

40 *years*

# impact report

2024-25





***“Not many people understand what it truly means to be a parent and caregiver to a very special kid... The assistance, respite and support Very Special Kids provides to our families is invaluable.”***

*– Ryan, father of 7-year-old Callum who has Sanfilippo syndrome*



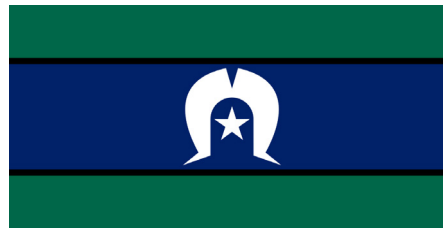
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*Pictured: Ryan and Callum walking into hospice (above); very special child Sophia celebrating our 40th birthday (front page).*



## 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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# About us



# Our vision

Navigating life, death and grief with families and communities.

## Our purpose

Very Special Kids improves the quality of lives of children and young people with life-limiting conditions, and their families, through:

- Holistic paediatric palliative care
- Emotional and spiritual support to the entire family
- Advocacy and building compassionate communities that support families

## Our principles

- We offer compassionate, individualised care for families across their entire journey
- Our approach is forward thinking, positive and authentic
- We collaborate to deliver the best support for families
- We are purpose driven and act with integrity, respect and kindness

*Pictured: Chris, a very special kid who was the face of our 1994 hospice appeal.*







# Message from our leaders

2024–25 marked 40-years of care at Very Special Kids and our first full year of uninterrupted hospice operations following its rebuild in 2023.

After a number of years of significant disruption, 2024–25 represented a full year of uninterrupted services and support for the families in our care. With the multiple interruptions navigated since 2020 now behind us, in particular the rebuild of the hospice, we have now re-established the full suite and scale of important services to families and children in our care.

## Our inspiration

As many of you know, our First Employee, Patron and visionary leader, Sister Margaret Noone IBVM AM died in January at the age of 91. Margaret led such a long and fulfilling life and her death has created a challenging time for Very Special Kids. While Margaret's health declined in her last few years, we remain forever grateful that she was able to cut the ribbon which marked the opening of the new Sister Margaret Noone Hospice at Very Special Kids House. She remains our Patron and will always inspire our efforts and sustain our steadfast alignment to our purpose. Since her death, we've been moved by the many heartfelt tributes shared by those whose lives she touched.

## Operational excellence

During the 2024–25 financial year, we reestablished our complete suite of services in our world-class hospice. This achievement was driven by several key developments:

- A rebuilt registered nurse roster, including the onboarding of specialised paediatric and palliative care expertise
- Significant increase in supporting families through end-of-life and after death care episodes, offering compassionate and flexible care
- Strengthened partnerships with the Victorian Paediatric Palliative Care Program, The Royal Children's Hospital and Monash Children's Hospital



## Strategic direction

During the past year, we launched our 2025–28 Strategic Plan, setting a clear direction for the future of Very Special Kids, with our hospice rebuild completed and in full operation. As part of this work, we refined our mission, purpose and principles to ensure they continue to reflect the evolving needs of the children, young people and families we support.

In the coming year our focus will be on enhancing service excellence and improving access, particularly for families across regional Victoria. Key initiatives include expanding referral pathways and introducing new service enhancements to address emerging gaps in family care. It also reinforces our continuing role in supporting established and new paediatric palliative care services nationwide.

This ambitious plan will require significant focus and resourcing, and we are prepared to meet these challenges through ongoing internal investment and by seeking additional support from government and our philanthropic community.

## Sustainability

Despite a challenging global economic and political climate, Very Special Kids achieved modest income growth in 2024–25. This was predominantly driven by the increasing strength of our robust philanthropy program, streamlined event portfolio and the continued generosity of individuals and organisations. Through enhanced funds management, our financial resilience will help to ensure the continuity of our essential services, as well as supporting our future investment in statewide service enhancements.



## A very special thank you

In a world facing many challenges, we are enormously grateful for the people and communities who stand alongside Very Special Kids. Our donors, volunteers, staff and supporters not only provide the resources that make our work possible, they help us uphold the care families deserve. Your belief in our mission grounds us, motivates us and ensures we can continue delivering the best quality of life. Thank you.

**Peter Polson** Chair  
**Michael Wasley** CEO

*Pictured: Michael Wasley (left)  
and Peter Polson (right).*



# Our history

# Four decades of care

For 40 years, we've stood alongside thousands of families as they navigate unbearable circumstances.

What began as two families supporting each other through their sons' battle with leukaemia became a shared vision: to create the care they wished they'd received.

By the start of 1985, their aspiration had become a reality, and Very Special Kids was established.

At the centre of the organisation was Sister Margaret Noone IBVM AM, a Loreto Sister and former teacher and junior school principal, who became our First Employee and a pioneer in paediatric palliative care.

With her guidance, Very Special Kids became the first organisation in Australia to offer holistic, total active care for a child's mind, body and spirit outside of acute hospital settings, while also supporting their families.

*\*Very Special Kids House opened in 1996.*

**Our impact from  
1985 → 2025**



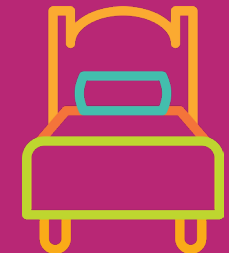
**6 → 782**  
families assisted



**26 → 449**  
volunteers



**1 → 108**  
staff members



**0 → 1,823**  
respite, end-of-life and  
after death care bed nights\*





## **Four stories**

***“With Very Special Kids we weren’t patients, or problems or statistics. We were just normal people.”***

Leah, bereaved mum of 11-year-old Chris who was born in **1985**.

[Read more](#) 



***“I still get emotional when I think about the last day at the house and all of those goodbyes... There’s nothing quite like it out there.”***

Lisa, mum of 26-year-old Jack who was born in **1999**.

[Read more](#) 



***“When your child dies,  
everyone else steps away.  
But Very Special Kids stay.”***

Jess, bereaved mum of 6-year-old Henry  
who was born in **2007**.

[Read more](#) ➤

***“We trust Very Special Kids. We’ve got  
that confidence that when we drive off,  
they can handle a situation.”***

Ken, dad of 1-year-old Sophia who was born in **2024**.

[Read more](#) ➤





# Sister Margaret's legacy

As we celebrate four decades of Very Special Kids, we also honour the life of Sister Margaret Noone IBVM AM, our First Employee and long-time Patron, who died peacefully on 3 January at the age of 91.

Since 1985, Margaret has been the heart of Very Special Kids. She was a trailblazer in children's palliative care, driven by a deep sense of justice, humility and compassion for families facing unbearable circumstances.

In the early 1980s, when two grieving families came together to fill a gap in support, Margaret was invited to meet them. She had just returned from studying theology at the University of California, Berkeley, where she'd volunteered with seriously ill children. What began as a conversation quickly became a calling.

"The beginning was difficult," she said. "Although I saw there was a need, and the families saw it, we had to convince other people."

She began training volunteers and visiting hospitals, both important first steps to help families and children in a way that had never been done before. "Particularly for country families who couldn't be there all the time," she once said. "To ring and say, 'I've seen your child today,' it meant so much to them."

In 1989, Sister Margaret received a Churchill Fellowship to study children's hospices across the United Kingdom.

The knowledge she brought back helped shape the creation of Very Special Kids House in 1996 – Australia's first children's hospice.

She often described the hospice not as a building, but a feeling.

***"The building as such is only bricks and mortar, but Very Special Kids House is more, much more. It is a home in the true sense of the word."***

*- Sister Margaret Noone, Very Special Kids Patron and First Employee*



Margaret remained deeply involved in the organisation long after stepping down as director in 2002. She guided its vision as Patron and never stopped advocating for families facing childhood life-limiting illness.

She was a member of the first committee for the Palliative Care Association of Australia and the International Work Group on Death, Dying and Bereavement. In 2000, she was recognised for her work with a Member of the Order of Australia award.

After 25 years of serving families, Very Special Kids House was decommissioned in 2021 to make way for a new world-class facility. When the doors opened in 2023, the hospice was named in her honour – The Sister Margaret Noone Hospice at Very Special Kids House – to reflect the dignity, innovation and nurturing she championed.

➡ In her final national interview on **The Project** in July 2024, she shared,

“It’s 24-hour care. As one dad said, ‘My wife sleeps one night, I sleep the next.’ How long can you go on like that? It’s really important we’re here.”

Her impact continues not just in the buildings, but in the culture she helped create. Former Premier of Victoria Jeff Kennett remembered her as:

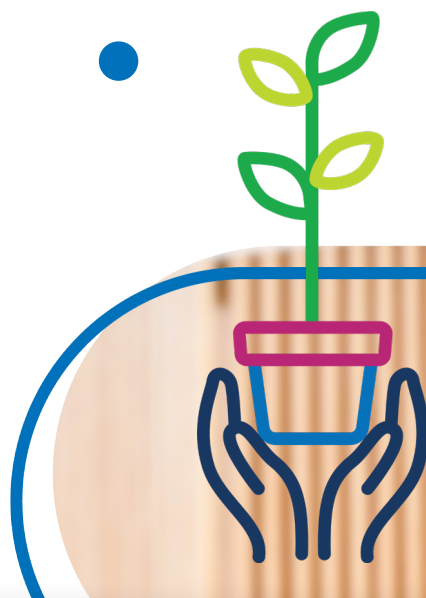
“A very committed, focused individual for all the right reasons...[she] planted an acorn that has grown into a very big, strong and caring tree.”

Margaret’s vision was built on the belief that every child deserves dignity and joy, no matter how short their life may be. She deepened our death literacy, gave us space for grief and offered a model of care in action.

Her presence is deeply missed, but her legacy will continue to surround us.

*Pictured: Sister Margaret Noone surrounded by children at a Very Special Kids event (previous); Margaret visiting the hospice shortly after its rebuild (below).*

**Play Margaret’s reflection video here**



# Our impact



# Becoming a home

**The Sister Margaret Noone Hospice at Very Special Kids House is much more than a clinical space. It's a place of comfort and care, brought to life by our dedicated team of doctors, nurses, personal care workers, allied health professionals and trained volunteers.**

Rebuilt in 2023, it remains the only children's hospice in Victoria and one of the leading paediatric palliative care facilities globally. Purpose-built, the hospice features thoughtful, child-friendly spaces – including a wheelchair-accessible playground, a hydrotherapy pool, a soft play zone and dedicated rooms for music and creative therapy. Medical equipment is discreetly integrated and family areas offer calm, private space for togetherness or retreat.

## Weekend escape

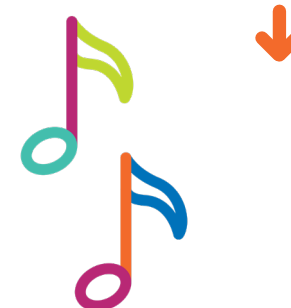
This year, our VIP Weekend returned as an inclusive retreat for adolescents aged 12 to 18. The weekend was packed with activities – including a MasterChef-style cooking challenge, in-house DJ, video game tournaments and even a mobile barber offering fresh fades.

From Gelato Messina runs to time with our music therapist, every moment was designed to build independence, create memories and offer young people with life-limiting conditions freedom of choice and the chance to just be themselves.

***"It was great seeing new people and making new friends!"***

*- Anonymous participant from VIP Weekend*

*Pictured: Very special child Riyan and our music therapist Isaac at the VIP Weekend.*



## A disco party with Emma Memma

When beloved children's entertainer Emma Memma visited, the hospice came alive with colour, sound and joy. With her signature warmth and inclusive approach, Emma spent one-on-one time with each child – singing, dancing and signing in Auslan.

For many families, it was more than just entertainment. It was a meaningful experience, where each child's needs were embraced and celebrated. For some, this tailored event was the only way their child could experience and see one of their idols, with complex care needs making a traditional Emma Memma concert near impossible.

*Pictured: Very special kid Ethan and Emma Memma.*

Play the concert  
video here





# Different shades of goodbye

At Very Special Kids, we walk alongside families with compassion and tailored support through the final days, after death and beyond.

## Under one roof

When staying close matters most, our onsite accommodation gives families space to rest, share meals and welcome loved ones – with our palliative care team just steps away.

Ashley, mum of newborn Mila who had a rare and fatal neonatal condition, shared, “We could stay close to Mila, hold her, talk to her...That privacy and support made a deep and lasting difference in how we were able to process our grief.”

## Moments of ease

For many families, our hydrotherapy pool is a place of calm during end-of-life care. The sensation of warm water can ease pain, reduce anxiety and offers families treasured final memories.

Kelly and Nigel, parents of 17-year-old Olivia who had FOXG1 syndrome, shared, “In that quiet space, we could hold Olivia, play, laugh and just be together, happy and smiling.”

We’d like to thank Ian and Kristeen Urquhart for funding the aquatic physiotherapy program.



# 225%

increase in end-of-life and after death care nights compared to 2023–24

*Pictured: Baby Mila surrounded by her dad Gene and siblings Ezra and Charlotte (left); very special child Olivia with her mum Kelly and sister Holly (right).*





## Time to breathe

Bathed in soft light, the Balam Balam suite includes a climate-controlled bedroom where families can remain with their child's body for up to seven nights, allowing time to grieve, reflect and plan. Balam Balam is the Woi wurrung word for butterfly – the language of the Wurundjeri people of the Kulin nation, on whose land Very Special Kids House resides. Helen, mum of 11-year-old Storme who had neuroblastoma, shared, "I was truly able to just be with Storme in those last days, without worrying about anything else. I don't know another place that would have allowed it that way."



## Returning home

For some, the wish to return home for their child's final days is deeply personal.

One family, newly settled in a regional town, was just beginning life in their first home when their child faced a sudden, life-limiting medical crisis. After weeks in hospital and a terminal diagnosis, they came to Very Special Kids House for end-of-life care.

After eight weeks of support, the mother quietly asked, "Can we take him home?" remembering her son's words: "I love this house, Mummy". With just days to plan, our team worked with more than 20 health and community partners – including the Royal Flying Doctor Service – to arrange road and air transport for the 600km journey. Their child spent 10 peaceful days at home before his death, a memory the family now carry forward.



*Pictured: Very special child Storme with his mum Helen (left); very special family at airport making their journey home (right).*



## A final farewell


For those who wish, a guard of honour is offered when a child leaves Very Special Kids House for their final resting place. Staff, family and friends line the main doorway to pay their respects.

The farewell may include a favourite song, the child's face gently visible, siblings walking alongside or the child being held, resting on a bed or in a coffin. However the moment unfolds, it is shaped entirely by the family's wishes.

Mila's mum shared, "When I turned and saw all the staff behind us, I felt an overwhelming wave of support, compassion and shared grief".

## In loving memory

Some families choose to honour their child's memory by helping others – like Lucie's family, who chose in-memory donations to Very Special Kids as their way of giving back.

Learn more about how Very Special Kids provides compassionate end-of-life and after death care [here](#). 

*Pictured: Very special child Lucie (left) with her parents, Kath and Alvaro, and sister Ana.*

***"We spent four nights with Lucie at Very Special Kids after she died. It was heartbreaking, but comforting to be surrounded by wonderful professionals."***

*- Kath, mum of 4-year-old Lucie who had Miller-Dieker lissencephaly syndrome*





# Leading the way



Sister Margaret's vision shaped Very Special Kids as a leader in paediatric palliative care. She believed families deserved holistic, home-like care beyond hospital walls, leading to the opening of Australia's first children's hospice in 1996.

Since then Very Special Kids House has provided:



## 47,000+

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

As new hospices emerge – including Sandcastles in Western Australia and Mounties Care Cottage in New South Wales – Very Special Kids continues to assist with early planning and shares learnings to guide their development.

*Pictured: Nurses Aoife  
and Tara at the hospice.*





## Supporting national standards

In 2025, Palliative Care Australia took further steps toward implementing the Paediatric Palliative Care National Action Plan.

Our staff contributed to working groups focused on timely referrals, transition planning and developing tools to help clinicians navigate the complexities of palliative care.

Our lived experience network, including bereaved families, parent mentors and siblings, continues to shape national conversation and guide our care.

Their voices ensure policy, practice and our 2025–2028 Strategic Plan reflect the realities of life, death and grief.

## Families at the centre

Our Youth Advisory Group (YAG), generously supported by the Newsboys Foundation, won the prestigious Victorian Government Group Achievement in the Community Award as part of the 2025 7NEWS Victorian Young Achiever Awards.

YAG member Grace hoped the accolade may, “show other organisations the value of listening to young people’s voices and inspire other Youth Advisory Groups to form”.

We also expanded our Family Advisory Committee to include more diverse representation, broadening perspectives and deepening our understanding of what families need at every stage of care.

## Strengthening alliances

Referrals rose by 28% in 2024–25, thanks to stronger ties with Monash Children’s Hospital, the Royal Children’s Hospital (RCH) and community providers.

The introduction of weekly hospice visits from a clinical nurse consultant from the Victorian Paediatric Palliative Care Program (VPPCP) enhanced collaboration, shared care planning and streamlined referrals.

Our hospice team also contributed to the RCH Complex Care Hub’s case review meetings, reinforcing shared goals.

*Pictured: Members of the Youth Advisory Group at the 2025 7NEWS Victorian Young Achiever Awards ceremony.*



## Building death literacy

Led by chief medical officer (CMO) Dr Katie Moore, Very Special Kids continued to educate current and future healthcare professionals about holistic, family and child-centred paediatric palliative care. In 2024–25, Katie delivered education sessions across hospital units, universities and regional health services. Advancements led by our CMO were made possible thanks to the generous support from the Bertalli Family Foundation and the John T Reid Charitable Trusts.

In one session, at the RCH Paediatric Intensive Care Unit, bereaved mum Seol spoke alongside Katie about the Balam Balam suite, where her family were able to grieve and farewell son Tae Yoon in their own time after his death.

***“We spent about a week there. It allowed us to be with Tae’s body, to process his death in a way that felt right for us.”***

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

**Listen to Seol's story here**



Seol’s grieving process for Tae Yoon was markedly different from that of her late husband Greg, who sadly died in 2019. The sudden removal of Greg’s body from the hospital had left her feeling lost and alone.

“I was terrified that the same thing would happen with Tae, but the Balam Balam suite made it a beautiful memory rather than a dark one.”

In a moving radio interview during National Palliative Care Week, Seol expanded on her story on ABC’s *The Conversation Hour*, sharing the importance of increasing knowledge and death literacy, particularly around after death care.

*Pictured: very special child Tae Yoon in hospital (left).*



# Inclusive family care

**Since 1985, Very Special Kids has met the evolving needs of children and families. This began with community support and peer-to-peer connection, and gradually expanded to include hospice care, sibling programs, holiday accommodation and other services.**

For many families, their journey with Very Special Kids begins with a family support practitioner (FSP) – someone who can listen, offer emotional care and practical advice, and connect families with the right services as their needs change.

From checking in on how a child or sibling is adjusting to a new diagnosis to grief counselling, our team of FSPs – based across Victoria – help families develop trust and foster belonging.

## Connecting through grief

In August 2024, we piloted a new bereavement program, Connecting Through Grief. Delivered over four weeks, this workshop created a supportive environment for bereaved parents to explore their grief and share memories of their child. All participants reported meaningful connection, with one reflecting, “Sharing these experiences in a safe space brings vivid colour to the memories of our children”.

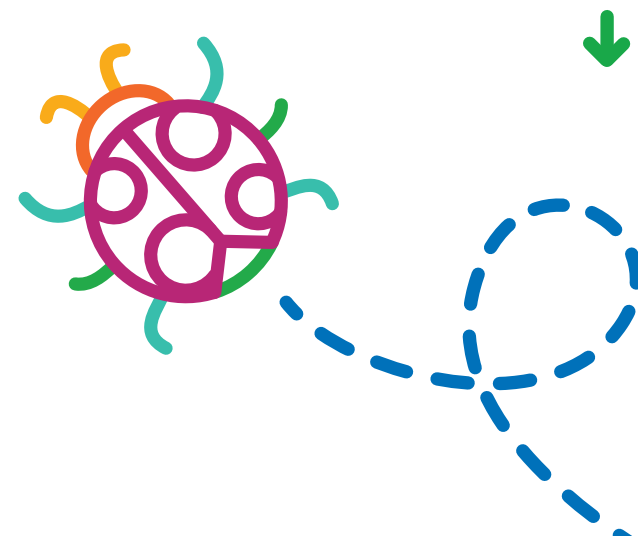
## Building confidence and belonging

Programs like our Adolescent Weekend and Sibling Days help children who have, or have had, a brother or sister with a life-limiting condition find their place in a world that’s shifted around them. In September, the Mittagundi Camp, enabled by the Newsboys Foundation, brought together adolescent siblings for a transformative off-grid outdoor experience. For most, it was their first Very Special Kids program without their family – empowering them to build friendships, confidence and a sense of belonging.

**“The camp was challenging for me, but I overcame my fears and pushed through it and ended up having so much fun.”**

*- Liv, bereaved sibling of 4-year-old Monique who had a DIPG tumour*

Very Special Kids introduced a new initiative for bereaved families in our care, partnering with the Ladybird Care Foundation to offer connection and support through their Peer Mentor Program. Families can take part as mentors or mentees, linking with others who have experienced similar loss. For newly bereaved parents, these one-on-one relationships provide consolation and understanding; for those further along, they offer a therapeutic way to give back. The program has proven deeply meaningful on both sides, helping parents and carers feel seen, heard and comforted wherever they are in Australia.





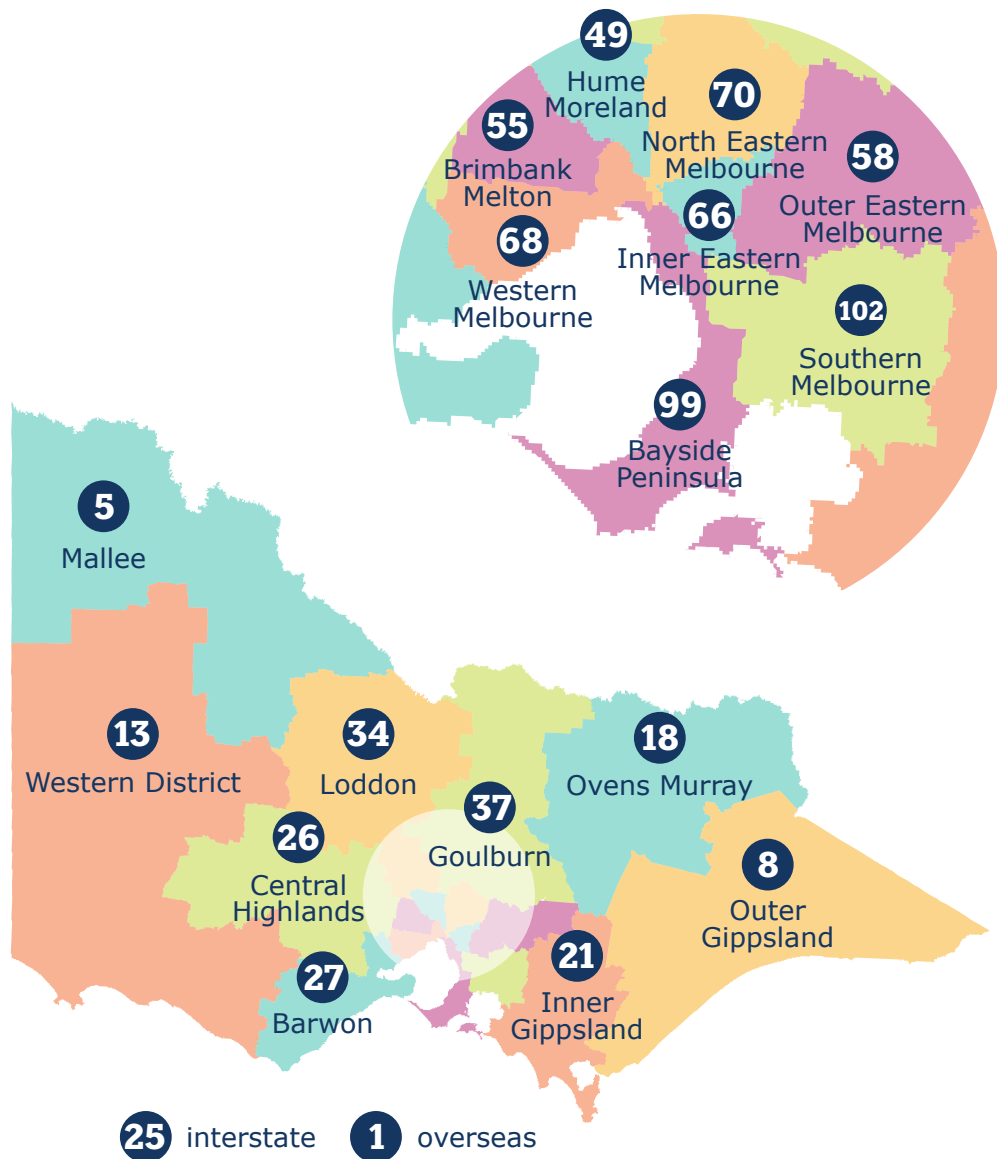
## Reaching new heights

For more than 30 years, the Very Special Kids family weekend at Lord Somers Camp, funded by the Newman's Own Foundation, Freemasons Foundation Victoria and the Earl of Dunmore Lodge, has helped families relax and recharge by the seaside. At this year's camp, the Royal Australian Air Force Balloon created moments of awe, giving children a literal and emotional lift. "It's about bringing joy, fostering connection and showing these kids they can dream big," said balloon pilot Squadron Leader Samuel Wright.

*Pictured: Lord Somers Camp volunteers and very special sibling Ario waving (right).*



## Supporting families across Victoria



## Our impact from 2024–25



**4,060**

hours of counselling  
and emotional support



**\$130,240**

saved by families in holiday  
accommodation fees



**1,170**

attendees at our  
family activities



**33,064kms**

kms travelled by our Road  
to Respite van\*

*\*Our Road to Respite program is run in partnership with Royal Flying Doctor Service. Thank you to CMV Group Foundation for their ongoing sponsorship of this program, and to Qantas Regional Grants for their significant funding throughout 2024–25.*

# Sophia's story

Sophia was born with a rare genetic condition that affects the communication between her nerves and muscles. After four months, mostly spent in hospital, her airway collapsed.

"They said that there's no safe way to send her home unless they put an artificial airway in," shared Sophia's mum Zoe.

In a cruel twist of fate, Zoe was diagnosed with triple-negative breast cancer shortly after giving birth. She began chemotherapy almost immediately, while still trying to stay connected to her daughter from a hospital bed.

"On the worst days of chemo, I just used to FaceTime her," Zoe recalled. "I could only hold my phone for about five minutes before I had to hang up. I didn't even know if she knew I was her mum."

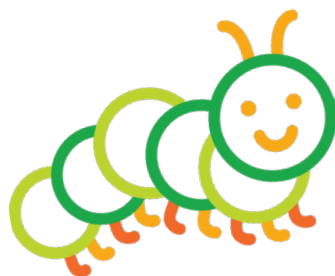
With Sophia's complex medical issues and Zoe facing her own battle, a five-week emergency respite stay at Very Special Kids House provided crucial support that helped the family transition from the hospital to their home with better confidence.

Now in remission, Zoe and her husband Ken continue to access respite care at Very Special Kids House. For Sophia, it's a place she loves. For her parents, it's a lifeline.

***"Very Special Kids helped us figure out what life was going to look like... We didn't know about it before, but now I'd shout it from the rooftops."***

*- Zoe, mum of 1-year-old Sophia who has a congenital myasthenic syndrome*

*Pictured: very special child Sophia with her parents, Zoe and Ken, at her The Very Hungry Caterpillar-themed first birthday party.*





# Our community

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# Our people

## Patron

- Sister Margaret Noone  
IBVM AM (dec)

## Board

Volunteer members who provide strategic direction and governance to help drive our mission:

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



## Management Committee

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



## Foundation Committee

Volunteer members who support our fundraising:

- Glenn Carmody (Chair)
- Philip Endersbee OAM
- David Gibbs AM
- Claudia Haeger
- Andrew Macmillan
- Patrick Prendergast
- Hamish Rotstein
- Quin Scalzo AM
- Justin Whitford

## Life governors

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

- Sister Margaret Noone  
IBVM AM (dec)
- Rod Bennett
- Prof. Glenn Bowes AO (dec)
- Jane Fenton AM
- Paula Fox AO
- David Jones AO OBE KStJ (dec)
- Connie Kimberley
- Roger Nicholson OAM (dec)
- Andrew Penn AO

## Life members

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

- David Agnew
- Gary Anderson
- Cliff Breeze AM (dec)
- Dr Doug Bryan AM
- Dr Elizabeth Carew-Reid OAM
- Glenn Carmody
- The Hon Peter Costello AC
- Anne Dakin (dec)
- Robert Davey
- Chris Gillman
- Prof. Sharon Goldfeld AM
- Janet Hawkins OAM
- John Hope
- David King
- Bill Le Lievre (dec)
- Keera Le Lievre (dec)
- Andrew Miller
- Jean Miller
- Dr Annie Moulden OAM
- John Nairn
- Maureen O'Keefe-Anders
- Heidi Roberts
- Dr John Rogers AM
- Wendy Swift
- Wendy Thorpe OAM
- Jim Wilson



## In memory of two of our life governors

In 2025, we farewelled two influential supporters from our early years – Professor Glenn Bowes AO and David Jones AO OBE KStJ – both life governors who played vital roles in helping realise Sister Margaret’s vision.

Professor Glenn Bowes, who died on 16 January, was a trusted clinical ally of Sister Margaret and an equal advocate for the need for a children’s hospice. As a well-respected professor of paediatrics, he championed holistic, community-based care for children with life-limiting conditions at a time when few in the medical community recognised it. Glenn also played a pivotal role in shaping our clinical policies and model of care ahead of the hospice’s opening in 1996.

David Jones, who died on 24 February, first became involved with Very Special Kids after meeting Sister Margaret and learning about the challenges families faced. He once reflected, “I came away thinking what a marvellous person and what an excellent job the organisation was doing in the community”.

As chairman of Tattersall’s, David carried this conviction to his Board, sharing how the organisation constantly struggled for funds and hoped they, “might help a little”. This decision secured a \$5 million gift to establish Australia’s first children’s hospice, support that continues to touch families today.

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*Pictured: Professor Glenn Bowes (top); David Jones (bottom).*





# Our culture

The care we provide begins with our people, whose compassion and commitment shape the culture of Very Special Kids.

In April, staff and volunteers gathered for a remembrance day in Sister Margaret's honour, sharing stories, creating rituals and pausing to reflect. Just as in our family programs, these rituals help normalise grief and offer space for healing – not to 'get over' loss, but to learn to live with it.

This spirit of compassionate practice and partnership is also reflected in how our staff feel about their work and their place within Very Special Kids.

Our latest employee engagement survey reports meaningful improvements across nearly every category – especially in recognition, support and belonging.

**97%** of staff understand how their **work contributes to our goals**

**95%** feel a strong **sense of accomplishment**

**95%** are **proud to work at Very Special Kids**

## Embedding inclusion, strengthening care

This year, we finalised our organisation-wide Diversity, Equity and Inclusion (DEI) Strategy, funded by the Tank Foundation and developed with input from our consumer groups. The strategy celebrates the many backgrounds and experiences within our community – across culture, ethnicity, gender, sexual orientation, socio-economic status, geography and more – and sets out tangible actions to foster a safe and welcoming environment for all.

*Pictured: Nurse Rita Moreno.*



## Rita's 20-year milestone

For two decades, registered nurse Rita Moreno has witnessed the hospice evolve and the needs of children change, yet one principle has remained constant – bringing thoughtful, personalised support with a creative, respectful spirit.

Rita sees diversity as a key strength:

"I'm proud to do something I love... We all come from different cultures, academic backgrounds and life experiences. That diversity is our strength and means we can stay flexible and creative in our care."

# Our volunteers

**Sister Margaret developed our first volunteer training program in 1986, equipping a team of 26 people with the skills to provide a listening ear and practical help in homes, hospitals and over the phone.**

According to Margaret, their role was never to fix or solve. "Most people are not looking for answers," she shared. "They need someone to listen to their feelings and emotions and to be allowed to express themselves. We are there to walk with them. We do not try to take away their pain."

Decades later, that ethos continues to drive our volunteer program. From serving on the Board or Foundation Committee, to helping in the hospice, at fundraising events and out in the community, they remain the backbone of Very Special Kids.

## Meals that matter

Karen Phillips brings warmth and nourishment to Very Special Kids House – cooking meals for the children staying in the hospice and mindfully adapting to their complex dietary needs. She has also prepared meals for families during end-of-life and after death care, offering comfort at the times they need it most.

With more than 600 volunteer hours to date, Karen's dedication goes far beyond the kitchen. She's also a familiar face at fundraising events – she was recently spotted waitressing at the 24-Hour Treadmill Challenge, bringing the same care and energy she shares with families.

Karen has supported administration tasks, supporter engagement and more. Her advice to others considering volunteering for Very Special Kids? "Do it. There's something for everyone, and it's very rewarding."

*Pictured: Volunteer Karen Phillips at our 24-Hour Treadmill Challenge event.*



## Handmade with heart

The roots of Craft for Kids trace back to the late '80s, when Isabella Edgoose OAM and her husband Graeme helped establish the Friends of Very Special Kids – a passionate group of volunteers dedicated to community fundraising and support.

When local artist June Woods OAM joined the fold, a single art exhibition soon became a joyful tradition of creative giving.

Now, a dedicated team of volunteers creates and sells exquisite handmade items at stalls across Melbourne, raising more than \$75,000 to date. But their gifts go far beyond dollars. The group also handcrafts bespoke items for the hospice, like quilts for cots and beds – offering warmth and cosiness to every child who stays.

*Pictured: Members of the Craft for Kids group.*



## Volunteer impact 2024–25



**7,567**

hours of time  
were contributed



**316**

corporate volunteers  
stepped in to lend a hand



**849**

hospital visits were  
made by volunteers



**\$342,385**

saved in staff wages thanks  
to volunteer contribution



# Volunteer milestones



## 30 years of service

This year, we honoured David Gibbs AM for an extraordinary milestone: 30 years of service as a Foundation Committee member and volunteer.

David brings professional expertise as a chartered accountant and business strategist, along with a personal commitment shaped by his family's experience with childhood illness.

His passion for sibling support has driven and shaped our programs over many years – including the long-standing partnership with Mittagundi, which continues to offer life-changing experiences for adolescents in our care.

Thanks to his tireless advocacy and extensive networks, David has helped raise hundreds of thousands of dollars for Very Special Kids – most notably through the creation of our longest-running fundraiser, the Piggy Bank Appeal – and yes, he still wears his Piggy Bank Appeal tie with pride decades on!



# Volunteer milestones

- Emma Nicholson
- Lucy Nicholson
- Ashley Sibbing
- Sarah Valdez
- Uyen Vu

*Pictured: Volunteer David Gibbs (previous);  
volunteer Jemma Munoz-Richards (below).*

## 20 years of service

- Gayle Goldsmith
- Sharon King
- Kate Wright

## 15 years of service

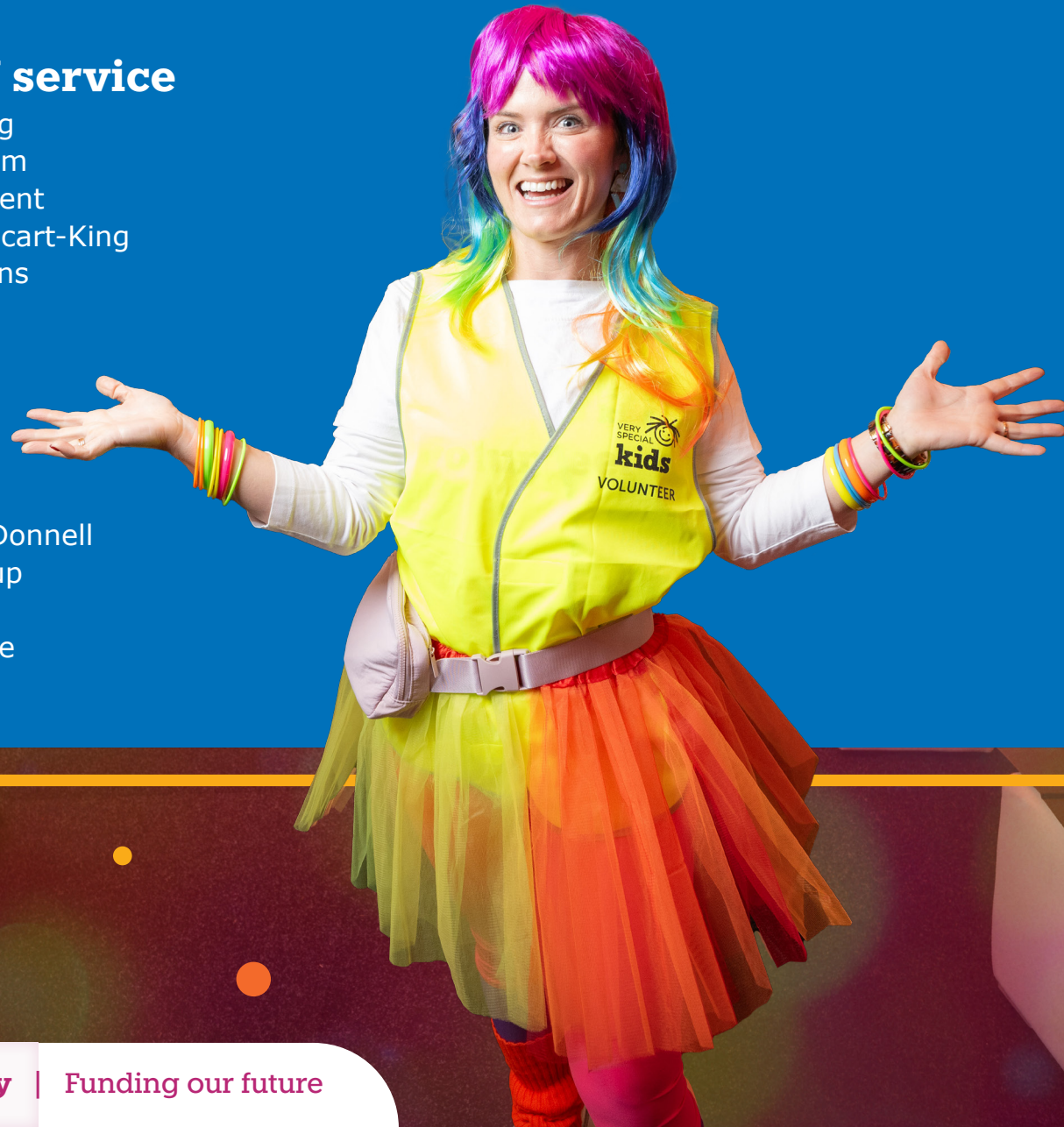
- Vincent Sharp
- Julie Stapleton
- Sigal Witkin

## 10 years of service

- Nilusha De Alwis
- Julie De Vercelli
- Peter De Vercelli
- Marian Jackson
- Vic Jackson
- Rhys Jewell
- Georgina Johnstone
- Carmel Kennedy
- Kirstie Le Quesne
- Amy McKimm
- Jemma Munoz-Richards
- Angela Neilson

## 5 years of service

- Janelle Bragg
- Sarah Braham
- Julia Broadbent
- Yasmin Cathcart-King
- Joanne Downs
- Felicity Ellis
- Peter Fisher
- Aviv Gafni
- Maggie Gao
- Alice McCall
- Tayah O'Dell
- Maureen O'Donnell
- Tiffany Pickup
- Prita Rifianti
- Jaimee White



# Funding our future



# Investing in our future

**For 40 years, the generosity of our community has made it possible for Very Special Kids to provide free, holistic support to children with life-limiting conditions and their families.**

In 2024–25, despite a challenging economic climate impacting the fundraising sector, we continued to strengthen and diversify our income mix to ensure our care can continue for generations to come. This progress was driven by our robust philanthropy program and the ongoing commitment of our major supporters and funders, whose significant and generous gifts remained resilient amid economic uncertainty.

*Pictured: Very special child Josiah with his parents, Ruth and Travis, and sister Phoebe (right).*

## Expanding support

By reaching more people and inspiring them to take action, we are reducing reliance on our long-standing givers and creating a broader, more sustainable movement committed to making a long-term difference.

Digital campaigns have become a powerful driver of growth. Targeted social media activity reached more than 3.1 million people and doubled the number of people actively donating to Very Special Kids. A heartfelt video campaign featuring Ruth, a very special mum, touched hearts across Victoria – 64% of campaign contributions were inspired by her powerful words.

***“Very Special Kids has been instrumental in us having a much-needed break... we’re very grateful.”***

*– Ruth, mum of 5-year-old Josiah who was born with a hole in his heart*

**Play Ruth's  
video here**



Our annual matched giving day, A Very Special Day, once again exceeded expectations. More than \$500,000 was raised in just 24 hours, thanks to the generosity of our community and the support of our matching partners:

Advent Partners, Clive and Jenny Batrouney, efm Logistics, Francis Venues, GO Salary, John Wheeler and Sue Hadden, Kempen Family Foundation, M. Ringersma Trust, Robyn and Ross Wilson and the Tank Foundation.



## Events with impact

In 2024–25, we continued to streamline our event portfolio to deliver fewer, but larger, high-impact events. With refreshed formats and newly formed volunteer event committees, each was designed to grow participation or attendance, enhance guest experience and improve return on investment.

**A Very Special Ladies Lunch** raised \$92,000, delivering an elevated guest experience. The Champagne Dame captivated attendees with her champagne artistry, while event sponsor Runway Room added glamour through beauty stations and complimentary makeup touch-ups.

Our inaugural **Very Special Ride** shifted from a virtual format to a road-based experience. Fifty cyclists completing a 120km journey from Albert Park to Sorrento, raised \$290,000, a 42% growth from the previous event. The ride was made possible thanks to generous sponsors and supporters, including Chadstone Toyota, Boongalla Group and Jellis Craig.



See the ride  
in action here



Our iconic **24-Hour Treadmill Challenge** returned to pre-COVID-19 strength, raising nearly \$980,000 compared to \$670,000 in 2024. More than 1,000 participants kept 36 treadmills moving for 24 hours, with encouragement and on-the-ground radio coverage from 3AW.

Our **Footy Fever** lunch was reimagined and drew record-breaking attendance raising \$370,000, a 95% growth from the previous year. We deepened our partnership with Hyundai Help for Kids, whose donated Hyundai VENUE added a high-impact car raffle. This brought a memorable close to the day when very special mum Louise was drawn as the winner. In an earlier speech she shared,

***“Your support is not just a financial transaction. It is a lifeline”.***

- Louise, mum to 5-year-old Axel who has IQSEC2 and twin sister Aria who sadly died at 19 months old and had leukodystrophy



*Pictured: Very Special Ride participants.*

## Partnerships that last

A highlight of 2024–25 was celebrating five years of partnership with Lowe Living, whose generosity and commitment have made a lasting impact. Over this time, they have contributed more than \$320,000 through sponsorship, fundraising, gift-in-kind support and volunteering.

Emma Lowe, co-founder and managing director, also played an instrumental role as a member of the A Very Special Ladies Lunch Committee, further strengthening the connection and support for the Very Special Kids community.

She shared, “We are honoured to celebrate this five-year milestone with Very Special Kids. Their compassion and dedication to supporting children and young people with life-limiting conditions is truly inspiring, and we are proud to continue standing alongside them in making a meaningful difference.”



**Play Lowe Living's  
video here**



Special thanks go to our dedicated event committees, whose commitment and networks played a vital role in this year's success:

A Very Special Ladies Lunch:  
Simone Braid, Mandy Hall and Emma Lowe.

Very Special Ride: Richard Abel, Neal Dunne, Paul Kelly, Shannon Laffey, Andrew Macmillan, Lee Matenga, Paul McCann, Matthew Mullins, Robert Ralph and Julian Rowell.

Footy Fever: Patrick Prendergast, Peter Sidwell and Justin Whitford.



*Pictured: Emma Lowe (left) and Michael Wasley (right).*



## Community in action

Across Victoria, individuals and community groups rallied together to raise more than \$475,000 this year.

One powerful example is from very special dad Ryan, who spotted the Very Special Kids logo at the Nike Melbourne Marathon on the very same day his daughter Annie was receiving care at the children's hospice. Moved by this moment, Ryan joined 'Team Very Special Kids' the following year. Running alongside 100 other runners, they raised more than \$120,000 for Very Special Kids.

***“Very Special Kids is an amazing organisation. It was great knowing Annie was in a safe place that was equipped with everything she needs.”***

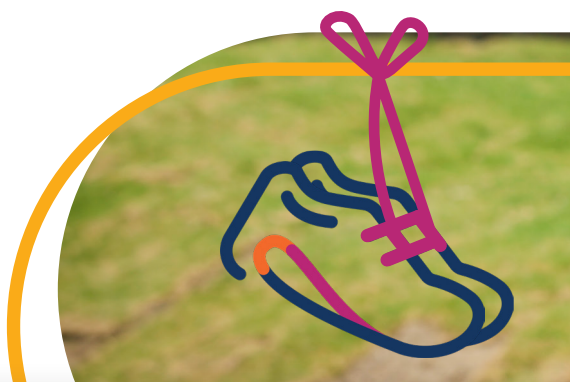
*– Ryan, dad of 6-year-old Annie who has Aicardi syndrome*

## Leaving a legacy

Being a Very Special Guardian offers those who leave a gift in their Will an opportunity to continue Sister Margaret Noone's vision for future generations. More than \$590,000 was received in bequests in 2024–25.

Volunteer and fellow Very Special Guardian Libby Clarke reflected on her 28-year journey with Very Special Kids, “Creating safe, nurturing spaces for children and families has been the most meaningful part of my work with Very Special Kids. To know that legacy will live on through my bequest gives me great comfort.”

*Pictured: Very Special Ride participants (left); very special child Annie and her dad Ryan captured by James Wiltshire (below).*



# 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
- Anywise Consulting Pty Ltd
- Austunnel Pty Ltd
- Balcon Group
- BTIG Australia Limited
- Commbank Staff Foundation
- dopTM
- efm Logistics
- Ernst & Young
- Francis Venues
- Guild Group
- International Power Australia Pty Ltd (trading as ENGIE in Australia)

- Jemena
- Lovelight
- Lowe Living Co. Pty Ltd
- Metropole Property Group
- Monark Property Partners
- Parkdale Community Branch
- Paypal Giving Fund
- Petstock Foundation
- Sidcorp P/L
- Slade Pharmacy Management P/L
- Turi Foods
- Whitbread Insurance Brokers
- William Buck

## Trusts and foundations

- The Alfred and Jean Dickson Foundation
- Anderson Estate
- Australian Communities Foundation
- Australian Philanthropic Services Foundation
- The Baker Foundation
- Batrouney Family Charitable Foundation
- Bertalli Family Foundation
- Brian M Davis Charitable Foundation
- Cassandra Gantner Foundation
- CMV Group Foundation
- Corio Foundation
- Donkey Wheel Fund
- Dorman Family Foundation
- The Douglas Whiting Trust
- Ducas Paul Foundation
- Flora & Frank Leith Charitable Trust
- Foundation of Graduates in Early Childhood Studies

- The Fox Family Foundation
- Freemasons Foundation Victoria
- Gringlas Family Charitable Fund
- GW Vowell Foundation
- Harry Cohny Charitable Foundation
- The Highland Foundation
- Hooley Family Foundation
- John T Reid Charitable Trusts
- The Johnstone Family Foundation
- Kempen Family Foundation
- Lord Mayor's Charitable Foundation
- The Lyle Foundation
- MacKenzie Family Foundation
- The Marian & E H Flack Trust
- Marjorie M. Kingston Charitable Trust
- Mavrix Investments
- McAllister Family Foundation
- MRC Foundation
- Newmagoo Family Trust
- Newman's Own Foundation
- Newsboys Foundation
- The Orloff Family Foundation
- Paint & Hardware Legends Club
- Pierce Armstrong Trust
- Qantas Regional Grants
- SeriousFun Children's Network
- Steadfast Foundation
- Stocks Family Foundation
- The Stuart Leslie Foundation
- Sunraysia Foundation
- Tank Foundation
- Trinity Families - The Trustee For The Roman Catholic Diocese Of Sale Charitable Fund
- Waters Perpetual Charitable Trust
- The William Angliss (Victoria) Charitable Fund



## Individuals

- Angela Baldi
- Clive & Jenny Batrouney
- Jack & Meg Bowen
- Margaret Brown
- Shaun Clarke
- D'Lan Davidson
- Damian & Julia Degenhardt
- Annie Dunn
- Meredith Evans
- John & Jenny Fast
- Angela Found
- Bob Glindeman
- Goldsmith Family
- Judy Greig
- A R Griffiths
- John Wheeler & Sue Hadden
- Dennis & Suzanne Harvie
- Robert Hooke
- Brandon Howard
- Joseph Hsiao
- Kevin Kelly
- Connie & Craig Kimberley OAM
- Tony & Sandy Kirkhope
- Sharon Landy
- Laurence Law
- Susan Le Rossignol
- Irene Messer
- Anne & Ian Muir
- Daniel Mundy
- Jan Pannam
- David Scheinberg
- Grace Scoleri
- Glenda Shelley
- Peter Strauss

- Susan Turner
- Doug & Charlie Tynan
- Ian & Kristeen Urquhart
- Brett & Simone Webb
- Robyn & Ross Wilson

## Very Special Guardians

- Estate of Diane Collins
- Estate of Valma Mary Cox
- Estate of Jean Violet Davidson
- Estate of Mark Raymond Finn
- Estate of Warren Francis Mills
- Estate of Kathleen Yvonne Nowik
- Estate of Jean Margaret Oldfield
- Estate of Natalie Mary O'Sullivan

## Media partner

- 3AW

## Gift in kind

- Bridged Group
- Chadstone Toyota
- CK Formwork Constructions
- Corrs Chambers Westgarth
- Deloitte
- GSS Group
- Harry the Hirer
- Hyundai Motor Company Australia P/L
- Linfox Logistics
- NAB Global Occupier Services
- Novofit
- Od bods Group Victoria

- PFD Foods
- Rapid Relief Team
- Runway Room Cosmetics
- Shane Delia
- Stefano de Pieri AM
- Sutton Grange Winery
- Toyota Australia

## Program partners

### The Victorian Paediatric Palliative Care Program



Royal Flying  
Doctor Service  
VICTORIA

red  
nose

LSC



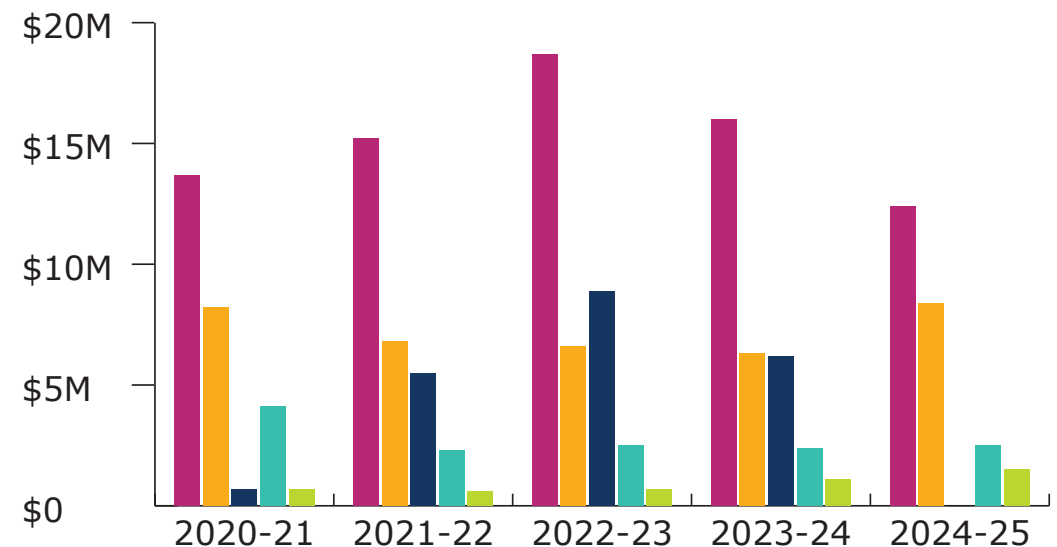
# Financial snapshot

In 2024–25, Very Special Kids continued to benefit from strong fundraising and sustained government support. In previous years, significant funds were drawn down to support the hospice rebuild, temporarily inflating revenue. With those funds no longer accessed, we returned to more typical fundraising streams and delivered a modest surplus.

This outcome reflects the strength and sustainability of our philanthropy program, as well as the enduring commitment of our major supporters and funding partners. We continued to streamline our event portfolio and our flagship 24-Hour Treadmill Challenge returned to pre-COVID-19 income. The surplus, was also underpinned by careful financial stewardship to ensure long-term impact. Looking ahead, we anticipate a more challenging fundraising environment as we work to secure the revenue needed to cover the full cost of delivering our essential services and implementing our new 2025–28 Strategic Plan.

The Board and management remain committed to ensuring the long-term financial sustainability of the organisation, while maintaining the highest standards of care and engagement with the families we support.

## Financial overview for the year ended 30 June 2025



- **\$12.4M** Total operating revenue
- **\$8.4M** Fundraising income
- **\$0** Funds drawn down for hospice
- **\$2.5M** Government income
- **\$1.5M** Investment income

## Where our income comes from



- 27% Donations
- 20% Government grants
- 14% Events
- 12% Investment income
- 9% Corporate fundraising
- 9% Trusts and foundations
- 5% Gifts in Wills
- 4% Community fundraising

## Where the money goes



- 75% Service delivery
- 16% Fundraising
- 9% Administration



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.





**vsk.org.au**

**1800 888 875**



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