

NEWS

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Rafael enjoying the hospice
prior to *A Very Special Project*
commencing. **Update inside!**

“FROM THE CEO

Very Special Kids has encountered plenty of challenges as we navigate COVID-19 and adapt to a changed operating landscape. Without stepping through our challenges and resolutions, I will instead focus on the outcomes from our dedicated staff and their efforts, as well as the regard from our many stakeholders.

We have continued providing essential respite and end-of-life care to families, maintained vital counselling support and connection during the lockdowns, and our staff have embraced technology and adapted incredibly well to telehealth services. Since the beginning of the pandemic, many of our fundraising events have been postponed multiple times. However, we continue to be supported by our generous communities, allowing our focus to remain on service adaptation rather than scaling back.

Despite a six-month delay, our hospice rebuild project commenced in August. Through Federal Government and Victorian Government support, combined with incredible leadership from our Capital Campaign Committee and remarkable donors from across our community, I am pleased to announce our rebuild project is fully funded. We anticipate opening our new world-class facility in early 2023, raising the bar in our care for children and supporting their entire family.

As another sign of assistance, Monash Children's Hospital has kindly offered space in their facility while the hospice is rebuilt, ensuring minimal disruption to our services and continuity of care for children and families.

As we head into the last quarter of 2021, we continue to adapt our services and rebuild our fundraising platforms. I am so proud of how staff and supporters continue to unite to ensure we respond to our challenges swiftly and professionally. Thank you to our generous community for the important role you play in enabling our work and allowing us to continue supporting vulnerable people in our communities.

Michael Wasley
CEO, Dad and Donor



Machinery and tradespeople in hi-vis vests will be the new norm at Very Special Kids, with demolition of the original hospice now complete and construction of the new building set to begin. COVID-19 restrictions notwithstanding, we aim to celebrate the opening of the new hospice in the first quarter of 2023.

“This is a landmark moment, by far the most significant improvement project in our history, made possible thanks to you, our wonderful community of supporters.”

The new facility will elevate the level of care we provide families and solidify our position as leaders in children's palliative care. It will ensure the highest level of internationally led best practice care can be delivered for children with life-limiting conditions and their families across Victoria for generations to come.

It is also an opportunity to thank and acknowledge the magnitude of support from the Federal and State governments. With each tier contributing \$7.5 million respectively, the hospice rebuild project is now a reality.

New hospice build *underway*

At this time our highest priority is to maintain support and care for families with a sick child with minimum disruption. It is with great thanks that we have secured a private and dedicated space at Monash Children's Hospital, with the capacity to accommodate four beds for planned and emergency respite, as well as a separate space for end-of-life care.

Families and children can access all activity spaces and facilities throughout the hospital, including group therapy areas, indoor and outdoor spaces, play areas and therapy rooms. Our Family Support program will continue as normal, along with both face-to-face and telehealth consultations, and therapy programs.

So, with funding from government, as well as remarkable individuals, organisations and the philanthropic community, backed by the efforts of our Capital Campaign Committee, the project is now fully funded.

The project had an overall target of \$22.5 million, encompassing demolition, construction of the new world class centre and operational costs.

Our original hospice provided thousands of seriously-ill children and their families with a home-away-from home for over 25 years and created many lasting memories for families.



Today, the clinical needs of children are significantly more advanced and children are living longer with these conditions into adolescence, thereby placing higher care needs upon their families as full-time carers.

As many are aware, Very Special Kids is a predominantly self-funded charity, relying on the generosity of the community. As construction of the new hospice progresses we will keep you regularly informed.

Would you like to learn more? Please contact Jane Dinn, our Fundraising Lead, Private Giving and Capital Campaign Manager on 0409 886 166 or email jdinn@vsk.org.au.



A vital lifeline to families like Wil's

Very Special Kids relies substantially on the kindness of our community to allow us to continue to provide our services free-of-charge to families. As we continue to navigate our way through lockdowns, it is with a spring in our step that we can report an outstanding response to our most recent appeal and what it means to children like Wil and his family.

Thanks to generosity from across our community and your exceptional support, we raised more than \$200,000 to ensure children like Wil continue to receive the care and support they rely on. In times like these it's a remarkable effort, giving a boost to Wil and his whole family as they deal with his life-limiting illness.

Wil's mum Mel recently shared some photos with us, capturing celebrations from Wil's 10th birthday. It was a special milestone, as doctors had informed Wil's parents that it was a birthday he might never celebrate. So to have sister Aubrey beside him as the birthday candles were blown out marked an occasion the family will never forget. Your support means lasting memories are possible for families like Wil's.

It is with thanks to people like you that we can continue to offer families – just like Wil's – access to planned and emergency 24-hour respite. Parents tell us again and again how important it is to have a breather, to rest and reenergise. The community support also means we can carry on providing social, emotional and practical support for the whole family. We can offer counselling for parents in need and actively advocate to corporates and tiers of government, communicating the roles our people and programs play.

It means our sibling support programs can not only be sustained but evolve, further improving the opportunities for other young people experiencing similar situations to meet and engage with their peers. We can forge ahead with our hospice therapy programs, helping to build emotional, sensory and motor skills. Finally, and crucially, we can continue to train a cohort of in-home volunteers.

We extend a heartfelt thank you for your generosity – you are making a genuine difference to the children and families in our care.



Meet Helena Olofsson

As a student Helena made it her mission, once graduated, to provide support for vulnerable children and their families. She is a professionally trained and registered music therapist, adapting music to facilitate meaningful experiences unhindered by illness or disability. Helena is a vibrant presence at Very Special Kids, in a position funded with great thanks to the Campbell Foundation.

"Music enhances non-verbal and verbal communication, provides comfort and relieves distress," says Helena. "A child's wellbeing and quality of life can be enhanced, and music can also be adapted to support families to create a musical legacy of their child within end-of-life care."

Helena has a unique role at Very Special Kids, adapting musical interventions to meet different needs and facilitating music therapy sessions. "Using music as a support tool that is motivating for engagement and emotionally meaningful is very special to my role," she says.

A violinist herself, Helena hails from Sydney and thrived in student orchestras, as well as playing netball and dancing. She loves camping and is an avid traveller, most particularly to Europe and Sweden, where she has family.

Music Therapy continues to be part of our multidisciplinary services thanks to the ongoing generosity from the Campbell Foundation.



Outer North school holiday programs

It's thanks to Freemasons Foundation Victoria that we have been able to expand our Family Support program to Melbourne's outer north. The new South Morang office provides families in the area access to sibling and family days which commenced in April this year.

The new location is proving popular, with one parent reflecting: "The quick 20-minute trip was super convenient and we all really hope Very Special Kids can offer Epping activity days again."

An indoor family day was also held in late June, with families enjoying art activities, billy cart making and racing, a delicious lunch and plenty of inter-generational mixing. Our team was thrilled with the connections made between siblings and family members who had met earlier in the year.

Expanding Sibling Programs to the outer north metro area was made possible thanks to a generous grant provided by Freemasons Foundation Victoria and supporters like you across our community.

The feedback makes it all worthwhile, with another parent letting us know that, "the kids came home bursting from excitement, absolutely raving about the best day ever! Thank you for putting all of this together."

Yarraville Bereaved Parent Group

With thanks to support from Freemasons Foundation Victoria, a recent pilot program gave parents an opportunity to reflect and share the meaning of the death of their child and how it impacts their lives.

The funding enabled Family Support Practitioners to run the four-week program for the Yarraville Bereaved Parent Group with the aims of normalising grief experiences and building resilience.

At the end of the program, parents were overwhelmingly positive, with a shared sentiment that the program was ideal to "open up and learn from others."

Some of the parents admitted to a sense of apprehension beforehand but once face-to-face meetings were possible those feelings melted away. There was a connection to the struggle other parents were experiencing, and relief to be invited to talk about their children with those who felt the acute pain of loss and grief.

"I feel like the course is stirring and planting seeds of healing that I had not quite uncovered," noted one parent. "We developed a sense of connection amongst the group," said another. "Although our circumstances are different it didn't matter as our grief was the same."



The Greenland family remember Jonah

“I don’t want anyone to go through this horrible journey and not feel the love and support around them, like what we get from Very Special Kids.”

Caleb was taken to receive some breathing support, and Amy and Brett spent their precious time with Jonah making him feel as loved as possible. Shortly after word came that Caleb was breathing independently, Jonah slipped away - just 90 minutes after his birth.

Thanks to community support, the family have access to a dedicated Family Support Practitioner to help them cope with life after the death of Jonah. They also attend family networking programs and events, access bereaved sibling support for Jonah’s brothers and sisters and attended the bereaved parent weekend in May this year, all made possible thanks to supporters like you.

Wanting to make sure that other families have access to the same support they received, the Greenlands have been phenomenal in raising thousands for Very Special Kids. In addition to their annual Christmas lights display, last year the Greenland family raised funds for our first ever Giving Day. Now an annual fundraising ‘call to arms’ this year we are holding A Very Special Day on Thursday 7 October, when all donations will be matched for a 24-hour period.

“My message to any individual that wants to donate... whatever it is that you’re going to give could change someone’s world. Could provide the hope that they need just to survive... Right now, without Very Special Kids we wouldn’t be here. We wouldn’t be where we are today as a family.”

You can support A Very Special Day by visiting
vsk.org.au/averyspecialday

The Greenland family refer to Very Special Kids as a club that not many people know about, and that you wouldn’t choose to be part of. But, rather than focusing their energy on the heartbreaking circumstances that brought them into the Very Special Kids club, the family show remarkable determination to create hope and positivity from their experience.

Amy and Brett faced an unbearable prospect in 2018. They had three children when they found out they were having twins, but were told early in the pregnancy that one of the twins was unlikely to be born alive.

This was a devastating time for the family and it’s only now, three years later, that they feel ready to share their story.

They describe Jonah’s story as one of hope. He was a fighter. When Jonah was born, the paediatrician told Amy and Brett they may only have a few minutes before he passed. But six minutes later when twin brother Caleb was born and they were reunited on Amy’s chest, Jonah suddenly improved.



Jane Ansell



David Gibbs AM

Volunteer Service Awards

The opportunity to recognise the devotion and talents of our Very Special Kids volunteer cohort is a highlight of our calendar. Although we couldn’t host the appreciation night, for the second year running, we were able to acknowledge some remarkable volunteer milestones.

David Gibbs has now twice missed out on collecting his 25-year voluntary service award, however he did pick up a Queen’s Birthday Order of Australia honour earlier in 2021 for his significant service to the community and to the chartered accounting profession. Well done, David! We also pay tribute to the tireless efforts of another long-term volunteer, Jane Ansell, who received her 25-year volunteer service award. She recently spoke of her love of volunteering at Very Special Kids, an organisation she first heard about from a friend.

“I had been thinking of doing some type of voluntary work but wasn’t sure what,” Jane says. “I had thought I would like to be with a family but nothing came up for quite a while, and I was offered a place on the hospital team at The Royal Children’s Hospital. That is where I stayed for 16 years.

“It was a wonderful experience and a privilege to be with some families at very difficult times in their lives. [Now] I’m looking forward after last year, to helping raise money for this wonderful organisation. It is very true that volunteering in such a caring and supportive environment which gives you so much more than you could ever give back.”

Without the commitment and dedication of volunteers, we simply wouldn’t be able to offer the breadth of what we do.



Melbourne Cup Carnival volunteer opportunities

Hats and frocks at the ready, because in exciting news we are once again the official charity partner of the VRC (Victoria Racing Club) 2021 Melbourne Cup Carnival! This will be our third and final year of the partnership and we are hoping to surpass our previous efforts, aiming to raise \$1 million towards essential services like the rebuild of our children’s hospice.

We need armies of volunteers to assist with selling pins at Flemington Racecourse throughout the carnival week. So, if you thrive in the racing atmosphere, or perhaps it’s something new, please check your availability for any of the below dates and get in touch with Lou on lcooney@vsk.org.au.

Scheduled race days:

Saturday 30 October - Penfolds Victoria Derby Day
Tuesday 2 November - Lexus Melbourne Cup Day
Thursday 4 November - Kennedy Oaks day
Saturday 6 November - Mackinnon Stakes Day



You can support by purchasing a Lexus Melbourne Cup souvenir pin from vsk.org.au/shop
Pin sales contribute towards our \$1m target.

How to get involved

There are many ways you can support Very Special Kids so we can continue to provide our essential services to children and families free-of-charge.



Make a regular tax deductible gift

Monthly, quarterly or yearly



Collect donations in a piggy bank

Work, school or home



Leave a gift in your will

Ensure your legacy lives on



Ask for donations in lieu of gifts

Birthday, wedding, bar/bat mitzvah or any other celebration



Volunteer

In the hospice, with families or help with fundraising and administration



Develop a corporate partnership

Sponsorship, cause-related marketing, workplace giving, volunteering or in-kind support



Organise your own fundraising event

A fun run, trivia night, food and wine function, movie night, concert or fashion show



Attend or support one of our fundraising events

Piggy Bank Appeal, 24 Hour Treadmill Challenge, Footy Fever Debate, Golf Day, Ladies Lunch, and Annual Fair



Make a donation

@ vsk.org.au

✉ Mail a cheque or money order payable to **Very Special Kids**,
321 Glenferrie Road,
Malvern, Victoria 3144

☎ Call **03 9804 6222**