

# special lives



## Celebrating World Hospice Day

Music, art and a special dog called Olive made for a fun and therapeutic day when Very Special Kids celebrated World Hospice Day on Saturday 8 October.

On a day that recognises the amazing care given by our hospice nurses and carers, we also showcased the range of programs offered including art therapy, music therapy and pet therapy.

Many children who stay at Very Special Kids Hospice cannot communicate verbally or have difficulties hearing, seeing, moving or responding.

Our Music Therapist Amy Howden said "the impact of music, art and pet therapy on these children is extremely beneficial.

"The opportunity to be an active participant in a shared musical experience can be powerful for these children who are severely disabled. For them, music is their voice."

Welcome to  
our November  
newsletter!



## Rewarding career caring for children

Theresa Haasbroek shares some stories about her rewarding work as a nurse at Very Special Kids Hospice and what World Hospice Day means to her.



### **What does World Hospice Day mean for you as a nurse working at Very Special Kids?**

Celebrating World Hospice Day is to draw attention to the unique and wonderful work of paediatric hospices and palliative care providers around the world.

Very Special Kids is unique in our palliative care services as we use a holistic approach that aims to enhance quality of life. Our music and art therapy programs play an enormous role in the way we support not only our vulnerable little children but also their siblings. The quality of care we give is second to none.

### **What do you find most rewarding?**

It's such a rewarding job because I am gifted with endless reminders of the value of selflessness and unconditional love. I find a great sense of accomplishment and meaning in being an advocate for patients and families without a voice.

I am honoured to be called into the most sacred and vulnerable time in young people's lives. Helping children and their family have as much control as possible at the end of life helps me appreciate how many choices I have in my life.

### **What have you learnt from your experiences of working as a nurse?**

I have learnt how to live and love more fully. My experiences in the hospice have taught me to cherish precious time spent with my loved ones, and my limited time here on earth.

I get daily wake up calls to the temporary nature of life. If I ever had a chance to change my career the only thing I would have done was to become a Hospice Nurse at Very Special Kids much sooner.



# Riding for a worthy cause

The Shepparton community came together for the Powercor Tour de Depot – a family friendly, bike riding event that raised more than \$50,000 for Very Special Kids.



On Sunday 23 October, community participants started the ride at Victoria Park Lake and had the option to ride five or ten kilometres. More serious riders took part in the time trial riding a distance of 20 kilometres.

As riders crossed the finish line they were greeted by cheering crowds and joined a community festival with activities for the whole family. From carnival rides, face painting and Powercor's Static Bike Challenge to food stalls and local entertainment, it was a fantastic, action-packed day.

One family that took part in the community ride was the Holmes family. After losing their six-year-old son Henry, the Holmes family are supported by Very Special Kids'

bereavement program and understand the importance of community fundraising events.

"I'm so thankful for all the support," Jess Holmes said. "When Henry passed away, we not only lost our child, but we lost so much more. The one constant thing has been Very Special Kids and taking part in the Powercor Tour de Depot is our way of giving back."

Powercor Regional Business Manager Ian Gillingham said he is thrilled with the overall result of the day. "We believe that for us to be the best we can be, we must give back to the communities in which we operate and recognise the support they provide. The Tour de Depot is our way of saying thanks."

## I would like to support Very Special Kids

### My donation

I would like to make a gift of:

- \$50
- \$100
- \$500
- \$1,250

Or my choice: \$ \_\_\_\_\_

### My info

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Phone: \_\_\_\_\_

Mobile: \_\_\_\_\_

Email: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

### My payment

- I would like to donate by cheque / money order (payable to Very Special Kids)

**OR** please debit my credit card:

- VISA  Mastercard  AMEX

Card Number:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Expiry: \_\_\_\_ / \_\_\_\_

Signature: \_\_\_\_\_

Name on card: \_\_\_\_\_

### Send to

#### Very Special Kids

321 Glenferrie Road, Malvern, Victoria, 3144

Phone: 03 9804 6222

Fax: 03 9822 1252

All donations over \$2 are tax deductible and help care for children with life-threatening conditions.





## Taking care of the carer

Taking care of yourself is one of the most powerful ways to take care of others.

We asked some parents supported by Very Special Kids what they do to get through the hard times. They came up with these tips for looking after yourself while caring for a child with a life-threatening condition.

- I find I talk things through a lot, with people I trust. I find that my counselling sessions help a lot
- It helps me to sleep if I have a long hot bath with candles, a glass of wine and meditation music just before bed
- Scheduling date nights with my husband and going on a girls' night out helps too
- When the going gets tough I try to remind myself to just deal with today, don't stress the tomorrow or next week, just get through today
- If I know it's a long hospital admission I get a volunteer for my child and I have a sleep or cup of tea by myself
- Three breath hug: In times of deep distress and fear gather together, arms around each other and take 3 deep breaths together

## Sibling Day reflection



Sibling Days are full of activities for primary school children who have a brother or sister with a life-threatening condition. Twelve-year-old Mila explains why they are so much fun.

Ever since Grade One, I have enjoyed the Sibling Days of fun-filled activities at Very Special Kids. I would be driven to Malvern anticipating the exciting things we would do as part of the theme of the day.

Whether it was Adventure to the Land of your Wildest Dreams Day or Yabba Dabba Doo Day, there was sure to be all sorts of craft, sport and scavenger hunts to entertain all of us.

As we walked through the door of Very Special Kids, there was almost always a magnificent cake sitting on the table. Oh, the colours and size of that sweet goodness – that I knew would be enjoyed at lunch and, even better, the adults wouldn't restrict us to only one piece! I remember there once being a beautiful green tree cake

and last time, the Olympic Rings cake.

Next year I am graduating to be part of the Adolescent Sibling Program. This will mean going on camp if I choose and going to a couple of special days throughout the year.

When it came to the sheet which we would fill in at the end of Sibling Day the answer to the question 'Is there anything you did not like about today?' was always no and I guess that question and answer practically sums up my thoughts on Sibling Day.

It is really nice going somewhere to meet a group of other kids who share something with you that most people don't. I think I will always remember my Sibling Days and the fun I had.



## My trip to hospital

Nine-year-old Braya shares with us the story of when she organised for her brother Darcy to be taken to hospital – all while her mum wasn't at home with them.

I was watching television when Tammy, who is my brother Darcy's carer, called out to me because Darcy was having a seizure.

I bolted into Darcy's room, then I started to sing a song while I was patting his chest. We did this for about five minutes and then I had to call mum, because Darcy wasn't coming out of his seizure. Mum said to tell Tammy to give Darcy six Drops of Rivotrol.

Three minutes later he still wasn't coming out of the seizure, so mum told me to tell Tammy to give Darcy some midazolam and then call an ambulance. So, I hung up on mum and Tammy called an ambulance while I was standing next to Darcy.

While Tammy was talking to the ambulance on the mobile phone, mum called us back on the home phone so she knew what was going on.

I asked mum if she would like me to pack Darcy's bag and she said "yes, that would be lovely thank you." I

stayed on the phone with mum asking what I should put in the bag.

Still on the phone to mum, I then went into the garage and cleared a path for when the paramedics arrived. I was talking to my mum giving her updates on Darcy, until the paramedics arrived.

When they arrived, mum had a little talk to one of the paramedics, who was mum's friend. That's when I realised I had packed the wrong bag for Darcy, so one of the paramedics had to repack the bag.

Finally, mum and dad got home and Darcy got lifted onto the bed and then wheeled into the ambulance. I had my photo taken in the front seat of the ambulance.

It was weird in the ambulance – it had all tubes, medication, bandages, band aids, slings and other things. It was a long drive, about 30 minutes, but we eventually got there.

The ambulance arrived at Monash Hospital and mum and my other

brother Spencer arrived shortly after. The doctors and nurses looked after Darcy, while I sat in a chair and played on my iPad. Then we got told that Darcy was well enough to come home – yay!

In the car on the way home, I had a wrap from McDonalds and then finally we were home. I went to bed at about 1.15am. Man was I tired! But I'm glad Darcy is okay.



## Family Christmas Party reminder

Don't forget the Family Christmas Party at Very Special Kids on Sunday 20 November from 11am to 2.30pm.





## Piggy Bank Appeal fundraising awards



### ALH Group

#### Highest in Category A

St Albans Hotel \$5,629

#### Highest in Category B

York on Lilydale \$12,534

#### Highest in Category C

Blackburn Hotel \$16,629

#### Recognition Awards

Oakleigh Junction Hotel \$4,524

Gateway Hotel \$11,429

Seaford Hotel \$12,464



### Commonwealth Bank

1st Mornington \$3,592

2nd Castlemaine \$2,890

3rd Rosebud \$2,776

#### Recognition Award

Eden Rise Village \$1,175



### Community Fundraisers

#### Lotto outlets

1st Inverloch Lotto \$7,331

2nd Clifton Hill Lotto \$5,894

3rd Heathcote Champions

Super IGA \$1,110

#### Community supporters

1st Pantry Brighton \$37,222

2nd Westend Market Hotel \$13,303

3rd Keilor East RSL \$13,000



### Volunteer Recognition Awards

Efstra Dalaveris

Lucy Nicholson

## Lauriston Girls' complete their own treadmill challenge



Following on from the success of our 24 Hour Treadmill Challenge, Lauriston Girls' School has completed its own treadmill challenge to raise \$51,285 for Very Special Kids.

In continuous motion for six hours, the 11 treadmills at the Lauriston Girls' School were propelled by 188 students, ranging in age from 10 to 18 years.

The girls took on the fundraising challenge by raising money in groups and their wonderful effort has collectively delivered more than 40 nights' accommodation in our hospice for children with life-threatening conditions.

Lauriston Girls' School principal Susan Just said she was pleased the students had found a healthy way to help Very Special Kids.

"Inspired by Very Special Kids Hospice and wanting to do

more than just bring in money, a number of the senior girls set about organising the event. The girls wanted to extend themselves and work for the contribution they make to their community.

"We are all motivated by the work of nurses and carers at Very Special Kids Hospice, who typically spend six hours on each shift on their feet, and sometimes running, while caring for critically-ill and high-needs children," Susan said.

The treadmills were generously donated to Lauriston Girls' School by The Fitness Generation, who also supply all the equipment for the Very Special Kids 24 Hour Treadmill Challenge.

## Very Special Kids Fair

Children can meet My Little Pony's Twilight Sparkle, Transformers' Optimus Prime and Mr Potato Head at our Fair on Saturday 19 November.

The Christmas-themed Fair will be held on our grounds in Malvern and will feature a footy handball competition, bungy bounce trampoline, animal farm, face painting and Santa photos.

Alongside the family entertainment is a market selling homemade cakes, boutique wines, fresh flowers and plants, quality toys, baby goods and homewares that make perfect Christmas gifts.

The Fair is open between 9am and 3pm and entry is by gold coin donation with 100 percent of the proceeds going to Very Special Kids.

**If you can generously give an item, such as toys and cakes, please contact Kristi Ingrilli on 03 9804 6217 or [kingrilli@vsk.org.au](mailto:kingrilli@vsk.org.au)**



## Very Special Kids Fashion Sale

Calling all shopaholics! The Fashion Sale is back again at the Malvern Town Hall on Saturday 19 November from 9am to 2pm.

Gather your girlfriends for a shopping spree with clothing, jewellery and accessories, donated by top Australian labels, on sale at up to 90 percent off.

Held in a great location at the Malvern Town Hall, you can make a day of it with shopping followed by lunch just across the road at Very Special Kids Fair.

Very Special Kids Fashion Sale Ambassador, Jess Dempsey, said she can't wait for the special sale.

"It's great to be able to pick up a brand-new designer dress for \$50, but I also like knowing that the money I'm spending is going towards helping families and children that need it the most," she said.





## Special Snippets



### Rewarding an outstanding volunteer

Lucy Nicholson's outstanding efforts with all things pink and piggy has been recognised with the Volunteer Rising Star Award for this year's Piggy Bank Appeal.

Lucy went above and beyond expectations by contributing many hours of volunteering for Very Special Kids while balancing university projects and other commitments.

When asked about her highlight of this year's Appeal Lucy said "getting to meet so many new volunteers. I love speaking to other people and learning why they became involved with Very Special Kids."

"I love the sense of purpose you gain. Very Special Kids is such a fantastic grassroots organisation and has such fantastic staff coordinating the volunteers - which is very hard to find!"

Lucy can be seen above in a piggy costume with The Bachelor's Sam and Snezana at The Pantry Party fundraising event.



### In memory of Elle

Lisa O'Rourke's family connection to Very Special Kids has helped her raise more than \$1,000 to care for children just like her niece, Elle Schneider.

Elle was born alongside twin brother Leo in August 2014, but Elle sadly only lived for thirteen short days. Very Special Kids has supported the family with

grief counselling and peer networking.

Lisa raised the funds through the proceeds of her small business, Lala's Soy Candles. She donated 20 percent of the profits from a market held on Elle's birthday, collected extra donations in a tin and set up an In Memoriam page for Elle on Everyday Hero.