A very special annual report

2021–22

Improving quality of life

VERY SPECIAL kids

> *“Very Special Kids is another light in our darkness. They have walked with us through many of our biggest moments.”*
>
> **KAT**, mum of 12-year-old **NOAH** who has mitochondrial disease

Images: (this page) Noah and Kat, (front cover) very special child Cassandra and her brother Andrew.

Contents

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 pay respects to them, their Elders and communities past, present and future.

Very special child Everley.

Our impact

We believe all children and young people have 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 their families – through life, death and bereavement. Our integrated approach includes emotional, clinical and practical support to help improve quality of life and create positive, lasting memories.

81 in-home respite sessions

5,669 counselling & emotional support sessions

387 holiday accommodation nights at Glen Osmond Farm

869 families supported

101 families streamed Remembrance Day video

121 bed nights in our temporary home at Monash Children's Hospital

14 end-of-life care nights

29 coffee groups hosted for parents

Allied health impact

105 music therapy sessions	**115** physiotherapy sessions	**150** art therapy sessions	**22** occupational therapy sessions

Tailored care & support

Holistic palliative care for children, young people and their families

As one of Victoria's leaders in children's palliative care we take a proactive approach to tailor the right services and support, as we understand that every child and every family's needs are unique.

Family counselling

"There are not many people you can honestly and openly talk about such darkness with and at the same time laugh about the wonderful moments."

KAT, mum of 12-year-old **NOAH** who has mitochondrial disease

Peer support networks and activities

"[I love] the friendships we continue to make within Very Special Kids, to know we are not alone. It's a great day out where we can just hang out away from grief."

FAMILY who attended the Adventure Park Geelong family day

Sibling support

"The Sibling Support Program – where they meet other kids who have a sibling with a terminal condition – allows them to share experiences, challenges and fears in an open, responsive and playful environment."

KRISTY, mum of 7-year-old **JETT** who has KCNQ2

Holiday accommodation

"Most families with children with a chronic illness don't have the luxury of using their paid or unpaid holiday leave for actual holidays. To have access to accommodation totally free-of-charge means so many families can actually go on a holiday."

JAKE, dad of 8-year-old **EDEN** who has lissencephaly

Family accommodation near our hospice

"We booked into the hospice's family accommodation for three nights and it was a lifeline. I was able to get a good night's sleep for the first time in years... I could check in on [Elliott] when I wanted to, the staff just loved him, he was so happy."

JANE, mum of 4-year-old **ELLIOTT** who has tracheobronchomalacia

Images (top right): Face painting at a family day, (middle): Very Special Kids nurse and child at our children's hospice in Malvern.

Hospice care

"Very Special Kids is our second home. Staying at the hospice was the best decision I made. They have helped us a lot to cope with our situation with Cassandra... Our worries were lessened, and we felt secure with them."

JHOSA, mum of 2-year-old **CASSANDRA** who has spinal muscular atrophy

End-of-life care

"The level of compassion and care was amazing. The nurses really put us at ease and enabled us to focus on just being mum and dad."

JACQUI, bereaved mum of 5-year-old **CURTIS** who had a DIPG brain tumour

Post-death care

"Whilst it will never be okay, it is more bearable knowing Reggie was able to spend his last hours at the Very Special Kids hospice surrounded by those who love him."

CHRIS, bereaved dad of 2-year-old **REGGIE** who had infantile-onset Pompe disease

Bereavement counselling

"When Monique passed away the care from the hospital and the palliative care team suddenly ended. Thanks to Very Special Kids we didn't feel so alone, they were there to pick up the pieces."

DANIELLE, bereaved mum of 5-year-old **MONIQUE** who had a DIPG brain tumour

Message from our leaders

In 2021–22, Very Special Kids continued to refine the way we deliver our holistic palliative care services to children and young people with life-limiting conditions, and their families.

Perseverance and moving forward

Despite the reoccurrence of COVID-19 restrictions and lockdowns, our frontline team of nurses, counsellors, carers and allied heath staff remained in high spirits, adapting our essential services to ensure the safety and quality of life for the children and families in our care.

We were challenged in August 2021, when the hospice was decommissioned to commence a rebuild. In order to sustain respite and end-of-life care services, a temporary site was established at Monash Children's Hospital in Clayton. However, the immense strain on the healthcare sector resulted in our relocation to Monash being placed on hold until April 2022. In the interim, our clinical staff and allied health therapists delivered in-home respite support sessions, while our family support practitioners continued to offer online and remote telehealth sessions when required.

Very Special Kids House

The Sister Margaret Noone Hospice at Very Special Kids House is due to open its doors in early 2023. Despite ongoing supply shortages and challenges in the construction sector, the project remains on time and within budget. The new hospice will result in the creation of a world-class, best practice paediatric palliative care facility for children and families facing the most difficult of times.

This watershed moment is only possible thanks to the tireless efforts from our Capital Campaign Committee, Federal and Victorian Government financial contributions and the philanthropic community.

Increasing our reach and impact with families

Very Special Kids provided 869 families across Victoria with emotional, clinical and practical support in 2021–22, including 87 new families.

As an organisation, and in addition to providing our regular services, we endeavour to provide a platform for children, siblings and parents to share their thoughts and opinions on the aspects of our support that directly affect them. To complement the existing Family Advisory Committee, the Youth Advisory Group was introduced this year to ensure the voices of children and young people are also heard. Insight and feedback from these groups and committees helps Very Special Kids to evaluate our services from a family perspective. These committees provide valuable insight into how we can better meet their complex needs.

Sustainability

COVID-19 continued to impact the fundraising activities of self-funded charities like Very Special Kids this past year. Despite this hardship, the creativity, innovation and passion of our fundraising team has not faltered. We built more sustainable income streams; via the launch of a new Gifts in Wills program, strengthened relationships with our supporters and delivered our second annual matched giving day, A Very Special Day. We were also fortunate to see the return of many of our flagship fundraising events and remain dedicated to continue to raise the funds required to support Victorian children and families for generations to come.

Ongoing support from our loyal community of major supporters, funders, corporate partners and generous bequestors has allowed us to navigate these uncertain times, as well as finish our year with a surplus. We were delighted to gain the support of many new donors and corporate supporters who share our vision and passion for helping children with life-limiting conditions.

A very special thank you

The past two years have seen many hardships, particularly for the children and families in our care, as well as our donors, volunteers and corporate supporters. It is a testament to Sister Margaret Noone's influence, and the generous nature of our stakeholders, that Very Special Kids has emerged in such a solid position from the greatest societal challenge of our time.
We are in awe of our very special community for their ongoing passion, dedication and drive. Thank you.

Peter Polson Chair | **Michael Wasley** CEO

Images (left): Michael Wasley, CEO,
(top left): Peter Polson, Chair, (top right):
Sister Margaret Noone, Patron and Founder.

Message from our Patron and Founder

As the last 12 months have passed, it has been heart-warming to see the isolation of the last two years begin to ease, and we move forward with renewed optimism for the future.

We are thrilled to have recommenced many activities and events for the children and families in our care. Seeing the children, their siblings, parents and extended families reconnecting, both in person and virtually, has brought joy to all of us at Very Special Kids.

I am always proud of, and inspired by, the staff and volunteers who continue to provide families with the support, care and understanding they need during the most challenging times. Our incredible team of nurses and personal care workers have shown exceptional resilience and flexibility as we welcomed children to our temporary hospice facility at Monash Children's Hospital.

This year has seen tremendous progress on the rebuild of our hospice, a project that I personally am delighted to see coming to fruition. The facilities, care, and comfort we can offer families in the new hospice will be second to none, and along with the whole organisation, I look forward to its completion in early 2023.

Sister Margaret Noone,
Patron and Founder AM IBVM

Leaders in children's palliative care

Very Special Kids continues to be one of Victoria's leaders in palliative care for children, young people and their families. Due largely to the expertise and dedication of our staff and volunteers.

As the only provider of its kind in Victoria, our holistic palliative care is delivered by a team of clinicians, hospice and respite carers, therapeutic experts, and child and family counsellors, as well as our trained family volunteers.

Together, we provide the emotional, clinical and practical support children, young people and families need to navigate their individual journeys.

Sharing our knowledge

In 2021–22, our service delivery team actively contributed to improving conversations around illness, grief and death.

We are participating in the Palliative Care National Action Plan Project, funded by the Australian government and led by Palliative Care Australia.

The three-year project identifies 10 key activities to support health professionals and address the needs of parents and carers. Key stakeholders from Very Special Kids are involved in the development of this national project, advising on improvements that can be made in the sector. Exchanging knowledge and experience with other key paediatric palliative care providers is key to how we advocate for the best palliative care for children, young people, and their families.

The Very Special Kids service delivery team also shared their expertise at the Consortium Managers meeting in Victoria to raise awareness of children's palliative care amongst health care providers, ancillary services, and community groups. Furthermore, key staff members from our counselling, allied health and hospice team presented at the Sydney Children's Hospital Network – Paediatric Palliative Care Symposium, the Oceanic Palliative Care Conference and the Palliative Care for Nurses Australia Conference.

Enhancing the way we care

The opening of the Sister Margaret Noone Hospice at Very Special Kids House is set for early 2023 and a key focus of our service delivery training in 2021–22 has been in preparation for our new world-class facility.

Our hospice team undertook 73 education sessions, including ventilator training from Royal Children's Hospital and community visits with Palliative Care South East. Training sessions and refresher courses, like this, ensure we stay abreast of best practice in paediatric palliative care.

This practice extends to our metro and regional family support team, who undertook domestic violence training under the Family Violence Multi-Agency Risk Assessment and Management (MARAM). The outcomes of this training have profound impact on wellbeing and quality of life for the children and families we support.

3 therapists

10 personal care workers

Belinda providing physiotherapy at our children's hospice.

In April 2022, we also implemented an electronic quality and risk management system, known as eQstats. This tool has enabled us to improve incident, quality and risk reporting, and investigation and response processes, while providing more transparency across the organisation.

Our hospice team has expanded with the creation of a new Clinical Nurse Coordinator position, which has been funded thanks to the generous support of the Baker Foundation.

We welcomed Anna-Lee Walden into the new position, a role that is fundamental in supporting the reopening of the children's hospice in 2023. Anna-Lee has 14 years of experience in paediatric palliative care and forms part of the senior nursing team, working both clinically on the floor and supporting the Hospice Manager operationally.

25 registered nurses

18 family support practitioners

Very Special Kids is committed to providing programs to develop and maintain a highly skilled workforce. Our Learning and Development Policy ensures all staff have maximum opportunity to develop and hone their skills to provide best practice paediatric palliative care.

International learnings brought home to Victoria

After spending six weeks overseas visiting 12 children's hospices across the United Kingdom, Scotland and Ireland, our resident Physiotherapist Belinda Luther says, "I have returned with an energy and passion for physiotherapy and paediatric palliative care like never before."

Belinda's travel was part of her Churchill Fellowship to investigate and implement best practice physiotherapy in Australian paediatric palliative care. The trip enabled her to establish connections, learn from and collaborate with international physiotherapists.

Belinda is applying her learnings from the Fellowship to the Sister Margaret Noone Hospice and is fulfilling the fellowship aim of sharing her newfound knowledge with paediatric palliative care and physiotherapy networks across Australia.

"I look forward to being able to implement and share the knowledge I have gained to ensure Australian children and young people with life-limiting conditions receive best practice physiotherapy."

We're incredibly grateful to Laurence Law, who funds Belinda's physiotherapy position within our hospice. Laurence made his donation in part to honour the memory of his wife Lilian, who like him, had a passion to support children in need.

Supporting families across Victoria

At Very Special Kids, we help families face the things they never thought they would have to say, do or feel. Our holistic services are available to children, young people and their families right across Victoria, with each corner of the state supported by our expert and professional team.

Very Special Kids provides holistic support services across Victoria.

During 2021–22, we were proud to help over 869 Victorian families access our children's palliative care services, including 87 new families. Our team has been privileged to physically and virtually sit with and support families' complex illness and grief journeys, while fostering and sharing in moments of joy, laughter and relief together.

Very Special Kids bereaved parents, Mel and Felix with their son Lucas.

Adapting to the times

Throughout the COVID-19 pandemic we continued to refine, innovate and embrace new ways of delivering services to the children and families in our care. We established a succinct hybrid service delivery model to enhance our connection with families across the region, providing online and in-person therapeutic and allied health programs.

Telehealth continued to play a vital role in communication with families this year, with our team delivering 944 consults. Telehealth has offered families across the state more flexibility, as travelling long distances or navigating time off work to visit our metro and regional offices can be stressful.

We also continued providing our interim in-home pilot program. This in-home care allows children and young people with high-complex needs to be cared for under the safety of our team, while offering family members valuable downtime and support in the comfort of their own home. The program delivered vital care while COVID-19 was prevalent in the community and our respite and therapeutic services at Monash Children's Hospital had been placed on hold.

Very Special Kids parents, Mel and Felix, were one of 39 families who took part in the in-home service, creating valuable memories with their 5-month-old son Lucas, who had spinal muscular atrophy and sadly died in March 2022.

Mel and Felix recount their experience coming home from hospital after Lucas had two episodes.

> ***"We did not dare to cuddle him, as repositioning him may cause blockage of his airways. Very Special Kids helped us and with their supervision, we finally cuddled Lucas again! I would definitely regret if I did not cuddle Lucas during the last period of his life."***

419 bereaved families

450 non-bereaved families

Connecting online

Like so many people across the globe, connecting online became integral to our work and lives.

Our Zoom Room sessions of music, stories and activities proved an effective platform, continuing to be a welcoming and therapeutic space for the families we support across the state. Sixty-six families united in a heart-warming singalong with Australian pop star royalty (and all-round kind human) Delta Goodrem.

Our online Bereaved Parent Support Group evenings enabled parents who may not always get the opportunity to come together to reflect on their grief and support one another.

Geeta, a bereaved parent who attended the session, says she found comfort in connecting with other parents who were on a similar journey to her.

> ***"Being able to share (or not) brought a sense of safety in these small groups and has been a welcome space and time to look forward to sharing or contemplating our children and the effect of living without them."***

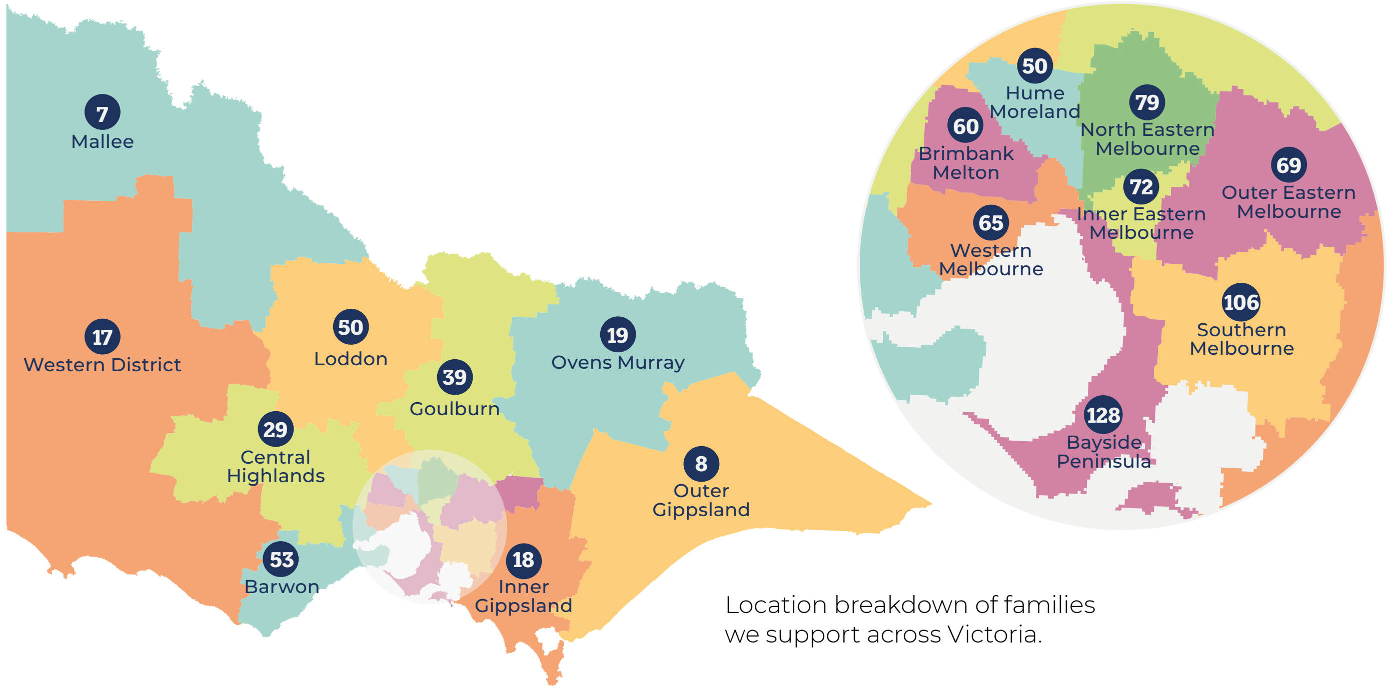
Meet our Service Delivery team

Family Support Manager Jessica Birnbaum and Hospice Manager Kirsty Blair share their joint vision for Very Special Kids.

"By collaborating we can focus on the medical and wellbeing needs of families in both a community and clinical setting. We work together to ensure families across the state feel surrounded by high-quality care that promotes cohesion, greater agency and informed choice," shares Jess.

"We may take different pathways, but our overall vision and desire for the children and families we support is unified. It is extraordinary to imagine what we will be able to do as a team, once we are under one roof again," concludes Kirsty.

Image: Jessica (left) and Kirsty (right)



Location breakdown of families we support across Victoria.

Connecting very special families

12 family activities

Events such as our family days help children, siblings and parents connect with other families who understand the complexities of caring for a child or young person with a life-limiting condition.

While 2021 and early 2022 continued to present challenges due to the pandemic, we collectively breathed a sigh of relief as we gradually reintroduced in-person peer-support networks and activities. The sound of laughter, chatter, music and games was a beautiful way to be reminded of the importance of in-person connections.

As the safety and wellbeing of the children and families in our care remains our priority, we ensured that all activities followed COVID-19 safety protocols.

The Woodend Family Day was one of our first state-wide events to return, where we welcomed 28 families to our property at Glen Osmond Farm in Woodend.

Family Support Practitioner Anna Phipps explained that families felt overjoyed to be together and surrounded by fun therapeutic activities at the purpose-built, fully accessible farm, which is available to families to book for a much-needed break:

“Over the last couple of years, the children and families we support haven’t been able to engage with each other, as well as their Family Support Practitioner, in the way we would have ideally liked. So, to be together in-person again was really special.”

We also saw the return of other in-person programs including our Bereaved Parent Weekend, which is funded by William Angliss (Victoria) Charitable Fund. One parent who attended the Bereaved Parent Weekend in the secluded Hepburn Springs describes it as an emotional, heart-warming and confronting experience:

“It felt like we were able to spend a weekend with our child, to talk freely about them, our experiences, their memory, our grief, loneliness and to express our love in a safe and supportive way.”

Adolescent siblings experienced their own unforgettable week of adventure at the biannual Mittagundi Adolescent Camp. The camp offered bereaved and non-bereaved siblings the chance to come together and connect over their shared experiences, while they explored Victoria’s rugged Alpine region.

Jude, a bereaved sibling who attended the camp, says:

“These camps are not only opportunities to have an absolute blast participating in camp games and activities, but also a special time in which you can connect with other young people who live in similar life situations who you might not be able to connect with as easily otherwise.”

Thank you to Coca-Cola Australia Foundation for championing our youth and making opportunities like Mittagundi Adolescent Camp possible.

Aria & Axel’s story

When Louise and Raymond were rocked with the news both their twin babies Aria and Axel were diagnosed with differing rare genetic diseases, mum Louise says, “it felt like one blow after another”.

A referral to Very Special Kids helped set up emotional and clinical support for the whole family. With the assistance of TLC Ambulance, our multi-disciplinary team was able to curate a family trip to Melbourne Zoo before Aria sadly died in May 2021, at 19 months old.

“Being told that Aria didn’t have long, we weren’t really strong in ourselves to leave the house without anyone with us. We were greatly appreciative they made that happen and that we got to have that experience as a family.”

Their family support practitioner, Angela Flood, has continued to provide emotional support to the family, helping them navigate their grief, and cope with looking after Axel during this difficult time. Louise shares,

“Very Special Kids has been a godsend. Angela has not only helped with Aria but has continued to support us through Axel’s journey. She has assisted me in so many areas. It’s amazing how her care has extended to the whole family.”

Images (top): Louise and Raymond with their three children; Charli, Axel and Aria, (left): Mittagundi Adolescent Camp.

Hearing their voices

As an organisation, we endeavour to provide a platform for children, siblings and parents to share their thoughts and opinions on the services that directly affect them.

Everything we do at Very Special Kids has the aim of creating a better quality of life for seriously ill children and young people, and their families.

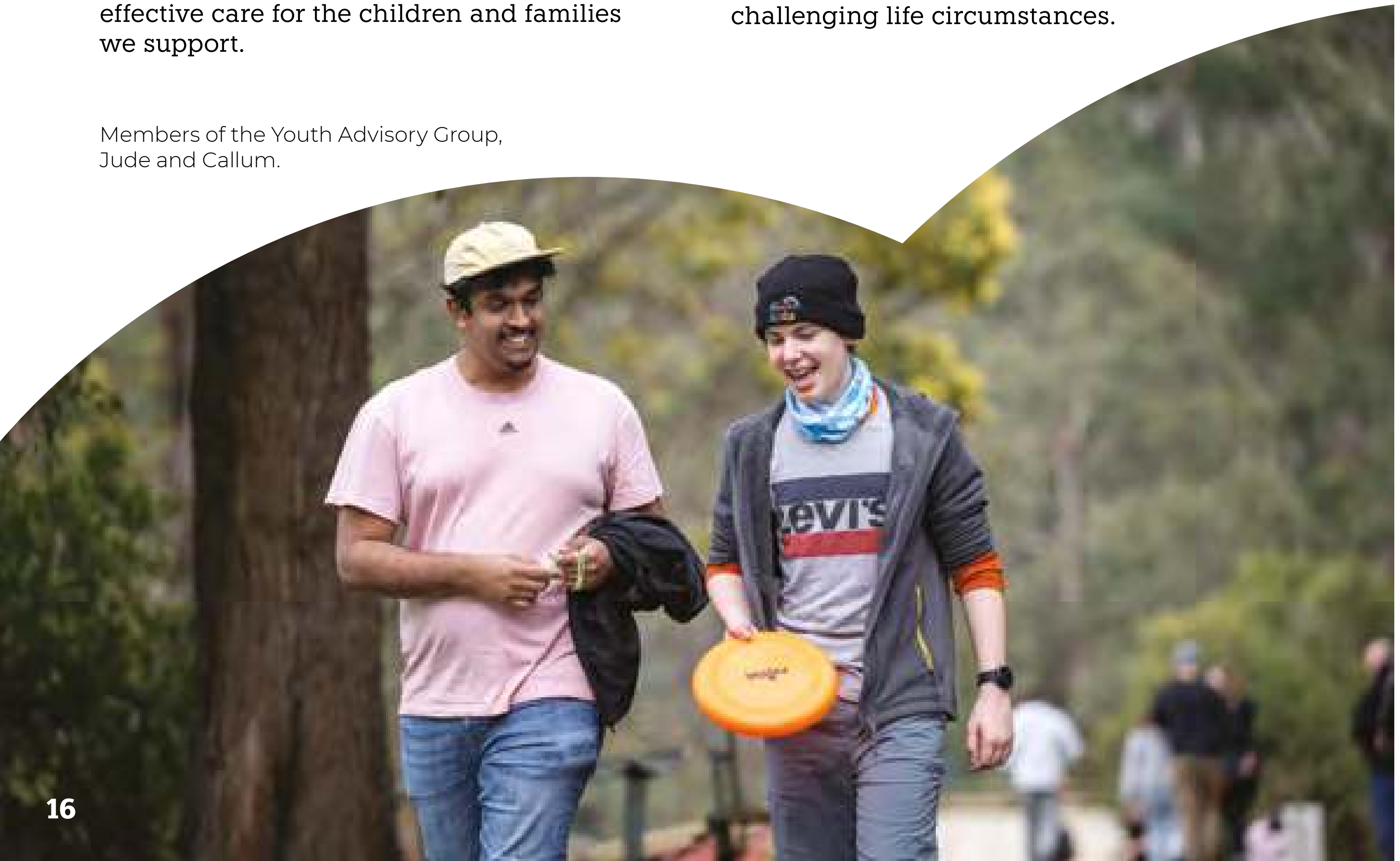
This has been strengthened by the implementation of our Consumer Engagement Strategy, which was developed to enhance our health literacy, inclusivity and engagement across our services.

To help deliver the strategy and meet National Safety and Quality Health Services (NSQHS) standards we have a range of committees, working groups and service delivery initiatives that are collaborating to ensure we provide safe, personal and effective care for the children and families we support.

After five years seeking input from our Family Advisory, and Diversity and Inclusion committees, during 2021–22 we added three more working groups to our strategy: the Rights of the Child Group, Education Group, and our newest addition, the Youth Advisory Group.

Across our five different working groups and two committees we have parents, siblings, consumer representatives and staff sharing their insights, skills and reflections on service delivery. At their core, all our working groups strengthen the way we advocate for children and embed the rights of the child into everything we do.

Working collaboratively and advocating together will ensure we can all provide the best resources, expert staff and volunteers, training, care and programs to help the children and families in our care, and their communities, through the most challenging life circumstances.



Members of the Youth Advisory Group, Jude and Callum.

Youth Advisory Group

Our Youth Advisory Group first met over Zoom in April 2022 and set the wheels in motion for generational change and innovation to take place.

The group is made up of nine enthusiastic, motivated, and inspiring young adult and adolescent siblings eager to express their thoughts and ideas in bold, creative ways. One member of the Youth Advisory Group shares,

"I'm inspired to bounce ideas off others, to make Very Special Kids more accessible, to improve communication and program diversity."

The Youth Advisory Group has been made possible thanks to the generous contribution of Freemasons Foundation Victoria, who fund the Youth program and empower young people supported by Very Special Kids to achieve their dreams.

The Youth Advisory Group's first online meeting.

A champion for kids' voices

Championing the voices of children and young people has been a passion of Meg Chin's since she began her role with Very Special Kids 11 years ago.

Meg has been fundamental in the development of our new Rights of the Child Working Group and has been a key voice at symposiums and conferences, presenting on the topic to her peers.

In May 2022, Meg flew to Norway to attend the International Work Group on Death, Dying and Bereavement. While there, Meg participated in a weeklong workshop and shared sector innovation and ideas, collaborated on projects and developed discussion papers for publication.

Meg has also embarked on her PhD, to better understand what exactly happens to a child in the years after their sibling's death. Her research project will gather evidence directly from bereaved siblings, aged from five to 12 years old.

"Research literature does not adequately reflect the important perspectives of children who are experiencing grief," Meg explains.

"I think as a society we have a lot more work to do when it comes to how we think and talk about grief. The contributions and perspectives of children will inform how we support and care for children who have experienced the death of a sibling, now and into the future."

Image (above): Meg Chin, Family Support Team Leader.

Rebuilding our hospice

The Very Special Kids grounds have been buzzing with excitement as construction of our new world-class hospice takes shape.

At our sod-turning ceremony in December 2021, we were joined by former Federal Minister The Hon. Greg Hunt MP and Parliamentary Secretary for Health, Mr Steve McGhie MP, along with other members of parliament and key supporters from our community.

After years of dreaming, planning and fundraising, this special event marked a watershed moment in our history and significant steps forward for paediatric healthcare in Victoria.

Our new world-class children's hospice will ensure the highest level of internationally led best-practice palliative care can be delivered for Victorian children and young people with life-limiting conditions, and their families, for generations to come.

Despite ongoing challenges in the construction sector, we are on track to open the Sister Margaret Noone Hospice at Very Special Kids House in early 2023, thanks to the support of our construction partner Plan Group.

The $22.5 million project was made possible because of the Australian Government, Victorian Government, local members of parliament, philanthropic leaders and the Capital Campaign Committee.

Members of the Capital Campaign Committee have worked tirelessly to secure funds and get A Very Special Project off the ground:

- Andy Penn (Chair)
- Paula Fox AO (Patron)
- Connie Kimberley (Patron)
- The Hon. Kelly O'Dwyer
- Glenn Carmody
- Neville Azzopardi
- Peter Polson
- Sister Margaret Noone (Patron)

Our temporary home

Throughout the new build process, our highest priority has remained providing support and care with minimum disruption.

Unfortunately, due to the pandemic, respite services at our temporary home, Monash Children's Hospital, were put on hold for an eight-month period.

Thankfully, we opened the doors to our interim space in April 2022 and within the first few months of opening we provided invaluable respite and clinical care to 28 new and familiar faces.

A heartfelt thank you to our staff and the children and families we support who have shown invaluable resilience during this transitional period. To Monash Children's Hospital, thank you for accommodating us.

Hospice rebuild progress.

Caring for Cassandra

When baby Cassandra was diagnosed with spinal muscular atrophy at 2 months old, her parents Jhosa and Aaron were told she "won't last the year".

For the doting family, it is nothing short of a miracle that their remarkable little girl will celebrate her 3rd birthday in September 2022.

"For us, she's, our superhero. She keeps fighting for her life," Jhosa and Aaron share.

After her diagnosis in hospital, the family was referred to Very Special Kids and offered 24-hour end-of-life care at the Very Special Kids hospice in Malvern, where they stayed for five weeks prior to its temporary closure.

"I think moving into Very Special Kids hospice is one of the best decisions we've ever made for Cassandra. It prolonged Cassandra's life. We're so lucky to be part of Very Special Kids."

The family have celebrated each of Cassandra's milestones along the way.

"She's getting stronger and stronger every day. That's a milestone that we didn't expect. It's also because of the help of the team that supports her — the nursing staff, physiotherapist, the OTs and the speech pathologists."

"I can say it's a miracle. Our daughter is a fighter."

> ***"Very Special Kids prolonged the life of Cassandra... staying there at the hospice made me realise that it's possible to enjoy life even if my daughter has a complex condition. There's still hope."***
>
> **JHOSA**, mum of 2-year-old **CASSANDRA**
> who has spinal muscular atrophy

Cassandra in her superhero outfit.

Our very special volunteers

Volunteering has been the heart of Very Special Kids since 1985, and our community of volunteers continue to inspire us with their generosity and commitment to the children and families in our care.

Our 1087 volunteers come from a diverse range of ages, backgrounds and cultures, and we value each of their unique and valuable skills and experience.

The pandemic continued to affect our ability to support families in-home, via family programs and at events. Our Volunteer Coordinator Nathan Brown turned to a range of innovative training opportunities and digital programs to keep supporting and connecting with new and existing volunteers.

> *"There was some trial and error, however, I've been really impressed with how our volunteer community worked together to deliver new initiatives to families. Their determination and adaptability eased Very Special Kids transition to online training and professional development sessions, supported regional volunteer recruitment, and helped with our transition to Monash."*

In recognition of these efforts, it was an honour to be awarded Volunteering Victoria's 2021 *Volunteering Award for COVID-19 Support and Coordination*. The award is testament to the flexibility and dedication of our wonderful volunteers and the leadership of our volunteer team during these challenging times.

To support the complex needs of the children and families in our care, volunteers complete an extensive training program to equip them with specific skills and knowledge.

In preparation for returning to the Very Special Kids hospice at Monash Children's Hospital, volunteers had the opportunity to attend monthly professional development sessions. The sessions helped our volunteers refine existing skills, as well as learn new techniques. Undoubtably, one of most popular sessions was a refresh course on how to best use our therapy dog Jaffa's behaviours, skills and tricks in a hospice setting.

Orientation commenced in June 2022, and the first group was able to return to the work they do best – providing support and care for children and young people who have life-limiting conditions.

Image (above): Our Volunteer team proudly accepted the Volunteering Award from the Governor of Victoria Her Excellency the Honourable Linda Dessau AC.

1,087
volunteers

1:9
staff-to-volunteer ratio

Australia Day Champion

After dedicating many years of her life to helping charities like Very Special Kids, volunteer Ros Ferres received the 2022 Australia Day Local Champion Award. This esteemed honour is well-deserved, as Ros has a long-term dedication and selfless commitment to helping others.

"I love volunteering for Very Special Kids, because everyone is treated equally, everyone is always included. It is just a really nice place to be," Ros shares.

> ***"If you are considering volunteering with Very Special Kids, don't think about it, just do it. There is plenty of ways you can get involved and make a difference. Fundraising, working at events, administration jobs – there is something for everyone and each role plays an important part in making sure families receive the care they need."***

Volunteers Ros Ferres and Margaret Burston.

Thanks to generous support from the Barr Family Foundation and other valued donors, volunteers like Tina can be trained with the skills and knowledge needed to support children like Alex and their families.

Alex's story

Through our Home Volunteer Service, volunteer Tina Theofanis visits six-year-old Alex and his family, bringing fun and adventure into Alex's life and some much-needed support for parents Bess and Mitch.

"We fell in love with Tina immediately, she was one of the few people we felt happy to trust with Alex's care," mum Bess shares.

Alex is one of five children in Australia known to be diagnosed with Pelizaeus-Merzbacher disease (PMD) – a disease that requires 24-hour care and impacts his ability to walk and talk.

"Knowing he was in such good hands meant I could spend a few precious hours on my own, resting and recharging my batteries over a long, relaxing coffee."

Image (above): Alex with his Very Special Kids volunteer, Tina.

Image (above): Volunteers celebrating their milestone achievement at our Volunteer Appreciation Night.

Milestone achievements

Thirty years at Very Special Kids

One of our longest serving volunteers, Steven Rosewarne, has celebrated his 30-year milestone.

"Thirty years... it does not seem like 30 years. I still feel I've got a lot to give, and I know by giving, that warms my heart as well."

Steven has been involved from almost the very start and credits his longevity to the breadth of volunteering options available.

Volunteers like Steven are invaluable — humble about his achievements and dedicated to supporting children and their families through the most difficult of times.

We are extremely grateful to all our volunteers for their dedication and passion towards Very Special Kids and the children and families in our care.

> ***"When you go and give yourself to volunteering, you make such an impact in someone's life, and in turn, that makes such an impact on you."***

A special thank you to the following individuals who have reached these incredible volunteering milestones:

30-year Service Award

- Steven Rosewarne

25-year Service Award

- Libby Clarke
- Shirley Graham

20-year Service Award

- Brad Crewe
- Jennifer Keat
- Julie Cascone
- Sandra Lewis

15-year Service Award

- Andrea Johnson
- Bruce Emerson
- Caroline Morgan
- Caroline Savage
- Genevieve Le Hunt
- Jan Silk
- Jessica Marshman
- Judy Curnow
- Kate Wright
- Katy De Valle
- Kay Sutherland
- Linda Miller
- Ray Sneddon
- Roslyn Ferres

10-year Service Award

- Anisa Khosh
- Diana Todhunter
- Holly Rominov
- Margaret Burston
- Michele Layet
- Peter Polson
- Stephanie Groube
- Sue McClean
- Tia Sparis

5-year Service Award

- Alison Jane
- Ally Liew
- Anastasia Lewis
- Andrea Ryan
- Angela Chen
- Anita Fothergill
- Anna Dawson
- Anne O'Connor
- Ann-Marie Trinh
- Barbara Hutchinson
- Ben Mabon
- Bridget Walker
- Caitlin Smith
- Callum McNicol
- Carmen Blatti
- Catherine Altson
- Catherine Sawyer
- Cecilia Kwok
- Cecilia Pynaker
- Chloe Balfe
- Claire Rasmussen
- Claudine Tsao
- Cody Oliveira
- Denise Joy Kallenberger
- Di Judd-Campbell
- Dianne Ryan
- Edward Kidd
- Elizabeth Zimet
- Fiona Gardiner
- Hamish Rotstein
- James Tavlian
- Joan Bruton
- John Dawson
- Lachlan Cauchi
- Latha Devaraja
- Laura Purcell
- Lia Wassell
- Lois Smith
- Luigina Panayi
- Luke Rycken
- Mandy Lobley
- Matthew Coleman
- Megan Mcgregor
- Megan Wimmers
- Melissa Kelly
- Melissa Savaglio
- Mingmei Li
- Naree Osmers
- Natalie Ward
- Nella Campagna
- Nikki Phillips
- Paari Palaniswami
- Rainer Kallenberger
- Sachi Mylius
- Sandra Alway
- Susie Gibb
- Tanya Azar
- Tina Theofanis
- Trent Toohey
- Vanessa Rubenstein
- Varsha Desai

Volunteer, Steven Rosewarne and our Patron and Founder, Sister Margaret Noone.

Our very special community

Very Special Kids' future relies on the generosity of individuals, organisations, philanthropic funders and the wider community to ensure we can continue providing the most comprehensive and holistic palliative care for children and young people, and their families.

The pandemic continued to push us to strengthen and diversify our income streams and refocus efforts on more sustainable sources of income. Investment and structural improvements in our philanthropy programs, including trusts and foundations, major gifts and a refresh and relaunch of our bequest program (read more page 28), played a leading role in our recovery plan, as did our giving day.

We were grateful for yet another terrific campaign this year, with A Very Special Day smashing its previous total and raising over $700,000. Our giving day is only made possible thanks to our community partners who committed to matching donations: Highland Foundation, ALH Hotels, John Wheeler and Sue Hadden, Simply Energy and Lowe Living.

Working towards a brighter future

Our many long-term partnerships are testament to our commitment of working with companies to support their goals, whether they be aligned to corporate social responsibility, staff engagement, corporate volunteering, workplace giving or event participation.

2021 marked the final year of our three-year Pin & Win partnership with Victorian Racing Club (VRC). More than $310,000 was raised for Very Special Kids through the sale of commemorative Lexus Melbourne Cup pins at the 2021 Melbourne Cup Carnival. Over the three years, the successful partnership delivered $1 million in donated funds, increased media coverage and awareness of Very Special Kids, and gave us the opportunity to work once again with VRC Ambassador Delta Goodrem.

A new, dedicated partnership with PayPal Australia in 2021 raised over $73,000 via their Give at Checkout program. From October to December 2021, customers could add a $1 donation to any purchase, setting Very Special Kids as their favourite charity via the PayPal app.

During the campaign we were proud to work alongside funny-man Jimmy Rees. Jimmy has supported Very Special Kids for many years after seeing firsthand the care we provided his 10-year-old nephew Rye.

By the time of publication, Rye had sadly died. His uncle shared: "May you Rest In Peace, pain free. What an incredible life of resilience, courage and strength. The mark you have left on us all will remain forever in our hearts. Uncle Jimmy will see you again soon buddy."

Images (left): Volunteers and staff selling Lexus Melbourne Cup pins at the 2021 Melbourne Cup Carnival, (top right): 13-year-old Steph, who has mitochondrial disease and spoke at the Ladies Lunch in March 2022, (right): ALH Hotels team participating at the Very Special Kids 24 Hour Challenge.

Connecting for a cause

After postponement, our Footy Fever Debate went ahead at Crown Melbourne in November 2021, attended by 150 people and raising $152,000. The event – which was MCed by Jacqui Felgate – saw football legends Daniel Harford, Tony Shaw, Russell Robertson and Brendan Fevola switch the field for the stage, battling it out in a heated debate. Thank you to major partners 3AW and Lowe Living for generously supporting the event.

Another crowd favourite is our annual Ladies Lunch in March 2022. Thanks to the support of 160 attendees, and our event sponsors Royal South Yarra Lawn Tennis Club and Lowe Living, we raised $77,000 to support the children and families in our care.

We've also seen a number of community fundraising events being held in-person again, including our Golf Days, where hundreds of supporters hit the greens across Victoria to raise a total of $117,555 for Very Special Kids. Special mention goes to Altona City Rotary, who has been organising their own golf day since 2006.

Read more over the page.

ALH Hotels

25 years of support

For 25 years, ALH Hotels has been a pillar of support, standing by Very Special Kids' side as a major partner.

They first made a $1,000 donation in 1997, and since then our partnership has continued to grow. Over the years, ALH Hotels has contributed over $5.3 million to support children with life-limiting conditions and their families.

ALH Hotels continues to be a significant partner across many of our key events and programs. They are a major sponsor of the Piggy Bank Appeal and support our Footy Fever Debate, Golf Days, 24 Hour Challenge and giving day.

Always the life of the party, this year ALH Hotels staff fully embraced the 24 Hour Challenge with a colourful kombi van cut-out and some of the best tie-dye, psychedelic prints and headbands around. With almost 200 staff across their venues participating, their team won the 24 Hour Challenge 2022 Fundraising Award, raising $138,000.

To the staff of ALH Hotels, who every year continue to put their hearts and energy into their fundraising – we would like to extend a resounding thank you for your ongoing generosity and impact.

Raising more than a sweat

After two years of onsite cancellation, nearly 1,000 participants came together for our flagship fundraising event, the 24 Hour Challenge.

The event, held in June 2022, asked teams or individuals to keep their treadmills in continuous motion for 24 hours, while those who couldn't attend had the option to DIY their active challenge at home. Our very special community put in an incredible effort, raising over $690,000 for seriously ill kids in 24-hour care.

Special mentions must go to our top team fundraisers ALH Hotels, Ernst & Young and Honan for their phenomenal efforts onsite, and to the 3AW team and AFL superstar Jimmy Bartel who DIY'd their challenge and raised almost $40,000 for Very Special Kids. Jimmy jumped on the treadmill in the 3AW studio for a live broadcast over the 24 hours, and through running and walking, single-handedly completed 100km.

> ***"If you're in the unfortunate circumstance that one of your children has been diagnosed with a life-limiting condition, you want these saints on your side. They do extraordinary work."***
>
> **Jimmy Bartel, Former Geelong FC player and 3AW Football team expert**

In the spirit of the 24 Hour Challenge, the Frankston Rotary Club completed their own Virtual Treadmill Challenge, where participants completed a 30-minute virtual workout. Ten teams and more than 80 individuals took part, raising $32,000.

The Very Special Kids 2022 Autumn Classic also celebrated its fifth year, raising $190,000. Twelve teams took on seven tough virtual courses of the famous Champs-Elysees in Paris. Competition was fierce but team InForm TMX MAKE took out the win. Even more sought after was the highest fundraising team award, which Toros won for raising almost $61,000 across their two teams – an incredible result.

> *"There are so many families out there who need support just like ours. This is our chance to give back in a small way."*
>
> **KRISTY** and **DAMIAN**, parents of 7-year-old **JETT**, who has KCNQ2

Kristy, Damian and Jett at the 24 Hour Challenge in June 2022.

Running for Reggie

In 2021, we relaunched our Team Very Special Kids community fundraising program. This included partnering with Nike Melbourne Marathon Festival for the first time and working with some inspiring community ambassadors.

Community Ambassador Chris was one of 579 participants who joined Team Very Special Kids. Together, the team raised nearly $70,000 for the children and families in our care.

Chris participated in the half-marathon, raising funds in memory of his son Reggie who died at age two in 2019 after being diagnosed with infantile-onset Pompe disease.

Reggie spent his last hours at the Very Special Kids hospice surrounded by family and our specialist team. Today, his family continues to access expert counselling and a range of support programs at Very Special Kids.

"Very Special Kids have been extremely important for us from the time of Reggie's diagnosis through to the continued support we receive today. We will forever be indebted," Chris says.

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

"Running was important to me immediately after Reggie's passing – it was my way of having some time with him."

Very Special Kids Foundation Committee member – and running superstar – Claudia Haeger also participated in the 2021 event, committing to the gruelling 42.2km full marathon. She crossed the finish line in under four hours and raised more than $3,000.

Claudia has been an advocate for Very Special Kids for four years.

> ***"I believe that with kindness, hope and through the great efforts of Very Special Kids, the world would be a better place."***

In a year when many members of Team Very Special Kids have faced their own challenges, on behalf of the children and families we support, thank you for this phenomenal outcome.

Image (above): Chris and his family before the Nike Melbourne Marathon Festival.

Our very special guardians

We are humbled by and truly grateful for the kindness of bequestors who left a combined $1.3 million to Very Special Kids in 2021–22.

When a person leaves a gift in their Will, they join a valued group of supporters who we caringly refer to as Very Special Guardians.

The relaunch of this bequest program gives us the power to plan and fund new projects, better supporting children and families in our care.

When a supporter remembers Very Special Kids in their Will, they are in many ways guarding the vision of our Patron and Founder, Sister Margaret Noone AM, for generations to come. Sister Margaret has spent her life caring for thousands of seriously ill children and their families. She shares,

> ***“A gift in your Will is the most joyful thing. It gives those of us blessed with longer lives the chance to share our good fortune with children and families whose time together may be fleeting.”***

In June 2022, 11 Very Special Guardians attended a morning high tea at the grounds of our hospice and kindly shared their ‘why’ for joining our generous circle of donors:

“Leaving a bequest is something I feel everyone has the opportunity to do, at whatever financial level, to set an example to family members to always give back to others.”

Adding Very Special Kids to a Will is a powerful tool for positive change. Every gift, big and small, makes a real difference to the children and families we support now, and into the future.

Images (left): Sister Margaret at the Very Special Kids hospice, (right): Very Special Guardians at Malvern for high tea.

A lasting legacy

We first met Margaret Brown in 2018 during a 24 Hour Challenge broadcast on 3AW, when she called up live on air and made a generous donation.

A registered nurse for 35 years, Margaret was a district nurse in the Myrtleford region and worked at St Vincent’s Hospital managing the outpatient service, so was acutely aware of the health needs of our community. We were blown away by her generosity then and have continued to be touched by her support in the years since.

The 65-year-old developed a strong connection with our work and keenly shared her love of children and animals, expressing her desire for Very Special Kids to have a resident dog for the kids. She was no doubt pleased that our very own therapy dog Jaffa joined the team in 2019.

After a few health scares, Margaret got in touch with our team to let us know she was leaving a property in our name, gifting her home to Very Special Kids. To personally thank Margaret, some of our volunteers thoughtfully stitched together a handmade coat for her dog Archie. While we know this small gift pales in comparison to Margaret’s generosity, she appreciated the thoughtfulness dearly.

Margaret sadly died in 2021. She will always be remembered for her generosity, kindness and passionate approach to looking after sick children and their families. Her extraordinary gift of her $935,000 home will have a profound impact upon the lives of the children and families in our care, well into the future.

Our generous supporters

Corporate

- Advent Partners
- ALH Hotels
- Arbee Real Estate
- Backburner Solutions Pty Ltd
- Balcon Group
- CMV Foundation
- Commonwealth Bank of Australia – Head Office
- Connell Australasia
- Delaford P/L
- Demak Timber & Hardware
- Ernst & Young
- Francis Venues
- Godolphin
- Guild Group
- Hippo Blue
- Honan Insurance
- Icon Group
- International Power Australia Pty Ltd
- JBWere
- Jellis Craig – Head Office
- Linfox Property Group Pty Ltd
- Lowe Living
- Motorsport Australia
- MRC Foundation
- Natalie Ann Rose Investments Pty Ltd
- Navy Health
- Officeworks
- Plan Group
- Professional Golfers Association of Australia Ltd
- Rose Grange Investments Pty Ltd
- Sandridge Roads
- SEMZ
- Shaw & Partners Foundation
- Tabcorp Holdings
- Tank Foundation
- Victoria Racing Club
- Viva Energy Australia
- Whitbread Insurance Brokers

Individuals

- Angela Found
- Brett Webb
- Cathie Reid
- Cherie Cork
- Daniel Trewin
- David and Susan Peake
- David Scheinberg
- Doug Evans
- Goldsmith Family
- Grace Scoleri
- James Doyle
- Jan Pannam
- Judy Greig
- Justin Whitford
- Katrina Fox
- Laura Oosterloo
- Laurence Law
- Margaret Brown
- Nicholas Bouseka
- Peter Kempen
- Peter Strauss
- Rhiannon Devine
- Rita Andre
- Simon Daish
- Stephanie and Robert Prowse
- Susan Harris
- Tony and Sandy Kirkhope

Estates and bequests

- Estate of Debbie Leigh McMillan
- Estate of Domenico Romeo Pertile
- Estate of Hollis Mary Callinan
- Estate of Joyce Garratt
- Estate of June Venecia Mary Collins
- Estate of Mara Langley
- Estate of Margaret Anne Brown
- Estate of Margaret Joan Titulaer
- Estate of Marjory Joyce Jones
- Estate of Natalie Jean O'Hehir
- Estate of Natalie Mary O'Sullevan
- Len Underwood

Our program partners

CATA

Royal Flying Doctor Service VICTORIA

red nose

Trusts and foundations

- Australian Philanthropic Services Foundation
- Barr Family Foundation
- Campbell Foundation
- Chain Reaction Challenge Foundation
- Corio Foundation
- Costello Family Foundation
- Crown Resorts Foundation
- Dorman Family Foundation
- Ducas Paul Foundation
- Freemasons Foundation Victoria
- Gringlas Family Charitable Fund
- MacKenzie Family Foundation
- Marjorie M. Kingston Charitable Trust
- McAllister Family Foundation
- McNamara Family Foundation
- Newsboys Foundation
- Norman, Mavis & Graeme Waters Perpetual Charitable Trust
- Packer Family Foundation
- Stocks Family Foundation
- Sunraysia Foundation
- The A L Lane Foundation
- The Alfred and Jean Dickson Foundation
- The Baker Foundation
- The Gall Family Foundation
- The Hazel Peat Perpetual Charitable Trust
- The Marian & E H Flack Trust
- The Noel & Carmel O'Brien Family Foundation
- The Pierce Armstrong Foundation
- The Stuart Leslie Foundation
- The Thomas O'Toole Foundation
- The William Angliss (Victoria) Charitable Fund

Media partner

- 3AW Radio

Gift in kind

- ARA Property Services Pty Ltd
- Bay Quilters
- Benestar
- Blackhawk Network Lifestyle Platform
- Bridged Group
- CM Liquor
- Corrs Chambers Westgarth
- Elmo Talent Management Software
- Helping Hand Group
- KPMG
- Linfox Logistics
- Lord Somers Camp and Power House
- Novofit
- Optical Audio Productions
- Penfold Motors Burwood
- PFG Australia
- Rapid Relief Team
- Rich River Golf Club
- Royal South Yarra Lawn Tennis Club
- Woodlands Golf Club

Government

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

Community fundraisers

- Blue Bell Hotel
- Carbine Club of Tokyo
- Chadstone Toyota
- Golf Clearance Outlet
- Grupetto
- Inform TMX MAKE
- Inverloch Lotto
- Jellis Craig Group Charitable Fund
- Jemena/Zinfra
- Keilor East RSL
- Malvern Xmas Trees
- Manningham Hotel
- Rotary Club of Altona City
- Rotary Club of Werribee
- Rotary Frankston Sunrise
- Sandown Park Hotel
- Seaford Hotel
- Seda Group
- Six Degrees Executive
- Skyways Hotel
- Slater and Gordon Medical Law
- Spiders
- Supersonic Jett
- The Flinders Challenge
- The Young & the Restless
- TORO
- Tramonto Estate Wines
- Trivelo
- Tudor Inn
- Westend Market Hotel

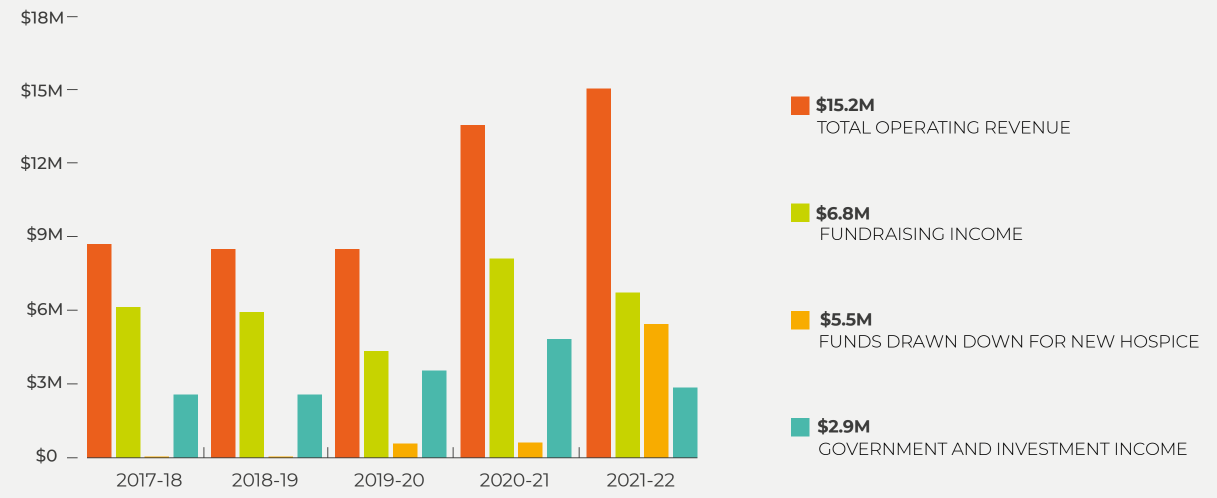
**Supporters over $5,000*

Financial snapshot

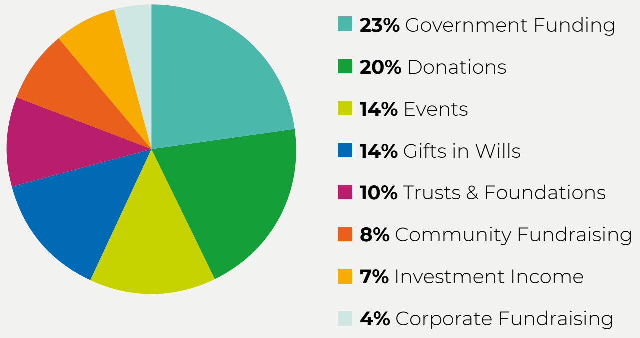
Over the course of the 2021-22 financial year, we were pleased to see a gradual return of general fundraising activities, including our flagship fundraising events. Thankfully, our focus on creating more sustainable income streams, meant strong fundraising results were achieved through major gifts and a significant bequest.

A substantial portion of our fundraising income was received in prior years and was drawn down as income in 2021-22 to support the rebuild of Sister Margaret Noone Hospice at Very Special Kids House. In the interim, our hospice team relocated and the extent of our service delivery was reduced to fit capacity in our temporary space. We expect the spend in this area to increase once we return to full capacity in our new hospice in 2023.

Financial overview for the year ended 30 June 2022

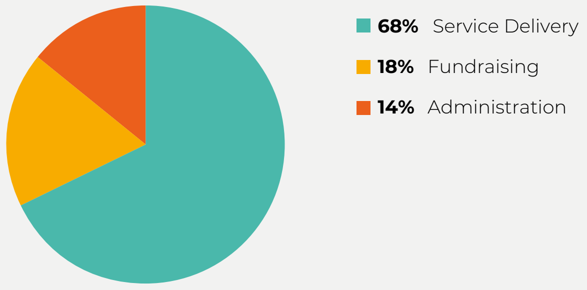


Where our income comes from



Income drawn down for the hospice rebuild has been excluded.

Where the money goes



Our people

Patron

- Sister Margaret Noone, AM IBVM

Board

- Peter Polson (Chair)
- A/ Prof Adam Scheinberg
- Cameron Fuller
- Dr Susie Gibb
- Heidi Roberts
- Luke Bell
- Rhys Jewell
- Therese Robinson
- Wendy Thorpe (resigned)

Management Committee

- Michael Wasley
  Chief Executive Officer
- Angie Dredge
  General Manager – Service Delivery and Improvement
- Donna Durston-McKenna
  General Manager – People and Culture
- Marcia Christmas
  General Manager – Fundraising and Marketing
- Matt Dunshea
  General Manager – Business and Finance
- Jane Baker
  People Operations and Office Manager
- Jessica Birnbaum
  Family Support Manager
- Kirsty Blair
  Hospice Manager
- Sharon Stynes
  Fundraising and Events Manager

Foundation

The Foundation is a network of supporters who raise the profile of Very Special Kids and identify influential contacts and potential supporters. Its members are:

- Glenn Carmody (Chair)
- Alex Lavelle
- Andrew Macmillan
- Andrew Perry
- Cass Becher
- Claudia Haeger
- David Gibbs
- David Szeleczky
- Hamish Rotstein
- Justin Whitford
- Neville Azzopardi
- Phil Endersbee
- Rebecca Rizzo

Life Governors

Life governorship has been conferred on the following members without whose efforts Very Special Kids would not exist in its present form:

- Sister Margaret Noone, AM IBVM
- Andrew Penn
- Connie Kimberley
- David Jones, AO, OBE, KSJ
- Jane Fenton, AM
- Paula Fox, AO
- Professor Glenn Bowes
- Rod Bennett
- Roger Nicholson, OAM (deceased)

Life Members

Life membership has been conferred on the following members who have given a substantial special contribution over a period of years and whose efforts have significantly affected the work of Very Special Kids:

- Andrew Miller
- Bill Le Lievre (deceased)
- Chris Gillman
- David Agnew
- David King
- Dr Annie Moulden, OAM
- Dr Doug Bryan
- Dr Elizabeth Carew-Reid, OAM
- Dr John Rogers, AM
- Gary Anderson
- Janet Hawkins, OAM
- Jean Miller
- Jim Wilson
- John Hope
- John Nairn
- Keera Le Lievre (deceased)
- Maureen O'Keefe-Anders
- Professor Sharon Goldfield
- Robert Davey
- The Hon Peter Costello, AC
- Wendy Swift
- Wendy Thorpe

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.

Image: Very Special Kids families attending the Eltham Miniature Railway family day.

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.

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