



Livewire Background & Overview

Why did the Starlight Children's Foundation decide to develop Livewire?

Starlight is committed to enabling **all** children and young people living with serious illness or disability access to our innovative programs to lift their spirits increase their self esteem and resilience as they cope with the challenges their condition brings.

Whilst many of the programs Starlight offers provide vital support across the age spectrum from young children to teenagers; it is apparent that the needs of young people change as they mature so they need different programs that are more relevant to their age and lifestyle.

It is hard to cope with the impact of serious illness at any age, to be taken away from all that is familiar, to miss school, unable to participate in sports or social activities and to have to cope with the fear and pain throughout treatment.

In many ways, adolescence is the most difficult stage to cope with these challenges, at the very time most young people are discovering a new independence the experiences of these young people is very different from the "norm".

This is why Starlight launched **Livewire.org.au**, an online community connecting young people aged over 10 and under 21, living with serious illness, chronic condition or disability, to help reduce the isolation and loneliness these young people often experience.

Why online? Well for the reason that this is where teenagers meet to share news, ideas and make friends today. Through Livewire, teenagers can make contact with each other wherever they live, even in remote or regional areas and whether they are at home or in hospital.

Livewire is an on-line community, not only for the young people themselves, but also for their brothers, sisters and parents. Developed in partnership with the Federal Government Livewire provides a platform that will reach children and their families from all charities, anywhere in Australia.

The initial investment will provide the most sophisticated safety and a platform that can be extended to bring help for parents, brothers and sisters and hundreds of thousands of people affected by serious and chronic illness and disability across Australia.

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LUMINARIES / KIEREN PERKINS AO / NEIL PERRY

PATRONS / THE HONOURABLE SIR WILLIAM DEANE AC KBE / MR JOHN NEWCOMBE AO OBE

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What is the relationship between Livewire and the Starlight Children's Foundation?

Livewire is a wholly owned subsidiary of the Starlight Children's Foundation. It was set up specifically as a separate entity to Starlight to administer the Clever Networks funding to develop the Livewire initiative.

The reason it was set up as a separate entity was to ensure that Livewire would have the focus required for this major project without impacting on resources for Starlight's core programs and that fundraising efforts could be separated in a transparent manner.

What is Livewire's mission?

Livewire is designed to empower and deliver social and emotional benefit to young people living with serious illness or disability, and their families, through the use of social networking and by providing inspirational and entertaining content.

What are the outcomes Livewire aims to deliver?

Livewire aims to facilitate connection, empathy and understanding between people who are experiencing similar situations. The program outcomes of Livewire are young people and their families who:

- Feel less isolated
- Receive more social support
- Can better overcome anxiety and stress
- Experience less bullying and predation
- Are alleviated from boredom
- Can creatively express themselves, and
- Feel an increased sense of belonging to the community

The positive impact of Livewire for its members is being measured by two independent therapeutic benefits research projects that are currently underway - one with Murdoch University and another with GFK Bluemoon. These projects are using quality of life measures to determine the impact of Livewire and the use of ICT on the social and emotional wellbeing of this cohort over time.

What are the needs that Livewire fulfils?

Livewire was established to support the needs of families in distress as a result of dealing with the impact of a serious illness or disability.



- An estimated 450,000 children and young people aged over 10 and under 21 years are living with the impact of a serious illness, chronic health condition or a disability in Australia.
- Serious illness or disability can profoundly affect the everyday lives of children and young people by increasing their risk of social isolation, disconnection, lower peer acceptance and lower emotional well-being. These problems are compounded by long hospital stays.
- Many families struggle to cope with a child living with a serious illness or disability. Siblings and parents often suffer a heavy emotional burden, physical stress and financial pressure.
- Livewire offers a solution for these young people and their families. Livewire delivers connection, interaction and support with other people who understand and can empathise with what they are going through.

How much funding does Livewire have?

Livewire will receive total funding of \$14.4 million – partly in cash and partly “in-kind” – for a project which stretches over 5 years. This 5 year period includes an 18 month pilot phase, two years of development and two years ongoing hosting.

The Federal Government’s Clever Networks program is providing \$7.2 million to the project. This funding is not guaranteed and will only be made available subject to the accomplishment of quarterly milestones.

This \$7.2 million is being matched dollar for dollar by cash and “in-kind” contributions from Starlight and other Livewire partners. Contributions that are “in kind” are when Starlight or Livewire partners provide services or resource to the project, rather than actual cash or invoiced services.

The funding from the Federal Government is for setting up the Livewire platform specifically and cannot be used for any of the core Starlight programs.

Starlight was one of 115 organisations who submitted for funding from Clever Networks in a competitive process. There were 26 recipients of funding following a rigorous review process.

How is Livewire using the funding?

The main Livewire.org.au site is a public interface and place for the young people to log into Livewire – the true Livewire network is a closed community for security reasons so the content games and community tools are password protected.

Livewire is free to use and has not carried advertising and does not endorse products to ensure Livewire members are protected.

The Livewire initiative incorporates:



- The development of an online community for young people living with a serious illness, chronic health condition or disability. There are actually 3 separate communities for ages 10-14, 15-17 and 18-21.
- Ensuring the safety and security for our members is a top priority. We are working with the Australian Federal Police and SIFT Pty Ltd, who are leading specialists in providing a broad range of information security services, on ensuring the security of the web application, hosting environment and sign up process.
- The development of a mobile service for members to remain connected to the community while they are away from a computer.
- The development of an online community specifically designed to meet the needs of siblings of young people with serious illness or disability. The siblings site also comprises 3 separate communities for ages 10-14, 15-17 and 18-21.
- The development of a community/service for parents who have children living with serious illness or disability.
- The rollout of a Livewire on Wheels program – Livewire on Wheels is a specially modified hospital bedside table using PC hardware and a wireless internet connection to the Livewire site. Launching at Canberra Hospital, the program will deliver 90 Livewire on Wheels units into seven hospitals around Australia.
- The establishment of a hosting platform that can be leveraged by other Not for Profit organizations. Examples of existing NFPs interested in leveraging Livewire include The Spastic Centre, Diabetes Australia, and the Haemophilia Association.
- Two independent therapeutic research projects to measure the impact of Livewire on its members.

Why did Livewire choose to build its own community and networking capability?

Existing freeware tools couldn't be used to accomplish the goals and outcomes of Livewire. Simply using an existing free network creator would not have ensured the safety and security of users, accessibility, moderated chat rooms, and control over the community:

- **Security and safety.** One of the key points of difference for Livewire is the measures we have in place to ensure the safety and security of our members. As mentioned above, we are working with the Australian Federal Police to ensure that access to the Livewire community, sign-up processes, chat host and volunteer training are optimised to keep our members safe.



Whilst no site is 100% secure from hacking, Livewire engages a 3rd party company to routinely verify that stringent systems, processes and implementation are of a high standard to resist attacks.

- **W3C Accessibility standards.** Livewire is being developed using the recommended W3C Accessibility Guidelines to ensure it is accessible to a wide range of people with disabilities and physical limitations.
- **Customised chat rooms and blogs.** All chats and blogs are moderated by trained chat hosts who undergo thorough background checks and training to ensure that Livewire is a safe and supportive environment.
- **Ability to moderate and monitor activities on the site.** Livewire is developing a moderation system to ensure both the content and tone of all user generated content remains age appropriate.

What feedback have we received about Livewire so far?

The best examples of the successful implementation of Livewire come from the testimonials of the members, parents and health professionals:

- *"I can't walk, I am in a wheelchair. I see others running around and jumping around, I can't do it. However the thing I can do is be on Livewire and if Livewire wasn't there I would have nothing to do."*
Andrew, aged 11.
- *"There's an immediate sense of togetherness because even if we don't say it, we all have something in common. That means you don't have to hide anything and aren't somewhat alienated like you can be around other kids".*
Tamaryn, aged 15.
- *"I think Livewire is giving Annie the opportunity to shine. It's letting her be herself. She's met so many friends, kids like her in similar situations, who have an understanding that her friends at school don't have."*
Robin, mother of Livewire member.
- *"Too often, it goes unrecognised that young people with chronic illness or disability can be affected by anxiety disorders, mood disorders, self harm and even suicidal tendencies, and that these go hand in hand with their situation. Livewire is wonderful because you have 24 hour a day, immediate connection with a community of people feeling exactly the same way. This can instantly reduce their sense of isolation and put them in touch with someone who understands."* **Michael Carr Gregg, Adolescent Psychologist.**