

# special lives



## Christmas cheer for Cooper

Christmas is a special time of year for Donna and Matthew Anderton and their three children Mitchell, Cooper and Reese.

But it is also a challenging time. Seven-year-old Cooper has Duchenne muscular dystrophy, which is a progressive muscle wasting disease. Over the next few years, Cooper will lose the ability to walk and will eventually be confined to a wheelchair. His life-span is limited to his early twenties. If that wasn't difficult enough for the family, eldest son Mitchell is in remission after recently undergoing chemotherapy treatment for Hodgkin's lymphoma, a type of blood cancer.

As a mother, Donna sees Christmas as an opportunity to recognise the joy her children bring into her life. "We get to see the kids' imaginations run wild with excitement over the prospect of what Santa is bringing. It's a wonderful time for our family and I cherish the time we spend together. For one special day, they can enjoy the magic and wonder of Christmas and forget about their daily struggles," she said.

Welcome to  
our Summer  
newsletter!

VERY  
SPECIAL  
  
**kids**  
Children's hospice  
and family support



## From the CEO

With the end of the year approaching, I would like to take a moment to reflect on the achievements of Very Special Kids in 2014. We are delighted with the recent success of the Piggy Bank Appeal, which raised \$1,157,000 through the outstanding contributions of businesses and community groups across Victoria. I would like to say a special thank you to the Appeal's Major Partners - ALH Group, Commonwealth Bank and Seven News.

Throughout 2014 we continued to review our services and the needs of the children and families we support. The services we offer were the subject of an in-depth research program conducted in collaboration with the Centre for Palliative Care and St Vincent's Hospital. Our family support workers were identified as a major benefit to families throughout the regions of Victoria, and our aspiration to grow this service in future years is supported by this research.

As we transition to a new year, the platform for our expanded services has been laid, but there is much work to be done in 2015 and we are more reliant than ever on the generous support of the community. In the coming months we look forward to opening our revamped family accommodation at Malvern, increasing the levels of nursing staff in our hospice, and improving the quality and effectiveness of our service.

I wish all our families and supporters an enjoyable break over the new year period and the very best of everything for 2015.

**Sarah Hosking,**  
Chief Executive Officer

"When Cooper was born, he was a bouncing, happy boy, just like a normal baby. But when he was about three years old, he started encountering physical difficulties," Donna said.

"One day Cooper was trying to ride a bike and I was pushing him, but his legs just stopped working - his body wasn't letting him do something that his mind wanted him to do."

Donna and Matthew decided to investigate what was impacting Cooper's physical ability by consulting doctors and pediatricians.

"I initially thought it might have been something like hip dysplasia, but tests results came back confirming he had a form of muscular dystrophy. It's a rare genetic disease, but Cooper has the most common form of muscular dystrophy in children."

Most children with Duchenne muscular dystrophy continue to develop motor skills and improve their physical capabilities until the age of six or seven years old. While Cooper is currently walking and is able to run and jump with the help of steroids, Donna can see that his decline has started.

"We have noticed that he is having more trouble walking and he is becoming slower. It's really hard as he has improved up until the age of six, but now we have to watch him lose all his abilities. By the age of about 10 or 11, it is expected that Cooper will lose the ability to walk and be confined to a wheelchair," Donna said.

While looking after Cooper and his condition, the Anderton family also faced another challenge with the health of their eldest son Mitchell.

"We noticed a lump on the side of Mitchell's neck in 2012. Matthew suggested we should get it removed, so we did. The pathology reports came back the following week and the lump was actually a form of Hodgkin's lymphoma - so it was a good call by Matthew to get it taken out," said Donna.

"Mitchell had two months of chemotherapy treatment and he is now in remission. While he has ongoing tests to check for any recurrences of the cancer, the specialists are pretty optimistic that it's gone."

Donna said the support provided by Very Special Kids has been extremely important in helping the family cope with the day-to-day challenges.

**"Our Family Support Worker Briana has been amazing. If I am having any struggles I know that I can always call her and she is there to chat to me in times of confusion."**

"It's been difficult to deal with the questions that Cooper asks such as, 'Will I stop walking?' 'Will I need a wheelchair?' Briana has helped me gain the strength to answer his questions as well as I can without scaring him."

Briana has also visited the family home to play with the kids and build a strong relationship with the Anderton family.

"Building that relationship has been really helpful as we have introduced Mitchell to the Sibling Days at Very Special Kids. Mitchell can come to the Sibling Days and see that a familiar face is there for him in a new situation," said Donna.

"Our daughter Reese is champing at the bit to come to Siblings Days when she is old enough next year - she can't wait and just wants to go now."

"I'm so grateful for everything Very Special Kids does for us. The journey for our family would have been a lot harder without the ongoing support we have received."





## Family News

### Volunteer at the Royal Children's Hospital

A reminder to families about the Very Special Kids Royal Children's Hospital (RCH) volunteer program.

Please remember to let us know if your child is admitted to RCH so that our volunteers are able to find you and offer support. You can do this prior to your child's admission by calling your Family Support Worker or the Duty Worker at Very Special Kids on **9802 6222**.

If you forget to do this, you can call us anytime of the day or night and leave a message advising your child is in and would like a visit, or you can visit the Family Resource and Respite Centre at RCH and ask them to leave a note for our volunteers to visit you.

**Don't forget the Family Christmas Party at Very Special Kids on Sunday 23 November.**



### Adventure on Adolescent Day

A group of enthusiastic adolescent siblings enjoyed an action packed day of competitive fun at Sidetracked Entertainment Centre.

The day kicked off with a game of laser tag, which was followed by ten pin bowling, with seven teams side by side, aiming for the ultimate strike. Before lunch everyone had a chance to return to their favourite activity with a few games of mini golf.

Pizza and chips took care of rumbling tummies before we revved those engines and took to the Go Kart track. Some proceeded with caution, while others put pedal to the metal clocking up impressively fast times as they completed the circuit.

Thank you to Barry, Mark and Helen at Sidetracked Entertainment Centre for making such an amazing day possible and to our wonderful volunteers Camille and Miranda for all their help on the day.

Don't forget the date for next year's Adolescent Weekend from Friday 20 to Sunday 22 March 2015 – it's a great weekend for siblings that is not to be missed!



# Family fun at Gumbuya Park

A fun day at Gumbuya Park was the perfect opportunity for families in the Gippsland and South-East regions to get together.

Gumbuya Park offered something for everyone - from amusement rides to picnic and BBQ areas, with a native animal sanctuary home to a variety of Australian wildlife. We enjoyed a fun-filled afternoon, as families took time to relax and get to know each other, and then come together for a grand afternoon feast. The weather was perfect with warm temperatures and blue skies.

It was great to see parents and children take to the rides, such as the twister karts, mini cars and paddle boats, with joy on their faces as the wind rushed past. There were also many happy moments with wildlife such as wallabies, dingoes, wombats and koalas. Thank you to everyone who attended for making this a memorable day.



## Super safari weekend

The annual Bereaved Sibling Sleepover for primary school aged siblings is held in winter each year.

The fun started on Saturday with a Super Safari day for siblings. It was attended by 26 children who were able to get to know each other while enjoying activities such as making a camp site, participating in a scavenger hunt and playing a human-sized game of snakes and ladders.

Sunday was a family day at Werribee Open Range Zoo, which was attended by 22 bereaved families. As the children were already familiar with each other from the previous day, the parents had a chance to meet and chat over a sausage sizzle.

After checking out some animals on foot, the Zoo's safari bus took everyone on a tour to see the animals. The family day was unique as it allowed parents and children to make connections with others who understood their journey and experience of loss.





## Piggy Bank Appeal fundraising awards

### ALH Group Fundraising Awards

Overall Highest Fundraiser

Skyways Hotel \$18,248

#### Category A

1st Glengala Hotel \$7,784

2nd Chelsea Heights Hotel \$4,708

3rd Blue Bell Hotel \$4,699

#### Category B

1st Pascoe Vale Hotel \$11,167

2nd Sands Hotel \$6,997

3rd Commercial Hotel

Werribee \$6,007

#### Category C

1st Skyways Hotel \$18,248

2nd Hallam Hotel \$10,117

3rd Blackburn Hotel \$7,086

### Commonwealth Bank Fundraising Awards

1st Castlemaine \$4,779

2nd Malvern \$4,117

3rd Mornington \$3,288

### Community Awards Tatts outlets

1st Inverloch Lotto \$7,638

2nd Clifton Hill Lotto \$6,724

3rd BP Prahran \$3,275

#### Community organisations

Westend Market Hotel \$11,952

Healesville RSL \$10,809

Essendon Football Club Windy

Hill Venue \$10,797

### Volunteer Recognition Award

Alan Hall, who volunteered over 90 hours as part of the Piggy Trails



## CMC cares for children's charity

CMC Property Services has been busy fundraising since selecting Very Special Kids as its charity partner in March.

Staff at CMC's head office in Hawthorn have organised super hero fancy dress days, cake sales and donated all proceeds from the CMC staff café to Very Special Kids. Many staff are also donating their time and energy to volunteer at Very Special Kids events. In addition to this, CMC raised over \$88,000 for Very Special Kids at its 20th Anniversary Birthday Gala.

CMC's Chief Executive Officer, Paul McCann said one of CMC's key strategic goals has always been to give back to the community.

"To mark our 20th anniversary this year, we sought to align ourselves with a charity partner whose cause is close to our hearts. This is the first time we have formally aligned ourselves with a children's charity and we are very excited.

"We have used every opportunity to raise funds for Very Special Kids such as our gala ball, family fun days, expos, conferences and our information sessions. We are committed to a long-term partnership that helps support families in need," Paul said.



Saturday 22  
November,  
9am to 3pm at  
Very Special Kids  
and Malvern  
Town Hall

Very Special Kids   
**FAIR**

## Fun at the Fair with Bob and Angelina

Bob the Builder and Angelina Ballerina will dazzle audiences on Saturday 22 November at the Very Special Kids Fair.

The Christmas-themed fair will be held on the grounds of Very Special Kids and feature performances from the much-loved children's characters, as well as an animal petting farm, face painting, jumping castle and a special visit from Santa.

Alongside children's entertainment there will be stalls selling homemade cakes and preserves, quality toys and baby goods, boutique wines, fresh flowers and plants, homemade Greek food, Devonshire Tea and more. Live entertainment and an abundance of food stalls will guarantee a great day out for the whole family.

Across the road at the Malvern Town Hall, the Very Special Kids Fashion Sale will feature top Australian and International brands on sale at up to 90 per cent off. Thousands of women's and men's designer clothing items, jewellery and accessories will be sold at rock bottom prices.

Entry to the Fair and Fashion Sale is by gold coin donation with 100 per cent of the proceeds going to Very Special Kids to support more than 800 Victorian families caring for a child with a life-threatening condition.





# Special Snippets



## Fantastic fundraisers

Holding your own fundraising event can be a fun and rewarding way for community groups, clubs and individuals to make a difference to children with life-threatening conditions and their families.

The 9th Annual Toby McCredie Golf Day recently raised over \$16,000 for Very Special Kids. The golf day is in the memory of Toby, who sadly passed away in 2006. Very Special Kids has supported his parents Penny and Tim and brothers Jake and Lachlan over the past nine years. The annual golf day has now raised more than \$100,000 for families like the McCredies.

If you are into your golf, there are some upcoming opportunities to enjoy a round and raise money for Very Special Kids.

- Flinders Five Golf Challenge. Friday 6 February 2015. Contact Ray on 0407 308 286
- Rotary Club of Altona City Charity Golf Day. Friday 27 February 2015. Contact Charlie on 0412 257 723

Many schools have recently found ways to support Very Special Kids. A special mention to Grade 1 student Ethan Scully, who performed a magic show and raised over \$1,000 with the help of his classmates at Pleasant Street Primary School in Ballarat.

Excellent school fundraisers have also been organised by Brighton Grammar, Caulfield Grammar, the Emerson School, Penleigh and Essendon Grammar, Glenallen School, Malvern Primary, Mater Christi College, Methodist Ladies College, Northcote High, Rowville Secondary, St Roberts Primary, Wembley Primary and Wesley College.

Other notable community fundraisers include Neroli Padfield's Girls' Night In (\$7,400); Church at Collective Trivia Night (\$7,117); City2Surf and Run Melbourne fundraisers (\$6,249); RMIT Student Conferences (\$3,000); and 10 Squared Evening (\$2,250).

## Welcomes & farewells

After more than eight years of service, Amber Skehan is leaving Very Special Kids. Amber has been integral to the success of our fundraising efforts by leading the Fundraising Events team. She has managed the Piggy Bank Appeal, which raises over \$1 million each year, and was crucial in developing the 24 Hour Treadmill Challenge, which raised almost \$500,000 earlier this year. We wish Amber the very best for the future.

After performing exceptionally in acting roles, Sue Kearney has been appointed as the Hospice Manager and Rachel Ficinus is now the Family Support Team Manager. We have also recently welcomed Katrina Hall in the role of Human Resources and OHS Manager, Naomi Ball as the Communications Coordinator and Jess Davey as the Family Support Team Secretary.



**Freecall**  
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Please contact us on 03 9804 6222 if you do not wish to receive any further communication from Very Special Kids.

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