



# NEWS

Edition 1 | 2022

*Very Special News*

You're part of our very special community



## FROM THE CEO

Thank you for your support of Very Special Kids and the children, young people and families in our care. We are truly grateful for the immense generosity each and every one of you have provided for seriously-ill children and their families.

As we commence a new year, the kindness from supporters like you ensures we are able to continue to adapt and change the way we deliver care to children and families to help improve their quality of life and death and create positive, lasting memories. Most importantly, your support means our expert team can continue to deliver the very best palliative care, alongside various vital services for the whole family for as long as they need.

This year we are excited to be able to bring back a lot of our staple fundraising events and programs that have been canceled or postponed over the past two years. Our recovery plan is now in place and in this newsletter, you can read about how you can play a leading role in it by becoming a Very Special Guardian.

At the beginning of the year, the Omicron variant of COVID-19 presented some further set backs to our interim respite services at Monash Children's Hospital. Despite this, the project to rebuild our hospice made significant progress and we are on track to open the doors to our new world-class facility in early 2023.

Thank you once again for your continued generosity, support and passion, you are truly impacting the lives of children, young people and their families across Victoria. We couldn't do it without you!

**Michael Wasley**  
CEO, Dad and Donor



## Building towards a brighter future

In December 2021, we were joined by Federal Health Minister, The Hon. Greg Hunt MP and Parliamentary Secretary for Health, Mr Steve McGhie MP along with other members of parliament and key supporters from across our community to turn the sod on our site. The special event marked a watershed moment in our history and significant steps forward for paediatric healthcare in Victoria.

The Very Special Kids grounds are buzzing with excitement, as construction of the new world-class facility moves from strength to strength.

With the in-ground services and foundation walls now completed, and the elevator shaft now in place, our construction partners, Plan Group, have established the basement floor. Towards the middle of this year, the ground floor and first floor areas will also be established, and we will start to see the above ground structures and supports take shape.

We are well on track to open this amazing new building in early 2023, and will be one of the world's best hospices for children right here in Victoria. All thanks to the remarkable support from the Federal and State governments, local members of parliament, Capital Campaign Committee and philanthropic leaders from across our community.

Thank you for sharing our vision and bringing our new hospice to life – you are all playing a very special part in the future of paediatric palliative care in Victoria.



## Your Impact

Although 2021 was another challenging year due to the ongoing impacts of COVID-19, the goodwill of our very special supporters, like you, allowed us to remain agile and pivot to enhance the way we delivered care during the pandemic, ensuring we continued to meet the needs of the children and families we support.

The families in our care not only face many challenges navigating their child's life-limiting illness, but ongoing isolation from social and support networks have been tough throughout the pandemic.

It is thanks to our wonderful community of supporters that our team have been able to continue to deliver the very best palliative care through our vital services to support seriously-ill children and young people, and their families.

In 2021, we are so proud of these things you helped us to achieve:



**874**  
families supported  
by Very Special Kids



**544**  
face-to-face  
consultations



**2,815**  
digital counselling  
and emotional  
support sessions



**139**  
in-home respite  
and end-of-life  
care sessions



**83**  
end-of-life  
care nights



**55**  
networking activities  
and support programs  
for parents, carers  
and siblings

## Adapting our care

The interim in-home respite service is just one of the ways we innovated and embraced new ways of delivering our services throughout the COVID-19 pandemic, thanks to your generosity.

The in-home service also allowed us to continue caring for children and families at the beginning of this year when the Omicron variant was prevalent in the community and our respite services at the Monash Children's Hospital was placed on hold.

Children and young people with high-complex needs are cared for in the safety of our expert team, offering family members valuable down time and support in the comfort of their own home.

Very Special mum, Laura shares how the interim in-home service helped her and her whole family last year,

“ We have found the in-home respite program so helpful, being able to go out with the boys on new adventures and Ivy getting one on one attention has been great. ”

Laura, mother of 6-year-old Ivy who has Developmental Epilepsy Encephalopathy. (pictured above)





## Everley's Story

**“It's organisations like Very Special Kids that have helped us enormously. You sort of think to yourself, where we would be had these guys not been involved?”**

Rick, father of 3-year-old Everley, who has Kabuki syndrome

Jo and Rick Rawson have three gorgeous children, Mila, Everley and Arlo. However, their home life is very different compared with most families.

Everley was born with multiple complications and spent the first six months of her life in hospital. Aged ten months, she was diagnosed with Kabuki syndrome, a rare, multisystem disorder. Now three and a half, Everley receives ongoing medical care and is looked after at home by her loving parents and siblings.

“We were told pretty much the worst-case scenario when she was a couple of weeks old,” says Jo. “She’s not going to walk, not going to talk, she’s probably going to be wheelchair bound.”

The family’s logistics are challenging; Rick works full-time, Jo tries to fit in 20 hours of work a week, while Mila attends primary school and Arlo has day care.

That’s why generosity from our incredible supporters, like you, is so important for families like Everley’s. It enables us to provide all the practical support, assurance, and some welcomed respite, ensuring the family are not alone in their journey.

Jo shares, “I’ve met other families in similar situations at the coffee mornings, which has been fantastic because sometimes it’s a lonely journey, especially as parents.”

The family reserve special praise for their trained volunteers, Coral and Simone.

Jo gets a much-needed break when Coral visits once a week to look after Arlo, while Mila is taken on outings by Simone.

Thanks to our wonderful community, Mila has benefited greatly from the Sibling Program, looking forward to every opportunity to mix and play with other kids.

Despite 23 surgeries and interventions, the prognosis for the quality of life Everley can experience is more optimistic than originally thought.

“Everley is stronger than what we were initially told she was going to be,” says Rick. “Walking and trying to communicate is over and above what we were expecting. So, we’re pretty lucky.”

“Everley is an amazing little princess, daddy’s girl, but in saying that, dad has shed a few tears over the journey,” says Rick. “You never want to see your kids come to harm. So don’t ever feel like you’re alone, because Very Special Kids have made such a difference.”

It’s thanks to the ongoing support from our very special community that Everley and her family are able to have the best possible quality of life and create positive lasting memories together.



## A Very Special Farm Experience

**“A little piece of heaven here! This place just recharges your soul and is so peaceful... Thank you deeply from us all.”**

Very Special Kids parent

Thanks to the compassionate support of our very special community, we can continue to provide accessible and free-of-charge holiday accommodation to the children and families we support across Victoria. Glen Osmond Farm has provided Very Special Kids’ families the chance to switch off and relax in the great outdoors.

It has offered families with a relaxing break at a peaceful farm just outside the township of Woodend for seven years. The purpose built, fully accessible farm continues to foster positive memories for children, young people and families across Victoria. The farm features two holiday cottages that can sleep up to eight people in three bedrooms, as well as a big barn for entertainment and amazing views across to Mount Macedon. And best of all, there is no charge for families to use the cottages thanks to the ongoing support from across the community. Special thank you to Joe Mediero, Ron Howard and Tania Howard for maintaining the property. And, Janet and Bernie Hawkins for their generous donation of Glen Osmond Farm. One family shared.

*“Glen Osmond Farm is truly a special place, and now holds a space in our hearts. We especially love the sheep and feeding them treats... Jenny loves sitting in the highchair and watching the kangaroos bounce past. We all learnt the sign for kangaroo. We are so grateful. Thank you.”*



## Championing the voices of our youth

At Very Special Kids, we are always inspired by the strength and resilience of the children and young people we meet. Thanks to Freemasons Foundation Victoria, we have been able to launch our Youth Advisory Group (YAG), a new initiative that offers very special siblings, between the ages of 14 to 25, a platform to share their voice and have an impact on the way we deliver our services.

YAG member and Very Special Kids sibling, Jude (17-year-old, pictured above left) shares, “As the youth who are being supported by Very Special Kids, we can talk to other youth members, and understand what they want out of each program. It really can allow events to be tailored to better fit the needs of different youth. Which is really awesome.”

The program offers young people a great platform to develop their leadership skills and connect with other like-minded young people across Victoria to exchange ideas, mentor others and understand the complexities of having a sibling with a life-limiting condition.

“It’s important for young people to just feel heard. So many kids want to be given responsibility and have a chance to make a difference. Especially when it impacts them,” shares YAG member Maryjo (23-year-old, pictured above right).

Thanks to the ongoing generosity from the Freemason Foundation, the YAG is an exciting opportunity for Very Special siblings and a great way to improve the way we deliver care to children and young people.

Chairman of Freemasons Foundation, Rodney Lavin shares, “We are proud to be announcing funding for some incredibly valuable projects that promise to benefit the Victorian community. These grants will support charities to help those in need or empower the youth of Victoria to achieve their dreams.”



MEET VERY SPECIAL KIDS SCHOOL CAPTAIN

# Noah

“

There are not many people you can honestly and openly talk about such darkness with and at the same time laugh about the wonderful moments. Our family support practitioner is magical. Just knowing she is there and there is nothing I can say to her that will shock her is a big deal.”

Kat, mother of 11-year-old Noah who has Mitochondrial Disease

Very Special child, Noah, is proof that leaders come in all shapes and sizes. The 11-year-old, who was born with Mitochondrial disease, has started his new school year with the distinguished title of School Captain. A big advocate for diversity, Noah is an active member of the Very Special Kids community and is dedicated to being a role model for other children who have a disability or life-limiting condition.

Noah, who normally gets around in a wheelchair he calls Bumblebee, was born with Mitochondrial disease (known as mito) - a debilitating and potentially fatal condition that reduces the ability of mitochondria to produce energy.

Born at just 29 weeks, Noah had an allergic reaction to everything his parents and carers attempted to feed him at birth. At 18-months old he began to suffer from stroke-like episodes and has experienced eight metabolic strokes in his lifetime.

Although now able to eat some 'safe' foods, the exhausting effort it takes to eat them necessitates that he has a tube feeding him a special blended diet directly into his stomach 24-hours every day.

Noah's family were referred to Very Special Kids in 2015, shortly after he received the diagnosis of Mitochondrial disease. Thanks to support from across our community, for the past five years, the family have been supported by one of our dedicated Family Support Practitioner's, Pauline.

Noah's mother Kat shares, "We love Pauline so much. She always seems to know when to give us space to process new information or big changes for Noah, but she also knows when to keep calling. There are not many people you can honestly and openly talk about such darkness with and at the same time laugh about the wonderful moments. She is magical. Just knowing she is there and there is nothing I can say to her that will shock her is a big deal."

Noah has had many visits and enjoyed special events at our children's hospice and attended the camp program, all while making some lifelong friendships with other children in our services.

Without the compassion from our kind supporters like you, life changing moments like these simply would not be possible for children like Noah.

Noah says, "I love playing with my friends at the camps. I also really love when the fire trucks and motorbikes visit. We get to go on the back for a ride, it is so much fun!"

Despite the impact of his condition, Noah, is dedicated to living his life to the full potential and being a role model for other children who have a disability or life-limiting condition. And Very Special Kids will be right beside him and his families to do all that we can to help Noah achieve these goals.

"I want to be a leader because my future job might need me to be a leader. I want other kids like me to know that there are no limits to life and to always have fun."

According to his Family Support Practitioner, Pauline, Noah has continued to capture the hearts of people around him with his playful, upfront, and determined self.

"Together, Noah and his mum Kat have a connection that warms the hearts of everyone in the room. Clearly, the pleasure is all mine, in supporting this family and I vicariously share the pride that comes with Noah's achievements. What a trooper he is!" - Pauline.



After two years apart, our powerhouse volunteers were all under the same roof for our end of year celebration.



## Volunteer achievements

The opportunity to recognise the devotion and talents of our Very Special volunteers group is a highlight of our calendar. We had an incredible time celebrating award milestones and reconnecting with the volunteers, who are the heart and soul of Very Special Kids at our end of year celebration.

We would like to recognise the upcoming milestone achievement of Steven Rosewarne, who is celebrating 30 years with Very Special Kids this year. Steven is one of our longest serving volunteers and has been with the organisation through tremendous change and growth, including the building of our original children's hospice in 1996. Volunteers like Steven are few and far between. He is humble about his achievements with Very Special Kids and dedicated to supporting children and their families through the most difficult of times. Steven, we cannot thank you enough for all your support over the years.

Another remarkable volunteer, Ros Ferres, recently received the Australia Day, Local Champion Award for her long-term dedication and selfless commitment to helping others.

This esteemed honour is well-deserved, as Ros has dedicated many years of her life to helping charities like Very Special Kids – supporting our services, since we first opened our doors in 1985. A modest volunteer, Ros did not expect to receive the Mornington Peninsula shire's award.

"I love volunteering for Very Special Kids, because everyone is treated equally, everyone is always included. It is just a really nice place to be. A lot of people don't realise that being a volunteer means a lot more than just supporting at the hospice. There is plenty of ways you can get involved and make a difference. Local crafts, working at the fair, admin jobs – there is something for everyone and each role plays an important part in making sure families receive the care they need," shares Ros.

**Without the commitment and dedication of our volunteers, we simply could not offer the breadth of holistic services we do.**

Learn more about Very Special Kids volunteer program at <https://www.vsk.org.au/support-us/individuals/volunteer/> or contact [volunteering@vsk.org.au](mailto:volunteering@vsk.org.au)





“Very Special Kids have been extremely important for us from the time of Reggie’s diagnosis through to the continued support we receive today. And running is important to me immediately after Reggie’s passing – it was a way of having some time with him. We will forever be indebted.”

Chris, bereaved father of 2-year-old Reggie who had Infantile Onset Pompe Disease



## TEAM VERY SPECIAL KIDS TAKE ON Melbourne Marathon

Last year, 579 participants joined Team Very Special Kids as part of the Nike Melbourne Marathon Festival, together raising nearly \$70,000 for the children and families in our care.

Thanks to this amazing support from our participants, Very Special Kids can continue providing specialist palliative care to improve the quality of life for children, young people and their families. Teams and participants ranged from first time marathon runners to seasoned pros.

Very Special Kids Community Ambassador and Former Miss Universe and Speech Pathologist, Olivia Molly Rogers, (pictured above right) was one of the participants running for Very Special Kids – leading the way and raising an incredible \$7,542.15 as our top fundraiser.

Olivia shared, “I have seen first-hand the work they do. It is just an incredible cause, and I cannot think of a better one to support. Running a full marathon has been on my bucket list and I thought what better opportunity to support Very Special Kids and do it for an amazing cause!”

Another Community Ambassador participating in the half-marathon was Chris, who has a personal connection with Very Special Kids. Chris’s son Reggie died at age two in 2019 after being diagnosed with Infantile Onset Pompe disease. Reggie spent his last hours at the Very Special Kids hospice surrounded by family and our specialist team. The family continue to access expert counselling and a range of support programs at Very Special Kids.

Chris has run in the Melbourne Marathon Festival since 2018 and has raised vital funds for Very Special Kids, year on year.

Chris said “Very Special Kids have been extremely important for us from the time of Reggie’s diagnosis through to the continued support we receive today. And running was important to me immediately after Reggie’s passing – it was a way of having some time with him. We will forever be indebted.”

Property advisory group SEMZ were the top fundraising team for Very Special Kids, rallying their staff to raise a remarkable \$7,283.

In a year when many members of Team Very Special Kids have faced their own challenges, this is a phenomenal outcome, and on behalf of the children and families we support we are so grateful to our dedicated and empathetic supporters.

**Want to get involved? Join us at Run Melbourne.**

If you missed the Melbourne Marathon or are ready to challenge yourself, consider joining Team Very Special Kids for Run Melbourne on **24 July 2022**.

Choose your challenge and go the distance to help Team Very Special Kids raise funds for children and young people with life-limiting conditions, and their families. Find out more by visiting our website at <https://runmelbourne22.grassrootz.com/vsk>



## A Very Special home

Award winning new home builder, Henley Homes are well entrenched in many communities across Victoria, and so too is their dedication to making a difference in these communities. This year, Henley Homes will help build a better quality of life for sick children and families by building and selling one of their stunning homes. All proceeds from the sale will be donated to Very Special Kids hospice rebuild.

Construction of one of Henley’s most popular home designs, the Ashbury 30, commenced at the beginning of March at The Dales, Bonnie Brook. Ben Griffiths, General Manager of Henley Homes completed homes division said, “Our aim with the building and sale of this double storey home is to ensure Very Special Kids has the resources to continue the care and support for children and young people with life-limiting conditions and their families.”

Located in Melbourne’s outer west, the double storey 30-square home boasting Henley’s popular Novello facade includes four bedrooms all with walk in robes, four living areas and an expansive master suite with an oversized dressing room. The home will be appointed with luxury fittings and fixtures, and finished with professional landscaping, decking, ducted heating and window coverings – everything a buyer needs to move straight in.

It will hit the market in early November with all proceeds from the sale going to Very Special Kids

**To discuss other partnership opportunities, please contact John Strachan on [jstrachan@vsk.org.au](mailto:jstrachan@vsk.org.au)**



## CommBank get pretty in piggy pink

As long-standing major partners of Very Special Kids, Commonwealth Bank held their annual CommBank Very Special Day in November last year. A total of 203 branches decorated their premises in all things piggy and pink and invited customers and local residents to purchase their piggy merchandise from their local branch.

Commonwealth Bank have been supporting the Piggy Bank Appeal since it began 24 years ago, raising a total figure of \$2.9 million. Thanks to their ongoing and generous support, generations of children and young people have had access to our services to better support their quality of life, and their families have been fully supported during the most difficult times.

Commonwealth Bank Regional General Manager Melbourne, Nicole Rahme and Regional General Manager Victoria and Tasmania, David Castle, said Commonwealth Bank is proud to continue its association with Very Special Kids and the amazing work they continue to do each and every day.

“In what has been an incredibly difficult couple of years for all charitable organisations, collectively we recognise that we can make a major difference to the lives of families with kids with life-limiting conditions and it thrills us to be involved in the appeal. We encourage all Victorians to join with us by buying some piggy merchandise or making a donation during the Piggy Bank Appeal in 2022,” they said.



## Becoming a Very Special Guardian



As Victoria's specialists in children's palliative care, the generous support of our community, especially gifts left in Will, has provided us the security to help generations of Victorian families.

Wills are a wonderful opportunity to take comfort in knowing that the people that matter to you the most benefit from your life's work exactly as you would wish. When you add a charity you care for, like Very Special Kids, Wills are also an incredibly powerful tool for positive change.

By leaving a gift in your Will, you will join a valued circle of supporters we refer to as Very Special Guardians. Together, we can provide future generations with holistic children's palliative care services, for the whole family.

We appreciate that leaving a gift in your Will is a big decision to make, it is important to research and understand your options, so you can make the best decision for yourself and your loved ones. Every gift, big and small, can make an incredible difference.

Our patron, Sister Margaret Noone AM shares, "A gift in your Will is the most joyful thing. It gives those of us blessed with longer lives the chance to share our good fortune with children and families whose time together may be fleeting."



### Sue's Living Legacy

Remembering Sue Hardiman, super volunteer and Very Special Guardian. For more than twenty years, Sue Hardiman devoted almost every spare minute of her time to volunteering with Very Special Kids.

For Sue, giving to those in need came easily, and it brought her great joy to see the comfort her efforts would bring. She told us that this was why she made the life-changing decision to leave a gift in her Will and become a Very Special Guardian. The future Sue imagined became a reality when she sadly died in 2021. She is greatly missed, but the comfort she took from becoming a Very Special Guardian is now felt by her loved ones — who know that her legacy lives on, helping to improve the lives of seriously-ill children and create positive memories for their families for generations to come.

**"I am a great believer that people should give back and when you make a Will, you leave it to the people who can benefit. I know that my gift will support a family who needs respite, emotional support, counselling and care and that is satisfying to think I can help provide that."**

Sue, Very Special Kids volunteer and Very Special Guardian

By becoming a Very Special Guardian, your kindness and generosity will extend beyond your lifetime, just as Sue's has done. Leaving a gift in your Will helps us plan for the future, ensuring we can continue to provide the best quality of life for children and young people with life-limiting conditions, and their families. It also gives us the chance to personally thank you for your generous support in your lifetime, while keeping you up-to-date on the expert care we are providing to families.

**Learn more about the Gift in Will program by contacting Emily Sheldon at [mail@vsk.org.au](mailto:mail@vsk.org.au) or call (03) 9804 6222.**



**"To those who help make all this possible by choosing to leave a gift in their Will. I could never thank you enough. Only those like us who have experienced the care you supply can truly understand what it means."**

Kristy, mother of 7-year-old Jett who has KCNQ2



# 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

Once or regularly each month



## Collect donations in a piggy bank

Work, school or home



## Become a Very Special Guardian

Leave your legacy in a will



## Ask for donations in lieu of gifts

Birthday, weddings, any celebration



## Become a Volunteer

Provide respite for families, help fundraise or offer administration



## Develop a corporate partnership

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



## Organise your own fundraising event

A fun run, trivia night, movie night, the options are endless



## Attend or support one of our fundraising events

Piggy Bank Appeal, 24 Hour Challenge, Autumn Classic, Giving Day, Footy Fever Debate and/or Annual Fair.



## Make a donation

@ [vsk.org.au](https://vsk.org.au)

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

☎ Call **03 9804 6222**

f @veryspecialkids

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in [linkedin.com/company/very-special-kids/](https://www.linkedin.com/company/very-special-kids/)

### Donate Now



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