

# Aru's Story



Waiting at the doctors with her six-month-old baby daughter Aru, mum Smital could never have imagined this visit would change their lives forever.

With suspected Pneumonia, Aru was sent for a chest x-ray. Her only symptom was she was breathing faster than usual. Scans revealed Aru's left lung had collapsed. Her heart was only functioning at eight per cent and was failing due to a virus which had severely weakened her heart.

Smital and dad Kiran were numb as doctors told them their only child needed a heart transplant. Her current heart wasn't able to pump blood to her organs. "The shock was unimaginable. Aru was born perfectly healthy and suddenly she needed life-saving surgery," Smital recalls.

The family stayed in Melbourne's Royal Children's Hospital for six months waiting for Aru's heart transplant. During those heartbreaking months, the family discovered Starlight. When Aru was first moved into the ward, Captain Starlight's visit brought a beaming smile to Aru's face – a big relief considering she was plugged into life-saving equipment and limited in her mobility.

Not long before her first birthday Aru underwent life-saving transplant surgery. Following her surgery, Aru requires weekly specialist care in hospital. Treatment complications have led Aru to develop a food aversion so now she is tube-fed. Aru is also currently undergoing treatment for post-transplant lymphoproliferative



disease (PTLD) – a rare complication of solid organ transplants.

"Our life is now centred around the hospital," Smital says, "I can't work anymore as I need to take care of Aru. My husband is our sole bread earner which limits us. Hospital is our new normal."

With hospital consuming their lives, they are thankful for the little moments of happiness that help Aru's family cope with the relentless strain and worry. "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."

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Aru, now a bubbly, chatterbox three-year-old, loves visiting the Starlight Express Room to play with Captain Starlight and do art and crafts. The family affectionately call it her "treat" after treatment and love that the room has something for children of all ages. "Every time my daughter has a painful procedure or drug infusion which makes her feel horrible, as soon as she sees Captain Starlight, her face lights up and she forgets the pain. They remember her every time we visit."

Smital says Starlight has such a positive impact on their lives, she can't imagine hospital without the fun and happiness Captain Starlight brings. "The Captains are Aru's favourite type of people! They empower kids by asking what they want to do – just having choices in an environment that typically strips those away means the world to sick kids."