

# special lives



## A life-long bond

It seems fitting that Helen Jackson shares the same surname as the family she volunteers for; what began as a fledgling friendship born out of her desire to help families caring for children with life-threatening conditions, has now become a connection that's as close as any family.

The Jackson family, Anne and Peter and their daughters Sarah (20) and Eliza (15), have received Helen's support for the past eight years as they've worked through the challenges of caring for Eliza, who has Rett Syndrome. The neurological disorder impacts Eliza's mobility and communication, and means she requires intensive round the clock care.

Anne said the family and Helen have developed a close friendship that goes beyond Helen being their Very Special Kids trained home volunteer.

"After so many years spent together you can't help but be close. Now she's just a part of the family," she said.

Welcome  
to our  
February  
newsletter!

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



## From the CEO

The team at Very Special Kids has been working hard to achieve our objectives of increasing the number of families we can support, as well as improving access to our hospice for all families, especially those that have longer distances to travel.

Thanks to funding support from the Baker Foundation we have substantially increased the number of nursing staff and made more beds available at Very Special Kids Hospice, allowing more children, including those with more complex conditions, to access this service.

The renovation and extension of our family accommodation at Malvern is now complete and it looks fantastic. Families have started to stay at the facility, which includes seven bedrooms across two dwellings plus a gorgeous spa. These improvements were funded by the Chain Reaction Challenge Foundation and enable more families to be close to their child during a stay at the hospice or to access medical appointments in greater Melbourne.

A collaborative partnership with Royal Flying Doctor Service Victoria is exploring possibilities to provide new transportation services for families. Responses from a survey to families identified transportation as a barrier to accessing our hospice and guided the planned improvements to transport services.

And finally, we are grateful as always to all our volunteers for their support and for sharing our passion to help more children with life-threatening conditions. In particular, in this edition I hope you enjoy reading about volunteer Helen Jackson and her beautiful bond with the Jackson family.

**Sarah Hosking,**  
Chief Executive Officer

Helen joined the Jacksons as their home volunteer, initially, to support a 12-year-old Sarah. The pair spent time together going to art classes, watching movies, playing board games, cooking and going to Sarah's netball games.

"With the care that Eliza needed, it wasn't easy for Anne to take Sarah to all those places, so I stepped in," said Helen.

Sarah said she remembers she always looked forward to her time with Helen, but when they first met she was very reserved.

"On our first outing together I just sat there for hours engrossed in my ceramic painting, not speaking to Helen. I came home and thought I'd had a great afternoon, but poor Helen was probably pulling her hair out!

"Now it's almost like having another mum. We've made life-long friends," she said.

"I've watched Sarah grow from a shy 12-year-old girl into a beautiful 20-year-old woman. I've been inspired by the care and compassion she's always shown her sister, displaying emotional understanding beyond her years," said Helen.

Anne said that having Helen around helped when she was trying to manage caring for Eliza, a young teen and supporting Peter in running his building design business.

"At that time it was a bit crazy, so it was great to have an extra pair of hands on deck."

With Sarah now an independent young adult, Helen has turned more of her attention to Eliza, taking her for walks, visiting her in hospital and when she stays at Very Special Kids House, and watching The Wiggles together.

“

Eliza is such a sweet girl, and even though she's non-verbal she laughs and giggles and says so much with her eyes. You also know when she's not happy!

**Helen Jackson,**  
Volunteer

”

Peter said that the time Helen has spent with Eliza when she's had to stay in hospital has been invaluable.

"Helen would sit with Eliza for hours, enabling us to do other things. You just can't put a value on that," he said.

"It's really valuable that someone's willing to offer their time and are willing to take the family as it is, sometimes it's chaos, sometimes it's controlled. It has been really helpful for me," said Anne.

When Helen first volunteered for the Jacksons, she was running her family's business, and currently works for a palliative care hospital. When asked how she finds the time to volunteer, Helen said it's never a chore.



"I've been blessed with a special relationship with a wonderful family and the opportunity to make a difference in their lives," she said. "I couldn't imagine not having it in my life."

Eight years since that first ceramic class with Sarah, Helen has now developed a relationship with the whole family that includes being there for birthdays, holidays together and a valued friendship with Anne.

Helen and the Jacksons agree that the success of the relationship comes down to the Family Support Team insight and training.

"The Family Support Team get to know you well during the training and match you with a family that has the same values and attitudes. It's quite extraordinary," said Helen.

"Because of their training the volunteers just get it. They understand what's going on and they're open to anything," said Anne.

Peter said they feel privileged to have had incredible Very Special Kids home volunteers help their family.

"It's the little things; the bits and pieces they do that all come together to make a big, big difference."



## Underwater magic at the hospice

SEA LIFE Melbourne Aquarium transforms our hospice bathroom into a magical, underwater adventure for children to enjoy.

The hospice bathroom has been transformed into a fun, playful and stimulating room featuring a submarine, a friendly stingray, brightly coloured fish, moving lights and a television. The makeover was made possible by SEA LIFE Melbourne Aquarium's community program, Merlin's Magic Wand.

On Thursday 8 January the opening of the bathroom was celebrated with a visit from SEA LIFE Melbourne

Aquarium's loveable mascot Sharkie, who joined the children in discovering the bathroom for the first time.

Very Special Kids also recently secured funding for a new specialised bath unit and shower trolley, allowing us to revamp the bathroom facilities for the first time since the hospice opened 18 years ago. Children can now enjoy an enchanting bathroom experience and up to date equipment.

## 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: \_\_\_\_\_

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

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### 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: \_\_\_\_\_

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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.





## 2015 Very Special Dates

**4tracks4kids Walk**  
Mon 9 Mar  
4tracks4kids.com.au

Very Special Kids is pleased to be a charity partner for this 37 kilometre walk to all four Melbourne racecourses – starting at Sandown via Caulfield and Flemington before finishing down the straight at Moonee Valley.

The Conlon family, who are supported by Very Special Kids, are taking part in 4tracks4kids again this year. Seventeen-year-old Michael makes the journey in his wheelchair and hopes to raise \$5,000 for the cause. To donate to Michael's journey, just click on the Sponsor a Walker button at 4tracks4kids.com.au

If you or your business would like to register as a walker to raise funds for the event, please contact Addy Wetzler on 9804 6227.

**24 Hour Treadmill Challenge**  
Fri 22 May to Sat 23 May,  
9am to 9am  
321 Glenferrie Road, Malvern

**Very Special Kids Fashion Sale**  
Sat 27 Jun, 9am to 3pm  
Malvern Town Hall



## Renovations pedaled to the finish line

Very Special Kids is thrilled to have been selected as a major partner of the Chain Reaction Foundation again in 2015.



This year's Ultimate Corporate Bike Challenge will be held from 1 to 6 March and take the Victorian-based riders on an incredible tour of New Zealand's South Island, riding some of the world's best cycling roads.

Funds raised from the 2014 Chain Reaction ride have paid for the renovation and extension of Very Special Kids family accommodation for families requiring hospice care for their children.

The funds raised from this year's ride will cover the fit-out of the family accommodation as well as the refurbishment of the children's playground and the creation of a new Garden of Remembrance on the grounds of Very Special Kids.

These exciting projects would not be possible without the support of the riders and the Chain Reaction Foundation. To learn more or to donate, visit [www.chain-reaction.org.au](http://www.chain-reaction.org.au)

# Are you up for the Challenge?

The annual 24 Hour Treadmill Challenge is a team event to raise funds for children in 24 hour care.

Over 1,000 participants will come together to keep our treadmills in continuous motion for 24 hours from 9am on Friday 22 May to 9am on Saturday 23 May. All proceeds raised from the 24 Hour Treadmill Challenge go towards helping Very Special Kids House provide care for children with life-threatening conditions.

The 24 Hour Treadmill Challenge is the biggest corporate event of its kind and is a great opportunity to engage your staff and customers.

Participants enter as part of a corporate team, and run or walk in half hour or one hour intervals, while being motivated and entertained by celebrities, DJ's and a massage teams.

To enter a corporate team, please contact Sharon Stynes on **03 9804 6240** or [sstynes@vsk.org.au](mailto:ssstynes@vsk.org.au)



 24 HR  
**treadmill**  
CHALLENGE



## Delicious hospice meals made possible by grant

The Newman's Own Foundation is helping us to continue providing nutritious meals to children staying at Very Special Kids House.

A grant from the Newman's Own Foundation has enabled Very Special Kids to upgrade our hospice kitchen to meet health and food safety standards. The grant allowed us to purchase a brand new fridge, freezer and dishwasher, as well as provided funding for our Kitchen Manager role.

Very Special Kids partners with many trusts and foundations, such

as the Newman's Own Foundation, that are dedicated to helping children with life-threatening conditions and their families.

These partnerships are important for our ability to provide the many programs and services we offer. We would like to thank the Newman's Own Foundation for its wonderful contribution to Very Special Kids.



## Diary Dates



Fri 20 – Sun 22 Feb  
**Lord Somers Camp**



Mon 23 Feb  
**Coffee Morning**  
– **The Firehouse, Ringwood**



Tue 24 Feb  
**Bereaved Parent Evening**  
– **Malvern**



Thu 12 Mar  
**Coffee Morning – McClelland Gallery Café, Langwarrin**



Fri 20 – Sun 22 Mar  
**Adolescent Siblings weekend**  
– **The Summit, Trafalgar East**



Mon 23 Mar  
**Coffee Morning – River of Yarrambat, Yarrambat**



Thu 26 Mar  
**Coffee Morning – Madelines at Jells, Wheelers Hill**



Sun 28 Mar  
**North West Family Day**  
– **Werribee Park**



Wed 1 Apr and Wed 8 Apr  
**Sibling Day – Malvern**



Thu 9 Apr  
**Bereaved Sibling Day**  
– **Malvern**



Sun 12 Apr  
**MG Family Day**  
– **Como Gardens, The Basin**



Tue 14 Apr  
**Creative Memories**  
– **Malvern**



Wed 15 Apr  
**Bereaved Parent Evening**  
– **Malvern**



## Christmas celebration for families

The 2014 Family Christmas Party was a great celebration, with exciting activities and entertainment for the whole family.

Very Special Kids' front lawn was turned into a family fun zone. On one side was the animal farm and face-painters, while on the other was the jumping castle and rides in the Melbourne Fire Brigade Cherry Picker, a hit with both kids and parents.

The arts and crafts corner saw creative talents unleashed while parents enjoyed meeting other Very Special Kids families at the coffee bar. At the suggestion of a parent, a special addition this year was 'Santa's Cave' where a professional photographer from

Heartfelt took family photographs with Santa. The party concluded with Santa's surprise visit on a fire truck bearing his santa-sack full of gifts for the kids.

A highlight for the Family Support Team was watching many families attend this annual party for the first time, leaving with smiles on their faces. We hope that through this annual event, families feel more strongly connected and more confident to access the range of supports offered by Very Special Kids.



## Let's go surfing

The Disabled Surfers Association of Australia provides safe and enjoyable surfing experiences for people with a disability.

Families supported by Very Special Kids are invited to the next 'Let's go Surfing Day' in March. Kim George whose grandson Matthew is cared for by Very Special Kids, has taken her family to surfing days and said it puts a big smile on everyone's faces.

"This group takes the time to help all children and adults with disabilities. Matthew loves every minute of it and my daughter Tamara can't stop smiling. It's an awesome time."

For bookings and further information please visit [www.disabledsurfers.org](http://www.disabledsurfers.org)

### Ocean Grove Main Beach

Sunday 1 March 2015  
8.30am registration  
Contact Julia 0413 925 970

### Point Leo Beach

Saturday 14 March 2015  
11am-3pm, registration open at 9am  
Contact [infodsamp@gmail.com](mailto:infodsamp@gmail.com)



## Siblings reach for The Summit

Very Special Kids Adolescent Camps offer a unique opportunity for young people to connect with other siblings who have had shared experiences.

This year's Adolescent Weekend will be held from 20 to 22 March, for adolescent siblings (both bereaved and non-bereaved) up to the age of 20. This year we are returning to The Summit campsite in Gippsland where there is something for everyone to enjoy.

Reece is an adolescent sibling who attends camp regularly and said that they are a life changing experience.

"VSK camps are ones that you won't forget. You meet new friends and learn things about yourself that you never knew. The camp itself consists of many fun activities that work on team building, commitment and confidence, and through these you will realise your true potential.

"It is a place where no matter who you are, or what you like, you have the ability to just be yourself, and be accepted for that. Overall, if you go

on the Very Special Kids camps, you are guaranteed to learn about who you truly are, to meet new friends and best of all, to have an experience you'll remember for the rest of your life," he said.

Whether you're a regular attendee or a graduate of the sibling program contemplating your first Adolescent Camp, we'd love to have you along. More information will be sent out to families in the coming weeks.



## Family News



### 'Tis the season at Glen Osmond Farm

The holiday season can be a challenging time of year for the families we support and this year many took the chance to get away from it all with a stay at Very Special Kids Glen Osmond Farm. Kheeran and Jini Dharmawardena and their children Ethan (10) and Anaya (16 months), escaped to the cottages in Woodend in December.

In 2012 the family lost their beloved daughter and sister Jade to an incurable brain tumor. The farm was a place they could reflect on

the good memories they have, away from the hustle and bustle.

"Christmas is always an emotional time of year, and it gave us the chance to pause and come together as a family," said Kheeran.

The family made the most of their stay, enjoying activities in the barn, cycling around the property, watching kangaroos, and visiting nearby Daylesford and the children's playground at Woodend.

### Your Family Support Worker

Very Special Kids cares for the whole family. Together with your Family Support Worker, you can decide the most appropriate services and level of support that best suits your family. Your Family Support Worker can help you in many different ways, including:

- Counselling and emotional support for all members of the family
- Connections to trained volunteers, respite options and community services
- Sibling activity days and camps
- Bereavement support
- Peer networking with other families
- Information about accessing Very Special Kids House
- Holiday accommodation at Glen Osmond Farm and Annie's Cottage

### Hospice holiday fun



Children at the hospice enjoyed a visit from Roaming Reptiles.



**Freecall**  
**1800 888 875**  
**Website and**  
**online donations**  
**vsk.org.au**

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