

special lives



The meaning of Mother's Day

As a parent of William and Hamish, who both have the same extremely rare genetic condition, Mother's Day holds special meaning for Natalie Watson and her husband Brian.

"Mother's Day is a day that we remember our beautiful mums and show appreciation for all the little things they do for others with love and unconditionally. It's a day we give ourselves permission to take a break from doing and just enjoy the moments and relationships we have with our children.

It's a day of mixed emotions for me, as are most days, but being a mum is both the best job and the toughest job in the world. In so many ways my two gorgeous boys have changed my life and nothing makes me prouder than being their mum," Natalie said.

Welcome to our May newsletter!



From the CEO

In March, I was invited to speak about Very Special Kids at the 11th Annual Paediatric Palliative Care Conference at Westmead Hospital in Sydney. It was a great opportunity to share the important work we do with clinicians from Australia and overseas.

Central to the presentation were the findings of a research project we recently conducted in collaboration with the Centre for Palliative Care at St Vincent's Hospital, which contained feedback from so many of our families throughout Victoria.

The findings highlighted the physical and emotional difficulties families may have when caring for children with life threatening conditions; the role that our Family Support Workers and volunteers play in helping over 850 families; and areas with room for improvement in the future.

The research identified that expanding our family support services to reach more families and offer more services, especially to regional families, is a key focus for the future. It will cost an additional \$1 million per year to extend these services and improve the support we offer to all families.

As we embark on our 30th anniversary year, we can reflect on the incredible achievements and plan a service for all who need us once an appropriate funding base is secured. Later in the year we will plan some important celebrations for our anniversary.

Very Special Kids remains the oldest and largest service of its kind in Australia, and also the most unique, thanks to the scope of our family support services. Thirty years is an incredible achievement and a testament to the solid base laid by the founding families and the amazing Sister Margaret Noone.

Sarah Hosking,
Chief Executive Officer



Seven-year-old William and five-year-old Hamish have an extremely rare genetic condition. The brothers are two of only six cases in Australia and 60 reported cases worldwide.

Natalie explained that the condition, Adenylosuccinate Lyase (AdsL) Deficiency, has caused severe progressive neurological damage.

"William and Hamish are both physically, visually and intellectually disabled. They require wheelchairs for mobility and suffer from daily uncontrolled seizure episodes.

Brian and I are their arms, legs and voice. We help them with every aspect of daily living, from dressing to feeding, monitoring for seizures and turning them over through the night to make them more comfortable," she said.

As AdsL Deficiency is so rare, it is hard to have a definitive prognosis. Natalie said the condition is progressing, as both boys' seizures have increased.

"We have been unsuccessful at controlling them completely with medication and diet modifications. We can't plan too far ahead, it becomes very overwhelming and heartbreaking. Every day we wish for them to have a better quality of life. It can be a real emotional roller coaster and it takes its toll on both of us," she said.

Very Special Kids has provided emotional and physical support to the Watsons, after the family was referred from the Royal Children's Hospital. Natalie said that Very Special Kids helps the family with respite care at the children's hospice

and emotional assistance through their local Family Support Worker.

"I know the boys can go to Very Special Kids Hospice and be provided with high quality care. I can relax because I know that they are okay. I know that the nursing staff will make the right decision for the best care of the boys and we are only a phone call away.

The hospice has a communal area where all the kids come together, so it's comforting to know William

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Natalie Watson,
Parent

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and Hamish are included in all the daily activities, as well as have times for quiet and rest. My boys love the amazing sensory room with music and calming lights.

The staff are friendly and caring and it's very professionally run - it feels like it's their home away from home," she said.

Natalie said that the respite Very Special Kids offers gives her and Brian "a break from being carers and time out to find ourselves again. It gives us all some breathing space. We love travel and have a passion for running. Respite is so important for everyone involved in caring for someone; you have to make it a priority to take that break and recharge.

"There is no other respite service like the hospice out there for us. Brian's family lives in the UK and he wouldn't get to see his family if it wasn't for Very Special Kids, as the boys can't travel on a plane.

Running is great therapy for us, as our fitness and attitude towards life is something we can control in a time when we have no control of our boy's condition.

Thanks to Very Special Kids minding our boys, we have been to the Blue Mountains and more recently New Zealand and completed an ultra-marathon. I really don't think I could cope without knowing we have

somewhere like Very Special Kids to support our family," she said.

The Watson family live in country Victoria, with limited services for hospice respite. Natalie said that she has also benefited from meeting other families from Bendigo who are in a similar situation through the activities organised by Marianne, the regional Family Support Worker.

"I have been to morning teas, parent lunches, pamper days and the family Christmas party. There are few families I have connected with and we support each other" she said.

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: _____
| | | | | | | | | | | |

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.

Horses and walkers beat the track for kids

250 walkers braved an early morning and 37 kilometres of pavement between Melbourne's four major race tracks to raise \$300,000 for children's charities including Very Special Kids.



The 4Tracks4Kids charity walk, organised by racing identities Richard Callander and Bruce Clark, started at Sandown Racecourse and finished at Moonee Valley via Caulfield and Flemington.

Participants were welcomed at the finish line by a notable crowd including the famous Melbourne Cup winner Subzero, leading trainer Gai Waterhouse and children from Very Special Kids Hospice.

17-year-old Michael Conlon, who has Cerebral Palsy and raised \$5,000 for 4Tracks4Kids, stole the show coming down the straight in his wheelchair after completing the event with his mum Debbie Conlon and step-dad Brad Fraumano. He was flanked by a team



of eight walkers from Very Special Kids, who provide care to Michael when he stays at the hospice.

Brad said the walk was a great way for Michael to give back to his community. "The ways in which Michael can give back are limited. This is an opportunity for him to use his unique situation to promote some great work done by many people and to raise money for those less fortunate," he said.


Just days before the event, Very Special Kids Hospice received a visit from Subzero and jockey Chris Symons. It was a first for the hospice, with the gentle Subzero able to come into the building and meet the children staying there.





Family News

Diary Dates

 Mon 4 May, 15 Jun & 10 Aug
Coffee Morning
- Rivers of Yarrambat, Yarrambat

 Fri 8 to Sun 10 May
Mates Weekend for boys
- Very Special Kids Hospice

 Tue 12 May
Bereaved Mums Group Lunch
- Shepparton

 Tue 12 May, Thu 23 Jul & Wed 12 Aug
Coffee Morning
- McClelland Gallery Cafe, Langwarrin

 Fri 15 May
Pamper Day
- Geelong

 Fri 15 May & 19 Jun
Coffee Morning
- The Mansion Cafe, Werribee South

 Sat 16 May
Pamper Day
- Warragul

 Tue 19 May
Pamper Day
- Shepparton

 Thu 21 May & 23 Jul
Coffee Morning
- Madelines at Jells, Wheelers Hill

 Sat 30 May
Pamper Day
- Traralgon

 Tue 2 Jun
Creating Memories
- Malvern

 Mon 22 Jun & 17th Aug
Coffee Morning
- The Firehouse, Ringwood

 Thu 2 & Thu 9 July
Sibling Days
- Malvern

 Tue 18 Aug
Parent Evening
- Albury/Wodonga



Family accommodation re-opens

The upgrade of the family accommodation next to Very Special Kids Hospice has increased capacity from three to seven bedrooms, across two separate apartments.

The rooms have been transformed with all new furniture and bright and contemporary homewares. Families who have recently stayed at the accommodation, which also includes a relaxing spa, are enjoying the peace and comfort during their stay. This expansion will enable more families to be close to their child during a stay at the hospice or to access medical appointments in greater Melbourne.

This improved accommodation for families was made possible by funding from the Chain Reaction Challenge Foundation, as well as donations of goods and services from a number of generous suppliers.

The accommodation is now available for families to make a booking. Please contact the Hospice on 9804 6218 for bookings and enquiries.



Working with non-verbal children

The recent Volunteer Professional Development session focused on working with children who are non-verbal and included expert advice from a Speech Therapist.

Gill Greenwood, a Speech Therapist from Glenallen School, facilitated the session where volunteers were given the opportunity to experience non-verbal communication. They shared thoughts and ideas about the challenges but also the rewards of working with children who are non-verbal. Volunteers learned about how a child who is non-

verbal communicates, through an interview with her mother, and they were shown many of the common communication tools used by children we work with. Gill's message of 'doing something is always better than nothing' was also helpful in encouraging volunteers to feel more confident when working with non-verbal children.

One volunteer summed up the session by saying "Thank you so much, it was a really great and useful workshop. I learnt a lot and feel less fearful or unsure when working with or meeting a non-verbal child".



Weekend camp a treat for families

Families were treated to a weekend of Caribbean-themed fun, including pirate activities and Latin dance classes, at the Lord Somers Camp on the Mornington Peninsula.

It was a chance for 18 families - 38 adults and 50 children - to get away from everyday challenges and enjoy themselves. Children were minded by a group of 100 volunteers as they participated in crafts, games, paddle board lessons and catamaran boat rides, while parents were able to relax in a dedicated retreat with osteopathy, massages and beautician services, or enjoy cheese and wine tasting.

Highlights of the weekend included a visit from the local fire brigade who let their water hoses loose on the volunteers, and motorbike rides

donated by the Dandenong Harley Owners Group (HOG). Generous donations were also given by BOUNCE Essendon Fields and the Dandenong HOG. A special thank you to The Bay Quilters who provided hand-made quilts to every family.

Danni Parks-Earl shared her family's experience and said "the sheer delight on our daughter Romy's face means everything. Camp was so inclusive of her needs and Lord Somers coordinators arranged all activities with her in mind. There was nothing that was in Romy's way of being

involved in everything she wanted to do. For us to plan an event that caters to the whole family in this way is almost impossible. A family weekend like this is pure gold".

These camps are made possible by Lord Somers Camp and Power House, which enables families supported by Very Special Kids to have a weekend away and make connections with other families in a similar situation.



2015 Very Special Dates

Rotary Club of Balwyn & Box Hill Miniature Steam Railway
Sun 3 May, 11am to 4pm,
Cnr Elgar & Belmore Rds, Mont Albert North

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

Very Special Kids Fashion Sale
Sat 13 Jun, 9am to 3pm
Malvern Town Hall

Canada Club of Victoria & Melbourne Ice Canada Day Classic
Sat 27 Jun, 4pm to 9pm
Medibank Icehouse, Docklands

Piggy Bank Appeal
Tue 1 to Wed 30 Sep
Visiting local communities all around Victoria

Footy Fever Debate
Fri 11 Sep, 7am to 9am
MCC Members Dining Room,
Melbourne Cricket Ground



Help feed our Piggy Banks

The Very Special Kids Piggy Bank Appeal aims to raise \$1 million from 1 to 30 Sept. There are many ways that you can fundraise for the Piggy Bank Appeal:



Sell piggy merchandise

Display a piggy merchandise box full of bright colourful products. The full merchandise range is available to order separately in addition to the merchandise box.

Collect donations with your very own Counter Pig

Display one of our novel piggy bank collection units or smaller collection tins on your shop counters, lunchroom or reception counter during the month of September.

Host a giant Piggy Trail stop

Our five giant piggy banks will hit the road in September to collect donations, sell merchandise and help you with your fundraising

activities. If you would like a 700kg pig trotting up to your business, school or community group, simply organise a fundraising activity and we will do the rest. (Subject to availability and fundraising commitment)

Hold a fundraising activity

Fundraising events and activities are only limited by your imagination! Sausage sizzles, piggy themed morning teas, casual dress days and head shaves are always crowd favourites.

To get involved in the Piggy Bank Appeal, please call Kristi Ingrilli on 9804 6223, email events@vsk.org.au or visit piggybankappeal.org.au.



Fundraising the focus of treadmill teams

With only a few weeks to go, it's not long now until over 1,000 participants come together to keep our treadmills in motion for 24 hours.

Held in a marquee on the lawn at Very Special Kids, more than 30 treadmill teams have signed up to take on the challenge of raising money for children in 24 hour care at our hospice and participants are now busy fundraising for the event.

One of those participants is Tony Morse, Ernst & Young's Director of Assurance. He has taken on the extra responsibility of being a team captain and the firm has increased its participation from one to two treadmills. "The extra treadmill will create a nice healthy rivalry internally and promote a greater reach externally to the vast networks of people we

ask to support Very Special Kids. The opportunity to participate in this very worthwhile and fun event helps our people appreciate the challenges others are going through while bringing a sense of teamwork and accomplishment for those involved. The whole 24 hours is full of energy, enthusiasm and spirit. With the event taking place on the grounds of Very Special Kids, it helps foster the sense that individual contributions are really supporting the children at the hospice," he said.

Tony offered some helpful advice to participants with his top fundraising tips:

- Ask your entire network, as you will be surprised who supports you
- Don't be afraid to call on your clients and customers
- Remember to thank your supporters to recognise their contribution

The 24 Hour Treadmill Challenge starts at 9am on Friday 22 until 9am on Saturday 23 May. If you are interested in joining one of our shared treadmills for a 30 min block and you can fundraise \$500, please email treadmill@vsk.org.au. General donations made at vsktreadmill.org.au.

Save the date: Fashion Sale

Top Australian and European brands have opened their warehouses for the Very Special Kids Fashion Sale on Saturday 13 June at the Malvern Town Hall.

Boxes and boxes of women's, men's and children's clothing, jewellery and accessories have been donated and will be on sale at up to 90 per cent off the retail price. Whatwouldkarlido.com blogger and Very Special Kids Fashion Sale Ambassador Jess Dempsey said the sale is a chance to give back to the community and shop for designer clothes at a fraction of the price.

"You can get amazing deals on top high-street and designer brands. I've picked up some great items, including a gorgeous Anna Sui dress," she said.

Fashion Sale is open from 9am to 3pm. Entry is by gold coin donation, with all funds raised going to Very Special Kids.





Special Snippets



Teeing off for charity

Golfers have been driving, pitching and putting their way to raising much-needed funds to support Very Special Kids.

Corporate supporter OHM Australia, a leading accounting and business advisory firm based in Malvern, ran another successful Charity Golf Day at Braeside's Southern Golf Club. The event raised more than \$25,000, taking the tally of OHM's support to over \$100,000 since the partnership with Very Special Kids began in 2012. Former Australian cricketer Rodney Hogg was a popular Master of Ceremonies, with OHM's loyal clients and partners digging deep to purchase some generously donated auction items.

Down on the Mornington Peninsula, the 10th anniversary of the Flinders Golf Challenge raised a record-breaking \$16,000 in perfect conditions at the picturesque golf course. Organised by the 'Flinders Five' volunteers - Ray Sneddon, Cyril Benjamin, Jeff Smith, John Montgomery and Paul Armstrong - the event has now raised in excess of \$100,000 over the past decade. Out in the west, Koorringal Golf Club was the scene of the 10th annual golf day run by the local Rotary Club of Altona City. Long-serving Very Special

Kids volunteer Alan Hall was on hand to see the club raise almost \$7,000, taking the total to almost \$70,000 raised since 2006.

Holding your own golf day or fundraising event can be a fun and rewarding way to help children with life-threatening conditions.

If you are interested in holding your own community fundraiser, please contact Addy Wetzler on 9804 6227 or awetzler@vsk.org.au.

Glitz and glamour at girls' hospice weekend



Five beautiful girls came together for the first ever all female Mates Weekend at Very Special Kids Hospice.

Activities included cafe outings, manicure sessions, card games and a fabulous rendition of Taylor Swift's Shake It Off with the hospice's Music Therapist, Amy.

The highlight of the weekend was Saturday evening when professional hair and makeup artists visited the

hospice and prepared the girls for a catwalk and fashion shoot. Mates Weekends are designed to bring together children who have high cognitive ability and are facing similar physical challenges. The next weekend will be for boys, held from 8 to 10 May.

Very Special Kids Hospice also runs Mates on the Move Weekends for children that are very mobile and have developmental and intellectual disabilities.