

# special lives



## Focusing on what's really important

For most of us the holiday season is both a wonderful time to spend with our families, but also a busy and potentially stressful time.

At the Winrow house, it's a quieter time. For parents Vanessa and Scott, having their beautiful son Josh, whose serious epileptic syndrome could send him to ICU without warning, has made them prioritise what's really important.

12-year-old Josh has Lennox-Gastaut, a syndrome that causes potentially fatal seizures. He also has an intellectual disability and is non-verbal. Christmas for the Winrow's centres around family time,

and doing things together that don't put too much pressure on Josh.

Up until Josh was two-and-a-half years old, the Winrow's had no idea there was anything seriously wrong.

Vanessa said that Josh's seizures came out of nowhere. "It was very frightening. We found ourselves calling the ambulance and we were unsure of what to do.

Welcome to our November newsletter!

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



## From the CEO

In 2015, Very Special Kids delivered on our objective to provide additional and even higher-quality services to a greater number of families. Some key initiatives included doubling the number of nurses we employ, making two additional beds available in the hospice and streamlining referrals and bookings to provide seamless services.

We have aspirations to do even more, including extending the reach of the counselling and support services provided by our Family Support Team. Demand consistently exceeds supply for many of our services, with our bereavement and sibling programs of particular note. Therefore, the challenges we face to sustain our income growth and our current service levels have never been greater.

Very Special Kids is also committed to maintaining external accreditation as a way of independently assuring and improving our quality of care. We have recently completed an independent survey and assessment of our safety and quality of care so that we can obtain accreditation against the National Safety and Quality Health Services (NSQHS) Standards. Very Special Kids will be the one of the first non-government organisation in Australia to be accredited and measured against this highest level of standards.

We are delighted with the recent success of the Piggy Bank Appeal, which raised \$1,043,788 through the outstanding contributions of businesses and community groups across Victoria. I would like to say a special thank you to all of our donors, especially the Appeal's Major Partners - ALH Group, Commonwealth Bank and Seven News.

I wish all our families and supporters an enjoyable break over the Christmas and new year period.

**Sarah Hosking,**  
Chief Executive Officer

It got quite out of control before the doctors were able to find any medication to stabilise it."

Now, Josh's syndrome means he requires constant care from Vanessa to meet his daily needs.

"I'm the nurse, the everything. I've had to learn how to medicate him in an emergency situation so that we don't end up in hospital," she says.

Very Special Kids Hospice, with its 24-hour nursing care, is the only place Vanessa can access when she needs to have longer stays away from Josh.

"None of the family could really deal with his seizures and it's too frightening for them. Whereas when Josh goes to the hospice I can walk out the door and I know he's going to be fine. There's a real sense of security that he's in good hands," she says.

Vanessa also receives emotional support from their Family Support Worker, Edwina, and attends coffee mornings where she can compare notes with other mums who have children with a life-threatening condition.

For Josh's eight-year-old sister Phoebe, it can be hard having a brother with a life-threatening condition. Phoebe attends Very Special Kids Sibling Days every

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**Vanessa Winrow**  
Joshua's Mother

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school holidays where she has fun and explores her emotions in a safe space with peers she can relate to.

"It's essential for Phoebe. It helps to have something that's entirely about her, where she is the special kid for that time," she says.

As Josh has been getting older and more independent, Vanessa and Scott have wanted for him to have his own friends. Recently the family have been assigned a Family Services Volunteer to spend time with Josh.

"We wanted Josh to have his own special friend. Our volunteer, Nick, is very caring and wants to help others. He's one in a million, I think," says Vanessa.

In the future, all Vanessa hopes for, is that Josh will be happy. "I think getting a friend is the first step to that," she says.



# Mittagundi magic

Eighteen adolescent siblings experienced an exciting week on the inaugural camp to Mittagundi Outdoor Education Centre.



The camp provided an opportunity for both bereaved and non-bereaved siblings to make lasting connections and share in new experiences together. The adolescents bonded in the face of adversity, as they were challenged with rain, snow, sleet and sunshine...all in the one day.

Mittagundi Outdoor Education Centre is a pioneer-style farm that was established with the belief that young people, mountains, purposeful work and challenges are natural partners. It is situated on a 400 acre property between Omeo and Falls Creek.

The group rose to the challenges they faced, with the learning and personal self-discovery helping to foster a massive sense of achievement, togetherness, trust and respect.

Many young people reported the highlight for them was skiing or seeing snow for the first time, but overwhelmingly, most people identified

the support and encouragement they received from their peers and the connections made as the thing they loved most about the camp.

Time spent together allowed for deep discussion about the many complex emotions felt by these extraordinary young people. Here's what one mother had to say about her child's experience.

"Thank you so much for the opportunity that my son had on the Mittagundi camp. He came home with such a buzz and excitement we hadn't seen from him in ages, which was truly amazing. He had the most memorable time and in his words it was all just 'a big blur of amazingness'.

"He said the other kids on the camp are like family and would be 'friends for life'. Very Special Kids is having a large impact on these young people - it's so rewarding and we thank you from the bottom of our hearts."

## I would like to support Very Special Kids

### My donation

I would like to make a gift of:

\$50  \$100  \$300  \$1,000

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:

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Expiry: \_\_/ \_\_

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

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

Single donation

I authorise Very Special Kids to make automatic donations to this value from my credit card until further notice

Monthly  Quarterly  Annually

### 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.





## Regional coffee mornings

Our regional Family Support Workers have been organising special coffee mornings that connect parents who have children with a specific condition.

A group of parents in the Barwon region have been meeting for some time now to share experiences of having a child with Duchennes Muscular Dystrophy. In the Gippsland region, a new group has started that brings together parents who have children with Dravet Syndrome.

Another new group has also began to meet in the Barwon region to learn from each other about being parents of children with organ transplants. One mum from that group said the coffee mornings are "a good opportunity to talk openly about my situation with other mums who totally get it. We laugh about the same things. I don't feel so isolated after those coffee mornings."

If you are interested in meeting with other parents in your region who have children with similar conditions, please contact your Family Support Worker.

## A day for remembering

The annual Remembrance Day enables families, volunteers and staff to come together to remember all the special children who have died.



For many families, Remembrance Day is an opportunity to honour and remember their child in a supported space with others who can understand some of their journey.

This year's theme of snowflakes reflected on grief being a unique and individual journey, as well as snowflakes all bearing their own unique qualities just as the children that were being remembered had.

More than 200 families attended the service at the Malvern Town Hall. Parents and siblings were involved in the service through the sharing of reflections, blessings

and through song. The balloon release after the service was a highlight and a way for parents to remember the children.

Children who spent time in the craft room with an amazing group of volunteers enjoyed making snow globes and a variety of snowflakes along with origami, playdough and story time.

Special thanks to Stonnington Council for the use of Malvern Town Hall, as well as the many staff and volunteers who help make such an important day happen.



## Subzero and showbags visit the hospice

Children at Very Special Kids Hospice have recently been treated to a visit from a retired racehorse and the excitement of opening showbags.

In October, the hospice received a special visit from former Melbourne Cup hero Subzero, who returned to Very Special Kids after coming in earlier this year.

Subzero and handler Graham Salisbury got up close and personal with the children, with the gentle horse nuzzling into the children's faces.

Michael Conlon received some special attention after feeding carrots to Subzero on the front lawn, while ten-year-old Kirniesha Bramich was lucky enough to kiss Subzero on the nose. In describing her experience, Kirniesha said that "Subzero was very friendly. I think he is a really nice horse." Trainers Wayne Hawkes and Lee

Freedman and jockey Daniel Moor were also there to meet the children. The trio are part of the team that raced to raise money for Very Special Kids during the Spring Racing Carnival.

In September, excitement filled the hospice as children and families supported by Very Special Kids were the first in Victoria to preview this year's Royal Melbourne Show showbags.

Children who had travelled with their families from across Victoria for the occasion, were thrilled as the showbags unveiled including Minions Movie, Littlest Pet Shop, Guardians of the Galaxy, Jurassic World, Freddo Family Deal, Peppa Pig and Frozen.

Alice Zaslavski from the children's cooking show Kitchen Whiz was there to launch the event and joined the children to explore all the showbag contents.

Royal Agricultural Society of Victoria CEO, Mark O'Sullivan, said "it was a pleasure to provide Very Special Kids with the opportunity to see the showbags before everyone else. We loved seeing the delighted faces of the children with their families."



**Don't forget  
the Family  
Christmas Party**

at Very Special Kids on  
Sunday 22 November  
from 11.30am - 2.30pm



## Piggy Bank Appeal fundraising awards

✓ **ALH Group**  
Highest in Category A  
Blue Bell Hotel \$6,080  
Highest in Category B  
Burvale Hotel \$12,258  
Highest in Category C  
Skyways Hotel \$20,121  
**Recognition Awards**  
Morwell Hotel \$5,322  
Olinda Creek Hotel \$11,001  
Seaford Hotel \$15,041

✓ **Commonwealth Bank**  
1st Castlemaine \$7,384  
2nd Mornington \$5,370  
3rd Traralgon \$2,521

✓ **Community Fundraisers**  
**Tatts outlets**  
1st Inverloch Lotto \$8,129  
2nd Clifton Hill Lotto \$8,076  
3rd BP Prahra \$3,170  
**Community supporters**  
1st Westend Market Hotel \$17,899  
2nd Pantry Brighton \$17,460  
3rd Keilor East RSL \$11,820  
**Recognition Award**  
Healesville RSL \$10,563

✓ **Volunteer Recognition Awards**  
Sue Serra, Renee Garner and  
David Szeleczky



## Giving a gift in celebration

Many people are choosing to ask friends and family to make a donation to Very Special Kids instead of a gift for their birthday, anniversary, Christmas or other celebration.

Jake Hayman and Skyla Howard recently celebrated their bar/bat mitzvahs and chose to forego gifts, instead asking friends and family to make donations to Very Special Kids. The pair raised more than \$13,000 between them, which is enough to provide support for two families for one year.

Both of the King David School students have a very personal connection with us. Jake's two-year-old brother Zack and Skyla's one-year-old sister Chloe died at Very Special Kids Hospice, in 2006 and 2001 respectively.

If you have a celebration coming up, whether it is a bar/bat mitzvah, a birthday, wedding or anniversary, why not make it a Very Special Celebration? It's a great way to raise money and awareness about the work of Very Special Kids - and we guarantee that you'll feel good about yourself.

**For more information, please contact Lorren Portolan on 03 9804 6247 or [lportolan@vsk.org.au](mailto:lportolan@vsk.org.au)**

## Peppa Pig and reptiles at the Fair

Prance and dance with Peppa Pig and see live reptile shows at the Very Special Kids Fair on Saturday 21 November.

The Christmas-themed Very Special Kids Fair will be held on our grounds in Malvern and will feature performances from the much-loved children's character Peppa Pig, bungee bounce, animal petting farm, face painting and Santa photos.

Children will have the opportunity to meet Peppa Pig after her performances, and get up close and personal with lizards, pythons and crocodiles.

Alongside children's entertainment there will be a market selling homemade cakes and preserves,

boutique wines, fresh flowers and plants, quality toys and baby goods and craft and home wares that make perfect Christmas gifts.

The Ritchie family, parents Amanda and Christian and their daughter Kennedy, are supported by Very Special Kids and attend the fair every year. Amanda said it's a great day out for the whole family.

"Kennedy loves the lucky dip prizes and also loves to bring a friend to share the day with. I enjoy seeing all the handmade goods on sale,

the beautiful bunches of flowers and plants, and we never go home without the homemade arancini balls!

"Going to the fair gives us another opportunity to support Very Special Kids and the great services it provides," she said.

Entry to the Fair is by gold coin donation with 100 per cent of the proceeds going to Very Special Kids.



## An evening of bargain shopping

Shopaholics take note! The Fashion Sale is moving to a new time this November with an evening sale on Friday 13 November from 5pm to 10pm.

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

Held in a great location at the Malvern Town Hall, you can make a night of it with shopping followed by dinner along Glenferrie Road or High Street.

Fashion blogger and Very Special Kids Fashion Sale Ambassador, Jess Dempsey, said she can't wait for the evening event.

"It's great to know that a night out with my girlfriends shopping will help provide much-needed services to families caring for children with life-threatening conditions," she said.



## Special Snippets



### Running fundraisers

There are many ways to raise funds for Very Special Kids and running challenges remain as popular as ever.

In September, more than 300 runners pounded the steep pavements of Belgrave South as part of the inaugural Run for the Hills fundraiser. Organised by local resident Trish Flanagan, the event raised funds for both Very Special Kids and the South Belgrave Precinct Development Fund.

The Mullan family represented the 27 families from the Dandenong Ranges

currently supported by Very Special Kids. Craig powered home in the 10 kilometre event, while eight-year-old Lucy ran an impressive time in the 4 kilometre run. Lucy was followed home by mum Belinda and brother Jack, who enjoyed the bumpy ride in his modified wheelchair.

In other running fundraising news, Richard Winneke, Director at Jellis Craig Hawthorn, backed up his 24-Hour Treadmill Challenge effort with a sub-100 minute time in the Run Melbourne Half-Marathon. Not only

is Richard clearly fit, but also a terrific fundraiser, as he raised more than \$11,000 for Very Special Kids between the two events.

Jellis Craig have been a terrific supporter of Very Special Kids for more than a decade. Staff from across the real estate group's branches participated in this year's 24-Hour Treadmill Challenge, while the local Armadale branch runs the very popular Wine Stalls at our annual Fair each November.



### Teeing off for Toby

The 10th Annual Toby McCredie Golf Day recently raised more than \$20,000 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 \$80,000 for families supported by Very Special Kids, just like the McCredies.

**For those who are keen on golf, Very Special Kids is holding a Golf Day on Friday 18 March 2016. Check out [vsk.org.au](http://vsk.org.au) for more details.**