



"The experience of the pandemic has hugely underscored the value of social connections. For young people, it is all about social connections with peers. Having managed a peer support program for young people with complex health issues at the Royal Children's Hospital for 25 years, I can absolutely reinforce the value of Starlight's Livewire as a program that helps connect young people with each other – and to the wider world. And I am excited about Starlight's interest in how to integrate online and face-to-face elements."

Professor Susan Sawyer AM
Director, Centre for Adolescent Health, Royal Children's Hospital
President, International Association for Adolescent Health

Livewire Integration Project –

Vital Social Connection for Seriously ill Adolescents.
Wherever they are, whenever they need it.

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The Need

For young people dealing with complex, chronic health conditions, social isolation poses a far more serious threat than for their healthy peers, with both immediate and lifelong effects. In the short-term, seriously ill young people can develop mental health issues on top of their physical condition; in the long-term it can impact a young person's ability to develop the social and other skills required to flourish and become a fully functioning member of society.

Adolescence is a critical time of social, emotional, and physical development. It can be difficult enough without the added complexity of dealing with chronic illness or disability. It is a time of forming one's identity and sense of self. Friendships and social connections are a vital part of this, and teens with a chronic, complex health condition, who are constantly in and out of hospital, experience huge disruption from the "normal" experiences of adolescence, such as school, sport, and social activity. **This places this uniquely vulnerable group at extreme risk of social isolation and mental illness during this critical phase of their development.**

The Program

Livewire is a boutique, proven model delivered in hospital and outside the hospital, designed to overcome social isolation and improve mental well-being for seriously ill teens. Livewire has deep impact, helping teenagers with complex, chronic health conditions to not only survive but to thrive.

The hospital program has traditionally been delivered by Livewire Facilitators as face-to-face group workshops, ranging from T-shirt design to poetry-writing sessions and rapping competitions- with the aim of helping hospitalised young people make social connections and develop new passions and interests. Outside hospital, young people with complex, chronic health conditions are supported by Livewire Online, an innovative community where they can connect with others dealing with similar health issues in an actively moderated, safe environment that offers live chat, community content, livestreaming and blogs- all in a place where members can talk about whatever's going on in their life with other young people who just "get" them.

The Impact of COVID-19

For seriously ill young people, the impact of COVID-19 was profoundly isolating, as hospitals were forced to restrict in-person connection with and between teens. Suddenly Livewire Facilitators, usually on the wards with young people every day of the week, had to start delivering programs remotely- and Livewire Online and Livewire in-hospital became one and the same. It was a temporary solution, developed out of necessity, but what it revealed was that for some young people, particularly for those who are hardest to reach, it was effective. For them, the opportunity to watch a livestream of an activity and test the waters before jumping into face-to-face interactions removed a barrier to entry, and they became more likely to participate in an activity in hospital as a result. Once the connection with these young people was made, Starlight was able to continue to support them wherever they were, whether inside or outside hospital.

On the flip side, for some hospitalised young people the absence of face-to-face connections from Livewire Facilitators at their bedside made them more reluctant to sign up to the online community without the opportunity to experience a personal connection first. This meant that not only were these young people socially isolated while in hospital, but they also left hospital without any social support in place. In fact, even when health restrictions ease, 2 out of 3 of young people admitted to hospitals other than Children's Hospital at Westmead will continue to miss out on a facilitated introduction to Livewire.

CASE STUDY

Taleisa's Story

16-Year-old Taleisa lives with an 'invisible' illness. Looking well from the outside, the teen deals with chronic pain from a range of complex health conditions. Up until last year singing, dancing and acting were Taleisa's life. Suddenly that changed and Taleisa was unable to get out of bed, fatigued and crying in constant pain. She was diagnosed with Sheurermann's Disease, joint hypermobility syndrome, Postural Orthostatic Tachycardia Syndrome (POTS) and anaemia.

Since then, Taleisa has spent significant time in hospital and countless specialist appointments. Missing school and with dance classes put on hold, Taleisa's days were replaced with physio and occupational therapy sessions. The impact took its toll and Taleisa was also diagnosed with depression & anxiety. Taleisa said her illness was very isolating. "My life wasn't the best. It was hard to find people who understood what I was going through." That changed when Livewire visited Taleisa in hospital.

Livewire encouraged her creativity through hospital workshops and Taleisa was thrilled when her artwork of Kylie Minogue was a finalist in The Lester Prize for Portraiture Youth Section. Through the Livewire hospital team, Taleisa was introduced to Livewire online. She loves logging on to catch up with friends and check out the latest guests, events or competitions.

"It was just so wonderful to see her become so positive again. The Livewire online community has been an amazing support network helping Taleisa meet other teens like her and realise she isn't alone on this journey," her mum said.

"Livewire had a huge impact on me. It's amazing to talk to people who understand how I'm feeling."

"If Livewire wasn't there, I would have struggled a lot more with my mental health."



The Opportunity

Partnering to help adolescents with complex, chronic health conditions live their best lives

There is an opportunity to further deepen the impact of the boutique Livewire program and increase the support for this uniquely vulnerable and hard-to-reach group of teens by intervening to improve their social, emotional, and mental well-being at a critical time. Starlight would like to take advantage of the lessons learned- the silver lining- of COVID-19, by initiating a trial of an integrated Livewire experience which combines the online with the in-person, the digital with the human.

Starlight proposes a project trial to consolidate the integration of its online and offline Livewire programs, with the initial focus area of the Sydney Children's Hospital Network, with a base in **Children's Hospital at Westmead (CHW)** and **Parramatta Region** and with a view to rolling this out nationally upon successful completion. The approach will be multi-faceted and complement existing programs, while enabling new ideas & approaches to be tested. The **Livewire Integration Project** will encompass:

Livewire Activity	Description	Outcomes
Livewire Platform Upgrade	Upgrade of the site to create a fully integrated in-person and online experience and reflect contemporary digital user experiences	<ul style="list-style-type: none"> 18% annual increase in logins 20% annual increase in new members to 600 85+ NPS from teens experiencing Livewire
Facilitated Online Experiences	Creation of social connection and well-being support for young people with complex, chronic health conditions	<ul style="list-style-type: none"> 20 activities and experiences to connect young people on Livewire Online per month 114 hours of 'Live Chat' per week facilitated and moderated by Chat Hosts to promote peer to peer connection
Hospital Program serving Sydney Children's Hospital Network- Westmead as hub	Providing the integrated approach between online and in-hospital, including connecting young people with Livewire Online during their hospital stay to provide continuity of support when they leave hospital	<ul style="list-style-type: none"> 240 workshops per year, teaching skills e.g., art, coding & performance. as well as promoting Livewire online. 720 young people in Western Sydney to sign up to Livewire
Outreach Programs in Western Sydney (Parramatta)	Connecting young people outside paediatric hospitals who 'fall between the cracks' of support-e.g., Mt Druiit Hospital, Nepean Hospital, Campbelltown Hospital, Liverpool Hospital, adolescents receiving treatment at Westmead Adults hospital and young people in transitional care. Focus will be on inclusiveness and reaching the hard to reach (e.g., from CALD backgrounds) and leveraging 2020/21 learnings of using face-to-face programs as a gateway to online community support	<ul style="list-style-type: none"> 210 workshops with young people per year, teaching skills such as art, coding, performance etc. as well as informing them about Livewire Online 1050 young people in Western Sydney sign up to join Livewire Online
Self-Compassion Program Trial	Trial of positive psychology based self-compassion program for teens with chronic health conditions. This program has been researched and developed in partnership with Telethon Kids Institute and is now ready to be trialled within a health or community service in Western Sydney	<ul style="list-style-type: none"> 100 young people to participate in self compassion program and complete formal evaluation.
Evaluation and Knowledge Sharing	Evaluating and sharing learnings to contribute to knowledge and best practice both within Starlight and in the health and youth services sector	<ul style="list-style-type: none"> Publication of a peer reviewed Journal Article Presentation at national conference

Funding Request

Starlight is requesting \$960,000 for its Livewire Integration Project over the next three years to ensure high demand for support of seriously ill adolescents can be met. **Our social return on investment will be over \$5m in community value over this time¹.**

Livewire Activity	FY23	FY24	FY25	TOTAL
Livewire Platform Upgrade	\$150,000	\$50,000	-	\$200,000
Facilitated Online Experiences	\$30,000	\$30,000	\$30,000	\$90,000
Livewire Hospital Program in Sydney Children's hospital Network (CHW base)	\$150,000	\$150,000	\$150,000	\$450,000
Parramatta Outreach	\$50,000	\$50,000	\$50,000	\$150,000
Self-Compassion Program Trial	\$25,000	\$25,000	-	\$50,000
Evaluation and Knowledge Sharing	-	\$10,000	\$10,000	\$20,000
Government Funding Request	\$380,000	\$315,000	\$265,000	\$960,000

¹ 2013 Social Return on Investment (SROI) by Social Ventures Australia. Livewire Online creates \$5.30 in community value for every \$1 invested.