

special lives



Celebrating 30 years of care

Very Special Kids recently celebrated its 30th anniversary in style with a gala event featuring two very special guests.

More than 260 guests channelled their 1980's spirit with teased hairstyles and brightly coloured taffeta dresses to help us raise \$162,000. The stars of the evening were fifteen-year old Jasmine Rigby-Smith and sixteen-year old Lucy Paterson.

Lucy and Jasmine discussed the special bond they share after meeting at the Very Special Kids Hospice and provided insight into living with a life-threatening condition. Many in the crowd were

moved to tears as Lucy performed an original song to a standing ovation. Jasmine said that she really enjoyed the event and was proud to be involved.

"Lucy and I wanted to say a huge thank you for welcoming us on stage and letting us share our story with you at the Very Special Kids 30th Anniversary Gala. We were nervous but so excited to be part of such an awesome night. I hope everyone had as much fun as we did," Jasmine said.

Welcome to
our April
newsletter!

VERY
SPECIAL
kids
Children's hospice
and family support

Welcome to our new CEO Michael Wasley

We are pleased to announce that Michael Wasley will be joining Very Special Kids as our new Chief Executive Officer from Monday 2 May.

Michael comes to Very Special Kids from Karingal, a large not-for-profit provider of disability services throughout Victoria. He brings significant senior business leadership experience, having held a number of management positions at Karingal.

His most recent position was Executive Director of Strategy & Partnerships and he was previously Executive Director of MatchWorks, which is a subsidiary of Karingal that provides specialist employment services to people with a disability, medical condition or injury.

In addition to his management experience, Michael also holds three tertiary qualifications with a MBA, Postgraduate Diploma in Rehabilitation Counselling and a Bachelor of Science.

Michael was appointed to the position after our previous CEO Sarah Hosking moved with her family to New South Wales in February.

Sarah made an incredible contribution in her three years as CEO of Very Special Kids, including increasing the capacity of the hospice and family accommodation, extending the number of families we support from 800 to 900, securing \$4million in federal funding and seeing us through our inaugural National Standards accreditation.

We wish Sarah all the best in her new role as CEO of National Breast Cancer Foundation.

New office set to open in Bendigo

Families of children living with life-threatening conditions in the Bendigo region will now receive much-needed support with the opening of a local Very Special Kids office within the next month.



With the opening of the Bendigo office, Very Special Kids will be able to increase services to families including counselling for children, parents and siblings, group therapy programs, bereavement support and increased access to Very Special Kids Hospice in Melbourne for respite and end-of-life care.

Very Special Kids currently supports 27 families in the Greater Bendigo community, however, these families are currently serviced from our office in Ballarat. We also hope to reach more families in the region and estimate there could be as many as 30 additional families in Greater Bendigo in need of our services. The new office, which will cost upwards of \$100,000 per year to run, has been made possible

through a generous grant from Gandel Philanthropy of \$180,000 over three years, as well as funds raised by the Bendigo Tour of Tasmania cycling group.

Vedran Drakulic, Gandel Philanthropy Chief Executive Officer, said living in a regional centre should not prevent families from accessing such vital support.

“Very Special Kids is unique in supporting Victorian families to navigate their child’s life threatening condition and recovery, and in some instances cope with bereavement. It was also important that there was strong local support to make the Bendigo Office a reality and extend their services to families in and around Bendigo.”



Diary Dates



Thu 14 Apr
Creative Memories
Malvern



Fri 29 Apr to Sun 1 May
Mates on the Move Weekend
Very Special Kids Hospice



Tue 17 May
Bereaved Parent Afternoon Tea
Peninsula region



Tue 31 May
Creative Memories
Malvern



Fri 3 to Sat 4 Jun
Mates Weekend for Girls
Very Special Kids Hospice



Fri 17 Jun
Coffee Morning
Warrnambool



Sat 25 to Sun 26 Jun
Bereaved Sibling Sleepover
Malvern



30 Jun & 6 Jul
Sibling Days
Malvern



Tue 19 Jul
Creative Memories
Malvern



Fri 19 Aug
Coffee Morning
Warrnambool



Wed 24 Aug
Bereaved Parent Afternoon Tea
Peninsula region



Fri 26 to Sat 27 Aug
Mates Weekend for Girls
Very Special Kids Hospice

For the most up to date information about metropolitan Coffee Morning dates, please visit www.vsk.org.au

New Facebook Group for parents

Very Special Kids is now offering a private Facebook group for parents who access our services.

Parents will be able to more easily connect with each other and access peer support regardless of where they are, or the time of day. The group has been created as a forum to make connections, seek advice, share tips, find immediate emotional support in times of need, and to participate in healthy discussions about being a parent of a child with a life-threatening condition.

Daniel Parnell, a parent registered with Very Special Kids, will be the moderator for the group and helping to get the conversation started. In 2013, Daniel lost his son Marcus to Batten's Disease and he is looking forward to connecting with other parents who understand the unique challenges of being a parent of a child with a life-threatening condition.

"It's not always easy to meet other parents on a similar journey, especially if you live in a regional town or have a child with a rare condition. Having this Facebook group will help us all to reach out and support each other along the way," he said.

Daniel will be supported by Family Support Team Regional Manager Peggy Hogan, who will also be moderating the group.

We invite all parents to join the group by following the steps below, but if you need any help, please call 03 9804 6222.

1. Create a Facebook account (if you don't already have one)
2. Search for **Very Special Kids Parents** in the Facebook search bar
3. Click on the join button. Your request to join will then be verified by a Very Special Kids administrator
4. Once you have been verified, your request will be approved and you will be able to participate in the group

Special angels take the cake

Celebrating birthdays and other special events in the lives of your family members is something that is to always look forward to.

When your child has a life-threatening condition, these occasions can be filled with even greater meaning, and the need to celebrate every moment becomes paramount. Making or purchasing a special cake is something that can be difficult to arrange, no matter how much you would like to.

That's where Cake Angels can come to your rescue! Cake Angels is an organisation that provides cakes to kids in Victoria with life threatening illness through the help of 400 volunteers.

Cake Angels volunteers have been providing themed cakes to Very Special

Kids for our Sibling Days and Bereaved Sibling Days since 2011, so we know how creative these cake-making-volunteers can be. The siblings have loved 'Detective Cake', the 'Flintstones Cake' and the recent 'Water Slide Cake'.

So who is eligible for a Cake Angels cake? If your very special child, or another child in your family, has a birthday, please contact your Family Support Worker about your eligibility to receive a Cake Angels cake. Please allow six to eight weeks prior to the occasion when making this request.



Summer days and the summit for adolescent siblings

It has been a big start to the year for our adolescent siblings, with a Summer Festival Day followed by a weekend away at The Summit campsite in Gippsland.

It was a slippery slope to fun in the sun with an inflatable water slide being the highlight of the Summer Festival Day at Very Special Kids in January. The day was enjoyed by 25 young people with activities including DJ Benny B spinning tunes and a photo booth where memories were captured of their time shared together. A massive thank you goes out to our seven awesome volunteers and to Grill'd Malvern for providing burgers and chips to our hungry teens.

The Adolescent Sibling Weekend in March was enjoyed by 31 siblings, with each person discovering their inner courage and capacity to support one another during a full day of adventure activities. Comfort zones were pushed as the teenagers tackled the flying fox,

abseiling wall and the foam pit, before spending a relaxing evening together in front of the campfire toasting marshmallows and reflecting on everything they had achieved.

It is hard to put into words the magic that happens on camp and the powerful connection that develops between so many of these young people experiencing similar things.

Here are some reflections from participants who were asked to describe what camp means to them.

"Camp means getting away from your problems and being transported into a life where everyone understands and relates to your current situation."

"Adolescent camp is a chance for a group of kids who have something in common to get away together. We push our comfort zones and learn about who we are. It's an amazing experience."

"Camp for me is somewhere I can be myself and get away from my problems. I can meet new people and reunite with old friends. This experience is so fun and memorable."

"Finally I can go to a place where not all the attention is on my sister. A place where I can meet new friends who actually understand what happens at home."



2016 Very Special Dates



Mother's Day Lunch

Fri 6 May, 12pm to 3:30pm
Royal South Yarra Lawn Tennis Club



24 Hour Treadmill Challenge

Fri 20 May to Sat 21 May, 9am to 9am
321 Glenferrie Road, Malvern



Very Special Kids Fashion Sale

Sat 18 Jun, 9am to 3pm
Malvern Town Hall



Footy Fever Debate

Thu 1 Sep, 7am to 9am
MCC Members Dining Room,
Melbourne Cricket Ground



Piggy Bank Appeal

Thu 1 to Fri 30 Sep
Visiting local communities
all around Victoria



Call out for auction prizes!

Very Special Kids is looking for luxury prizes to be auctioned off at upcoming fundraising events. If you, your workplace or someone you know would like to contribute, please contact Sharon Stynes at **03 9804 6240** or [sstynes@vsk.org.au](mailto:ssstynes@vsk.org.au).

Mother's Day celebration and fashion frenzy

Ladies, find your diaries and pen these dates in for two special events.



On Friday 6 May we will be celebrating mothers at the Very Special Kids Mother's Day Lunch, and on 18 June we will be holding the famous Very Special Kids Fashion Sale.

Join us at the Royal South Yarra Lawn Tennis Club for a glass full of sparkling and a heart full of love, as we remember the women most important in our lives and fundraise for children with life-threatening conditions. At the Very Special Kids Mother's Day Lunch expect a gorgeous afternoon with television presenter Rhys Ulich, live music from Dani Marie and inspiring words from mums who are supported by Very Special Kids.

For those bargain beauties yet to experience a Very Special Kids

Fashion Sale, you are in for a treat. We will be selling brand new women's, men's, and children's clothing and accessories at up to 90% off, all donated by top high-street and designer labels. Entry is by gold coin donation with all proceeds from the event helping us to continue providing Very Special Kids services.

The Very Special Kids Mother's Day Lunch is on Friday 6 May from 12pm to 3.30pm at Royal South Yarra Lawn Tennis Club. Tickets can be purchased online at www.trybooking.com/KKHF

The Very Special Kids Fashion Sale is on Saturday 18 June from 9am to 3pm at the Malvern Town Hall.

Taking on the ultimate 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 20 May to 9am on Saturday 21 May.

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

Glenn Carmody, Oceania Market Segment Leader Consumer and Industrial Products at Ernst & Young, is one of those participants who is eagerly looking forward to this year's event.

"Ernst & Young encourage and support community involvement from our staff and the 24 Hour Treadmill Challenge

is the perfect event. It gives you the satisfaction of raising some much needed funds for the charity but also creates a great sense of teamwork.

The 2015 event was a competition between two divisions in the firm, which drove some friendly competition with the funds raised. It is a much anticipated date on the EY calendar and we are looking to expand our involvement in 2016," Glenn said.

All proceeds raised from the 24 Hour Treadmill Challenge go towards helping Very Special Kids Hospice provide respite care for children with life-threatening conditions.

To enter a corporate team into the 24 Hour Treadmill Challenge, please contact Sharon Stynes on 03 9804 6240 or [sstynes@vsk.org.au](mailto:ssstynes@vsk.org.au)



Dreams and lights create fundraising delights

Community fundraisers have shone brightly in recent months by raising money to provide services to the families we support.

Beaumaris couple Rob van Stokrom and Leonie Hill chose Very Special Kids as the charity partner for their annual Christmas Lights display. Hundreds of visitors came from far and wide to see one of Bayside's most impressive displays, helping to raise \$7,000. Lucy, Jasmine and Allegra (pictured) were enthusiastic visitors, taking a break from a hospice stay and getting right into the Christmas spirit.

To fundraising at a slightly difference pace, Dream Drives Melbourne raised more than \$9,000 at their inaugural 'A Very Special Dream Day' fundraiser. The luxury car hire company drove some of the world's most expensive sports cars down to the hospice to brighten up some children's days. Engines were revving as the fleet of Ferraris, Lamborghinis and Porsches wowed the children.



Special Snippets



School holiday magic at the hospice

Potions were brewed and spells were cast at the Once Upon a Time themed school holiday program at the hospice

Over three spellbinding weeks, children petted cute koalas, mixed magical potions, enjoyed musical activities and went on exciting excursions to the Tivoli Theatre and Scienceworks.

Wheelchair makeovers proved to be the most popular craft activity, with children racing around as fiery dragons

on wheels. The enchanting stories spun by visiting storyteller Matteo also left children spellbound.

Children donned wonderful hats for a delicious Mad Hatter's Tea Party, and created mystical dragon eggs and magical wands with help from Svetlana from The Art Cabriolet.

Operating four times each year for children staying at Very Special Kids Hospice, the school holiday program ensures that children with life-threatening conditions have access to activities and outings in a safe and controlled environment.

Very Special Kids achieves hospital standards

Very Special Kids has achieved National Safety and Quality Health Service Standards Accreditation, earning our eight-bed children's hospice the same stripes as the country's largest hospitals.

National Safety and Quality Health Service Standards (NSQHSS)

Accreditation, is usually reserved for large government-funded health providers. Very Special Kids independently achieved this accreditation to ensure its services were of the same high standard as the organisations that refer patients for hospice care and family support.

We excelled in our engagement with families, resulting in the NSQHSS survey team recommending a Met with Merit (MM) rating. With NSQHSS accreditation achieved, both families and health professionals can have additional confidence in the services we provide.



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