research Foundation (Inc.)

**Phone:** 9363 7400

**Email:** andrea@childcancerresearch.

com.au



## **Foundation Update**

Children's Leukaemia & Cancer Research Foundation Inc

#### **UPCOMING EVENTS**

- Motive to Move Event October 2017
- Friends of Finlay Camp Out November 2017
- Dance for A Cure underage event January 2018

Please note: dates and locations to be confirmed closer to the events.

Please follow us on Facebook for updated information facebook.com/CLCRF or visit our website: childcancerresearch.com.au



#### **CONTACT US**



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Email: admin@childcancerresearch.com.au

**Phone:** (08) 9363 7400 **Fax:** (08) 9382 8798

www.childcancerresearch.com.au



**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).

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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

