

Pre-Budget Submission | 2020 - 21

# Happiness Matters

Helping children with complex, chronic health conditions to live their best lives



Brightening the lives of seriously ill children, teenagers and their families

*"Starlight does an amazing job of taking away the stress from Aru's hospital stays. This is so important for kids like Aru who can spend months in hospital. When you see your child singing and dancing with Captain Starlight, it's a stress-buster for you as parents, too." Aru's mum*

Aru, 3 years old



[starlight.org.au](http://starlight.org.au) | 1300 727 827



# Starlight Children's Foundation

Starlight has been an integral part of the Australian paediatric health care system for over 30 years, now investing more than \$20M per year into the public health care to support the total care of children, young people, and their families. With a Social Return on Investment (SROI) of over 5.7:1, this is over \$100M of community value each year.

Working in partnership is part of our DNA, with 58 partners across 108 collaborations currently underway. We share what we learn and regularly present our research and evaluation findings, helping to play a broader role in ensuring a better health care experience for all children and young people.

Starlight is a much-loved charity and is the #1 most reputable charity brand supporting children and young people in Australia. Starlight has 400 employees across Australia and thousands of volunteers who help us deliver our programs effectively. Starlight enjoys high levels of trust, brand awareness and is recognised as an employer of choice.

When searching for a partnership Starlight's credentials are unparalleled.



*"It's not hospital, it's about that we're going to see the Captains now, and the doctors are just a part of the things that we have to do when we come to see the Captains." Kylie, mum*

*"The work of Starlight is to me equally as important as the work of the therapies used to treat their illness. Without joy and happiness, children cannot remain mentally well through treatment. Mental wellness is so important to recovery – and Starlight provide happiness to patients through fun and play." Leanne, mum*



*"Starlight dramatically helps with kids' mental health and putting them in a good mood to tackle whatever they have to face in hospital. Not having Starlight would be debilitating on Gus' mental health." Lisa, mum*





# HAPPINESS MATTERS

## What happens in childhood lasts a lifetime

*Starlight's vision is a world where everyone experiences a happy childhood.*

*Why? Because happiness matters.*

A happy childhood can be out of reach for children with a complex, chronic health condition, with their reality one of missing out on spending time with family, building friendships, going to school and just being a child. The lifelong impact is immense, because a happy childhood makes the world of difference to lifelong psychological wellbeing, sense of self, social connections, and healthy behaviours.

Australia has one of the best health care systems in the world. However, sick children and young people need more than the exceptional care our clinicians can offer. They need the social connection and emotional support that lets them be a child. This is Starlight's role - to deliver innovative and unique programs that protect the right of every child - no matter their health condition or circumstance - to mental and emotional wellbeing, social connections, and a sense of belonging.

What Starlight does is not a "nice to have" - it is a fundamental right that kids can be kids and teens can be teens, even when they are facing the unimaginable challenges of serious illness.

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*"If children are unable to fulfil their social and developmental potential, this not only harms their futures, but also the societies in which they live"*

- Selina Lo, Pamela Das, Richard Horton The Lancet, Vol. 389, No. 10064

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### Supporting children and their families across Australia

Starlight is an integral part of the Australian paediatric health care system, working with clinicians in every State and Territory to bring play, creativity and social connection to children, young people, and their families in their toughest times. This reduces anxiety and depression, increases treatment compliance, reduces missed doctors appointments and improves the morale of the hospital staff.

Starlight supports children and their families throughout their healthcare journey - this is often for many years. Nationally each year Starlight provides support through:

- **168,000** visits to a Starlight Express Room, hubs in ten hospitals where families can play, connect, and receive much needed social support
- **156,000** visits by Captain Starlight to children on the wards, who are too unwell to leave their beds however still need to laugh and play
- **22,310** experiences for Aboriginal and Torres Strait Islander children in some of our most remote communities, helping to ensure essential clinic visits are a positive and child-friendly experience
- **44,000** engagements with teenagers in hospital, particularly those receiving treatment for acute mental illness where their treatment can require them to be isolated from friends and their usual support network
- **24,000** logins by teenagers to a safe, peer support online community where they connect with other teens who just 'get it', understanding what it is like to be a teenager living with a complex, chronic health condition that impacts every aspect of your life.

The impact is significant, with independent research<sup>1</sup> finding \$5.70 of community value is created for every dollar invested.

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<sup>1</sup> Social Return on Investment (SROI) study, PWC, 2015. Update audited 2019.



# FUNDING REQUEST

For over 30 years Starlight has relied on community support to deliver programs in hospital and in community. This equates to around \$400M invested by Starlight into Australia's Paediatric health care system. Our fundraising and program reach has been significantly impacted by Covid 19 and we do not want to regress several years in our program delivery. To this end we would like to partner with the Federal Government ensuring equitable health outcomes for all Australian children continue. This investment will enable Starlight to meet both immediate funding needs and sustainable program delivery, ensuring the long-term support of the social and emotional needs of children and teenagers with serious illness now and into the future.

Starlight is currently researching the impact of the reduction of our in-hospital presence. Here are a couple of early excerpts:

*"...daily I get the question: "When is Starlight coming back?"*

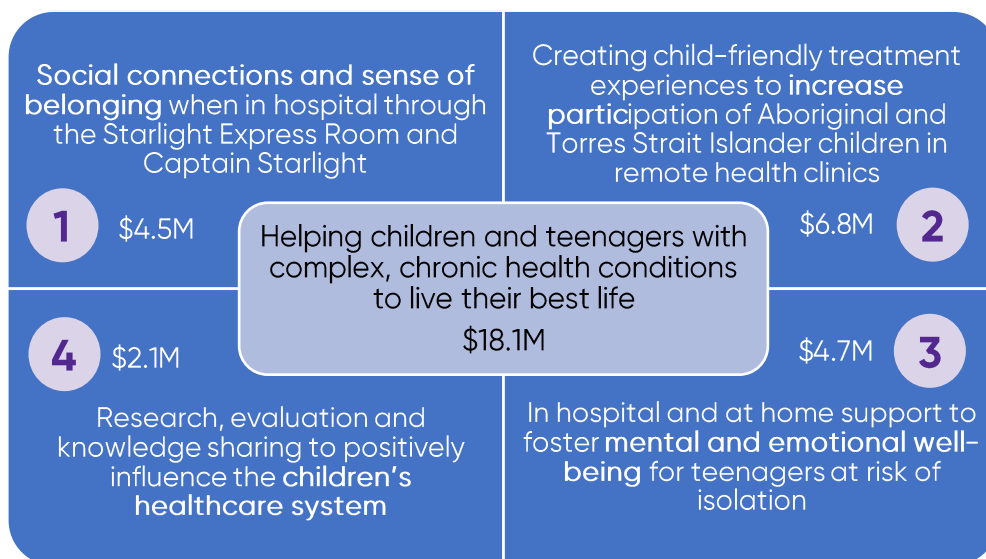
Health Professional, Mental Health Unit

*Interviewer "...on a scale of 1 to 10, how important do you think it is to have Starlight in the hospital?"*

Health Professional – "I would say 11"

We require \$18M of Government support over the next 3 years to enable Starlight to meet the program need. This funding represents only 27% of Starlight's total investment in public health care over this time and will reduce each year moving towards Starlight's return to sustainability in 2023/24.

We will use this funding to make a positive and lasting difference in the following areas:



Starlight Programs Investment	2020/2021	2021/2022	2022/2023	TOTAL
TOTAL SPEND	\$21.1M	\$22.1M	\$23.3M	\$66.5M
Government funding request	\$7.3M	\$6.2M	\$4.6M	\$18.1M
Government funding request as % of Starlight Annual Investment	35%	28%	20%	27%



# STRATEGIC RESPONSE

1

## Social Connection and Belonging

Providing social connection and respite for children and families and increasing participation in the healthcare system

### The Need

Children and young people in hospital can feel fear and anxiety and experience a loss of control due to the restrictions of the hospital environment. Hospitalisation can impact their sense of privacy and ability to make choices, as well as their opportunities to express their creativity and socialise. These opportunities for social connection, positive emotions and play are critical for healthy child development and overall wellbeing. This need is exacerbated for children with serious illness who experience repeat or extended hospitalisation.

### Starlight's Response

In every paediatric hospital in Australia, Starlight creates a fun, and vibrant environment where children and families can find respite from treatment and receive emotional, social and practical support. Starlight Express Rooms (SERs), provide a hub within the hospital for social connection and engagement and play a crucial role in combatting the isolation experienced by families removed from their usual community supports.

Captain Starlights - professional, costumed performers - entertain and engage children in activities which support their positivity and wellbeing in the SER and visit children on wards who are too sick to leave their beds.

### The Impact

- Immediate positive distraction from the stress of hospitalisation and treatment, while in the longer term they help provide a greater sense of agency and control, which can change attitudes to hospital treatment and improve medical compliance and health outcomes.
- SERs provide an overwhelmingly positive benefit for all hospitalised children and families, however those that benefit most are the most "highly distressed families with lower psychosocial functioning". This means that Starlight fills a gap for the families who are the least likely to find that support elsewhere.

2

## Positive Healthcare Experiences

Creating child-friendly treatment experiences to increase participation of Aboriginal and Torres Strait Islander children in remote health clinics

### The Need

Australia's Indigenous population experiences a burden of disease at 2-3 times that of the non-Indigenous population, with Indigenous children experiencing some of the highest levels of preventable chronic diseases in the world. For these children, accessible healthcare means more than just the provision of health clinics. Attendance at health clinics needs to be reframed as a positive experience, to establish trust and achieve the engagement required for regular clinic attendance and the participation required to improve long-term health outcomes.

### Starlight's Response

In remote communities, Starlight Healthier Futures Initiative partners with health teams to visit clinics focused on detection and early treatment of chronic health conditions, creating child-friendly, positive health care experiences through music, art, games and storytelling, strengthening community relationships and building trust.



## The Impact

- Captain Starlight at remote clinics improves attendance with fewer walk-offs, an improved clinic environment, and increased clinic efficiency.

3

### Thriving Mentally & Emotionally

Supporting resilience & social connection of adolescents in need

## The Need

Adolescence is a time of intense physical, psychological, emotional and social change, when young people become focused on relationships with their peers and start to explore their own identity. For those with serious health conditions, these normal development stages can be delayed or compromised. Repeated hospitalisation, long hospital stays, the restricted nature of hospital wards and the effects of illness disrupt the young person's development.

For young people who are admitted to mental health facilities, the impact is even more acute. The rigorous lockdown and safety measures of secure mental health units severely restrict the capacity of young people to engage with friends, family, and all their most familiar support mechanisms – just at the time when they need them most. Beyond hospital, serious and chronically ill young people are at high risk of social isolation and impaired emotional well-being. For teenagers in rural or regional areas, social isolation is often compounded by a lack of peers with similar experiences and limited availability or access to support services.

## Starlight's Response

In hospitals, Starlight's Livewire programs encourage young people to use their creativity and learn new skills through ward-based activities and skill-based workshops and event nights facilitated by Starlight facilitators. These activities helping to transform their experience and support personal development.

Beyond hospital, Starlight's online platform continues to support these young people, and others affected by serious and chronic illness or disability, by providing vital peer support. This community is a unique place where these young people who are at risk of social isolation can connect with others dealing with the same issues they are in an actively moderated, safe and supportive environment. 40% of active members live in regional or remote areas.

## The Impact

- Immediate to short term benefits include young people feel more understood, accepted and supported and learn new skills and improved their health management.
- Long-term benefits identified include increased sense of wellbeing, enhanced social skills through mentoring opportunities, better ability to cope with their health condition and equipped to fulfil their potential.

Health professionals report that young people in mental health units engaging in the Livewire program demonstrate better compliance and engagement with their hospital treatment because of participation, contributing to their confidence in pursuing social connection with others on the ward.



4

## Improved Health Outcomes through Research Collaborations

Collaborating and sharing to positively influence the children's healthcare system beyond our own programs.

### The Need

The Australian healthcare system is world class however we are currently in a time of significant challenges from rising demand and cost pressures. These challenges can only be met through innovative approaches and collaboration to expand capacity and improve outcomes. When health professionals work in partnership with consumers and one another, better quality care is achieved. Patient-centred care models contribute to improved patient health outcomes, better use of resources, decreased costs and increased patient satisfaction with care.

### Starlight's Response

With a permanent presence in every children's hospital in Australia and with expertise in delivering programs every day to positively engage children and young people, Starlight occupies a unique position in the children's healthcare environment. Starlight's national presence and reputation enable it to take a leadership role in championing collaboration promoting cooperation and knowledge-sharing and driving research outcomes that benefit seriously ill children and young people across Australia.

Starlight's innovation, research and evaluation collaborations help to support a more effective health care system and better outcomes for children, teenagers, and their families.

Example of these collaborations include:

The Listen Carefully Project, a national project about the right of children to be heard, specifically to understand current practice in applying this right during hospitalisation. Seven hospitals have been peer-selected as best practice and case studies are being developed, as well as identifying barriers that exist to this right in healthcare. Future phases of this project will develop practical tools and support to overcome these barriers.

A research project investigating the role of an online community, such as Livewire, in supporting good mental health.

Investigating the importance of play and peer support in supporting the health and wellbeing of Indigenous children.

Exploring the use of creative spaces in children's hospitals for promoting wellbeing.

### The Impact

Influencing and making a positive difference to the healthcare experience of the Australian children who make up the 790,000 paediatric admissions, 2 million outpatient appointments and almost 380,000 emergency presentations every year.