

FRIENDSHIP



Hello my name's
Ginny and I'm a
Starship kid

Summer 2019

Thanks to
everyone who
supports Starship

A word from Aisha

Dear Friends,

It is always a privilege to be able to share with you the stories of our brave Starship children, inspiring medical teams and of you, our compassionate supporters. It is also a delight to be able to demonstrate the impact of your generosity.

In this edition of Friendship, there are stories of how together we are lifting the spirits of our young patients, saving lives across the nation, transforming surgeries and providing more families and children with the support they need.

Thank you for giving our children better health and brighter futures.

Ngā mihi nui ki a koe – great acknowledgments to you all.

Aisha Daji Punga

Chief Executive, Starship Foundation



Celebrating our runners at the Auckland Marathon event.



A huge thank you to our Five Star Partners:



Taking you Inside Starship

We know how much you love hearing from the Starship children who have been helped by your support. In response to your feedback, we created a very special video series where Starship kids get to be the heroes.

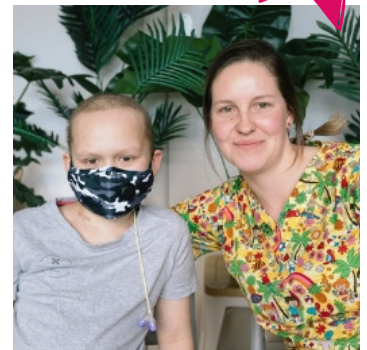
It's the human side to Starship that's revealed in Inside Starship, our series of video interviews where heart-warming moments and laugh out loud interactions provide a real insight into some of the personalities and characters that are part of the Starship community.

In episode 7 Elroy Pinto is interviewed by Mala'e from Gisborne (top left corner), who came to Starship in 2018 for surgery to repair heart valve damage caused through rheumatic fever.

As a Play Specialist on the heart ward at Starship, Elroy Pinto supports children by helping with preparation for surgeries, distraction through procedures and activities when play is possible.

"If I can make them laugh while they're here, then I think I'm doing a good job," he says.

Episodes 1 to 12 of Inside Starship are out now on our social channels, so if you haven't seen them yet, now's a great time to take a look.



Visit us on Facebook and Youtube:

 /starshipfoundation

 /starshipfoundation

Meet vivacious Virginia

One Starship star's story

Virginia Grey might just be the sassiest six-year-old in New Zealand. Her mum Joanna describes her daughter as a bold and beautiful girl with the most extraordinary eyelashes. The little star of our recent Inside Starship video series (see story on p.3) unquestionably let our film crew know who was in charge, despite a serious liver disease that has seen her spend much of her life at Starship.

At just three weeks old, Virginia (Ginny) was diagnosed with biliary atresia, a rare but serious condition that blocks bile flow from the liver to the gall bladder, causing liver damage and ultimately, liver failure. In Ginny's case it required a life-saving operation to remove her damaged liver and replace it with a new one from a donor.

Her mum Joanna explains; “We were on the transplant list for four months. The way it works is that you wait until your child is the sickest on the list. It's a tough wait.”

At six months of age, Ginny ended up in Starship's Paediatric Intensive Care Unit (PICU) where she was kept alive for six days while she waited for her new liver. Thankfully, her little body accepted the liver, which was a really great outcome, and the family went home.

Ginny's condition and the daily anti-rejection medication means she is immune suppressed and extremely vulnerable to infections. In her short life she's had many severe allergies and reactions, two bouts of pneumonia, cryptosporidium and rotavirus, each time requiring a lengthy hospital stay. Notification of a sick child at her school can mean Ginny needs to stay at home for several



Above: Baby Ginny in Starship.

Right: Dr Helen Evans and Ginny, now aged six.

weeks as a precaution. Illnesses that other children might recover from quickly could be life-threatening for kids like Ginny; it's just not worth the risk.

Despite what she has been through, Joanna says her daughter loves coming to Starship. “It's ‘her’ hospital; they're ‘her’ doctors.” Ginny has access to a team of specialists and surgeons that Joanna says are now like aunts and uncles to her daughter. As well as this there are the nurses, consultants, play specialists and Starship's on site school that aim to make children's hospital time as comfortable and ‘normal’ as possible. She says it's been an incredibly positive experience.

Ginny receives on-going Starship care including monthly check-ups and an annual “warrant of fitness” to ensure her liver is healthy and functioning normally. On top of all this there is also something in Ginny's make up that causes her blood to clot more quickly than normal and damage the surgical work put in to assist her. This creates difficulties with any future surgery options for Ginny.

The transplant has extended Ginny's life. Twenty five years ago there wouldn't have been any hope of survival for babies like Ginny. It is thanks to modern technology and advances in healthcare that transplants are now possible to save and extend the lives of babies and children with liver disease.

It is also thanks to our generous supporters like you. Your kindness means we are able to provide the best training, equipment and support to help treat children with even the most challenging and complex illnesses, like Ginny's. It has given her family time to get to know her wonderful personality, see her grow and celebrate life's milestones.

Because of the risks with her immune system, it's only very recently Ginny has been allowed to go swimming and her mum says she is now a total water baby. The transplant has given her a healthy liver, for now, so for Ginny and her family, it's about making the most of every day.

"Ginny builds the most amazing connections with those around her. She is cheeky and smart and is going to make the most of her life. We are thankful and grateful for it."

Joanna, her husband Kane, Ginny's big sisters Alabama and Georgia and little brother Elvis are along for the ride and they wouldn't have it any other way.



Accelerating simulation training across the nation

An extraordinary \$9 million gift from the Douglas Charitable Trust will improve healthcare and outcomes for sick children and their families and accelerate the future of simulation training for paediatric experts at Starship and around New Zealand.

The funding will grow and develop the current programme to benefit children throughout New Zealand. This will include paediatric simulation training across the country, simulation based training for families, simulation of complex non-emergency activity and lead simulation research and outcome development.

The \$9 million donation from the Douglas family will be used to set up an endowment fund that will transform Starship's Simulation Programme and fund it year after year.

Starship currently has six high-fidelity, computer-driven 'manikins' or sim children, ranging from a premature baby through to a 14-year-old. They enable realistic recreations of any imaginable medical emergency or important situation.

This helps train paediatric doctors, nurses and other staff, particularly around the complex teamwork required in a medical crisis. Clinical teams can practise a wide range of procedures such as putting in breathing tubes and drips, giving fluid and medication, and inserting a chest drain.

Starship's Director of Medical and Community, Dr Mike Shepherd, is a paediatric emergency specialist and a global expert on simulation training. He says; "Simulation training teaches us not only how we might respond to a medical emergency to provide the best possible outcome for these children, but helps to improve patient safety and the way we work together. It makes us better at saving children's lives and delivering excellent clinical care to children and whānau."

We are incredibly grateful to the Douglas family for this truly extraordinary donation.



Trish Wood - Starship Simulation Programme Manager, Melanie Esplin - Starship Foundation, Aisha Daji Punga - Starship Foundation Chief Executive, Jeff Douglas - Douglas Charitable Trust.

Transforming spinal surgeries for our children

A new O-Arm surgical imaging system has changed spinal surgeries at Starship by making 3D assessment possible during operations.

Starship performs over 100 spinal surgeries every year on children from all over New Zealand. Given the increased complexity of paediatric spinal surgery, it's important to equip our team of highly skilled orthopaedic surgeons with the latest medical technology.

These surgeries have now been transformed thanks to the purchase of an O-Arm surgical imaging system which makes 3D assessment possible during operations.

Dr Haemish Crawford, Starship Orthopaedic Surgeon, says: "The O-Arm has greatly contributed to the quality and safety that we can perform with our spinal surgery in children. It allows for accurate placement of the instrumentation that we use and allows us to visualise the complex paediatric spinal deformities that we encounter intraoperatively.

"Not only are we able to use it during the actual surgery to guide us in the placement of the screws but it also allows us to check the placement and correction before the patient is woken up. The O-Arm allows us to perform more complex surgery and to improve our outcomes and decrease the reoperation rate on these patients.

"Without the generosity of our donors we would have been unable to fund this important piece of equipment which is benefiting our children so much."

It was due to the extraordinary generosity of four wonderful couples that the Starship Foundation was able to fund the purchase of the O-Arm hardware. The software was funded thanks to our generous community of supporters. Together you have enabled better outcomes and quicker recovery for our young patients.

We feel incredibly fortunate to be able to provide equipment that enables the best treatment, care and support for the seriously ill and injured children who arrive at Starship from across New Zealand every day.



O-Arm surgical imaging equipment.

Finding the answers in genes

We all have approximately 20,000 genes in our body. About 90% of these we don't really understand.

Dr O'Grady, a paediatric neurologist at Starship, has received funding from the Starship Foundation for a very special research project to better understand some of these genes. This work will help children and their families with conditions affecting the brain, muscles and nerves.

Using next generation DNA sequencing technology, her research aims to seek diagnoses for New Zealand families of children with neurogenetic conditions. This technology is at the cutting edge of medical advancement in the field of diagnosing neurogenetic conditions. Instead of looking at a single gene, next generation sequencing technology is able to look across all of the genetic code for "spelling mistakes", or errors in the genetic code, underlying the child's particular condition.

Gina has enrolled 26 families located around New Zealand, and so far her research has provided a diagnosis for seven of those families. This means they finally have the answer they've been seeking for years.

Dr O'Grady explains; "Often a diagnosis can be really important in taking away guilt. It is nothing that they have done; it's related to an error in the genetic code. It can also help families connect with other families in similar situations around the world through the likes of Facebook groups."

Dr O'Grady's project is on-going. Sequencing will continue to be offered to families with severe neurogenetic disease, undiagnosed through commercially available tests. Clinical research and innovation saves lives and helps to give our children a better chance of tomorrow, today.



Dr Gina O'Grady.

This year the Foundation is committing an additional \$1 million to fund new clinical research projects. We thank the Athlae Lyon Starship Research Trust for their support of Dr O'Grady's research.

Giving hope to future generations

The Starship Foundation is committed to investing in important research, like Dr Gina O’Grady’s, that can bring better health and brighter futures to our children. We believe a vibrant research culture at our national children’s hospital is vital and having your support helps make this possible.

One way to support the Starship Foundation is to join our wonderful Guardian Angels who leave a legacy to provide hope for future generations.

Diane Clare from Nelson decided to leave a gift to Starship in her Will several years after her beloved son Mark passed away. Diagnosed with cerebral palsy after undergoing surgery for major heart complications, little Mark was just three when he sadly passed away.

At the time she couldn’t make sense of it, though Diane says it turned her life around. She changed her career to become a Clinical Psychologist and began helping other families coping with similar circumstances. Through her huge loss, Diane was also motivated to give hope to future generations and she saw becoming a Starship Guardian Angel as a way for her to create a special legacy for Mark.

“What I love about Starship is how it’s centred on the care of children and their families. I was impressed by the really personal things – the way the environment is so child and parent friendly.”

“So my plan is paying it forward to enable something positive and hopeful for someone else’s child or grandchild. It makes me feel good to know that something is happening down the track when I pass away that will remember Mark in a practical way. It’s an uplifting idea that something significant will happen because of it.”

If you are interested in becoming a Starship Guardian Angel you can find out more information on our website www.starship.org.nz or call Marnie Fleming on 09 307 4949 for a confidential chat or to request an information pack.



Diane Clare, Starship Guardian Angel.

More children now getting neuropsychological support

Starship supports research and innovation to make sure that we are providing world-class healthcare to those who need it most.

In the past 15 years, growing research has made us aware that children whose brains are affected by illness, injury or treatment are at higher risk of cognitive, behavioural and mental health difficulties. These could include a brain injury sustained at or after birth, a brain disease or neurological disorder as well as extend to a medical diagnosis that may impact on brain function. Some examples are cardiac disease, diabetes, and metabolic disorders.

Research has also shown the many benefits of neuropsychological support for children with a wide range of medical conditions. But while the need has grown, resourcing and service restrictions have meant many children have not had access to this support.

In 2017 a Starship Foundation-funded pilot made neuropsychological support available to more children at Starship. Your generosity has helped develop guidelines to prioritise and increase referrals for children that would benefit, increase the number of children seen for assessment and intervention, and provide a beneficial service for children and families.



Thanks to your generosity last year and the amazing results, the Starship Foundation is supporting a second year of funding for this important service through the support of our Five Star Partner Mercury so a case can be prepared for the DHB to provide on-going funding on the basis of the results of the pilot programme.

Some great outcomes from the pilot include a 100% increase in referrals and 200% increase in appointments, with wait times quartered from 12 to three months.

We are so proud to have enabled this important service for children and families at Starship. If you'd like to read more about some of research projects currently underway, visit www.starship.org.nz/foundation/current-fundraising-projects/lifechangingresearch/.

Innovative technology lifting spirits of Starship children

The Starship Foundation has introduced new technology which helps children and their families who are unable to leave the hospital to enjoy some wonderful New Zealand experiences.

Together with Five Star Partner, Mercury, the Starship 360 Experience uses 360° technology and live streaming to “virtually transport” children around New Zealand.

After a successful pilot of the Santa Parade in 2018, a behind-the-scenes visit to the penguin enclosure at Sealife Kelly Tarlton’s Aquarium was live streamed on January 23rd allowing in-patient children to get up close with the penguins at feeding time.

The benefit of lifting spirits is becoming increasingly recognised as having a positive impact for children in hospital and regular activations of the Starship 360 Experience are planned on an ongoing basis.

Helen Waldron, Nurse Unit Manager, Starship Child Health, says, “Children in Starship and their caregivers are often away from other family members and their support networks, and many spend extended periods of time in hospital. Clinical research has shown that psychological wellness is often associated with faster recovery times and less institutionalisation, so this fully immersive 360 experience is fantastic. It’s great to see the kids enjoying it.”

Mercury and its customers have funded the project which includes supplying eight VR headsets and

eight mobile tablets for patients to take part either in Starship’s Atrium area, or for some patients in their hospital room.

Mercury’s Chief Marketing Officer, Julia Jack, says, “This is about giving Starship children the freedom to connect with the outside world without the usual limitations they may face in hospital.”

“We want to inspire Kiwis about the wonderful things they can do, and we’ve already been using VR technology with our customers for some time now. This is a great extension of that – an opportunity to play a small part in the wellbeing of some really deserving kids and their families. So we’re delighted to help bring the Starship 360 Experience to life.”



Check out [Facebook.com/mercurynz](https://www.facebook.com/mercurynz) to find out more.

Thank you



From the heart: thank you from Aimée's family.

Last year we introduced many of you to gorgeous wee Aimée and her family, from Blenheim. Aimée was born at just 32 weeks gestation. Sadly her twin sister Grace didn't make it. Shortly after her birth, Aimée's paediatrician detected an issue with her femoral pulse. She was flown to Starship by air ambulance where she was diagnosed with coarctation of the aorta, a serious heart condition.

Aimée was one of more than 150 critically sick babies and children flown to Starship from all over New Zealand by air ambulance last year. Thanks to the skilled Starship

NICU, PICU and Cardiac teams, baby Aimée was successfully treated. This included two open-heart surgeries, one at just 10 days old, weighing a tiny 1.9kg.

Many of our wonderful supporters shared messages of hope, strength and joy with us in response to the Christmas letter we sent about Aimée's Starship journey. Her family really loved reading these – especially big sister Chloe, and we want to thank everyone who sent them in.

Aimée is now a healthy and happy toddler, adored by her sister and

her parents. The family have recently donated a park bench at a local reserve in memory of Aimée's twin sister Grace. They are also looking forward to welcoming another baby into the world! We can't be happier for them, and we know you will be too.

Thank you for helping us to mend tiny hearts like Aimée's. And for the many ways you help so many other children and families. The impact of your support is enormous, with your help we reached our target of \$280,000 for Starship.