

A very special
**annual
report**

2023–24

A new chapter for
paediatric palliative care





“Very Special Kids was amazing. You just feel such a big weight off your shoulders... like you can breathe easier.”

— Nadja, mum of 9-year-old Luca who has an undiagnosed life-limiting condition

Acknowledgement of Country

Very Special Kids acknowledges Aboriginal and Torres Strait Islander people as the First Peoples and Traditional Custodians of the lands and waters throughout Victoria and pays respect to them, their Elders and communities past, present and future.

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Pictured: Very special child Luca playing with his mum Nadja in the multisensory room (left), nurse caring for child at Very Special Kids House (front cover).

Our impact

We believe every child has the right to quality of life, no matter how long or short their life may be.

Very Special Kids provides holistic palliative care for children and young people with life-limiting conditions, and tailored support for families – through life, death and bereavement.

Here are some of the ways we made a very special difference in the 2023–24 financial year.



704
families
supported



6,650
hours dedicated
by our volunteers



4,856
sessions of
counselling and
emotional support



75
activities to
connect families



622
nights in holiday
accommodation



1,093
nights of respite,
end-of-life and
after death care



212
nights in family
accommodation

97%

of families who used
Very Special Kids House
said their child's **quality
of life improved**

94%

of families strongly
agreed that their child
**enjoyed their stay
and had fun**

81%

of families who stayed
at Very Special Kids House
**don't use any other
care facilities**

Message from our leaders

Very Special Kids has taken a significant step forward for paediatric palliative care in Victoria in 2023–24.



Opening Very Special Kids House

In November 2023, we unveiled our world-class children's hospice. Named in honour of our patron and first employee, the Sister Margaret Noone Hospice at Very Special Kids House has maintained a home-like atmosphere. At the same time we have significantly enhanced our clinical support for children and young people with life-limiting conditions. Its progressive design integrates accredited family support and hospice services under one roof.

This seven-year project incorporates world-leading research from the University of Melbourne School of Design and has received validation from clinical staff and families alike. The facility has offered more than a thousand nights of respite care to children, as well as compassionate support to dozens of families during their child's final days. Thanks to generous contributions from our philanthropic community, including the Australian and Victorian governments, this ambitious but important project is now a reality.

With an enhanced medical model of care, Very Special Kids House is set up to nurture the growth and education of our hospice team. We have also expanded the capacity of our chief medical officer, welcoming Dr Katie Moore to head our dedicated team of doctors.

Sister Margaret's milestone

The opening of Very Special Kids House wasn't the only milestone commemorated this year. We were also privileged to celebrate Sister Margaret's 90th birthday. A trailblazer and pioneer for Australia's paediatric palliative care, Sister Margaret has dedicated 39 years of her life to Very Special Kids and remains a frequent visitor to the hospice. Like its namesake, the hospice will revolutionise the way we provide paediatric palliative care now and into the future.

Sustainability

Very Special Kids has continued to successfully navigate the fundraising challenges that arose from COVID-19 disruptions. Like the wider Victorian community, we have also been impacted by a taxing economic climate. Despite these challenges, we have generated sufficient annual income to pay for the costs of maintaining our much-needed services for children and families.

In 2023–24, we refreshed a number of our longstanding events to improve guest experiences and financial returns. Additionally, we are securing long-term sustainability through the growth of our Very Special Guardian community, who have generously committed to leaving a gift to Very Special Kids in their Will. Furthermore, we remain supported by invaluable individuals and organisations who year on year enable us to help families when they need us most.

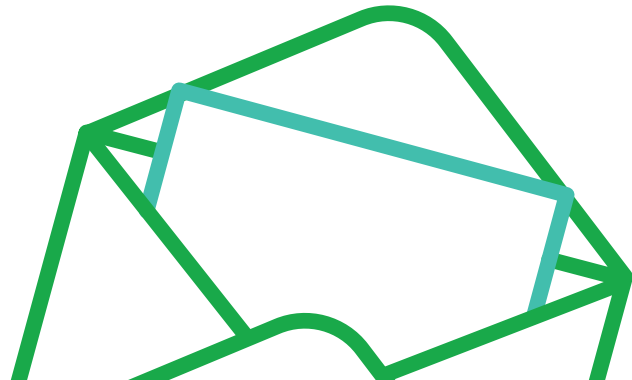
With the capital costs of rebuilding and refurbishing the new hospice now behind us, our next focus is to build and strengthen our fundraising streams. This will not only support our present work with families, but will equally prepare us for future generations of families who will need our support. Our family, youth and children's advisory groups have continued to provide valuable first-hand feedback on our programs and services. They ensure Very Special Kids can tailor our essential care and respond to the challenges families face.

A very special thank you

Despite Australia's challenging economic climate, hundreds of volunteers and thousands of individuals and organisations remain committed to helping Very Special Kids deliver our essential services, including the Victorian Government and our vital corporate partners. The combined efforts of this community motivate and fuel our directors, managers and team members to continually enhance our programs – fostering a better quality of life for each child and family who needs us. Our supporters remain our bedrock, and we deeply value their partnership. Thank you.

Peter Polson Chair | **Michael Wasley** CEO

Pictured: Peter Polson, Chair (top left), Michael Wasley, CEO (bottom left), Sister Margaret Noone, First Employee and Patron (right).



In the spotlight

Message from our first employee and patron

The last 12 months have brought me such joy as we welcomed children and families back to Very Special Kids House.

The reopening of our children's hospice has been a highlight that I, and the whole team at Very Special Kids, have been eagerly looking forward to. It has been heartwarming to see the smiles on the children's faces and hear them explore the many wonderful new areas during their stay. Offering much-needed respite to families, and the comfort of knowing their child is in safe hands, is very important to us at Very Special Kids.

There has been a great deal of change in recent years, and I am so proud of how the staff and volunteers at Very Special Kids have adapted and welcomed new ways of supporting children and families in our care. We are privileged to be there for these families when they need us and are committed to providing upmost compassion and care during their most challenging times.

Sister Margaret Noone,
First Employee and Patron AM IBVM





A very special house

On 21 November 2023, Very Special Kids celebrated a significant milestone with the grand opening of the newly rebuilt Sister Margaret Noone Hospice at Very Special Kids House.

The day marked the beginning of a new era in paediatric palliative care for Victorian children, young people and their families. Notable figures such as Assistant Minister for Health and Aged Care The Hon. Ged Kearny MP, Parliamentary Secretary for Health Infrastructure Tim Richardson MP and senior Wurundjeri elder of the Kulin nation Aunty Joy Murphy Wandin joined our very special community for this auspicious occasion. Read more on page 27.

When Very Special Kids House first reopened its doors, we accommodated a select group of children and young people for respite care, to help familiarise staff with the new space. Occupancy increased through the year, with 1,093 nights of respite, end-of-life and after death care delivered.

Our children's hospice is a place where life is celebrated and every moment is cherished. It is also, importantly, a place parents and carers can rely on for a much-needed break.

The world-class facility is purpose built, offering seriously ill kids the highest level of medical care, comfort and support. Each space is designed




“I trust this place with my daughter’s life... I went home, and I slept for the first time without playing doctor, nurse, support worker, or anything else.”

— Margie, mum of 12-year-old Mia who has holoprosencephaly

to provide a sense of freedom and personal choice – from soft play, multisensory and multimedia rooms to accessible outdoor spaces, like the courtyard and playground. Inside, the lounge, kitchen and dining area mirror a home environment, offering children a feeling of familiarity and warmth. Essential features – like medical gas outlets and ceiling hoists – have been discretely placed throughout the building to help make the hospice feel more like home.

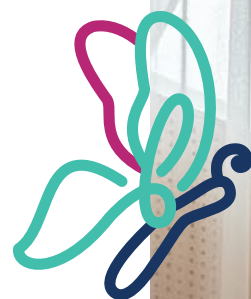
One of the hospice's standout features is the Balam Balam suite, named after the Woi wurrung word for butterfly – the language of the Wurundjeri people of the Kulin nation whose land Very Special Kids House resides. Bathed in soft light, the peaceful suite provides a private, calming environment for families to spend precious moments with their child after their death.

Inside the suite, a special bedroom is climate controlled to safely care for a child's body. Unlike a hospital, families can have up to seven nights in the Balam Balam suite to breathe, grieve and remain together while they plan the next steps in caring for their child and preparing for their final resting place. → [Continued.](#)

 **1,093**
nights of respite, end-of-life and after death care

 **723**
hours of allied health support, including music, play, creative, physio, aquatic physio and occupational therapy





“The Balam Balam suite made it a beautiful memory rather than a dark one... It allowed us to be with Tae’s body, to process his death in a way that felt right for us.”

— Seol, bereaved mum of 11-year-old Tae Yoon who had Shwachman-Diamond syndrome

Another unique aspect of our holistic approach to care is the presence of our cook, Brad Leitch, and trained kitchen volunteers, who create home-cooked meals tailored to each child’s dietary, medical and cultural needs. They also ensure families eat well when staying for end-of-life and after death care.



more than
2,000
meals prepared

“When Storme was passing away, I didn’t know up from down,” shared bereaved mum Helen. “You don’t know if you’re hungry, thirsty or just sad. During those really hard times, Brad would be there to deliver a tray of food or offer me a coffee. Carers don’t usually get a lot of care, but I felt really supported and never felt pressured to eat.”

Our approach to meal preparation is not just about nutrition; it’s about building opportunities for connection and delight. One memorable occasion involved a sibling who, inspired by cooking shows, invited other children staying in the hospice to watch a “live” cooking session with her and Brad, making gnocchi. These activities offer children another avenue of play, allowing them to engage in make-believe and focus on being a kid.



Our versatile range of allied health services helps us meet the diverse needs of each child. From music therapy to physiotherapy and occupational therapy – each program complements our holistic approach.

The introduction of a child life therapist, Cassie Keogh, has enhanced the hospice’s holistic model of care. Cassie develops therapeutic activities tailored to each child’s emotional and developmental requirements, and will also further develop the sibling and bereavement support programs to ensure the whole family receives the emotional and psychosocial support they need. Thank you to the Brian M. Davis Charitable Foundation for funding our child life therapy role.

The new hydrotherapy pool has been a favourite for many. The pool offers a unique opportunity for children who, due to their complex health, may have never had the chance to experience swimming, to enjoy the freedom of floating in water unencumbered or just simply splash and play with the support of our highly trained physiotherapist.

“I like going in the pool when I’m there. I just swim about, play some games... It just feels different, a relief,” shared 15-year-old Anthony who has Duchenne muscular dystrophy.

Aquatic physiotherapy in the pool provides numerous benefits, including pain relief, muscle strengthening and improved social interaction. It also offers a calming effect for children with sensory processing disorders, making it an essential part of the hospice’s therapeutic offerings. We’d like to thank Ian and Kristeen Urquhart for funding our hydrotherapy program.

Thank you to our philanthropic community who helped us build our world-class hospice. Special mention to our Capital Campaign Committee and the Australian and Victorian Government.

Pictured: Celebrating the official opening of Very Special Kids House (page 8), very special child Mia and her mum Margie before a respite stay (page 9), the Balam Balam suite (pages 10 and 11).

Leading the way

For nearly 40 years, Very Special Kids has evolved to meet the changing needs of children, young people and their families, combining medical and emotional support to improve quality of life.

Enhancing our medical model of care

In addition to the new hospice's physical infrastructure, Very Special Kids has introduced an enhanced medical model of care. This program was funded by Bertalli Family Foundation, John T Reid Charitable Trusts and Percy Baxter Charitable Trust.

We expanded our chief medical officer role from three hours to 15 hours per week, allowing for more robust medical leadership and support of our hospice team. We also improved our nurse-to-patient ratio to deliver a higher level of clinical care for each child.

Another key development was the introduction of an admissions nurse, who works closely with our multidisciplinary team to create a tailored care plan and ensure a seamless experience for both the child and their family from admission to discharge.

Advocating for comprehensive care

Our advocacy efforts encompass statewide and global initiatives to improve children's palliative care.

In July 2023, we hosted an education day for health professionals, offering immersive and informative insight into the therapeutic spaces and medical expertise at Very Special Kids House. According to survey feedback, 100% of attendees felt more equipped to discuss paediatric palliative care with their patients and make referrals to Very Special Kids after completing the day. This was well reflected by the 50% increase we saw in referrals in 2023–24.

Very Special Kids also hosted the launch of the Paediatric Palliative Care National Action Plan with Palliative Care Australia in July 2023. This action plan represents Australia's first nationally aligned approach to paediatric palliative care, presenting a roadmap for a future where individuals across the country receive the same high standard of care. The action plan has helped shape some new organisational goals for Very Special Kids, while validating pre-established initiatives. For example, we actively involve parents and carers in care planning through our Family Advisory Committee and siblings through our Youth and Children Advisory Groups – the first program of its kind in Australian children's palliative care. Read more on page 16.

On a global scale, we began collaborating with UK-based Global Treehouse Foundation to develop a framework for self-assessment of paediatric hospices. This framework will benchmark future facilities worldwide and underline our commitment to sharing best practices and fostering innovation in this critical field.

Communicating with our community

To better meet the diverse needs of our growing community, we completed a website redevelopment with independent performance agency Next&Co in May 2024. The new custom-built site is user-friendly, accessible and incorporates refreshed language that is both child and family focused. We involved various stakeholders in user-experience testing to ensure ease of navigation, especially for registered families who may visit our website during stressful or emotionally challenging times. These insights also informed how we keep our supporters engaged and informed about the impact of their contribution and help health professionals submit a referral for eligible children with ease.

Our service delivery team provide round-the-clock care, day and night.



- 5 doctors
- 35 nurses (33 registered and 2 enrolled nurses)
- 14 personal care workers
- 4 allied health therapists
- 1 commercial cook
- 18 family support practitioners

Co-creating our future

As part of our future planning, we partnered with management consultants Nous Group to conduct an environmental scan of the paediatric palliative care landscape. Through surveys, focus groups and feedback conversations, we received critical insights from parents, siblings, children, supporters and other service partners. This first-hand understanding of our current and future services, will continue to guide our efforts to enhance equity and access in paediatric palliative care, ensuring our plans are responsive to the needs of those we serve.

In early 2024, as our Board and management began development of the next three-year organisational strategic plan, we prioritised incorporating valuable insights from the Paediatric Palliative Care National Action Plan and Nous Group report. The new strategic plan will include service enhancements that improve access, quality of care and strengthen our future sustainability.



Sharing a commitment to holistic care

Dr Katie Moore joined Very Special Kids as chief medical officer (CMO) in October 2023. Katie's medical journey began at the prestigious Guy's and St Thomas' Hospital in London, where she laid the foundation for a career in paediatric oncology. After moving to Melbourne, she continued her training, completing fellowships in paediatric oncology and bioethics. Katie also gained her Masters of Clinical Bioethics and a Masters of Family Therapy.

Her role at Very Special Kids is not just a professional appointment but a culmination of her lifelong passion for comprehensive, child and family-centred care. Katie shares:

"In my view, the best medical care is the same as the best palliative care. It encompasses physical, psychosocial, emotional, and spiritual support."

In her role as CMO, Katie heads a dedicated team of doctors who provide 24/7 on-call support for the children in our care.

"The care we provide at Very Special Kids is not just about treating symptoms. It's about understanding what these illnesses mean for the whole family."

This philosophy aligns perfectly with the ethos of Very Special Kids, which strives to support children and their families through every stage of illness and beyond.

Pictured: Dr Katie Moore, chief medical officer.



Statewide support

Very Special Kids is committed to making life easier for families across Victoria, ensuring that distance and location do not limit access to essential childhood palliative care.

Challenges of regional living

When Marley was born extremely premature at 24 weeks, he barely fit in his mother's palm. He spent his first six months at The Royal Children's Hospital, not strong enough to travel to his family home in Geelong. But after defying considerable odds, Marley was able to make that journey home with his parents, Steve and Kellie.

Since then, managing Marley's complex medical conditions has been a continuous challenge, with frequent hospital visits and long commutes to and from Melbourne stealing precious family time.

Being referred to Very Special Kids felt like a turning point, offering relief and support to ease the stresses of daily life.

"With Marley's needs, not just anyone can look after him. Having Very Special Kids there gives us the freedom to relax, recharge and regenerate," shared Kellie.

Support across Victoria

Very Special Kids provides a range of support services for regional families like Marley's to ease the burden of distance.

For those who need to stay close to the hospice, our short-term, on-site family accommodation offers comfortable, fully equipped apartments.

Kellie recalled, "It's really difficult to leave your child in someone else's care for the first time, especially when we live so far away from Melbourne. Having the opportunity to be next door gave us that peace of mind and now we have no hesitation."

These homely spaces were refurbished in January 2024 with generous support from Adriatic Furniture, Harvey Norman, Sealy, Jaspa and Koala Kids.

"I like it because there's a chef. I also like playing with Jaffa and getting her to chase the ball!"

— Eight-year-old Marley who has complications from premature birth



11,977km

travelled in the
Road to Respite van



\$143,680

saved by families in holiday
accommodation fees

In partnership with the Royal Flying Doctor Service, our Road to Respite program offers children like Marley accessible transportation from their regional homes to Very Special Kids House, ensuring families don't have to endure long, taxing drives. The van was purposefully refitted to meet the complex medical needs of the children and young people in our care. A registered nurse accompanies each child to ensure quality care during every trip.

Kellie noted, "When Marley sees the van he gets so excited, he knows it's time for his holiday... It also gives us a few nights of good sleep, so we have the energy to keep going."

Building connections and memories

In addition to medical care, Very Special Kids offers statewide counselling and emotional support. Our highly skilled family support practitioners help family members navigate their emotions at every stage of their journey.

Families also had the opportunity to spend 622 peaceful nights away at our popular holiday accommodation sites, Glen Osmond Farm in Woodend and Annie's Cottage near Bairnsdale.

"We often struggle to find the spare money to go on holidays because of medical bills. Glen Osmond Farm takes that pressure off, and you can just relax," said Kellie.

Many of the children and families we support need to spend extensive time in and out of hospital, with short or long stays and appointments. Our hospital visiting volunteers bring a piece of Very Special Kids to The Royal Children's Hospital and Monash Children's Hospital. This support can brighten the days of children and families and help alleviate the anxiety and stress of hospital stays, particularly for regional parents who are far from their support networks.

Kellie recalled, "The volunteers make your day. Sometimes you just need a break and you've had no visitors into the hospital. They'll sit and play with Marley. It's just a godsend to have some time that you need by yourself." You can read another family's hospital experience on page 23.

Pictured: Very special child Marley and our therapy dog Jaffa.

Connecting families

Very Special Kids programs are thoughtfully designed so families can cherish every smile and experience a better quality of life.

Our programs consider each family member, incorporating feedback from our family, youth and child advisory groups. By listening directly to the wants, needs and desires of consumer groups, we can ensure their voices are heard and their insights shape the direction of our services.

In 2023–24, we enhanced our sibling support programs to help children and young people develop a stronger sense of self.

During the April school holidays, we held an adolescent camp at the beautiful Cottage by the Sea in Queenscliff, attended by 17 young people.

This two-night camp offered older siblings a retreat from their daily routines and provided a variety of activities, such as paddle boarding and a boat tour, allowing them to push boundaries and explore new interests.

The camp built a sense of community and belonging, with 100% of attendees stating they enjoyed the weekend and felt supported by staff and volunteers. Feedback also showed that 100% agreed the weekend helped them to understand how connecting with others can be of benefit to them.

We also held two engaging sibling days in Malvern and Epping for 30 primary-aged siblings.

The theme, "All About Me" gave kids the opportunity to reflect on their unique qualities and enjoy activities like photography and self-portrait creation.

These days are more than just fun; they offer a safe space for siblings who have or have had a brother or sister with a life-limiting condition to connect with peers who understand their journey.

Our sibling day program



One parent shared, "my daughter loved having so many adults giving her undivided attention as at home we are often doing multiple things at once with our Very Special Kids daughter."

In addition to our sibling programs, we hosted family days at Adventure Park and Gumbuya World. These free-of-charge events offer a fun-filled day for families, with unlimited rides and attractions.

Our family camps, supported by Lord Somers Camp and Powerhouse, continue to provide a much-needed escape for children and families. This year, Lord Somers Camp introduced a new 'teens club' thanks to insights from our Youth Advisory Group. This initiative, launched at the February 2024 camp, aims to create a more inclusive environment for young people.

We also held our annual end-of-year family day in Malvern, where more than 100 families enjoyed a festive and stress-free celebration with interactive stalls and activities.



"Without Very Special Kids we would never be able to afford to take our four other children and parents to experience places like this... We love being able to continue to make precious memories."

— Anonymous family who attended the Gumbuya World family day

Our bereavement programs, including the Walk to Remember in Malvern and Castlemaine, provided a space for families to honour the memory of their loved ones and connect with others in their grief journey. Veneta, a bereaved mum, shared that a Walk to Remember is another way she can honour her daughter Macey's memory each year: "it is a lot to do with being a mum and not wanting your child to be forgotten".

Creating Memories, supported by Red Nose Australia, continued to provide bereaved families a valuable space to gather, share, and preserve cherished memories through scrapbooking.

Thank you to CMV Group Foundation, The Corio Foundation, Lord Somers Camp and Power House, Newmans Own Foundation and Turi Foods for making events like these possible.

Pictured: Very special child Yavanikha and volunteer Nathan at the Gumbuya World family day.



Our people



Patron

- Sister Margaret Noone, AM IBVM

Board

- Peter Polson (Chair)
- Luke Bell
- Lisa Evans
- Cameron Fuller
- Dr Susie Gibb
- Rhys Jewell
- Therese Robinson
- A/Prof. Adam Scheinberg

Management Committee

- Michael Wasley, Chief Executive Officer
- Dr Katie Moore, Chief Medical Officer
- Julia McAlpine, General Manager Clinical Services
- Marcia Christmas, General Manager Fundraising & Marketing
- Matt Dunshea, General Manager Business & Finance
- Donna Durston-McKenna, General Manager People & Culture
- Jessica Birnbaum, Family Support Manager
- Kirsty Blair, Hospice Manager
- Jane Baker, People Operations & Office Manager
- Jacqueline Templeton, Marketing & Communications Manager

Foundation Committee

Members who raise our profile and support our fundraising:

- Glenn Carmody (Chair)
- David Gibbs, AM
- Phil Endersbee, OAM

- Claudia Haeger
- Andrew Macmillan
- Patrick Prendergast
- Hamish Rotstein
- Justin Whitford

Life governors

Members without whose efforts Very Special Kids would not exist in its present form:

- Sister Margaret Noone, AM IBVM
- Rod Bennett
- Prof. Glenn Bowes
- Jane Fenton, AM
- Paula Fox, AO
- David Jones, AO, OBE, KSJ
- Connie Kimberley
- Andrew Penn, AO

Life members

Members who have given a substantial contribution over a period of years and whose efforts have significantly affected our work:

- David Agnew
- Gary Anderson
- Dr Doug Bryan
- Dr Elizabeth Carew-Reid, OAM
- The Hon. Peter Costello, AC
- Robert Davey
- Chris Gillman
- Prof. Sharon Goldfeld
- Janet Hawkins, OAM
- John Hope
- David King
- Andrew Miller
- Jean Miller
- Dr Annie Moulden, OAM
- John Nairn
- Maureen O'Keefe-Anders
- Heidi Roberts
- Dr John Rogers, AM
- Wendy Swift
- Wendy Thorpe
- Jim Wilson

Family Advisory Committee

Parents and carers who use their experience and knowledge to improve the quality of our services:

- Shelley Brown
- Penny Dimitropoulos
- Alex Gaythorpe
- Daniel Parnell
- Shane Rowlands
- Donna Sweetnam
- Jennifer Vick
- Nicole Zois

Youth Advisory Group

Siblings, aged between 14 and 25 years old, who provide first-hand feedback to help improve our services:

- Oliver Bell
- Jude Chrisan
- Tayla Elovarris
- Daniel Gourlay
- Grace Hall
- Liz May
- Dom Mazzei
- Jarrod McKee
- Kristen Oklobdzija
- Callum Patty
- Maryjo Saliba

Children Advisory Group

Siblings, aged between eight and 13 years old, who provide first-hand feedback to help improve our services.

- Aria Cataldo
- Nick Danaher
- Ella Macnee
- Audrey Phelan
- Walter Phelan
- Emmah Ure

Glenn Carmody, Chair of Foundation Committee

This year, Glenn Carmody celebrated his 10-year volunteering milestone with Very Special Kids. Glenn's commitment and many hours of volunteer effort have helped Very Special Kids be there for sick children and their families when they need us most. Glenn also received the 2023 Higgins Community Spirit Award, which recognised his compassion and generous contributions to Very Special Kids, not only as a volunteer but as a dedicated supporter since 2008.

After four years on our Foundation Committee, Glenn assumed the role of chair in 2018, his guidance and counsel has significantly shaped many fundraising initiatives and events.

Glenn's leadership on the Foundation and Capital Campaign Committee has significantly bolstered funding efforts – contributing upward of \$11 million. Glenn has also forged key long-term partnerships with organisations like Henley, Petstock Foundation, The George on Collins and Victoria Racing Club.

As Ernst and Young's Assurance Leader for Oceania (up until 30 June 2024), Glenn brings more than thirty years of audit expertise, advising major global corporations. Glenn leverages his extensive business acumen and connections to advance Very Special Kids' mission of supporting children and families.



In the spotlight

Celebrating a milestone

Sister Margaret Noone is a Loreto Sister, former teacher and junior school principal, and the first employee of Very Special Kids.

A trailblazer and pioneer for Australia's paediatric palliative care, Margaret has advocated for seriously ill children and their families for more than 35 years. She was recognised in 2000 with a Member of the Order of Australia award and led Very Special Kids until her retirement in 2002. Now as Patron, Margaret continues to inspire our staff, and is a heartfelt comfort to the many children, young people and families that she has crossed paths with.

In November 2023, our staff were privileged to celebrate Margaret's 90th birthday with her. The celebrations rightfully continued during the official opening of our world-class hospice, when we collectively celebrated Margaret's joint 162nd birthday with long-term supporter and 3AW presenter Neil Mitchell.

Pictured: Foundation Committee Chair Glenn Carmody (left), 3AW's Neil Mitchell and Sister Margaret celebrating their birthdays together (below).



Our culture

Each department at Very Special Kids is pivotal in making a profound impact, from delivering compassionate medical care to providing emotional support and ensuring smooth operational functions.

Employee engagement and satisfaction

Our excellent staff retention rate of 76%, combined with the results of our latest employee engagement survey shows our team's continued confidence that their feedback will lead to meaningful action.

Employee engagement survey insights



Promoting health, wellbeing and education

As part of our commitment to fostering a supportive workplace, we introduced a new employee orientation program. It offers a warm welcome, introduces our organisation's history and structure, and includes an all-staff morning tea for networking and community building.

To promote cross-departmental collaboration, our commercial cook prepared quarterly team lunches that encourage staff from various departments to connect and engage in meaningful conversations. We also held an end-of-year team building scavenger hunt to encourage creative-thinking, problem-solving and friendly competition.

To further support our team's health and meet the mandatory vaccination requirements for our hospice team, we offered a convenient, onsite flu vaccination program to all staff. Members of the team who were unable to attend onsite also had cost reimbursed. This not only supports the health of our workforce but helps reduce the risk of infection of the vulnerable children and young people in our care.

Our hybrid 'Lunch and Learn' program, continues to enhance our team's health and wellbeing knowledge and promote better death literacy and education throughout the organisation. Service delivery staff were also encouraged to attend interstate conferences, such as the Annual Paediatric Palliative Care Symposium, to network and learn from their peers.

Embracing sustainability and culture

To align with the opening of Very Special Kids House, we collaborated with social enterprise Assembled Threads for the ethical manufacturing of our hospice uniforms. Every uniform purchased by Very Special Kids helps Assembled Threads bridge employment gaps for refugee, asylum seeker and migrant women. The uniforms were also thoughtfully designed by Little Rocket, a First Nations owned and operated agency with a strong relationship to Country and community.



Little Rocket also helped create unique indigenous illustrations of animals for our bedroom identifiers in the hospice. Next to each animal is its name in Woi wurrung – the language of the Wurundjeri people of the Kulin nation, whose land Very Special Kids House resides.

Very Special Kids collaborated with Elder Aunty Gail from the Wurundjeri Woi Wurrung Cultural Heritage Aboriginal Corporation to choose the animals that would represent our eight bedrooms and after death suite.

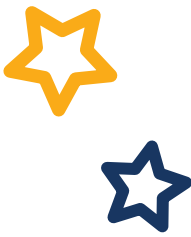
This year, we engaged local consultancy firm Inclusion & Diversity Solutions to start developing a comprehensive Diversity, Equity, and Inclusion (DEI) strategy. This initiative, funded by the Tank Foundation, is designed to respect and celebrate the diverse backgrounds and experiences of the children and families we support, as well as staff and volunteers, recognising differences in ethnicity, culture, gender, sexual orientation, socio-economic status and more.

Application of our DEI strategy will keep us compliant with the National Safety and Quality Health Service (NSQHS) standards and help us set tangible guidelines to foster an inclusive and welcoming environment for all.

In the spotlight



"There have been some very rewarding experiences for me in counselling and emotionally supporting families."



— Andrew Martell, family support practitioner

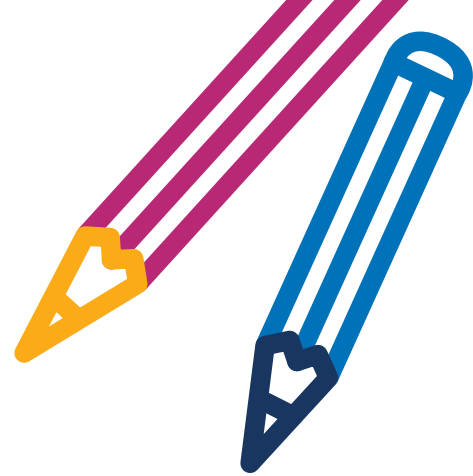
From intern to family support practitioner

With a master's degree in social work from the University of New England, Andrew Martell specialised in therapeutic and counselling frameworks and modalities, focusing on trauma-informed care and suicide prevention. During his studies, he completed an intensive 500-hour full-time student placement at Very Special Kids, an experience that profoundly shaped his approach to social work.

Now, as a vital member of our team, Andrew provides therapeutic support to families in the Melbourne metropolitan area. He actively collaborates with colleagues to design, execute, and evaluate family programs, ensuring that each family's unique needs are met with care and compassion.

Andrew shared, "Being able to be involved in supporting families is really a position of extreme privilege. I look forward to working with other staff to continue providing well-rounded care."

Pictured: Family support practitioner Andrew Martell helping families at our Gumbuya World family day.



 **1:5**
staff-to-volunteer ratio

 **287,735**
saved in staff wages thanks
to volunteer contribution

Our very special volunteers

Our dedicated volunteers come from diverse ages, backgrounds and cultures. From grandparents and retirees to master's-level genetic counselling students, they bring a rich tapestry of experience and skill.

Our volunteers participate in a wide array of programs and all play a critical role – from family support through regular home visits and family days to assisting with hospice care or maintaining our beautiful grounds.



Strengthening our community

Re-engaging our existing volunteer cohort has been a significant focus this year. Our volunteer services team contacted our entire volunteer database, fostering an open dialogue to identify key interests and motivations. This approach has revitalised the program, deploying volunteers into relevant roles that match skillset and availability.

Our hybrid training model, which includes three flexible modules, is purposely designed to equip volunteers with the necessary skills to support children and their families.

In 2023–24, we successfully trained 100 new volunteers, incorporating feedback from staff, families and advisory groups to continually enhance our training methods.

To stay at the forefront of volunteer management, our volunteer team attended the 2024 Advanced Volunteer Management Symposium. This eight-week program provided an opportunity to engage with volunteer leaders globally, encouraging us to rethink and transform our volunteer engagement strategies, ensuring we adapt to an ever-evolving global landscape.

Care in action

At Very Special Kids House, we have 130 trained hospice volunteers who support our service delivery team and the children and families in our care. These volunteers receive specialised training, allowing them to engage in activities like our therapy dog program and aquatic physiotherapy. Additionally, volunteers in the hospice kitchen are provided with external training and hospital-level safe food handling certificates, ensuring they can safely contribute to our food services.

Families across the state can also engage with our 58 Home Links volunteers, who provide companionship and support. This service is particularly helpful for siblings of very special kids, offering dedicated time to have fun, explore and connect with a volunteer. Speaking to a proud moment, volunteer Berkkan shared, "I helped the oldest sibling prepare their resume so that they can apply for their first job!"

Thanks to all our valued volunteers who make a very special impact, every day.

In the spotlight

"I get to play with the kids and chat with parents, bringing a piece of the Very Special Kids team to families at a time when kids are potentially disconnected from all their other networks."

— Danielle, Very Special Kids volunteer



Bibi's hospital heroes

Our hospital volunteer program continues to make a profound difference for families navigating hospital visits. At The Royal Children's Hospital, 22 trained volunteers provide a seven-day visiting service; at Monash Children's Hospital, 18 volunteers offer on-call support.

For five-year-old Bibi and her mother, Bronwyn, frequent visits to the Neuromuscular Clinic can be overwhelming, with long waits and multiple appointments. "It's very hard to entertain a five-year-old in a small space and help them be patient under circumstances like this," Bronwyn explained.

Bibi formed an instant bond with her volunteer, Danielle, and enjoyed activities like art, crafts and reading. This not only lifted Bibi's spirits but allowed Bronwyn to discuss Bibi's condition with her geneticist without distraction.

Our trained hospital volunteers have visited families in the hospital 786 times this year, providing comfort and much needed relief to many families like Bibi's.

Pictured: Visiting volunteer Danielle and very special child Bibi playing together at the hospital.

Milestone awards

Thank you to the following individuals who have reached these very special volunteering milestones:

20-year service award

- Annette Cammaroto
- Barbara Cohen
- Jo Mooney
- Tori Pavlidis
- Nirmala Phillips

15-year service award

- Kate Bell
- Vivian Bullen
- Lucy Chau
- Wendy Priddle
- Linda Zhang

10-year service award

- Lynette Algie
- Voula Allimonos
- Catherine Balon
- Michelle Board
- Charlene Braybrook
- Paul Brennan
- Karen Brenner
- Brenton Cross
- Miranda Cross

- Veeru Dhaliwal
- Margaret Inglis
- Jacqueline Jiang
- Belinda Muir
- Lynn O'Sullivan
- Helen Pavlidis
- Jessica Renn
- Benjamin Robinson
- Lisa Vasiliadis
- Sutanter Wander

5-year service award

- Ann Allen
- Valery Bausch
- Bella Blaher
- Stephen Bogнар
- Alexandra Byrne
- Felicity Byrne
- Jacqui Callil
- Diana Cardamone
- Marcus Chivell
- Courtney Cini
- Georgia Cooke
- Coral Cooper
- Sarah Cormie
- Tessa Cummins
- Kathy-Louise Danziger
- Nicola Delaney

- Madeleine Evans
- Peta Finn
- Hannah Fulton
- Ellie Hall-Prvulj
- Kiley Harkness
- Alanah Healey
- Jane Holroyd
- Erryn James
- Lihini Jayathillake
- Simone Johnston
- Susan Karunaratne
- Anthony Lacco-Nash
- Danielle Lissek
- Maddie Meek
- Vicki Neil
- Annie Nish
- Lisa Pedretti
- Jenny Prosser
- Jenny Reeves
- Tanya Stork
- Clare Tuttleby
- Daniel Vigne
- Dee Walsh
- Janet Wheeler
- Summer Woo
- James Xavier
- Cameron Yee
- Paula Young



“I’m blessed that the last 20 years of my life has been with Very Special Kids and an amazing group of volunteers. My life and hopefully others are better for it.”

— Jo Mooney who is celebrating her 20-year milestone as a volunteer



Antony's story

For senior sergeant Antony, turning on the flashing lights and sirens of his police car during visits to Very Special Kids' Lord Somers Camp is a heartwarming tradition.

Working at the Hastings Police Station, he takes joy in attending the local camp, knowing firsthand the profound impact Very Special Kids can have.

Antony and Michelle's son, Ted, was diagnosed with a rare mitochondrial disorder at birth, which severely affected his ability to metabolise carbohydrates, leading to breathing difficulties and frequent seizures.

“I just remember feeling so much fear. We were both first-time parents, and you have this Hollywood idea of what having your baby will be, and it wasn't that at all,” Antony recalled.

Introduced to Very Special Kids during Ted's treatment at The Royal Children's Hospital, Antony found solace speaking with his dedicated family support practitioner.

Despite Ted's brief recovery, his health declined after a metabolic stroke, and he sadly died at 14 months of age.

Since then, Antony's commitment to Very Special Kids has only grown. As a police officer, he now visits Lord Somers Camp, bringing smiles to children's faces and reflecting on how much Ted would have enjoyed the outdoor adventures. “It gives me comfort to know that I can perhaps help those kids and those families that are going through what we went through,” Antony said.

A heartfelt **thank you** goes to Lord Somers Camp and Power House for providing families with a weekend haven for joy and respite. Their support allows children of all abilities to enjoy adventures by the sea while parents find much-needed rest and connection with other families in similar situations.

“The knowledge and genuine empathy that comes with the people at Very Special Kids knowing what you're going through makes the difference; it just makes it relatable and more sincere and genuine.”

— Antony, dad of 14-month-old Ted who had a mitochondrial disorder



Pictured: Very special volunteer, Jo Mooney (left) and very special child Ted and his dad Antony (above).

Investing in our future

Every child and family’s experience of a life-limiting condition is unique, and we believe our approach to their care should be just as individualised. As a predominately self-funded organisation, we can only provide this level of tailored care thanks to the individuals and organisations in our community, who, like us, are invested in creating a better quality of life.

Built for lasting impact

In 2023–24, the economic pressures of rising inflation and increased living costs continued to challenge Very Special Kids’ financial growth. While we experienced a reduction in income in our events, we remained resolute in our mission to diversify the fundraising mix – building long-term income streams and strengthening relationships with our very special community.

We’re grateful for the ongoing commitment of our Foundation Committee members, who volunteer their time to provide valuable support and advice. They continue to advocate for Very Special Kids and connect us to their networks, which significantly contributes to our cause and fundraising efforts.

Our growing philanthropic community of major donors, trusts and foundations share our commitment to seriously ill children and their families. Many choose to fund specific hospice services or family programs, such as the Campbell Foundation’s significant three-year contribution to our music therapy program. Without generous support like this, many of our essential therapeutic and medical services wouldn’t be possible.

We were also privileged to receive bequests from our generous supporters and are continuing to see more

widespread commitment to leaving gifts in Wills to Very Special Kids. You can read more about the impact of these Very Special Guardians on page 32.

Every year, thousands of people support Very Special Kids by attending our events or participating in community fundraisers. Despite this dedication, our event income has been challenged by COVID-19 and the cost-of-living crisis. To combat this, we commenced a review of our events to ensure they remain viable into the future, such as our Very Special Ladies Lunch. Additionally, we launched a new community fundraising program, “Do Something Very Special”, to encourage more individuals, organisations or community groups to fundraise on behalf of Very Special Kids.



Transformational partnerships

Our corporate partnerships grew from strength to strength. Many long-term partners reconfirmed their commitment to Very Special Kids including ALH Hotels, Lowe Living and Petstock Foundation. We also welcomed several new partners to our community, including Hyundai Help for Kids, CMV Foundation and efm Logistics.

Thanks to Hyundai Help for Kids, Very Special Kids families were given opportunities to create some unforgettable memories. From meeting their football heroes and featuring in official team photos to forming a guard of honour at a Carlton game and running onto the field with captain Patrick Cripps, many football fantasies came true. → [Continued](#).

In the spotlight



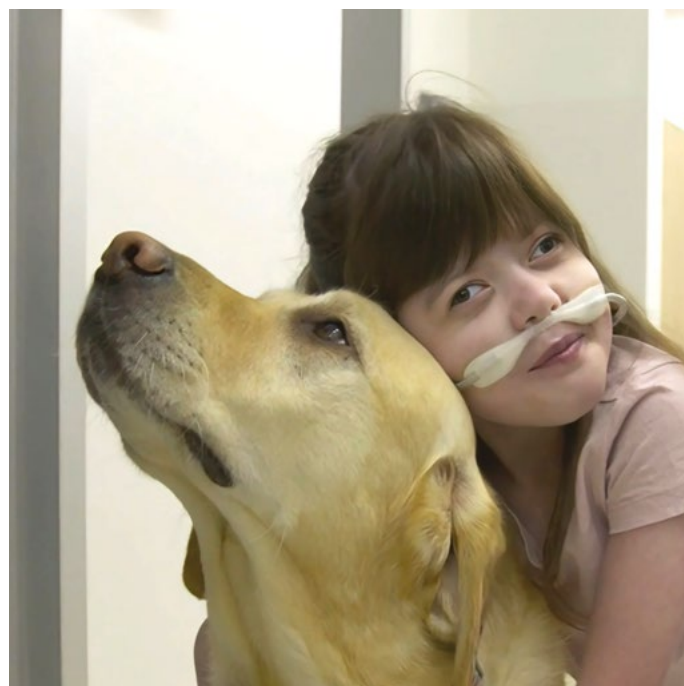
24 hours of giving for 24-hour care

The grand opening of Very Special Kids House coincided with our annual giving day, A Very Special Day, where public donations were doubled for 24 hours.

This year, we raised a record \$827,748, thanks to the generosity of our donors and the support of our matched partners: Tank Foundation, Fox Family Foundation, The Highland Foundation, John Wheeler and Sue Hadden, The Gaudry Foundation, The Barr Family Foundation, John and Jenny Fast, and Peter and Elaine Kempen. Notably, 35% of giving day donations came from new supporters, significantly expanding our very special community network.

We couldn’t have achieved this level of success without the generous support of Neil Mitchell and the 3AW team for their onsite coverage of the hospice opening ceremony and A Very Special Day.

Pictured: Very Special Kids volunteer calling supporters on A Very Special Day.



“Very Special Kids House just makes life that little bit easier. Breana loves coming to the hospice and spending time here, she has so much fun with all the staff and Jaffa.”

— Nicole, mum of 9-year-old Breana who has DiGeorge syndrome

The Petstock Foundation continued to play a pivotal role in supporting our therapy dog program, and involved Very Special Kids in two in-store campaigns – raising more than \$150,000.

Through this partnership, therapy dog Jaffa featured in the Herald Sun and Channel 10's Pooches at Play, alongside very special child Breana. Mum Nicole shared her gratitude for the support her family receives, emphasising how Jaffa's presence at the hospice has brought joy to her daughter Breana, who faces numerous serious health challenges due to having DiGeorge syndrome.

Another partner making a very special difference is Francis Venues, a family-run hospitality group. The company has strengthened its partnership with Very Special Kids through multiple fundraising initiatives and by engaging its staff in volunteering activities. Tom Francis, managing director of Francis Venues shared, “As a family-run business, Very Special Kids is very close to our hearts. We hope our contribution can help seriously ill children and their families access the best quality of life, no matter how long or short their lives may be.”

Together for a cause

For a second year, The George on Collins hosted its “Gather to Give” event with resounding success, raising more than \$200,000. The night of generosity and glamour was a vibrant celebration with high-value auction items, premium food and drinks, and lively music to pack the dance floor.

We also revamped and elevated our Very Special Ladies Lunch, where guests indulged in riverside views at our new venue, Leonda by the Yarra. Previously a biannual event, the lunch was scaled up to run once a year. The change proved successful, with the lunch raising a record-breaking \$124,000, surpassing the previous year's combined total. During the heartfelt lunch, one lucky guest won a 1ct pink sapphire, to be set in a custom piece, courtesy of boutique Melbourne jeweller Tallulah. Special thank you to our presenting partner, Lowe Living, who has dedicated four years to supporting Very Special Kids events like this. We look forward to delivering more strategic and sustainable events of this calibre in the future.

Our annual Footy Fever Debate and multiple Golf Days across the state brought our community together for friendly competition and a shared commitment to our cause, including the Flinders Golf Club event, which raised a record-breaking \$39,500.

The 24-Hour Treadmill Challenge saw more than 800 participants keep treadmills running for 24 hours, raising more than \$650,000. Football legend and 3AW commentator Jimmy Bartel supported the challenge by taking on his own virtual cycle from Geelong to Mildura, raising more than \$35,000 and further promoting our cause.

Pictured: Very special child Breana and our therapy dog Jaffa (above), Very Special Ladies Lunch (page 26).



In the spotlight



“It really does create a wonderful sense of community and it’s a real pleasure for us to be a part of it.”

— Rob and Leonie, Very Special Kids fundraisers

Holiday lights illuminate hope

For 15 years, Rob van Stokrom and Leonie Hill have transformed their Beaumaris front yard into a Christmas wonderland, delighting families with a dazzling light display each December.

What began as a small personal project has grown into a spectacular annual event, attracting thousands of visitors year on year.

In 2015, inspired by their tour of Very Special Kids' hospice, they decided to support our organisation, turning their festive display into a fundraiser. Since then, their annual Christmas lights display has raised more than \$100,000 for Very Special Kids.

Their efforts have not only spread holiday cheer but have also fostered a strong sense of community, with families making the light display a cherished Christmas tradition.

The Very Special Kids Christmas lights program grew 60% in 2023–24, spreading double the Christmas cheer.

Pictured: Rob and Leonie's front yard in Beaumaris (top) and Rob and Leonie outside their home (bottom).

Our supporters

Thank you to our very special community of supporters who have each made significant contributions this year.

Government

- Federal Government of Australia
- State Government of Victoria
- Magistrates' Court Of Victoria – Melbourne

Corporate

- Advent Partners
- ALH Hotels
- Allens Law Firm
- Balcon Group
- CMV Group Foundation
- Commbank Staff Foundation
- Community Bank Parkdale
- Corrs Chambers Westgarth
- Newmans Own Foundation
- efm Logistics
- Ernst & Young
- Francis Venues
- Guild Group
- Icon Group
- International Power Australia Pty Ltd
- Jemena
- Lovelight
- Lowe Living
- Marsh
- Mercedes-Benz Waverley
- Millbrook Group
- MRC Foundation
- Navy Health
- Paint & Hardware Legends Club
- PayPal Giving Fund
- Petstock Foundation
- Ricky Productions Pty Ltd
- Tank Foundation
- The George on Collins

- Turi Foods
- Viva Energy Australia
- Whitbread Insurance Brokers
- Woods & Co

Trusts and foundations

- Australian Communities Foundation
- Australian Philanthropic Services Foundation
- Barr Family Foundation
- Batrouney Family Charitable Foundation
- Bertalli Family Foundation
- Brian M Davis Charitable Foundation
- Campbell Foundation
- Cassandra Gantner Foundation
- Corio Foundation
- Dorman Family Foundation
- Ducas Paul Foundation
- Flora & Frank Leith Charitable Trust
- Foundation of Graduates in Early Childhood Studies
- Freemasons Foundation Victoria
- Grace and Emilio Foundation
- Gringlas Family Charitable Fund
- Harris Family Foundation
- Hooley Family Foundation
- John T Reid Charitable Trusts
- MacKenzie Family Foundation
- Marjorie M. Kingston Charitable Trust
- McAllister Family Foundation
- Montgomery Foundation Pty Ltd
- Newsboys Foundation
- Norman, Mavis & Graeme Waters Perpetual Charitable Trust
- Percy Baxter Charitable Trust
- Perpetual Trustees
- Pierce Armstrong Trust
- Stocks Family Foundation
- Sunraysia Foundation
- The Alfred and Jean Dickson Foundation
- The Gaudry Foundation
- The Johnstone Family Foundation
- The Marian & E H Flack Trust
- The Noel & Carmel O'Brien Family Foundation
- The Orloff Family Foundation
- The Pratt Foundation
- The Stuart Leslie Foundation
- The William Angliss (Victoria) Charitable Fund

Individuals

- Sunitha Alexander
- Angela Baldi
- Ken Barbarick
- Clive & Jenny Batrouney
- Margaret Brown
- Pamela Bursztyn
- Simon Daish
- Annie Dunn
- Meredith Evans
- Goldsmith Family
- Angela Found
- Suzanna Gibson
- Judy Greig
- Richard Healey
- Kevin Kelly
- Peter & Elaine Kempen
- Tony & Sandy Kirkhope
- Laurence Law
- Stephen McGowan
- Anne & Ian Muir
- Peter Noone
- Jan Pannam
- David Scheinberg
- Glenda Shelley
- Ian & Kristeen Urquhart
- Brett & Simone Webb
- John Wheeler & Susan Hadden

Very Special Guardians (estates)

- Estate of Valma Mary Cox
- Estate of Natalie Mary O'Sullivan

Hospice rebuild

- Jack & Meg Bowen
- John & Jenny Fast
- The Fox Family Foundation
- The Highland Foundation
- Connie & Craig Kimberley OAM
- Newmagoo Pty Ltd
- Peter & Rosemary Polson
- Heidi Roberts
- Ken & Gail Roche

Media partner

- 3AW

Gift in kind

- Adriatic Furniture
- Andrew Penn & Kallie Blauhorn
- ARA Property Services
- Bridged Group
- CM Liquor
- Corrs Chambers Westgarth
- Deloitte
- Harry the Hirer
- Harvey Norman
- Hyundai Motor Company Australia P/L
- Linfox Logistics
- Melbourne Cool Room Hire
- Next&Co
- Nigel
- Novofit
- Penfold Motors Burwood
- PFD Foods
- QANTAS
- Rapid Relief Team
- Sealy Australia
- Wallop Events and Promotions
- WTLR

Program partners

The Victorian Paediatric Palliative Care Program





A very special legacy

Simone's journey with Very Special Kids began nearly two decades ago when her ten-month-old son Zack was diagnosed with Tay-Sachs, a devastating and life-limiting genetic condition.

Caring for Zack was all-consuming and Simone and her family desperately needed respite. That's when they found Very Special Kids.

"Our first visit to the hospice was a turning point. I soon realised Zack was in the best hands," shared Simone. Very Special Kids offered a sanctuary for Simone's family and Zack received loving care to the end of his life.

Now, Simone has honoured Zack's memory by committing to a gift in her Will for Very Special Kids, becoming a Very Special Guardian. Her decision underscores the profound impact of Very Special Kids on her family's lives and the enduring support we provide to families in need.

"Very Special Kids will always be a part of my life and my connection remains steadfast," she said.

For bereaved parents Karen and Chris, Very Special Kids is deeply tied to the memory of their 11-year-old daughter, Charlize. Karen and Chris have also chosen to leave a lasting legacy gift in their Wills to Very Special Kids.

"Charlize's greatest gift was her love of life and kindness to others... What greater legacy could we want than to know this gift not only honours our Charlize but helps other children and their families," shared Karen and Chris.

"I'll never forget how peaceful Zack's final moments were and I am eternally grateful to Very Special Kids."

— Simone, mum of two-year-old Zack who had Tay-Sachs disease



We would like to extend our sincere condolences and grateful thanks to the families and friends of our Very Special Guardians. We'd also like to acknowledge those who have committed to a bequest, ensuring their legacy can continue beyond their lifetime.

Pictured: Very special child Zack.

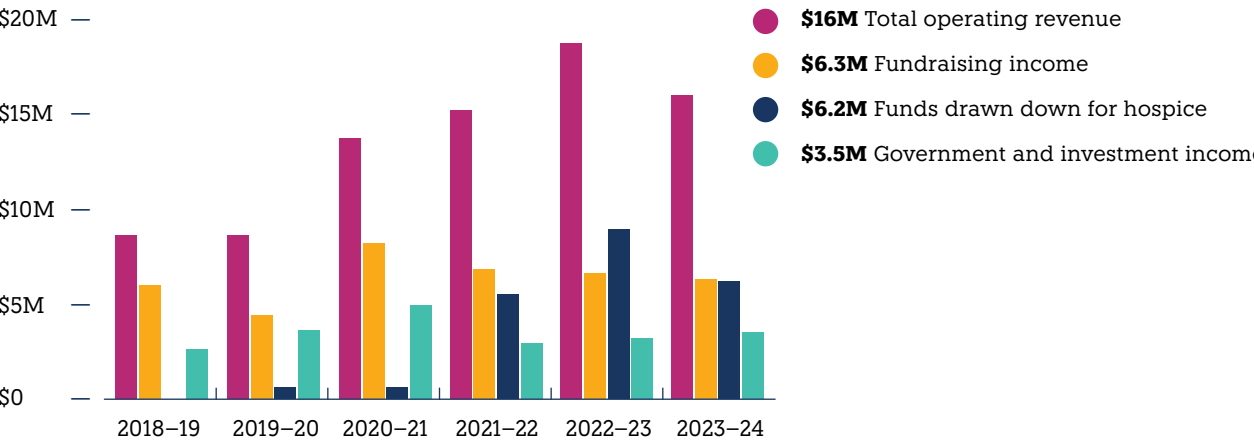
Financial snapshot

In 2023–24, Very Special Kids' operational costs heavily focused on the completion and opening of our newly rebuilt hospice facility. To generate sufficient annual income and deliver essential paediatric palliative care, we relied on a combination of fundraising activities and previously committed capital funds. All remaining capital funds were

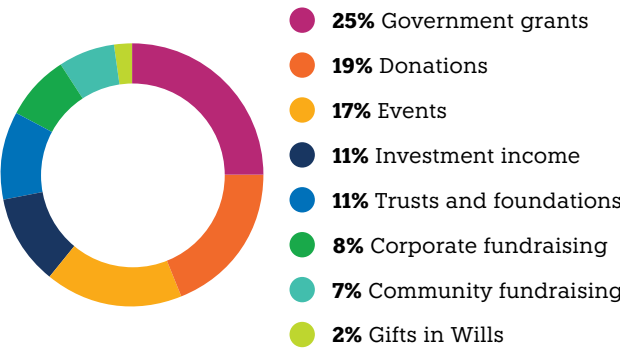
drawn down and recognised as revenue and will continue to assist with running costs of Very Special Kids House for a few years. Should the current economic conditions continue, we foresee short-term challenges as we aim to increase our operational income to keep up with the rising cost of providing our services.

As an organisation, we remain resolute in our mission to diversify the fundraising mix and have seen an increase of corporate and community fundraising, and philanthropic income. We will continue to build our long-term income streams and strengthen our events to generate small surpluses year-on-year in the near future.

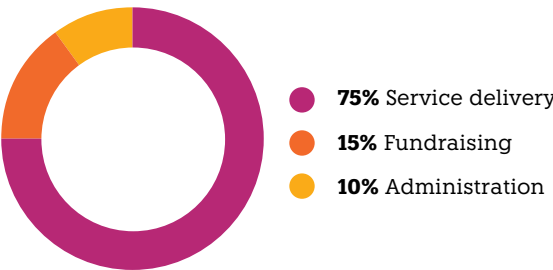
Financial overview for the year ended 30 June 2024



Where our income comes from



Where the money goes



NB: Excludes income drawn down from hospice rebuild



Very Special Kids welcomes people of all backgrounds and respects that the families we support are different in many ways including country of birth, ethnicity, culture, gender, gender identity, sexual orientation, socio-economic status, religion and ability.

Very Special Kids is a not-for-profit company limited by guarantee, accredited by The Australian Council on Healthcare Standards and is a Child Safe Organisation. Very Special Kids is proud to display the Registered Charity Tick to highlight our Charitable status through The Australian Charities and Not-for-profits Commissions' Charity Register.

Pictured: Very special child Pip and her mum, Jasmine, at the Gumbuya World family day.



vsk.org.au

1800 888 875



@veryspecialkids