# A very special annual report







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# Our impact

## Our children's hospice is a home away from home for children and young people with life-limiting conditions.

The first of its kind in Australia, Very Special Kids House was the vision of our first employee and patron, Sister Margaret Noone. After seeing firsthand the benefits of dedicated children's hospices in the United Kingdom, Sister Margaret vowed to bring the same level of care to Australia. To this day it remains Victoria's only children's hospice.

We provide holistic palliative care that spans the physical, mental and emotional needs of the children and young people we care for across Victoria. We are there when a family needs us most – be that through family counselling, sibling programs and holiday accommodation or our visiting volunteer program, peer networking opportunities and bereavement support.

Here are some of the ways we made a very special difference in the 2022–23 financial year:





counselling and emotional support sessions



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



holiday accommodation nights



# Allied health impact

# Message from our leaders

During 2022–23, we prepared to take a significant and long-awaited step forward for paediatric healthcare in Victoria.

# Overcoming hardship with resilience

While many communities put COVID-19 disruptions behind them, Very Special Kids remained impacted by challenges within the construction sector. Staff and supply shortages resulted in a 10-month delay to our hospice rebuild project. Although Monash Children's Hospital was kindly able to extend our stay at our temporary hospice, we did experience a three-month period where neither facility was available to the families in our care. Thankfully, our nurses, carers and counsellors maintained incredible focus during this hardship, ensuring Very Special Kids families remained our highest priority.

# A house with a bright future

Our hospice rebuild was an ambitious project, inspired by Sister Margaret Noone's legacy, informed by international best practice research and designed by expert architects and building consultants. It is a world-class facility that will support thousands of Victorian families for many generations. Despite construction delays, the project was achieved within budget and Very Special Kids has no ongoing debt to service. We extend our gratitude to the Commonwealth and Victorian Governments, our Capital Campaign Committee and the many donors who helped turn our vision into a reality.

We anticipate the early months of 2023–24 will hold a mixture of challenges and excitement as staff prepare the facility and begin to welcome children for respite

stays and end-of-life care. At the time of publication, we expect the Sister Margaret Noone Hospice at Very Special Kids House will be operating at full capacity.

This is a watershed moment, not only for Very Special Kids but for the progression of paediatric palliative care in Australia.

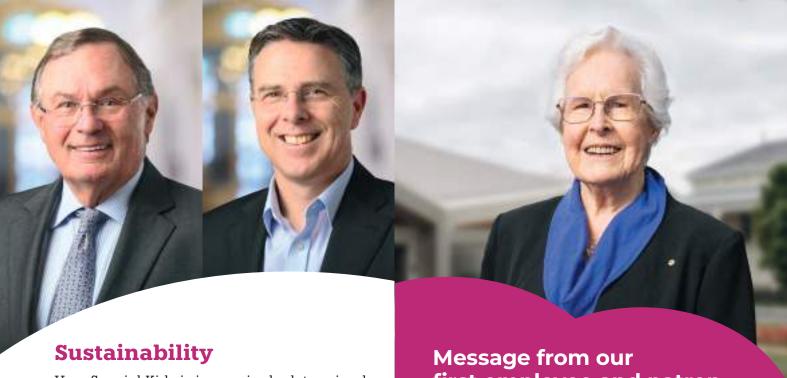
We can now focus on the future with optimism as we strengthen and develop our strategic plan to meet the evolving needs of children with life-limiting conditions across the state. Very Special Kids staff have showcased their resilience, managing the disruption of the past three years with great professionalism and a high regard for our stakeholders. The Board are indebted to everyone's overwhelming dedication.

## **Our commitment to families**

Very Special Kids provided 795 families across Victoria with emotional, clinical and practical support in 2022–23, including 96 new families.

In April, Very Special Kids achieved our three-year accreditation extension against the National Safety and Quality Health Service Standards, an acknowledgement of our ongoing high standards in the provision of support to children with complex care needs. The auditors particularly highlighted our commitment to families and the important holistic point of difference in our model of care.

In 2022–23, we established our inaugural Children's Advisory Group for siblings aged between eight and 13, following the success of our Youth Advisory Group (siblings aged between 14 and 25) that launched in 2021–22. These groups provide a valuable child's perspective, ensuring we can improve and refine our service delivery to best meet the needs of the entire family.



Very Special Kids is increasingly determined to balance the high medical needs of current families, while ensuring our long-term financial sustainability is secure.

In 2022–23, we formed valuable connections with new corporate and philanthropic funders and invested in proactively growing our regular giving program. Our recently implemented gifts in Wills program continues to receive positive support. Increasingly, many individuals are choosing to leave their legacy to ensure the next generation of Victorian families can navigate childhood life-limiting illness. These types of fundraising further support our long-term organisational planning.

Very Special Kids has also placed considerable emphasis on strengthening our major fundraising events so they can return to their pre-COVID-19 success. Our 24-Hour Treadmill Challenge, for example, continues to be popular for loyal and emerging supporters.

# A very special thank you

Despite challenging economic times, our loyal supporters, corporate partners, volunteers and the Victorian Government continue to underpin our current services and long-term financial sustainability. It is thanks to their dedicated support that we can confidently care for sick kids, and their families, at the time they need us most. We remain forever grateful and inspired by our very special community of supporters. Thank you.

Peter Polson Chair | Michael Wasley CEO

# first employee and patron

As we reflect on the last 12 months, I am filled with pride and joy to soon see the doors of our exciting new hospice opening to the children and families in our care.

We are all privileged to support children and families during their most challenging times and are inspired by their resilience in the face of the unimaginable. Families can turn to us for comfort, compassion and reassurance whenever they need, and the team at Very Special Kids will be there for them.

As we near the opening of Very Special Kids House, it is heart-warming to see our team of nurses and personal care workers come together with the excitement of new beginnings. With many new features to learn about, they are eager to welcome children back to Very Special Kids House for a fun and enjoyable stay, and give their families a break and some much-needed respite.

I am so proud of the whole team at Very Special Kids for their flexibility during this time of change, their positivity for the future and their ongoing commitment to the families we serve.

Sister Margaret Noone, First Employee and Patron AM IBVM

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



After six years of meticulous research, development and planning, our long-held dream of a world-class children's hospice is becoming a reality.

The Sister Margaret Noone Hospice at Very Special Kids House – Victoria's only children's hospice – fulfils our vision to offer clinical care of the highest international standard combined with a warm, welcoming space for the children and families we support.

In 1996, Very Special Kids built Australia's first children's hospice, which provided a much-needed home away from home for children and families over the last 25 years.

The clinical needs of children today are significantly more complex than they were 25 years ago. Children are living longer with these conditions into adolescence, placing higher care needs upon their families as full-time carers.

The hospice rebuild is our most significant service improvement project to date and a monumental step for children's palliative care in Australia.

# Our vision brought to life

Through an initial international research study, the University of Melbourne's expert practitioners from the Melbourne School of Design identified the key requirements of an improved clinical care capacity, presented as a home-like facility.

Our construction partner Plan Group and key architects Barbara Bamford and Andrew Simpson have expertly and thoughtfully executed and enhanced this vision for our hospice. Barbara notes, "It's the same class and has all the servicing you'd see in a major hospital, but while it's a hospice, it's also a home."

Andrew adds, "The idea should be that when you enter into this building, there is a sense of familiarity, a place that people were comfortable and families in all sorts of circumstances could come and feel like it was a place that their child could stay."

Carefully curated spaces, where joy and laughter merge with best-practice clinical facilities, will support children and young people with a range of complex conditions.



Very Special Kids House.

The clinical improvements and additions to the hospice were purposefully designed to be discreet, keeping the space fun and inviting for children.

The new building itself incorporates environmentally sustainable design and solar energy, and is Green Star rated – an internationally recognised Australian sustainability certification.

"We are so excited for Eden to spend time here. It means she can make more independent memories, like all kids do."



**JAKE**, dad of 9-year-old **EDEN** who has lissencephaly

Children, families, staff and visitors will find inspiration and safety in the bright colours, natural building materials, plants and light within the hospice. To accommodate the diverse needs of our community, purpose-designed therapy rooms, such as a multi-sensory room,

creative therapy room and soft play space, are included. We also have a dedicated space for adolescents and a covered outdoor play space and accessible playground.

During respite stays, children and families can use the new hydrotherapy pool in individualised aquatic physiotherapy sessions. While sessions in the water bring many benefits for symptom management, ultimately, time spent in the pool is also about making memories and having fun.

A very special part of the new hospice is the Balam Balam suite, meaning butterfly in Woi wurrung – the language of the Wurundjeri-willam people of the Kulin Nation, the Traditional Owners of the land on which Very Special Kids House resides. This suite offers greater privacy for after death care and has been designed as a home-like environment, including a family room, kitchen, outdoor verandah and purpose-built bedroom.





Resident music therapist Helena and very special child Mia in the central courtyard.

The Balam Balam suite and our eight hospice bedrooms were each assigned a unique indigenous name and illustration of an Australian animal. Very Special Kids had the honour of working with Elder Aunty Gail Smith from the Wurundjeri Woi Wurrung Cultural Heritage Aboriginal Corporation to help select the animals, and First Nations owned and operated agency, Little Rocket, to illustrate and bring them to life. Children will have the opportunity to use their autonomy and pick their favourite animal-themed bedroom for their respite stay. Renowned First Nations artist Reko Rennie was also commissioned to create a captivating sculpture for the hospice's central courtyard. Inspired by Australian wildlife and his Kamilaroi heritage, the artwork provides a stimulating and interactive element to the space.

# **Overcoming hurdles**

As with any large construction project, the new hospice build has had its challenges. Staff and supply shortages facing the construction sector heavily impacted progress and extended the project timeline by 10 months.

Close up of a bird in Reko Rennie's sculpture.

Significant delays with the manufacture and supply of windows, door and window frames, roof sheeting, balustrades and cabinetry all contributed to a delayed handover.

While the hospice was being rebuilt, we moved our services to Monash Children's Hospital to ensure continuity for the children and families we support. We extend our gratitude to the Monash team who generously extended our stay by six months to accommodate the delays we experienced.

Our hospice team also persevered and adapted our model of care to suit the temporary space. Hospice manager Kirsty Blair comments, "This former hospital research unit became a warm and friendly environment that had the Very Special Kids magic we seem to sprinkle everywhere we go."





Very Special Kids panel at Live the life you please screening, including very special child Wil.

## As one of Victoria's leaders in paediatric palliative care, Very Special Kids plays an essential role in the state's healthcare ecosystem.

In the toughest times, Very Special Kids continues to provide vital emotional, clinical and practical support to children, young people and their families.

By advocating for wider community awareness through projects like the Paediatric Palliative Care National Action Plan project, bereaved and non-bereaved families can benefit from greater community support throughout life-limiting illness and death.

# Recognising our culture and processes

In April 2023, Very Special Kids successfully achieved ACHS accreditation by meeting the requirements of the Australian Commission on Safety and Quality in Health Care's National Safety and Quality Health Service Standards.

Our accreditation has been held since 2015 and this re-accreditation demonstrates that our care for children with complex medical needs meets the same high clinical standards as public healthcare organisations and providers. For the families we support, it offers confidence and trust that our care will meet their child's unique needs in a safe setting.

Our service delivery team dedicated considerable time and effort to meet the seven applicable National Standards required for accreditation. The final report acknowledged our organisation's commitment to delivering high-quality care and continuous quality improvement, as well as our dedication to partnering with families for collaborative care planning.

# Listening creates better outcomes

Very Special Kids engages a range of voices to plan and design safe, tailored care programs.

Parents, siblings, supporters and staff share their insights and reflections on service delivery through working groups and committees. Drawing on lived experience, members contribute by evaluating practices, reviewing policies and providing innovative solutions to challenges.

An important outcome of the Rights of the Child working group in 2022–23 was to release a new Rights of the Child Charter and review the Child Safety Policy to ensure every child feels safe in our care.

By regularly participating in conferences and symposiums, our staff continue to gain and share knowledge to remain at the forefront of children's palliative care. Six staff members represented Very Special Kids at symposiums and conferences across the country in 2022–23, including speakers at the 2022 International Childhood Trauma Conference and the Australian Paediatric Palliative Care Conference (APPCC).

Sibling representatives from our Youth Advisory Group (YAG) attended the APPCC to teach healthcare professionals the importance of involving young voices in conversations about the support their families receive. Read more about YAG's impact on page 15.

Our hospice staff engaged in 35 formal education and training sessions in preparation for the opening of our new hospice. Meanwhile, our family support staff have undertaken two strategic planning days with expert consultant and facilitator, Juliette Alush. These sessions focused on developing a framework for consistent, accountable and equitable practice across the whole state ensuring the best outcomes for families in our care

# Using our voice

At Very Special Kids, we utilise our expertise and knowledge of children's palliative care to raise awareness, educate and drive essential conversations about life-limiting conditions.

Live the life you please, an insightful film-led social impact campaign about living and dying in Australia, similarly opens a vital dialogue about palliative care. A very special family in our care feature in the film, sharing their story of palliative care and the impact of Very Special Kids' support. Read very special children Wil and Elle's story on page 18.

Very Special Kids was proud to sponsor this groundbreaking campaign, acting as the key representative for paediatric palliative care. We participated in Q&A screenings across Victoria to highlight our work and address the many misconceptions surrounding children's palliative care.

# International connection sparks new ideas

In March 2023, family support practitioner Angela Flood was awarded a unique opportunity to visit childhood bereavement organisations and paediatric hospices in the United Kingdom and Ireland.

Angela's travel was made possible thanks to the University of Melbourne's Vera Scantlebury Brown Memorial Scholarship. The trip gave Angela a rare chance to learn from international paediatric palliative care organisations, establish connections, collaborate and share some of our support methods with her international peers.

A highlight of Angela's experience was her time volunteering at Barretstown, a bereaved family camp in Ireland. Angela witnessed how the camp "gave families an opportunity to connect with each other, remember and honour their children and feel less alone on their journey".

Angela reflects, "Supporting bereaved families is an important part of our work at Very Special Kids. Observing organisations that solely focus on bereavement services highlighted the crucial role we play in educating the community and other professionals around the impact of the death of a child.

"I hope to be able to champion some of the ideas from these settings as programs we could adopt at Very Special Kids to support families on their paediatric palliative care journey here in Victoria."

We'd like to acknowledge the program partners who have enhanced our services in 2022-23.







# Supporting families across Victoria

In 2022–23, Very Special Kids provided support to 795 families throughout Victoria. Whether in metropolitan Melbourne, a regional city or a rural town, each child's experience is unique, so it is important that our programs and services are accessible and diverse.



families



# The best care, home and away

Travel across Victoria is an ongoing challenge faced by children and families that live in regional areas. Our Road to Respite program, made possible through a partnership with the Royal Flying Doctor Service (RFDS), provides essential, free transportation support. This service eases logistics for families who are already juggling multiple responsibilities, including the complexities of their child's life-limiting condition.

Every journey is carefully facilitated, with an RFDS driver and a dedicated Very Special Kids nurse or personal care worker accompanying the child. This ensures the highest standards of care are maintained during the transportation experience.

During the 2022–23 financial year, Scott Chapman, CEO of RFDS Victoria, took on a gruelling motorbike rally to raise funds on behalf of Very Special Kids. His efforts raised enough money to purchase a new transport van for the Road to Respite program. Read more about Scott's very special challenge on page 28.

Road to Respite is not the only way we support families away from our hospice. Working in tandem with the family support practitioners at our outer metro and regional locations, our home volunteers help families receive practical and emotional support at home.



Image (right): Charlotte spending time with our resident therapy dog, Jaffa.

Home volunteers are carefully matched to each family's requirements and circumstances to ensure tailored care is provided. Read about Janelle, a home volunteer, and the family she supports on page 23.

To help rebuild this program after COVID-19, we created a contract volunteer coordinator role to develop a comprehensive strategy to expand our volunteer base in regional Victoria. This focus will allow Very Special Kids to provide better statewide support to the families in our care, as well as staff and volunteers. Read more about other changes to our volunteer team on page 22.

# **Inclusivity creates** connection

Generous support from the Freemasons Foundation Victoria has allowed us to establish two sibling advisory groups, which are an integral part of our youth program.

In 2022–23, we established our inaugural Children's Advisory Group (CAG) for siblings aged between eight and 13, following the success of our Youth Advisory Group (YAG) (siblings aged between 14 and 25) that launched in 2021–22. Both groups meet bi-monthly online, allowing children and young people from metropolitan and regional areas to be heard and build connections by sharing their opinions and ideas.

Members of the new CAG receive mentorship from the YAG to develop leadership skills and build a wider community of peers in a safe and supportive environment. A recent satisfaction survey of YAG members showed that all respondents felt more connected to their peers and Very Special Kids by being involved in the group.

"The youth advisory group is such an amazing initiative and I really love being a part of it."





If there was a contest for Very Special Kids' most popular team member, everyone agrees that Jaffa would win 'paws' down.

Our hospice manager, Kirsty Blair, says, "Therapy dogs, like Jaffa, help to create a relaxed environment in the hospice so children and young people can feel comfortable, settled and supported. She not only provides physical comfort to assist children in regulating their emotions when adapting to new and unfamiliar situations, but her interventions also provide pure joy."

Thirteen-year-old Charlotte, from Numurkah in Victoria's northeast, has a special relationship with Jaffa and looks forward to spending time with her whenever she stays at the hospice for respite care.

Charlotte was diagnosed with an extremely rare genetic condition in 2019. Labrune syndrome is a degenerative brain disease with less than 100 recorded cases worldwide, and Charlotte is the only known case in Australia.

Charlotte's mum, Louise, says, "Charlotte is a big fan of Jaffa! She always comes back and tells us about the time they have spent together at Very Special Kids."

Jaffa provides much-needed support to children like Charlotte, helping to create many moments of happiness.

Our therapy dog program is made possible thanks to the Petstock Foundation, who generously sponsor Jaffa's care and her programs.



Very special child Noah experiencing his first time on a stand-up paddleboard at Lord Somers Camp.

**Each year Very Special Kids hosts** carefully designed events - like our family days, camps and coffee mornings - to support families, build connections and create long-lasting memories.

Coming together in-person was a highlight for families in 2022-23, after the pause to many events during the pandemic.

This year, we held regional family days at Gumbuya World and Adventure Park Geelong. These inclusive events can provide an opportunity for both bereaved and non-bereaved families to meet in a safe and fun environment. For families whose child has a life-limiting condition. a day out at an adventure park can feel daunting. Very Special Kids helps take away the challenges and stress, so they can focus on fostering memorable moments together.

One family shares, "Having the support of Very Special Kids and the other families made us feel like we could conquer the day and we had the best time as a family."

We arrange events in locations across Victoria to ensure regional families can be involved without travelling too far. Our two family camps were held on the Mornington Peninsula in October 2022 and February 2023 with the support of Lord Somers Camp and Power House. These camps provide a much-needed weekend escape for children, parents and siblings in a relaxing environment. Importantly, camps also allow children to try out activities they usually couldn't.

Very special child Noah shares, "I loved the paddle boarding because I was included in it along with everyone else."

"In a world where we always have to say no, Very Special Kids camp is a place that always says YES."



**KAT**, mum of 13-year-old **NOAH** who has mitochondrial disease



One of our three Day to Remember ceremonies across Victoria.

Dedicated sibling adolescent camps were also held in September 2022 at Forest Edge CYC, Neerim and in April 2023 at Cottage by the Sea, Queenscliff.

Sibling camps help young people to connect with others who have or have had a brother or sister with a life-limiting illness. Many new friendships were made as participants took part in recreational and creative activities.

In Malvern, more than 60 Very Special Kids families joined our End-of-year family day in late November. The holiday season can be a challenging time for the children and families in our care, however, at this end-of-year celebration, families can get festive without stress. The only expectation at this event was to have fun and the day was full of touching moments, including a Santa visit and free family portraits.

Our annual Day to Remember allowed bereaved families to come together to pay tribute to and celebrate the legacy of their children. In 2022–23, the Very Special Kids community gathered at locations across Victoria to connect in their grief. Families took part in a beautiful therapeutic activity, creating mandala artworks to remember their children. One family shared: "I felt a great sense of comfort to know that our children will always be remembered by those who truly care. Thank you all very much for keeping the flame alive."

Thank you to The Hazel Peat Perpetual Charitable Trust, The William Angliss Charitable Fund, Freemasons Foundation Victoria and Brian M Davis Charitable Foundation for making events like these possible.





Elle and Wil on the right with their siblings Leo and Aubrey.

Having a child spend the first three years of their life in hospital is a situation no parent is prepared for. But that was a reality for Mel and her son Wil.

Wil was born with a CBL gene mutation that presents similarly to Noonan syndrome. His doctors were not hopeful of his prognosis and referred Mel to Very Special Kids for holistic palliative care and end-of-life support. Fortunately, over several years, Wil's complex condition stabilised, and he is now 12 years old, an age experts were never sure he would reach. Mel shares that the Very Special Kids hospice is Wil's "favourite place in the whole world".

"We don't know what Wil's prognosis is going to be; one day we may be coming here for end-of-life care – but at the moment, it's just all fun!"

Heartbreakingly, Wil is not the family's only experience with paediatric palliative care. When Mel became pregnant with twins, she was overjoyed, and felt as if this was a reward for the difficult path her family had navigated with Wil. Unfortunately, they discovered that one of the babies had a rare congenital heart defect, hypoplastic left heart syndrome, and their daughter, Elle, sadly died at 13 days old.

"When Elle died. I sat in the wardrobe because it was dark, it was quiet, and no one could find me.

"Our family support practitioner, Anna, is the reason I got out of that wardrobe... She helped me through the grief, and it made things so much easier."



MEL, mum of 12-year-old WIL who has a CBL gene mutation and ELLE, who sadly died at 13 days old

Mel's family story and connection to Very Special Kids is featured in a new documentary, Live the life you please. The film highlights Australians' lived experiences of palliative care and aims to open a vital conversation around life-limiting illness and living the life you please until the very end.

> Scan the QR code to stream Live the life you please





# **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

# **Management Committee**

- Michael Wasley
  Chief Executive Officer
- 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 Committee**

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, AM
- David Szeleczky
- · Hamish Rotstein
- · Justin Whitford
- Phil Endersbee, OAM
- · 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:

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

### 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
- · 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
- · Iean Miller
- · Jim Wilson
- · John Hope
- · Iohn Nairn
- · Keera Le Lievre
- Maureen O'Keefe-Anders
- · Prof. Sharon Goldfield
- · Robert Davey
- · The Hon Peter Costello, AC
- · Wendy Swift
- · Wendy Thorpe



Family support practitioner Jenn Gavito speaking with a very special sibling at an adolescent camp.

## Every staff member at Very Special Kids plays a fundamental role in supporting the children, young people and families in our care.

Whether on the frontline delivering clinical care, providing counselling support to families or operating behind the scenes to fundraise and educate – every person makes a difference.

# **Engagement in review**

In October 2022, we completed another successful annual employee engagement survey with an 80% participation rate. Our staff were keen to share their insights and thoughts about what makes Very Special Kids a great place to work and highlight ways we can continue improving.

Staff emphasised the importance of Very Special Kids' distinctive culture and flexible working arrangements and highlighted that safety, improvement and collaboration define what works well.

One respondent comments, "Everyone is helpful and supportive, and what stands out to me is that people are valued. Everyone is safe to express an opinion or idea or improvement, no matter where you are placed in the organisation."

- of respondents were proud to work for Very Special Kids
- know how their work contributes to the goals of Very Special Kids
- said their role allows them to make a positive difference

Our staff retention rate of 91% further demonstrates the satisfaction our employees feel knowing they are making a tangible, positive difference to children and families facing childhood life-limiting illness.

# **Focus on improvement**

In 2022–23, Very Special Kids successfully negotiated a new Family Support Enterprise Agreement for our family support practitioners, which included a salary increase and additional leave entitlements to better support the health and wellbeing of our team.

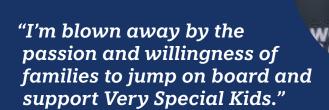
All staff have access to physical and emotional support through various programs, including the Employee Assistance Program, where highly skilled and experienced clinicians deliver evidence-based, practical solutions for personal and professional wellbeing.

Teams also have ongoing access to various tools, training and professional development required to uphold supportive and safe practices.

Since leaving our temporary home at Monash Children's Hospital, our hospice team are once again honing and developing their clinical skills in preparation for the hospice reopening at Very Special Kids House.

With the opening of the new hospice, different service delivery teams will be reunited physically in an environment where they can deliver new and existing services in one place. As an organisation, we are thrilled to come back together for greater collaboration and communication; breaking down silos between different areas has proven to achieve tremendous benefits across our range of services.

Jessica Birnbaum, family support manager, says, "Having members of our service delivery team under one roof promotes greater collegiality and opportunities for professional growth and development. This benefits families greatly as we draw on contemporary ways of working with families to meet their physical, emotional, spiritual and cultural needs."



**JOHN STRACHAN**, corporate development lead, employed July 2021



"The children and young people we support face daily challenges, whether that be physical, psychological or spiritual. I am motivated to do what I can to ease those challenges and support them to live their best lives."

**PHILIPPA SPICER**, senior registered nurse and clinical nurse educator, employed October 2012

Images (top right): John Strachan at Woods & Co fundraiser, (bottom left): Philippa Spicer undertaking simulation training with SimBaby.

# Our very special volunteers

Very Special Kids could not operate without the generosity and dedication of our volunteers. Their unwavering support has allowed us to offer life-changing and tailored care to children and families since 1985.

Our committed team of volunteers, ambassadors, advocates and committee members come from all walks of life, bringing unique and valuable skills and life experiences. This diversity benefits our whole organisation, but particularly the children and families in our care.

Very Special Kids volunteers provide support to families in so many ways, whether it's through a direct connection or work behind the scenes. From the fantastic group of reception volunteers who assist our administration team to the volunteers who make our events and fundraisers possible each year, every volunteer has a positive impact.

# **Building a stronger team**

The COVID-19 pandemic caused a significant decline in volunteer rates across Australia, including our very own volunteer community. We will forever remain grateful to our community of supporters who are no longer able to volunteer. Their contribution, both long- and short-term, has made a significant impact on the families in our care.

To help us rebuild our volunteer base, a new volunteer department was formed in September 2022 under the guidance of internally promoted volunteer manager Nathan Brown.

Two volunteer coordinators were welcomed to the team, with a respective focus on key pillars, events and program support, and hospital and hospice support. In March, an additional contract role was formed to support the redevelopment of the home volunteer program.

These changes meant we could expand and adapt our volunteer training program and recruitment, undertake a review of policy and procedural documents, and spend time understanding how existing volunteers would like to remain involved with Very Special Kids.

All newly recruited volunteers have the opportunity to scale up their training via our newly adapted three-module program. The introductory module provides all volunteers with an in-depth understanding of Very Special Kids services. The following two modules provide extensive training and techniques to help volunteers directly support the families in our care – in the hospice, at home or in hospital, and through programs and events we run, like family days and camps.

Continual professional development sessions and module training ensure that volunteers have the confidence and skills required to communicate effectively and sensitively with seriously ill kids and their families.

# **Expanded opportunities,** bright results

In 2022–23, we initiated a pilot volunteer working group to oversee our April school holiday sibling program. Twenty volunteers collaborated to develop and execute five fun and creative programs across the state.

"The energy the volunteers brought really added to the day. I am so grateful for their willingness, can-do attitude and ability to connect swiftly with siblings."



One of Very Special Kids' oldest running volunteer programs allows volunteers to provide respite support to very special kids and their families at The Royal Children's Hospital and Monash Children's Hospital. Due to COVID-19 restrictions, this program was paused for over three years.

In April 2023, we saw the return of the program and we are thrilled to be orienting new and existing volunteers to this vital support service.

Thanks to generous support from the Barr Family Foundation, and other valued donors, volunteers like Janelle can make a very special difference.





# One volunteer's impact

Nine-year-old Ryan had "lots of board games, but nobody to play them with" until Janelle, Very Special Kids home volunteer, started supporting the family two years ago.

The home volunteer program is a vital service that gives siblings like Ryan dedicated time to have fun, explore and connect with a volunteer.

Ryan's sister was born with a rare and debilitating skin condition, which requires round-the-clock care from their parents and a team of dedicated health professionals.

Rumana, Ryan's mum, says, "We worried we couldn't provide Ryan opportunities most kids might have at his age, then we see what Janelle does for him, and we can relax knowing he's getting the experiences in life that he has needed for so long."

Janelle has supported Ryan with going to the park or library, doing plenty of colouring and chatting – and accompanied Ryan to our family weekend, Lord Somers Camp.

Janelle reflects on her camp experience, "Being entrusted to take care of someone else's child for a night away is certainly a big responsibility, but also an immense privilege.

"It is extremely fulfilling to know you make a difference in people's lives. I know how grateful Ryan and his family are that I work with them."

Image: Home volunteer Janelle with very special sibling Ryan.

# Milestone achievements



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

### **30-year Service Award**

· Annette Parton

## 25-year Service Award

- · Bill Hearn
- · Isabella Edgoose
- Jenny Fast
- · June Woods
- · Louise Hillier
- · Pam Kershaw

## **20-year Service Award**

- · Andrew Macmillan
- Helen Jackson
- · Trifon Stafilis

### **15-year Service Award**

- · Alan Hall
- · Chris Coleman
- · Elizabeth Gidley
- · Heather Bell
- · Kim Waddell
- · Kylie Mclennan

## **10-year Service Award**

- · Annette Hayman
- · Denise Garrett
- · Duarte Da Costa
- Efstra Dalaveris
- · Elizabeth Egan
- · Georgia Psaltis
- · Helen Brennan
- · Liz Liston
- Mary Connell
- · Norman Lynch
- Perry Austin
- · Peter Silk
- · Robert Fleming
- · Sally Coles
- · Stella Costantino
- · Vicki Lynch

### **5-year Service Award**

- · Adam Scheinberg
- · Alice Doward
- · Anne Ingham
- · Barbara Capewell
- · Basant Ebaid
- · Bridget Millar
- · Cindy Hsiao
- · David Meffert
- · Emanuel Iacobs

- · Erin Tutty
- · Gaynor Von Bertouch
- Holly Alexander
- Jessica Kwong
- · Julie Jowett
- · Kathy Rendell
- · Louisa Ellis
- · Louise Russell
- Louise Scully
- Lucien Sankey
- · Martin Breheny
- · Mia Seccombe-Checuti
- Natalie Alexander
- · Orianne Rais
- · Peter Ingham
- · Rebecca Theochari
- · Sophie McCartney
- · Steffi Tan
- · Sylvia Beharis
- Tasia Rule
- · Vaios Malliaras
- · Vikki Zagami
- Wena Spies
- · Wendy Scott



"It is a rewarding experience that has given me a greater appreciation of life, family, health and friends, but most of all the importance of caring and kindness for others along the way."



**ANNETTE PARTON**, who is celebrating her 30-year milestone as a volunteer

Two very special sisters

Access to Very Special Kids' hospice respite care has been an essential lifeline to parents Claire and Andrew. With their daughters, Emily and Olivia, both living with life-limiting conditions and complex medical requirements, the family needed help and support beyond what family and friends could offer.

Things became a little easier when Very Special Kids came into their lives. Hospice respite care was the circuit breaker this family needed. With free access to overnight respite, plus essential services like physiotherapy and occupational therapy, Very Special Kids provides a much-needed break for Claire and Andrew.

"It was such peace of mind for us, knowing they had each other and would be well looked after – medically, physically, and emotionally."

**CLAIRE**, mum of six-year-old **EMILY** and four-year-old **OLIVIA**, who both live with life-limiting conditions

Emily and Olivia do everything together and share a special bond; they also share a love for all things creative, particularly art.

During their hospice stays, Emily and Olivia can immerse themselves in our creative therapy program, where children create paintings and artworks using their emotional, sensory and motor skills.

The girls often bring artwork home as a keepsake from their respite stays and are bursting with excitement to show-off their masterpieces.



Very special sisters Emily and Olivia.

Creative therapy, such as art therapy, enables expression beyond words while also building a legacy for children in palliative care through the artworks they create.

In 2022–23, our creative art therapy program was delivered in partnership with Creative Art Therapy Australia (CATA), an organisation with a holistic, person-centred approach that actively supports people in their adversity through safe, creative and thriving environments.

Our creative art therapy program was made possible thanks to the generosity of the Crown Resorts Foundation and Packer Family Foundation.

# Our very special community

As a predominantly self-funded organisation, we can only provide free-of-charge children's palliative care with the help of our very special supporters.

For many businesses and individuals, this year was challenging as they began to feel the pinch of rising costs and inflation. Thankfully, our incredible community has stood by our side during these trying times. With their support, Very Special Kids has continued to diversify our fundraising mix and rebuild income back to pre-COVID-19 levels in 2022-23.

In particular, our Foundation Committee has helped us form valuable connections with new corporate and philanthropic funders. We put more time and resources into managing philanthropic relationships and worked with funders to co-fund major service initiatives through multi-year arrangements. We also continued to place focus on our gifts in Wills program to support long-term income growth.

We launched a new regular giving program and invested in proactively growing the number of people who donate to Very Special Kids each month. The new regular giving program, Making Moments Matter, grew by 54% on the previous year. Regular giving reduces administration fees and provides regular monthly income to better plan ahead. This growth is key to the financial sustainability of Very Special Kids.

# The power of community

Our fundraising calendar was once again full of fun events and campaigns to draw the community together and increase the profile of Very Special Kids while raising vital funds. Our annual online giving day, A Very Special Day, raised more than \$500,000 with incredible contributions from our matched givers. Heartfelt thanks to Highland Foundation, John Wheeler and Sue Hadden, Fox Family Foundation, Connie and Craig Kimberley, Tank Foundation, Simply Energy and Advent Partners for their generosity and commitment.

We also hosted our regular annual events including Footy Fever Debate and two ladies lunches and golf days. Combined, these events raised nearly \$300,000 in much-needed funds while profiling the impact of Very Special Kids' services to the broader community.

Our biennial Art with Heart exhibition and live auction brought Melbourne's art community together for a special night showcasing Australian contemporary artwork. This year's event raised more than \$190,000 and would not have been possible without the support of the Art with Heart Committee, our presenting partner Kay & Burton, supporting partner Lowe Living, IAS Fine Art Logistics and other supporters.

"Being part of the Very Special Kids community has given me the opportunity to express my grief through art, communication and emotions. I have met some wonderful people through their amazing programs."



MARYJO, bereaved sibling of 14-yearold **JAMES** who had osteosarcoma

Image (right): Michael Wasley and Ben Griffiths in front of the sold charity home.

A very special thank you also goes to the contributing artists and their affiliated galleries, who generously donated 100% of the exhibition proceeds to Very Special Kids. We are especially grateful to Maryjo, a bereaved sibling, who told her family's story and auctioned her artwork created in memory of her brother, James.

# **Partnering with purpose**

At Very Special Kids, we partner with like-minded organisations that share our values of community, compassion, integrity and collaboration. Whether through corporate social responsibility, fundraising, corporate volunteering, workplace giving or event participation, our partnerships are vital and valued.

Throughout the year, two of our long-term partners – ALH Hotels and Commonwealth Bank – supported us through creative and fun activations as part of our annual Piggy Bank Appeal. ALH hotels adorned their venues in 'piggy pink' for our Piggy Bank Day in February, while Commonwealth Bank boosted funds through raffles and merchandise sales in branches across Victoria, and their annual CBA Staff Social Charity Club Diamond Ball. Thanks to ALH Hotels, Commonwealth Bank and other generous supporters, the Piggy Bank Appeal raised more than \$517,000.

Continued over page

# **Building a brighter future** with Henley Homes

In 2022, acclaimed home builder Henley Homes built and sold a very special charity home, to raise an impressive \$750,000 for Very Special Kids.

As part of Henley Homes' philanthropic program, project partners and suppliers donated their time, materials and labour to get the project off the ground.

Ben Griffiths, General Manager of Henley's Completed Homes division says, "Without our trades and suppliers none of this would be possible... They say it takes a village to raise a family and I can confirm it takes 100+ businesses and individuals to build a charity home.

"The sense of knowing 100% of all proceeds are going to the charity and 100% of your contribution to the house will make all the difference is extremely powerful."

The buyers, Hussain and Dr Baseerat Abbas, were thrilled to move into their new property. Hussain shares, "When we found out where the proceeds of the sale were going, we were very touched. Very Special Kids is a wonderful organisation doing great work, and we are humbled we can play a small part."

This generous contribution will support the opening and operation of our hospice at Very Special Kids House for many years to come.





Very special child Jett and his family at the 24-Hour Treadmill Challenge.

The George on Collins hosted a new event, Gather to Give, earning an extraordinary \$140,000 for Very Special Kids. The evening featured fine dining, music by well-known Australian DJs, delectable cocktails and a live auction, generating funds that make a very real difference to what Very Special Kids can achieve.

# **Turning passion into action**

It was a unique year for fundraisers, as legendary band KISS proudly supported Very Special Kids by gifting a one-of-a-kind auction experience during their August 2022 End of the Road tour. The auction raised \$75,000 and included dinner with the band, VIP tickets to their Gold Coast show and autographed guitars, drum skins and drumsticks.

From rock'n'roll to motorcycles, a very special challenge was taken on by Scott Chapman, CEO of our trusted partner the Royal Flying Doctor Service Victoria. Scott took part in the Indian-Pacific Cannonball Classic, a remarkable endurance race for pre-1949 motorcycles that spans 4,800km from Busselton, Western Australia to Merimbula, New South Wales. Riding his 1942 Harley-Davidson, Scott raised an outstanding \$100,000 for Very Special Kids.

Our on-site Autumn Classic cycling challenge and the annual 24-Hour Treadmill Challenge were once again highlights on the Very Special Kids calendar.

Riders from 11 teams raced to the virtual finish line in May during the Autumn Classic, raising more than \$165,000. Congratulations to team Grupetto, who topped the leaderboard with solid racing and fundraising efforts. Team Toros was our highest fundraising team, raising \$55,000, an incredible effort as this is their fifth year taking this title.

In June, more than 800 participants got ready to tready! They kept 25 treadmills consistently turning during the 24-Hour Treadmill Challenge in support of 24-hour children's palliative care. Our flagship fundraising event raised more than \$730,000.

We were grateful to have football legend Jimmy Bartel, from our media partner 3AW, take on his own very special walk around Melbourne to fundraise \$10,000 and raise awareness of Very Special Kids. It was great to also see Jimmy on site, meeting and motivating teams while clocking up some kilometres on the treadmill.

Special thanks to our proud supporters Novofit, Genesis Health and Fitness, and Harry the hirer, and to the many organisations who sponsor treadmills, keen participants and volunteers who make this event bigger and better each year.



# **Driven by generosity**

When Heath and his friends organised a casual motorbike ride in northeast Victoria, they had no idea it would turn into an annual Ride and Drive Day that would raise almost \$80,000 for Very Special Kids over the next two years.

Heath and his wife Leesa were given a heart-breaking prognosis when their daughter Tahlia was just three months old. Tahlia was born with cerebral palsy and epilepsy and required high-level care as she experienced complex health challenges day and night.

The family were referred to Very Special Kids as Tahlia grew older, and her care requirements increased. Initially hesitant about what to expect, Heath, Leesa and Tahlia's two siblings were astounded by the level of care and fun children and young people received. The family became involved

in various programs and activities at Very Special Kids, including sibling days and volunteering.

Realising a weekend motorbike ride was an excellent opportunity for a fundraiser, Heath immediately knew he could raise awareness and vital funds for Very Special Kids.

In February 2023, the community Ride and Drive Day included 82 cars and bikes travelling 85km from Jerusalem Creek, Eildon to the Bonnie Doon Hotel. The event raised more than \$40,000 in memory of their very special daughter, Tahlia.

Heath says, "When it started off, we planned on raising about \$3,000, we thought we'd do very well if we did that. A lot of people have seen the videos and realised what Very Special Kids do and hadn't heard of them before, and their generosity just has no end. It's been amazing."

# Our generous supporters

### Government

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

### **Corporate**

- AbbVie Pty Ltd
- · Advent Partners
- · ALH Hotels
- · Balcon Group
- CBA Staff Social & Charity Club
- CGR Sportswear
- · Chain Reaction Challenge Foundation
- · CMV Group Foundation
- Coca-Cola Australia Foundation
- CommBank Staff Foundation
- · Commonwealth Bank of Australia Head Office
- Corrs Chambers
  Westgarth
- · Ernst & Young
- Finer Power Transmissions
- · Francis Venues
- · GHD Pty Ltd
- · Guild Group
- · Harcourts Foundation
- · Hippo Blue
- · Honan Insurance

- · Honda Foundation
- · Icon Group
- International Power Australia Pty Ltd
- · Iemena
- · Kay & Burton
- · Lovelight
- · Lowe Living
- · Micro Focus
- Millbrook Finance Limited
- MRC Foundation
- · Navy Health
- Pacific Trends International
- Paint & Hardware Legends
- Parkdale Community Branch
- · Petstock Foundation
- Rose Grange Investments Pty Ltd
- SJD Homes
- Slater & Gordon
  Community Foundation
- · State Transport Pty Ltd
- · Tabcorp Holdings
- · Tank Foundation
- Tobin Brothers
  Foundation Ltd
- · Turi Foods
- · Viva Energy Australia
- Whitbread Insurance Brokers
- · Woods & Co

### **Trusts and foundations**

- · Araluen Foundation
- Australian Communities
  Foundation
- Australian Philanthropic Services Foundation
- · Barr Family Foundation
- · Brian M Davis Charitable Foundation
- · Campbell Foundation
- · Collier Charitable Fund
- · Corio Foundation
- Dorman Family Foundation
- · Ducas Paul Foundation
- Flora & Frank Leith Charitable Trust
- Freemasons Foundation
  Victoria
- Gringlas Family Charitable Fund
- · Hupert Family Foundation
- John T Reid Charitable Trusts
- MacKenzie Family Foundation
- Marjorie M. Kingston Charitable Trust
- McAllister Family Foundation
- · Newsboys Foundation
- Noonan Family Foundation











- Norman, Mavis & Graeme Waters Perpetual Charitable Trust
- Pethard Tarax Charitable Trust
- · Stocks Family Foundation
- · Sunraysia Foundation
- The Alfred & Jean Dickson Foundation
- · The Baker Foundation
- · The Collie Foundation
- The Hazel Peat Perpetual Charitable Trust
- The Johnstone Family Foundation
- The Marian & E H Flack
  Trust
- The Noel & Carmel O'Brien Family Foundation
- The Orloff Family Charitable Trust
- The Stuart Leslie Foundation
- The William Angliss (Victoria) Charitable Fund
- · Walker Family Foundation

### **Individuals**

- · Angela Found
- · Brett Webb
- · Chris Garnaut
- Christine & Terry Campbell AO
- · Claudine Revere
- · Clive & Jenny Batrouney
- · Daniel Trewin
- · David Slade
- Douglas Evans

- · Edward Federman
- · Glenda Shelley
- · Goldsmith Family
- · Ian & Kristeen Urquhart
- · Jan Pannam
- · John Bongiorno
- Judy Greig
- · Kerryn Smith
- · Kevin Kelly
- · Laurence Law
- · Lynette Swan
- Margaret Brown
- Meredith Evans
- · Nicholas Bouseka
- · Peter Kempen
- · reter kempe
- · Rita Andre
- · Robyn & Ross Wilson
- · Simon Daish
- · Toby Li
- · Tony & Sandy Kirkhope

# Very Special Guardians (estates)

- Estate of Gwendoline Mary Armstrong
- Estate of Patricia Frances Morgan
- Estate of Sarah 'Sally'
  Margaret Lilian Donnan
- · Estate of Sue Hardiman
- · Estate of Valma Mary Cox

### **Hospice rebuild**

- Connie & Craig Kimberley OAM
- · Dell
- Electrolux Home Products (EHP)
- · Fisher & Paykel

- Fleming's Nurseries
- Gaudry Foundation
- Henley
- Jack & Meg Bowen
- · JB Hi-Fi
- · John & Jenny Fast
- · Ken & Gail Roche
- · Paul & Claire McCann
- · Peter & Rosemary Polson
- · Pierce Armstrong Trust
- · Reece Group
- · Richard Jay
- · Samsung
- · Sony
- SureCare
- · Susie Gibb
- The Fox Family Foundation
- The George on Collins
- The Good Guys
- · The Highland Foundation

## **Media partner**

3AW

### Gift in kind

- · Adriatic Furniture
- · Bridged Group
- · Harry the hirer
- · Helping Hand Group
- KPMG
- Linfox Logistics
- Lord Somers Camp and Power House
- Novofit
- Penfold Motors Burwood
- PFG Australia

NB: Supporters over \$5,000



Volunteer Sue Hardiman spending time with a child at Very Special Kids House.

Sue Hardiman devoted more than 20 years of her life to volunteering with Very Special Kids. She then made the life-changing decision to leave a gift in her Will and become a Very Special Guardian.

The hardships of seriously ill children and their families touched Sue deeply, and it brought great joy to see the comfort her efforts could bring. From organising community fundraisers, participating in Very Special Kids events and providing loving support to families, Sue lived to make a difference at every opportunity.

When Sue decided to leave a gift in her Will, she joined an important group of people, known as Very Special Guardians. This impactful community are the reason children and young people with life-limiting conditions can continue to receive vital respite now and into the future. Knowing her gift would help improve the lives of seriously ill children and create positive memories for their families was something Sue was incredibly proud of.

Before she died in 2021, Sue explained why leaving a gift to Very Special Kids was so important.

"I know that my gift will support a family who needs respite, emotional support, counselling and care, and that is satisfying to think I can help provide that.

"I am a great believer that people should give back, and when you make a Will, you leave it to the people who can benefit."



**SUE HARDIMAN**, volunteer and Very Special Guardian

Although Sue is greatly missed, her loved ones know her legacy continues through her generous gift.

Thanks to Very Special Guardians like Sue, we were generously bequeathed more than \$660,000 in 2022–23.

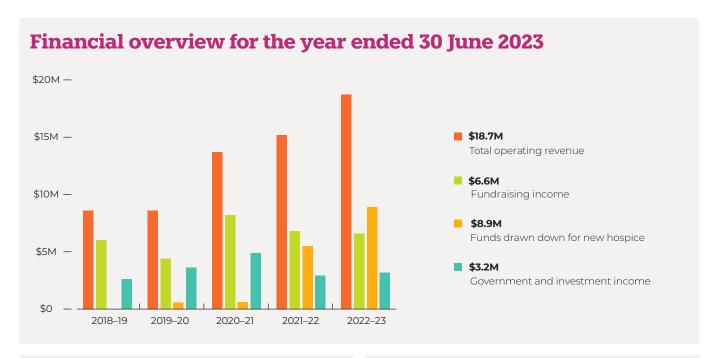
These valued members of our community leave a lasting imprint, giving us the means to support children, young people and families today and into the future.

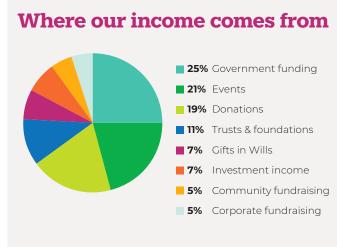
# Financial snapshot

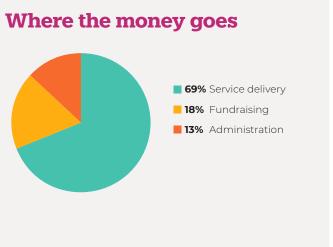
Challenging economic times had an impact on some fundraising activities in the 2022–23 financial year.

Thankfully, our prioritisation during COVID-19 on creating more sustainable income streams, resulted in a strong increase of our corporate and philanthropic income and growth of our regular giving program.

A substantial portion of our fundraising income was committed in prior years and drawn down as income in 2022–23 to support the rebuild of Very Special Kids House. During the rebuild phase, our service delivery costs reduced to match the smaller bed night capacity in our temporary space at Monash Children's Hospital. We expect the cost of supporting hospice bed nights and our general services to increase as we return to full capacity in our new hospice in 2023–24.













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