VERY SPECIAL kids

Annual Report

2019-20

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This page: Katy Vy and her twins Damien and Dominic.
The Vy twins were both diagnosed with the same rare genetic life-threatening condition, SMA1 – Spinal Muscular Atrophy. This illness will ultimately cause their tiny bodies to deteriorate to the point where they cannot walk, sit up or breathe on their own. The family has relocated to Australia so the boys are able to get the medical treatment they need and are given extra support through Very Special Kids. Their mum, Katy, says: "I didn't know a place like Very Special Kids existed until I needed to. Very Special Kids is our Australian family. There is nobody else I can trust to care for my children the same way I would. The staff understand their needs not just medically but also emotionally."

Cover: Vy twins

Our 2019/20 Impact

We support families during the toughest and most unforgiving time of their lives. From the point of diagnosis to bereavement and beyond, we are here to provide much-needed respite at Victoria's only children's hospice as well as emotional support and counselling for the entire family.

826 families supported by Very Special Kids

109 new families to Very Special Kids

104 end-of-life care nights in the hospice

54 families supported through end-of-life care in the home, hospital or hospice

102 employees

26 coffee groups hosted for parents

5 sibling days for bereaved and non-bereaved

122 families attended Remembrance Day 2019

1,874 specialised nights of respite and specialised care

7,064 virtual appointments with families

1,831 face-face appointments by Very Special Kids staff

1:10 staff to volunteer ratio

5,179 counselling support sessions

304 nights of onsite accommodation provided to families

394 nights at Glen Osmond Farm provided to families

Robbie, Steph and Kylie say Very Special Kids has supported them through their most challenging times.

Our Belief

There is hope in every life

Our Vision

Families supporting a child with a life limiting condition find and sustain hope

Our Mission

Very Special Kids provides holistic care for Victorian families facing the potential death of a child. We provide:

- **Counselling and emotional support for the whole family**
- **Extended and medically supported respite care**
- **End-of-life care and long term bereavement support**

Our Values

- Respect
- Collaboration
- Compassion
- Community
- Learning
- Integrity

Goals	Strategies
Pursue service excellence	• Build a world class hospice to meet families' needs. • Enhance accessibility to services. • Evaluate and improve our model of care. • Foster collaborative practices with key partners.
Strengthen financial independence	• Grow and diversify our income streams. • Implement and achieve our hospice fundraising campaign. • Ensure responsible financial sustainability.
Optimise organisational capability	• Infrastructure, systems and processes are fit for purpose now and into the future. • Ensure our organisational structure supports service delivery. • Foster an environment that embraces and lives our values.
Leaders in family-centred paediatric palliative care	• Grow and share our expertise in paediatric palliative care. • Advocate for better paediatric palliative care across Australia.

From our leaders

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Dedicated to caring for our families & staff during COVID-19

Like many charities, Very Special Kids encountered significant challenges in the second half of the year due to the global pandemic.

This impacted the structure and momentum of a number of our strategic projects, including the strong event-driven fundraising position Very Special Kids had established towards the end of 2019. We had to quickly adapt the way we delivered our core family support and hospice services, incorporating telehealth, technology and enhanced infection control measures. In this context we are extremely proud of the response of our dedicated workforce in maintaining a family-first approach in support of our vulnerable families.

It is important to highlight the incredible support provided to Very Special Kids by many stakeholders:

- Our families were understanding and flexible following the adjustment of our services
- Our staff demonstrated amazing resilience and dedication to their important work
- Our sponsors, donors, and foundation partners continued to support us despite the challenges of 2020
- Although there were less opportunities to be on the ground, our army of volunteers has remained engaged and supportive
- The Federal Government's JobKeeper support was significant in ensuring our staff could continue their work
- Our Board and Management teams have closely monitored cash flows to ensure future fund resources have been available to sustain services

Support for families

During 2019-20, Very Special Kids supported over 826 families throughout Victoria, 109 of them were new to our services.

Funding was secured to extend and introduce additional development therapy support within the hospice. Physio, music and art therapies were extended, and child play therapy introduced, all thanks to some wonderful foundations and private donors.

Importantly, service supports were sustained through the COVID-19 adjustment period, with modified contact methods including telehealth, and the infection controls within the hospice enhanced to ensure respite and end-of-life support could continue. Our Clinical Risk & Governance committee has provided extraordinary leadership and governance during the year.

Fundraising and Events

We're a predominantly self-funded charity that relies on numerous successful events to generate operational income and COVID-19 has significantly impacted our revenue generation. All fundraising events since March 2020 were cancelled or have been postponed until 2021. Despite a gloomy financial impact forecast in March, the generosity of many of our army of supporters and funders through to June has helped us to improve on the initial forecast. We achieved a better-than-expected operating deficit of $391,469.

The future financial year remains challenging as the pandemic restrictions are extended. However, we look forward to resuming many of our regular fundraising activities in early 2021. The incredible Fundraising team has embraced the challenges and continue to work hard at developing new and modified activities, to ensure we can fund our important hospice and family support services in future years.

The new Very Special Kids Hospice

Significant progress towards the realisation of the new hospice was achieved, with detailed planning completed, a project manager engaged and a capital campaign team recruited. These activities were initiated following the Federal Government's $7.5m contribution received in June 2019. The commencement of the new build has been postponed from February 2021 to August 2021. We remain confident and determined that a world-class, fit-for-purpose facility will be realised soon.

Thank you

This past year has been challenging for everyone, and many of our families have required additional time and support. Very Special Kids exists to meet the needs of the families we support, but we rely on our communities to make this happen. To our families, volunteers, staff, corporate and community partners, the Victorian State Government and to our many donors, thank you for your loyalty, generosity, and the resilience you create within Very Special Kids.

Peter Polson, Chairman
Michael Wasley, CEO

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Even greater quality of care

Over the last two years, I've been involved in the entire design process of the new hospice and I'm very excited by what's been finalised. Despite the challenges 2020 has brought for many of us, and the families we support, I'm thrilled that we will now continue with this project through 2020 and 2021.

It will bring the hospice staff and family support team together under one roof for the first time, and, importantly, it will retain heavy involvement from the volunteers.

This organisation was established by volunteers. They put in the hard slog in the beginning, and they are the essence of the DNA of Very Special Kids

The families have great respect for our volunteers and really do appreciate that they are giving up their own time to help give them a break.

I've had parents tell me that it means the world to them that our volunteers are providing their child with a different and positive energy in their day.

It's so important to give these children the opportunity to have as much normality in their lives as possible.

If I could sum up what the hospice is for someone who doesn't know, I would say it is a place for living. It's a place for hope. And it's a place where we treat everyone equally.

Society can be a difficult place for children with special needs, but we value all children and we need to be there for them and their families for many years to come.

Sister Margaret Noone, AM IBVM

”

Support for families across Victoria

3 in 4
families feel connected to an understanding community

Our services are available to families all over Victoria. Each family member is supported in unique and varying ways according to their personal needs. The family support services include counselling, advocacy, sibling support, bereavement support, networking and peer activities, trained family volunteers and specialist care at the hospice.

We are the only children's hospice in Victoria where we offer families access to planned and emergency respite, as well as end-of-life care. The hospice provides 24-hour specialist nursing care in a warm and welcoming environment.

In addition to the children's hospice and the office in Malvern, Very Special Kids is committed to providing family support across Victoria through offices in Yarraville, Brunswick, Ballarat (servicing the Grampians region), Bendigo (servicing the Loddon Mallee Region), Hastings (servicing the Peninsula Region), Pakenham (servicing the Gippsland/ Outer South East), Shepparton (servicing the Hume Region),Torquay(servicing the Barwon Region) and Port Fairy (servicing the South West Region). In 2020, a further office will be opening in South Morang.

244
bereaved families supported by a Family support Practitioner

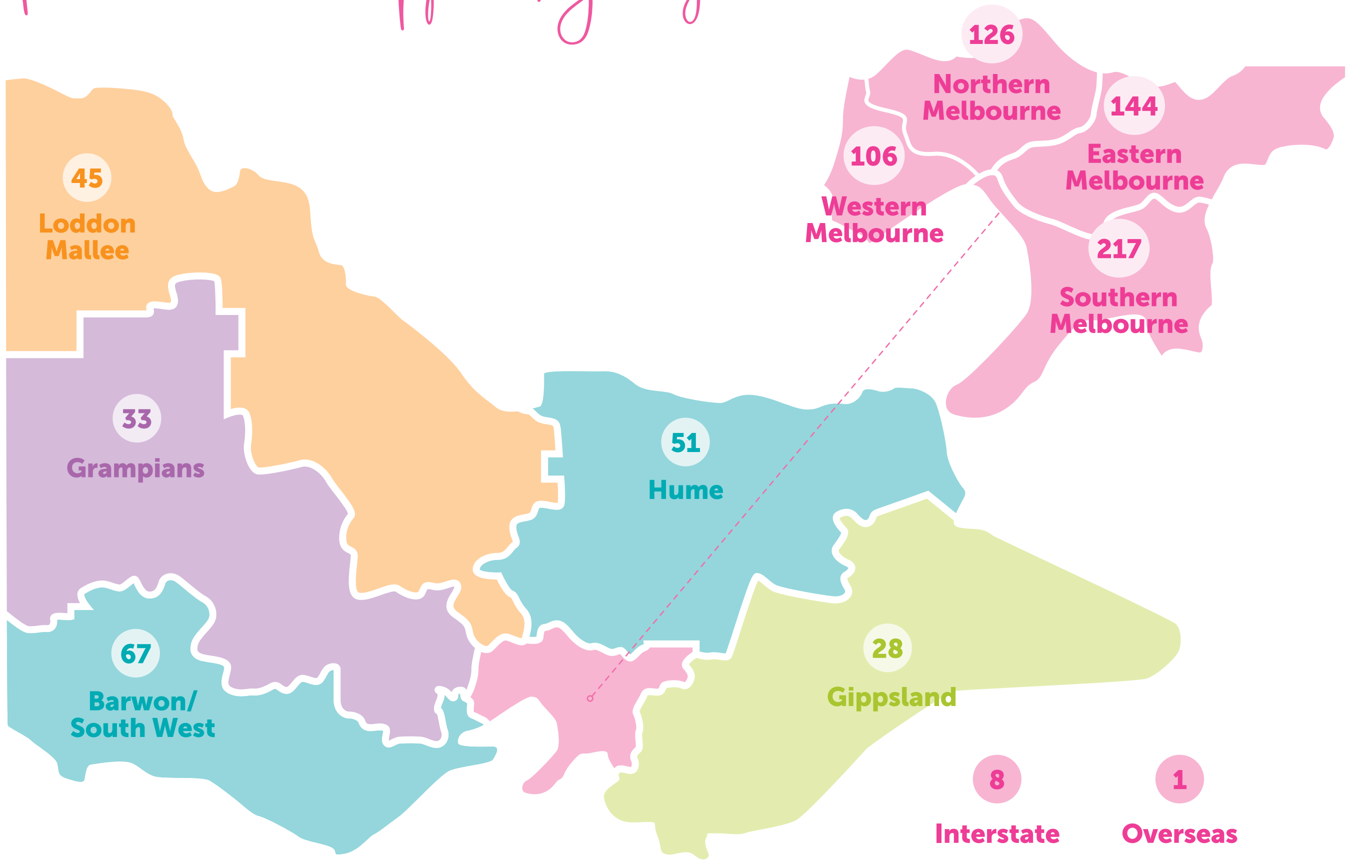
379
non-bereaved families supported by a Family Support Practitioner

224
regional Victorian families

593
metro Melbourne families

18
Family Support Practitioners supporting families across Victoria

Families we support by region



Road to Respite transports kids from regional Victoria

In partnership with the Royal Flying Doctor Service, the Road to Respite program gives families an alternative transport option to the hospice. Ambulance Victoria donated a van in 2018 and has been transporting children from all over the state ever since.

Jack, who died from a brain tumour, pictured before his death.

Finding positives in the unimaginable

Imagine dealing with the pain of knowing that your child is going to die. Thinking about your child's funeral, and even discussing it with them, is something that many parents simply couldn't face.

While the main role of a Family Support Practitioner is to provide counselling to families with a child who has a life-limiting condition, they wear many hats such as advocate, social worker, navigator of the health system, and networker.

Family Support Practitioner and trained Family Therapist, Libby Roden, works throughout the Gippsland Region, supporting more than 50 families. It's a vast region that requires lots of travel which is why having someone like Libby in the community is highly valuable.

One of the factors that makes Libby's role unique in the region is the end-of-life support she provides to families who choose to have their child die at home.

This was the case with 17-year-old Jack, who Libby was supporting, who had an aggressive brain cancer. Jack was diagnosed at the age of six and was recovering, but the cancer returned, and Jack was given weeks to live.

Libby soon became one of the key people helping to ensure that the time he had left was as rich and comfortable as possible. She became involved in the funeral planning; was able to facilitate the difficult conversations between the family; she was the counsellor to all family members; she worked with local health providers and would identify gaps in service provision; she arranged financial counselling for funeral costs, and she also assisted the family to ensure that his dying wishes were met.

He died in December 2019.

> "When he died, it was just the family and I left to debrief. When the role of other health providers ended, ours continues, and I think that's what makes Very Special Kids so unique," Libby said.

Libby continues to support the family nine months on and will continue to do so for as long as they need.

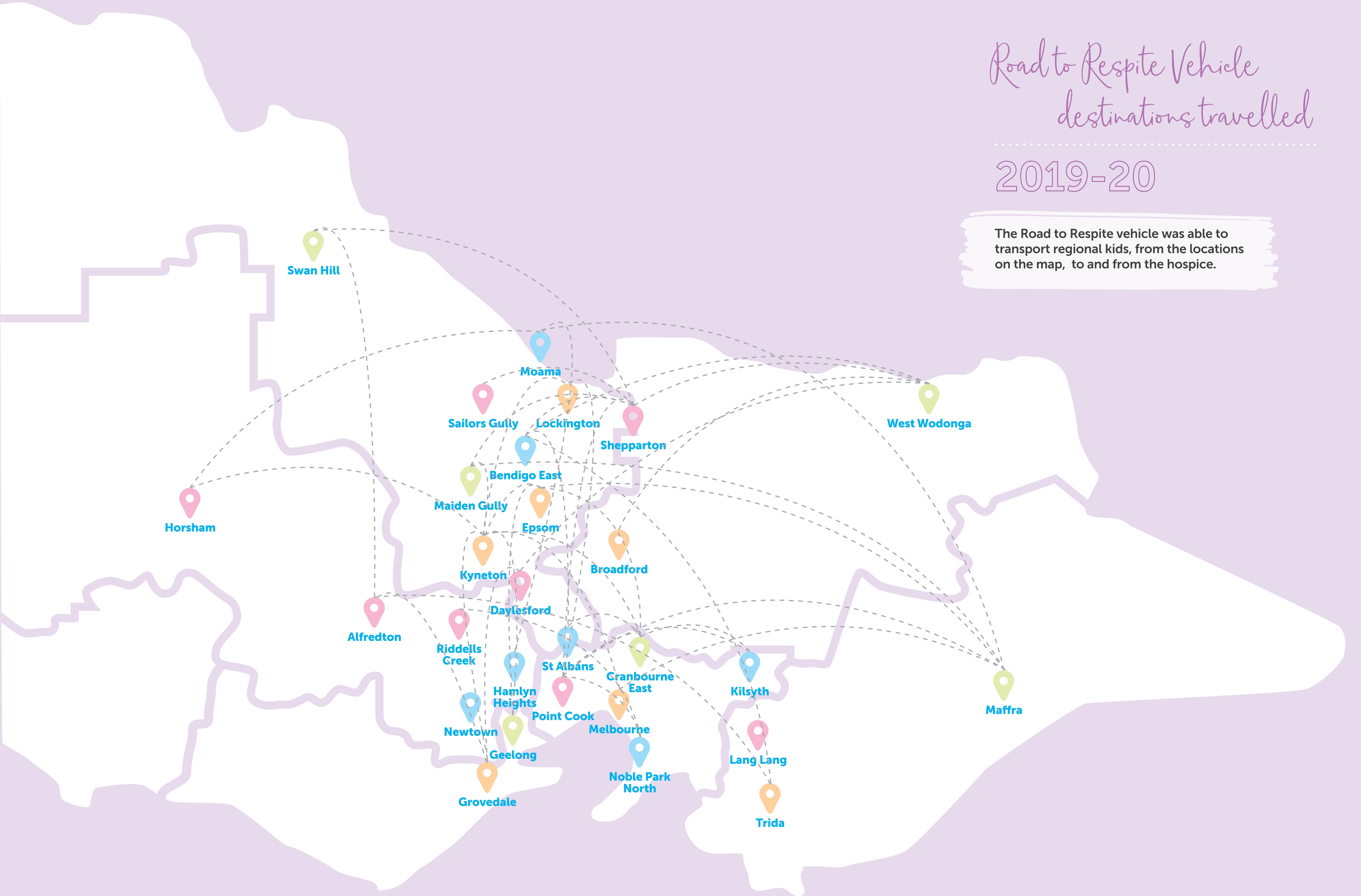
"It's usually the years after that are the hardest, two-three years on, and we are still there, we won't go anywhere as long as the entire family needs us – aunts, uncles, grandparents included," Libby said.

95% of bereaved families have created lasting memories with their dying child

Road to Respite Vehicle destinations travelled

2019-20

The Road to Respite vehicle was able to transport regional kids, from the locations on the map, to and from the hospice.



Bereaved parents were given opportunities to meet and connect thanks to our Family Support Team.

Keeping mentally strong

Very Special Kids Keeping Strong, Give Where You Live program, is a series of workshops designed to give parents an opportunity to try new ways to manage stress and to help develop resilience. We know that being a parent of a child with a life-limiting illness can be exhausting, and the mental impact of the death of a child can be devastating, which is why the Family Support Team implemented this program.

The workshops include yoga, mindfulness, meditation, art therapy and massage, and the response from parents has been overwhelmingly positive. One parent said: "The content of what we learnt about mindful meditation was great. These events really do help me connect with other parents particularly because we meet afterwards and can have an opportunity to chat about lots of things."

In September 2019, we held our annual bereavement support parents' weekend. This weekend was attended by 20 parents and gave them the opportunity to explore their grief and to honour their child in a supported space. Parents were able to learn new strategies to manage their on-going grief and to connect with others in a similar situation.

Across Victoria, the Family Support Team is constantly delivering programs such as coffee mornings, family days, sibling days, camps and Remembrance Days to support the well-being of the entire family.

> Until you've been through having a very sick child, and then through their death, you don't know how you will react and what will manifest. I can't put a price on the support we've been given from this wonderful organisation. It really is unique to Victoria and Australia.
>
> **Bonita – mum of Aiden**

Tongala family supported by Very Special Kids for almost 10 years.

80% of families feel more resilient with Very Special Kids support

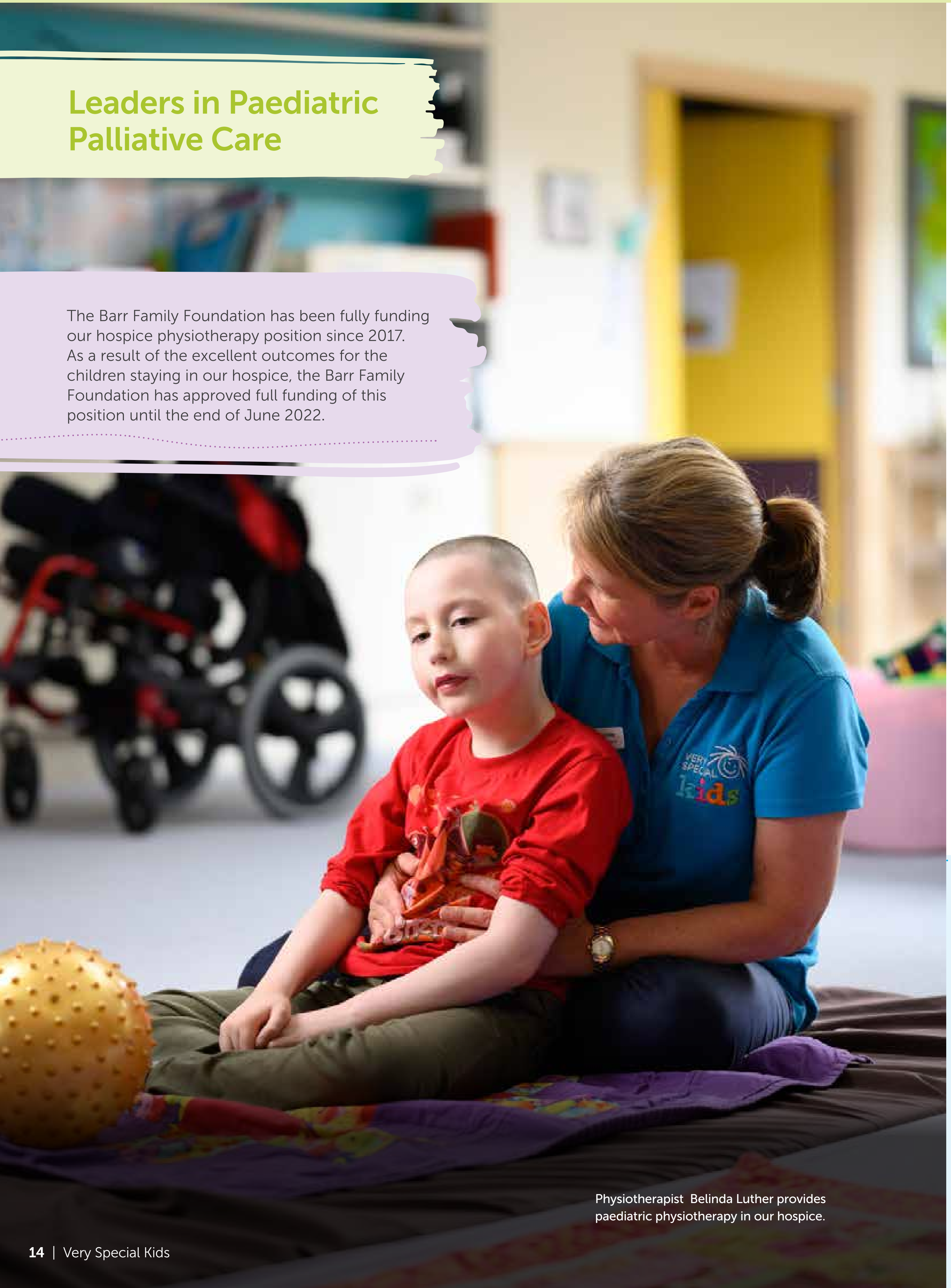
90% of parents said they are able to cope better thanks to Very Special Kids

Family Support Practitioner, Cath, has been delivering emotional counselling online to her families in remote areas across south-west Victoria.

> Family Support Practitioners across Victoria provide strong emotional support when families are going through particularly hard times. These families may have just been given a devastating diagnosis. They may be facing the imminent death of their child, or they might be learning how to live in a world without their beloved child. We are there to support them with all of these situations. We offer counselling, family days, coffee mornings, and sibling programs, which are provided online, by phone and face-to-face, right across the state. We provide support to families in ways that are best suited to them.
>
> **Peggy Hogan – Family Support Team Manager**

Leaders in Paediatric Palliative Care

The Barr Family Foundation has been fully funding our hospice physiotherapy position since 2017. As a result of the excellent outcomes for the children staying in our hospice, the Barr Family Foundation has approved full funding of this position until the end of June 2022.



Physiotherapist Belinda Luther provides paediatric physiotherapy in our hospice.

Over the past two decades, Very Special Kids has become a recognised leader in Paediatric Palliative Care in Australia. Today, it remains the only provider of its kind in Victoria.

We provide high quality emotional and psychosocial support and respite care to families all over Victoria, who have a child with a life- limiting condition. Our team comprises counsellors, nurses, doctors, therapists, personal care workers and specially trained volunteers.

29 Registered Nurses working in the hospice

17 Personal Care Workers

3 Visiting Medical Officers

1 Chief Medical Officer

4 Therapists – music, physiotherapy, occupational therapy and child life therapy

1 Art therapy program provided by Creative Art Therapy Australia

92% of parents said the quality of care (clinical, therapeutic and personal) directly contributed to improving their child's quality of life

100% of families who use the hospice said they were able to have quality time due to respite

Special training with The Royal Children's Hospital

Very Special Kids nursing staff collaborated with The Royal Children's Hospital in 2019 to receive specialised training so that they can provide respite to kids who rely on ventilators to breathe.

These kids are at very high risk of acute deterioration and adverse events that can be life-threatening, which adds to the complexity of these children's medical needs. The Very Special Kids nursing team felt it was important to be skilled in this care so they would be able to provide much-needed respite to these families.

100% of children received high-quality care

Around-the-clock care gives family overdue respite

Imagine spending every hour of the day knowing you need to keep a close eye on your child in case he stops breathing.

For Jayne and Corey, this is what they live with every day. Their youngest child, Elliott, almost two, has Tracheobronchomalacia, a condition that causes the wall of his airways to become weak and he requires 24/7 care.

The couple was in need of a break, and with only those with special medical training able to look after Elliot, Very Special Kids stepped in.

The nursing team had recently been trained up to care for children like Elliott.

“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 because I usually get up 5-10 times per night to Elliott. I knew I could check in on him when I wanted to, the staff just loved him, he was so happy – it was just phenomenal,” Jayne said.

Elliott had another stay in the hospice, giving Cory and Jayne a few nights away, as a couple, and they continue to be supported by their Very Special Kids family support practitioner. “I don’t know how families survive without Very Special Kids, they are a god-send,” Jayne said.

Elliott has a condition that requires 24/7 medical care.

Meg takes on child-led study to uncover the true impacts of sibling death

Very Special Kids Family Support Practitioner Meg Chin is embarking on her PhD *When a child dies from the life-threatening condition: hearing voices of bereaved siblings* to gather evidence and research from bereaved siblings, to better understand what exactly happens to a child in the years after their sibling’s death.

“When you look at all the literature, it’s from the adults’ perspective. Most of the limited research is from the perspective of a parent, which led me to see a real gap in lived experience evidence from the children themselves. To best support children who have experienced the death of a sibling we need to include them in the process of increasing our knowledge,” she said.

She says she wanted to focus her research beyond the first two years of a sibling’s death.

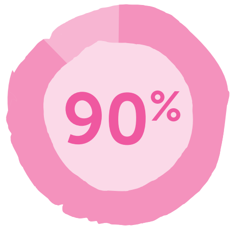
> “I’ve focused on the five to 12-year-old age group and those whose sibling died more than two years ago, because we know that the grief is just as hard two to five years following the death,” she said

Meg and her Family Support Team colleague, Angela, developed and co-facilitated a bereaved sibling group designed to be flexible and responsive as it is very much led by the children in the group and their demonstrated need.

Bereaved siblings, like Ruby and Carter, will benefit from Very Special Kids' research into sibling grief. Their sister, Alicia, died four years ago.

Meg says there is still little understanding in the community about sibling death and what it’s like to be a child when this happens, and often people, including those in schools, shy away from it.

This is why at the completion of her PhD, Meg is aiming to deliver resources and tools based on her data and findings to not only improve the way Very Special Kids delivers its services, but to also educate the community on sibling loss.



90% of parents are more accepting of their experiences

Family Support Team presents expertise to health colleagues

Our Family Support Team delivered their expertise in death, dying and bereavement to the following in 2019/20:

- Genetic Counsellors Statewide Meeting at **Monash Hospital**
- **University of Melbourne** RHD Colloquium
- **Australian Association of Social Work** National Conference in Adelaide
- **Oceanic Palliative Care Conference**. “Dual processes of interpretation: How language intermediaries can translate therapeutic interventions in a paediatric palliative setting.”
- **Swinburne University**– Trauma, Grief and Loss subject guest lecture on the Impact of diagnosis of a child with a disability or life-threatening illness
- **Gippsland Primary Health** Network meeting
- Latrobe Advocates, **Latrobe Council**
- **Children’s Wellbeing Initiative**, East Gippsland

> “In my role as Very Special Kids Chief Medical Officer, I provide medical guidance on a variety of issues as they arise, which included issues that arose through COVID-19. I support the client intake and eligibility process and am involved in clinical risk and governance activities. A typical week involves several visits to the hospice to review children who are there for respite, or multiple daily visits to those admitted for end-of-life care. My time at Very Special Kids has shown me what is possible with tremendous teamwork, compassion and skill, and the lasting impact that has for families navigating the most difficult of times.”
>
> **Dr Bronwyn Sacks – Chief Medical Officer**

> We walk alongside the family during and after the death of their child, if they let us, and that is such a privilege. Paediatric Palliative Care is about living for every moment in the best way you can.
>
> **Sue Kearney – Hospice Manager**

Essential care providers through the pandemic

As an essential service, we were able to reopen the hospice after a short closure at the beginning of the pandemic and implemented other restrictions to keep children, staff and families safe.

We felt it was important to continue to honour bookings for families who desperately needed respite during this time.

The need to stay open reflected our role as essential care providers within the health sector as well as the important role Very Special Kids plays in the well-being and coping of the families we support.

All therapies continued to be delivered onsite until level four restrictions, so Shari Manley (Child Life Therapist) and Pip Reid (Music Therapist) created the Zoom Room so children were able to continue therapy from home.

End-of-life care continued to be provided across Victoria, and, while the Family Support Team across Melbourne and Victoria was unable to do in-home visits, they continued to provide counselling and emotional support via phone and video.

The families we support coped in varying levels. However, to know we were there and available to them when needed was a huge comfort to them.

Therapies get creative

The Zoom Room, a therapeutic space for fun and engagement that utilises the Zoom platform, was created by Music Therapist Pip Reid and Child Life Therapist Shari Manley to deliver story and music sessions twice a week. These sessions were carefully planned with open-ended and inclusive experiences for people of all ages. The flexible and interactive format has enabled the growth and development of the program over a short period of time to include family support practitioners, volunteers and hospice staff alongside children and their families. The Zoom Room is set to become a permanent service offering because it was so popular, especially with regional children and those in hospital.

In-home respite pilot

Very Special Kids has trialled the delivery of in-home respite and end-of-life care to a selection of children and families. The objective is to determine whether respite and end-of-life care can be provided within the home as one feasible alternative to the way we provide hospice care during the rebuild period.

9 in 10

families feel less isolated thanks to Very Special Kids

Our music and child life therapists, Shari and Pip, have been delivering window therapy throughout COVID restrictions.

Nursing care and therapies continued in the hospice, with restrictions, through 2020.

The Calvert family is passionate about supporting access to music for all children in our hospice.

Expanding music therapy

In January 2019, The Lily Calvert Foundation donated $15,000 to establish the Lily Calvert Musical Care Program. The aim of the program is for children staying in the Hospice to be exposed to music seven days a week through equipping nurses and volunteers to provide this program. The Foundation was set up by Lily's parents, Will and Priyanka, in honour of their daughter, who died at 10-months of age, and it was brought to Very Special Kids following her death. Music was a big part of Lily's life and the couple want to ensure all children have access to music every day of the week while in the hospice.

Our Vital Volunteers

Very Special Kids is an organisation built on volunteer and community support. Without the generous support of volunteers, ambassadors, advocates, committee members and in-kind supporters, we wouldn't be able to offer the breadth of what we do.

Volunteers are at the heart of Very Special Kids. Their commitment to supporting families is unwavering and inspiring. In 2019/20, 89 individuals completed the nine-week training course to be a qualified Very Special Kids Family Services volunteer.

1000
volunteers
Support Families

- in the home
- during hospital stays
- in our hospice
- across our fundraising activities

Christine is more than just a volunteer

Christine spent more than 30 years working in hospitals as a cardiac technologist, so when she retired, she knew exactly where she wanted to volunteer – Very Special Kids.

She has a son with a disability, and the nurturer in her wanted to keep caring for kids. So, seven years ago she signed up to become a family support volunteer.

Christine was placed with a newly-arrived Korean family, who spoke little English. She was matched with the family to support their eldest son, who was two at the time, and whose little sister had an abnormal brain disorder.

"They had no family support in Australia and my role was really to help support this little boy in any way I could to ease some of the load on mum. I helped him to learn English, and because he's a smart little guy, he learned it really rapidly. I love teaching, so I also helped him with learning and physical development in the areas I identified where he needed help," she said.

Christine would spend around two to three hours in the family home, which has also enabled mum to go back to the thing she loves – teaching piano.

"Although my role was to look after a particular child, I see myself as a support for the whole family. The key to it working is to be non-judgmental and to follow their lead in what they need. It's obviously worked because I've now been with this family for seven years and I just adore them," Christine said.

Christine also adds that the structure of the volunteer program at Very Special Kids is what makes it so successful.

"I just love that it really is a community. The training is very comprehensive, and I feel so supported. I constantly have my allocated family support practitioner, Damienne, and volunteer coordinator, Nathan, checking in on me. Even through the pandemic, they continued to keep in touch. It's been wonderful," she said.

Christine has been volunteering at Very Special Kids for seven years.

New ambassador, Psychologist Sandy Rea.

Welcome to Sandy Rea as ambassador

In April, we announced psychologist Sandy Rea as an ambassador of the organisation.

Sandy is a leading practising psychologist in Melbourne of thirty years professional standing and has her own private practice, Sandy Rea & Associates.

She's Channel Nine's resident psychologist, and has regular spots on the Nine's Afternoon News. Sandy also writes a weekly column for News Corp Australia's Saturday Herald Sun in Melbourne.

She says she was excited to be approached to be an ambassador because of her speciality and interest in mental health and the importance of providing services like ours to families in need.

Sandy's role as ambassador, which is voluntary, is to advocate, and promote, the vital work of Very Special Kids.

Lou Cooney completed special volunteer training in 2019.

Professional leaders in volunteering

After seven years as Friends of Very Special Kids Volunteer Coordinator, and managing thousands of volunteers who support our fundraising, Lou Cooney became our first Volunteering Victoria Professional Leader of Volunteers, a 16-point Continuous Professional Development (CPD) program that improves volunteering sector knowledge, skills and future employability through accreditation.

Lou said she did the qualification so she could be the best she can be, for current and future volunteers.

"I just want to be the best I can be for them. They give up so much of their time, for free, and this qualification has made me more knowledgeable and trusted," she says.

Just over 50 volunteer coordinators gained the Professional Leader of Volunteer certificate in 2019.

Louise recognised by Premier

Our volunteer, Louise Hillier, was awarded a Premier's Volunteer Champions' Award for her 21 years of service to Very Special Kids.

Louise has offered every ounce of her compassion and kindness to care for our very special children. She is one of our longest serving volunteers, and will readily take new volunteers under her wing. Louise has created unique experiences for families to connect through journals, photographs, art therapy and events like Remembrance Day. Always patient and gently persistent, Louise provides solace for many families and has helped each child she meets to find joy in every moment.

Louise received her award at Government House from the Governor-General, the Honourable Linda Dessau AC.

The Whitnell family were part of the 2019 Piggy Bank Appeal.

Community generosity provides for our future

As a predominately self-funded organisation, we are humbled and grateful for the generosity we receive from the community.

This year, we raised funds through several successful appeals, community fundraising and events, including our first **Victoria Racing Club Pin and Win campaign**, our iconic **Piggy Bank Appeal** and **Footy Fever Debate**, as well as the **annual Community Fair**. Very Special Kids also receives a pool of tied funds which are contributions that major funders and supporters generously donate to fund specific projects. For example, our Art Therapy program launched in January 2020, thanks to a significant three-year grant from The Crown Resorts Foundation and the Packer Family Foundation. Thanks to this funding, one-to-one creative art therapy will be provided four days a week in the hospice, therapeutic art activities will be incorporated into our emotional support programs, and a pilot creative art therapy outreach program to support end-of-life children and families in their homes in metropolitan Melbourne will be trialled.

The 2019 Lexus Melbourne Cup Carnival was a great success for Very Special Kids as the Victoria Racing Club's (VRC) official charity partner. We were thrilled to raise over $450,000 in the first year of the Pin & Win Campaign.

Very Special Kids had a strong presence at the four big race days – Derby Day, Melbourne Cup Day, Oaks Day and Stakes Day – as well as participating in the Melbourne Cup Parade and Oaks Club Lunch.

We are incredibly grateful to the hundreds of volunteers who sold Lexus Melbourne Cup souvenir pins with a smile, even when braving the elements. Our volunteers are the backbone of Very Special Kids, and we couldn't have achieved such a fantastic result without their support and commitment.

Very Special Kids is excited to be partnering with Victorian Racing Club once again for the 2020 Lexus Melbourne Cup Carnival.

Very Special Kids Pin and Win Ambassadors (from left): Lisa Leverington, Olivia Molly Rogers, Lorinska Merrington, Chris Judd, Caty Price and Kirsten Stanley.

Participants of our 24 Day Active Challenge, like Andrew Wells, had to get creative at home for this year's virtual event.

Much like many other charities and organisations, COVID-19 had an impact on our income, following the cancellation or postponement of several events. However, we have used this as an opportunity to reassess and reinvigorate existing fundraising activities.

Our flagship **24 Hour Treadmill Challenge** was unable to go ahead in its usual format, so we quickly transformed the event into a virtual DIY active challenge. Over 24 days, participants were encouraged to stay active during Victoria's first lockdown by committing to 30 minutes exercise for 24 days, while raising much-needed funds for Very Special Kids. The event not only raised an incredible $349,616, but we were delighted to have many return teams join the new version, and to see a number of new participants get on board to support the event.

Our iconic Piggy Bank Appeal, which was in its 22nd year, raised almost $1m. This was thanks to a Victoria-wide campaign that saw collections all over the state, the Footy Fever debate, and significant contributions from corporate partners, Commonwealth Bank and ALH.

Although COVID-19 created many challenges and uncertainties for fundraising, we have been blown away by the response from our amazing community of supporters, in particular from the Philanthropic sector which has been responsive, engaged and nimble during the pandemic.

Our Patron Sister Margaret had a great time at 2019's annual Fair held in Malvern. The event raised $98,000 and was attended by more than 3,000 people.

We are fortunate to have the support of people in the community raising funds for us, like the classmates of Beau Stevenson, who died in 2019. They hosted a school fundraiser to give back to the organisation that supported Beau and his family. Pictured are Beau's parents Simone and Rob Stevenson, his friends, and Brigitte Johnson from our fundraising team.

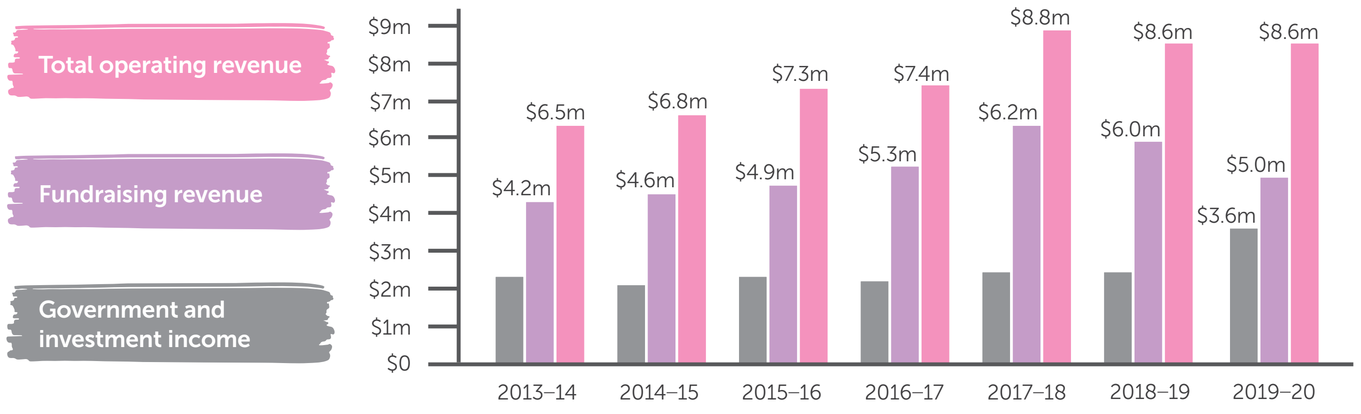
Financial snapshot

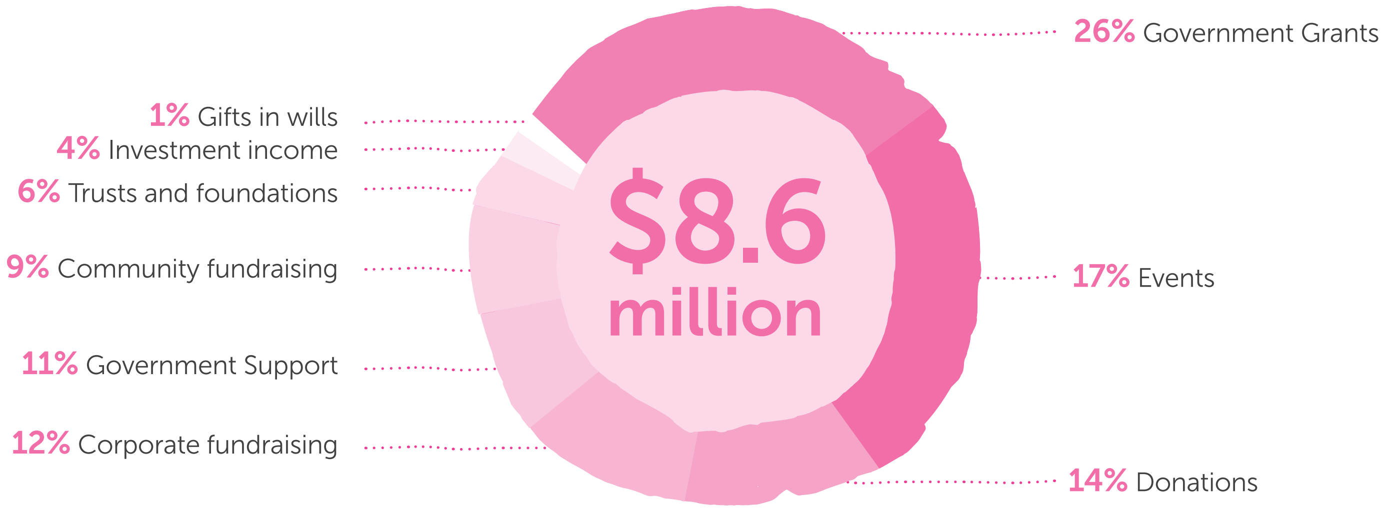
Very Special Kids child, Ace.

Due to COVID-19, we had to refine our thinking in regard to income generation in order to deliver our vital services during the pandemic. While the pandemic reduced our ability to hold large fundraising events, it provided several opportunities to introduce innovative ways to engage with our community.

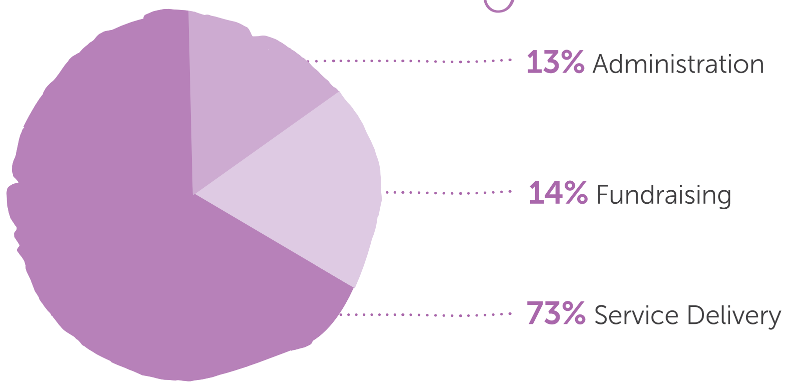
In 2019-20, our fundraising revenue diminished once social restrictions were enforced. Support from the state and federal government and the continued generosity of our supporters allowed us to generate as much income as the prior financial year. We are grateful to be in a fairly strong financial position, and as federal government supports reduces in the coming months, we are confident that we can emerge from this catastrophe relatively intact.

Where our income comes from





Where the money goes



View of the new hospice from Adelaide Street.

Rebuilding our hospice

Today, the clinical needs of children with life-threatening illnesses are significantly more advanced. Adolescents are living longer, and technology has changed, which places significantly higher care levels upon families.

It is important that the workforce and physical environment requirements adapt and respond to these changes, and to be equipped to support families for the next generation to come. It's for these reasons that we announced our intention to rebuild our hospice in 2019.

The Federal Government provided $7.5m towards the rebuild of our new hospice and at the beginning of 2020 we announced our intention to embark on our Capital Campaign to raise the further $15M for the project.

But due to COVID-19, and the challenges it continues to bring, the Very Special Kids Board made the decision to postpone the Very Special Kids hospice rebuild project by six months. As well as COVID-19 impacts, there were several other factors that led to the decision to postpone the project, in particular, our inability to commence our formal capital campaign that would aim to ensure the project is fully funded.

Therefore, the construction tender is now scheduled for March 2021 and the demolition of the existing hospice is now due to commence in August 2021. The Board will monitor this schedule as the longer term COVID restrictions are relaxed or extended.

We are very fortunate to have such an admired and respected committee who are personally leading this campaign. The full committee includes **Life Governors, Paula Fox AO, Connie Kimberley and Andy Penn; former Federal Cabinet Minister the Hon. Kelly O'Dwyer, businessmen Glenn Carmody and Neville Azzopardi, Very Special Kids CEO, Michael Wasley, Board Chair Peter Polson, and Founder and Patron; Sister Margaret Noone AM IVB.**

Gandel Philanthropy

We'd also like to acknowledge and thank Gandel Philanthropy for its incredible $1M towards the hospice rebuild.

Highlights of the new hospice

- Private end-of-life area to respect families final wishes
- Eight larger bedrooms with individual ensuites
- New technology to provide clinical care excellence for children with complex care needs
- Hydrotherapy pool for physio and end-of-life
- Encompassing natural light and warmth via a central courtyard, skylights and natural building materials
- Piped oxygen and suction available throughout so children can move freely inside and outside
- Separate spaces for art and music therapy, a multi-sensory room, multi-media room, soft play space, and additional therapy services

Chain Reaction Foundation

The Chain Reaction Challenge Foundation was the catalyst partner of our hospice rebuild project, and, over the past three years has not only ensured the project is thoroughly planned, and the outcome maximised, and, as of 2020, has contributed $1M towards the rebuild.

Inside the new hospice.

Our Generous Supporters

Partners

Supporters and event partners

Media partners

Program partners

Corporate supporters

- Advent Partners
- AFL Tasmania
- ALH Group
- Ausnet Services
- Balcon Group
- Cabrini Health
- Chain Reaction Challenge Foundation
- CMV Foundation
- Coca Cola Amatil
- Coles
- Commonwealth Bank - Staff Social & Charity Club (Vic) Inc
- Commonwealth Bank of Australia
- Coopers Brewery Foundation
- Daimler Truck & Bus
- Dragon Hot Pot
- Ernst & Young
- Guild Group
- Hippo Blue
- Icon Group
- International Premier Events
- Inverloch Lotto
- IOOF Foundation
- JBWere
- Jellis Craig Foundation
- Jemena
- Keilor East RSL
- Maddocks
- Motorsport Australia
- National Australia Bank
- Newman's Own Foundation
- QBE Foundation
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- Seacret Spa
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- Somerville Hotel
- Sportsbet Pty Ltd
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- Tobin Brothers Foundation Ltd
- Toyota - SRO
- Toyota Financial Services
- Turi Foods
- Victoria Racing Club
- Viva Energy Australia
- WE-EF
- Westend Market Hotel

Individual supporters

- Andrew Potter
- Angela Found
- Anton & Jenny Gaudry
- Barry Peake
- Bevan Slattery
- Clive Batrouney
- David Gillard
- David Lyall
- DGP Foundation
- Dorman Family Foundation
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- George & Julia Hicks
- Goldsmith Family
- Ian & Kristeen Urquhart
- Jan Pannam
- John & Jenny Fast
- John Wheeler & Sue Hadden
- Lynette Swan
- Margaret Brown
- Matt Latimore
- Narayan Sreenivasan
- Peter Hour
- Mr P T Kempen
- Rita Andre
- Shannon Hyde
- Simon Daish
- Simon Backhouse
- Stocks Family Foundation
- Stuart Giles
- Sunraysia Foundation

Government

- Commonwealth Government of Australia
- Victorian Department of Health & Human Services
- Magistrates' Court of Victoria - Melbourne

Trusts and Foundations

- Alfred and Jean Dickson Foundation
- Barr Family Foundation
- Bell Charitable Fund
- Brian M Davis Charitable Foundation
- Campbell Foundation
- Cassandra Gantner Foundation
- Corio Foundation
- Crown Resorts Foundation PAF
- Danks Trust
- Douglas Family Foundation
- Ducas Paul Foundation
- Eirene Lucas Foundation
- Freemasons Foundation Victoria
- Gandel Philanthropy
- Gertie's Charity Group
- Give Where You Live
- Hope and Tony Saba Family Foundation
- Lily Calvert Foundation
- MacKenzie Family Foundation
- Norman, Mavis & Graeme Waters Perpetual Charitable Trust
- Packer Family Foundation PAF
- Percy Baxter Charitable Trust
- Rado Family Foundation
- Rowe Family Foundation
- The Alfred and Jean Dickson Foundation
- The Johnstone Family Foundation
- The Marian & E H Flack Trust
- The Morris Family Trust
- The William Angliss (Victoria) Charitable Fund

Estates

- Estate of Robert John Buchanan
- Estate of Daryl Giles Howard
- Estate of Natalie Mary O'Sullevan
- Norman, Mavis and Graeme Waters Perpetual Charitable Trust
- Pethard Tarax Charitable Trust

Community supporters

- Ardina Davis & the Heathcote Community
- Australian Chinese Events Committee
- Grimwade House - Melbourne Grammar School
- Haileybury College
- Helping Hand Group
- Hoppers Crossing Sports Club
- Kananook Community Trust
- Robert Van Stokrom & Leonie Hill
- Rotary Club of Altona City
- Rotary Club of Melbourne
- Rotary Frankston Sunshine
- Redstock and Crash Landers
- The Flinders Challenge

ALH Group venues

- Bayswater Hotel
- Blackburn Hotel
- Bundoora Hotel
- Burvale Hotel
- Doncaster Hotel
- Excelsior Hotel
- Fountain Gate Hotel
- Keysborough Hotel
- Pier Hotel
- Plough Hotel
- Sands Hotel
- Skyways Hotel
- Somerville Hotel
- Village Green Hotel
- Westside Hotel

Gift in Kind supporters

- 3AW Radio
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- Elmo Software Ltd
- Grassrootz
- KPMG
- Lifestyle Rewards
- Linfox Logistics
- Merlins Magical Wand
- Optical Audio Productions
- QANTAS
- Rapid Relief Team
- Royal South Yarra Lawn Tennis Club
- Seven Network
- Sussan Group
- TEG Dainty
- Telstra
- The Just Group
- Woodlands Golf Club

*Supporters over $5,000.

Our People

Patron

Sister Margaret Noone, AM IBVM

Board

Peter Polson (Chair)

Dr Susie Gibb

Dr Adam Scheinberg

Therese Robinson

Rhys Jewell

Heidi Roberts

Wendy Thorpe

Executive Management Committee

Michael Wasley, Chief Executive Officer

Jane Baker, Office Manager and Executive Support

Marcia Christmas, General Manager – Fundraising and Marketing

Matt Dunshea, General Manager – Business and Finance

Sue Kearney, Hospice Manager

Peggy Hogan, Family Support Team Manager

Katrina Hall, Human Resources Manager

Sharon Stynes, Fundraising and Events Manager

Paula Mullin, Deputy Hospice Manager

Jessica Birnbaum, Deputy Family Support Team 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)

Michael Wasley

Neville Azzopardi

Phil Endersbee

Hamish Rotstein

David Gibbs

Claudia Haeger

Matthew Koce

Andrew Macmillan

Andrew Perry

David Szeleczky

Justin Whitford

Suzie McInerney

Life Governors

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

Mr Rod Bennett

Prof. Glenn Bowes

Ms Jane Fenton AM

Mrs Paula Fox AO

Mr David Jones AO, OBE, KSJ

Ms Connie Kimberley

Mr Roger Nicholson (deceased) OAM

Sr. Margaret Noone AM IBVM

Mr Andrew Penn

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:

David Agnew

Gary Anderson

Dr Elizabeth Carew-Reid, OAM

The Hon Peter Costello, AC

Robert Davey

Chris Gillman

Janet Hawkins, OAM

John Hope

David King

Professor Sharon Goldfield

Dr Doug Bryan

Bill Le Lievre (deceased)

Keera Le Lievre (deceased)

Dr Annie Moulden, OAM

John Nairn

Maureen O'Keefe-Anders

Dr John Rogers, AM

Wendy Swift

Jim Wilson

Andrew Miller

Jean Miller

Child Life Therapist, Shari, delivers play-based therapy in the hospice.

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. At Very Special Kids, we acknowledge the Australian Aboriginal and Torres Strait Islander peoples as the traditional custodians of the land. We acknowledge the traditional custodians of the lands across Victoria where our services are located.

We also pay our respects to ancestors and Elders, past, present and future.

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.

VERY
SPECIAL
kids

Children's hospice
and family support

FREECALL **1800 888 875** | WEBSITE AND ONLINE DONATIONS **VSK.ORG.AU**

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321 Glenferrie Road
Malvern
03 9804 6222
mail@vsk.org.au

Brunswick
Level 1/233 Sydney Road
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0408 910 878
0428 989 122

Peninsula
1973 Frankston-Flinders
Road, Hastings
0417 151 096

Barwon
Kurrambee Myaring
Community Centre
12 Merrijig Drive
Torquay
0400 007 693

South West
Port Fairy Community
House, Railway Place
Port Fairy
0428 393 162

**Gippsland /
Outer South East**
2 Olympic Way
Pakenham
0417 543 514

Grampians
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Ballarat
0457 727 505

Hume
23 Alexandra Street
Mooroopna
0408 583 378

Loddon Mallee
52-54 Derwent Drive
Long Gully
0428 240 031

ABN 86 109 832 091