

## **Little Star Beads to recognise the long Cystic Fibrosis journey**

**(July, 2016)**

Cystic Fibrosis patients at Sydney Children's Hospital, Randwick will now be offered a unique reward acknowledging the countless medical procedures they endure at the Hospital, as part of a new bead program launched this month.

The *Little Star Beads* initiative offers patients colourful beads for each individual treatment, recognising the long and challenging path for children with Cystic Fibrosis, the beads also serve as a tool to help children tell their medical journey to friends and family.

"Cystic Fibrosis is a serious life limiting genetic condition that mainly affects the lungs and digestive systems; they become clogged with thick sticky mucus causing infections and difficulty digesting food," says Prof Adam Jaffe, Consultant in Respiratory Medicine and Associate Director of Research at Sydney Children's Hospital, Randwick.

Seven year old Amanda Ford was diagnosed with Cystic Fibrosis following a routine heel prick test at birth. In just seven years, Amanda has had to undergo numerous blood tests, injections, lung function tests and associated procedures.

"We are thrilled the *Little Star Beads* program has launched. Amanda has been through so much. To her, it's an acknowledgement. It's something tangible she can show her friends to help articulate her journey," says Deb, Amanda's mum.

"One of the most challenging elements of Amanda's diagnosis is that she doesn't look sick so others don't recognise that she has a condition and needs support. *Little Star Beads* will allow Amanda to explain her condition and all she has endured in a way her peers will understand."

The *Little Star Beads* program is an initiative of the Stella Bella Little Stars Foundation. "The program was established to offer a little sparkle to the lives of seriously ill children. With the kind support of St. George Foundation, we are very proud to offer the program to the Sydney Children's Hospital, Randwick," says Founder, Suzanne Tunks.

Cadwell Construction & Interiors are sponsoring the ongoing costs of the program at the Hospital to enable patients to have access to the beads free of charge.

"Our frequent Hospital visits now have a silver, or should I say colourful lining", adds Amanda's Mum.

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**For more information, please contact:**

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# MEDIA RELEASE

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## **Stella Bella Little Stars Foundation**

The Stella Bella Little Stars Foundation was launched in 2012 to brighten the lives of children who are living with serious and long term illnesses. The foundation offers support and assistance to these children, and their families, regardless of their diagnosis. The Little Star Beads Program was founded in 2013 and provides a beautiful and tangible way for children to tell the story of their medical journey. The children in the Little Star Beads program feel a sense of pride and courage, when looking back through their beads, at all of the medical procedures they have endured. The beads offer a silver lining to their hospital visits and are a keepsake to treasure into the future.

For more information on the Stella Bella Little Stars Foundation, please visit [www.stellabellalittlestars.org.au](http://www.stellabellalittlestars.org.au)

## **St.George Foundation**

St.George Foundation was established by St.George Bank in 1990. Since that time, it has partnered with more than 800 community organisations across Australia to invest more than \$25 million to improve the lives of Australian children who are physically, socially or economically disadvantaged.

St.George Foundation is proud to be partnered with Stella Bella Little Stars Foundation in providing a \$26,000 grant to fund the extension of the Little Star Beads Program to cover the set up cost at the Sydney Children's Hospital, Randwick and other states.

## **Cadwell Construction & Interiors**

Specialising in healthcare construction, Cadwell Construction & Interiors have been able to add value to the clinical environment of patients and medical practitioners alike since 2003.

We are proud to be part of the team and supporting the Little Star Beads Program, bringing a little positivity to the lives of children living day to day with the challenges that cystic fibrosis brings.

## **About Cystic Fibrosis**

Cystic Fibrosis is one of Australia's most common life-shortening inherited diseases. Cystic Fibrosis is a genetic condition; the incidence of CF is approximately 1 in 2500 babies. 1 in 25 people carry the faulty CF gene usually without knowing. If two carriers have a baby, the child has 1 in 4 chance of having Cystic Fibrosis.

Cystic Fibrosis mainly affects the lungs and digestive systems. These become clogged with thick sticky mucus resulting in infections and difficulty digesting food.

Cystic Fibrosis affects everyone differently, but for many it involves a huge burden of care. Almost all people with Cystic Fibrosis are required to take tablets (enzymes) every time they eat. Many need other treatments each day to maintain their health. These treatments include; twice daily chest physiotherapy, oral and nebulised medications.

## **Sydney Children's Hospital, Randwick**

Each year, Sydney Children's Hospital, Randwick cares for more than 45,800 seriously ill and injured children from across NSW, Australia and beyond in a family-centred, multidisciplinary, expert environment.

Sydney Children's Hospital, Randwick is one the country's leading centres in paediatric clinical and research excellence and is part of The Sydney Children's Hospitals Network (SCHN), the largest network of hospital and services for children in Australia.

For more information visit [www.schn.health.nsw.gov.au](http://www.schn.health.nsw.gov.au)

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