

KAI WICKRAMARACHCHI

In February 2022, Sumali gave birth in Blacktown Hospital, NSW to her first child – Kai (meaning warrior). It was a relatively straight forward birth for the young couple who were so excited for the arrival of their little boy.

Over the first few days, Sumali and Heshan enjoyed the newborn phase and time together as a family of three. On day three, they were discharged from hospital, it was late January 2022, and there was another major COVID-19 outbreak and it was a challenging time for the hospital to keep up with demand. The following day, a midwife from the hospital arrived at their house for a wellbeing check of new bub and mum and to do a Newborn Bloodspot Screening test. “The nurse has a small cardboard booklet and advised they will have to take blood from my son. I wasn’t quite sure how this was going to even work, would it be accurate? I was also upset that they had to take blood from a tiny foot of a little bub,” said Sumali.

Following this, the midwife advised that unless there are abnormalities, they won’t hear anything from this test. Sumali and Heshan just resumed life as normal and continued to enjoy their time with Kai.

Three days later is when everything changed for their family. Sumali received a phone call from the hospital advising of abnormalities in Kai’s test, and they wanted her to go back into the hospital to complete more testing. At just seven days old, Kai was already back in the to the hospital for screening and more blood checks, little did they know this was the start of their journey and multiple visits to hospital. During this time, they were handed a leaflet on immunodeficiencies, which was not only daunting, but hard to understand and comprehend. As they read through the information, they struggled to digest the magnitude of the situation and the impact it would have on all their lives.

The family was then contacted by the immunology department at Westmead Children’s Hospital. They were advised that they suspect Kai has Severe Combined Immunodeficiency (SCID) and Sumali was told to stop breastfeeding immediately (due to the potential of passing CMV infection) and that they need to protect him from as many germs as possible and live in a bubble far from the outside world. This situation was both challenging and overwhelming mentally and physically, however they were grateful for the support of their immunologist Dr Melanie Wong & bone marrow transplant consultation by Westmead Children’s Hospital oncology clinic staff specialists who was able to guide and advise them during this time.



From this point on, it was test after test. How can my son have enough blood to give at just 14 days old Sumali thought. The emotions were high for all family members, and it was a very different experience than expected with a newborn baby.

They were then advised that Kai has received a positive result for SCID and he must now live in a ‘bubble’ for the next three months until he is strong enough for a bone marrow transplant. In late May, Kai underwent 7 days of special chemotherapy regime focused on monitoring patients’ blood cell generation and altering the upcoming dosage accordingly.



On 30th May Kai underwent lifesaving bone marrow transplant after chemotherapy and his father became the stem cell doner for the transplant. A small special human cell known as stem cells that are able to develop into many different cell types but peculiarly smell like creamed corn was sent through a central line to Kai's blood steam in hope of a growing functioning immune system. After staying nearly three months in the hospital going through different treatments, blood and plasma infusions Kai was able to finally reunite with family back at home in late July.

Kai continued to have post-transplant treatments using central line for another 6-7 months, which whilst is helpful but also caused two infections for him, causing him to return to hospital, but he was able to fight due to his strengthened immune system. After the transplant, Sumali and Heshan continued to isolate with Kai to make sure he was safe from infection.

Because he was diagnosed so early, Kai did very well with the transplant and has been relatively healthy. Westmead Children's Hospital Oncology centre staff specialist Dr Peter J Shaw, Dr Steven Keogh, Dr Melissa Gabriel along with all other doctors, nurses and staff made tremendous effort to make sure the wellbeing of Kai & family stays positive during challenging time, showing the fact it does certainly take a village to raise a child. He has been doing physiotherapy and speech therapy and the family have also received guidance to improve quality of life after a bone marrow transplant.

One year on and the testing has indicated that Kai has a good immune function and has completed his inactivated vaccines, which is a great outcome for the family. As far as they know, Kai doesn't have any significant impacts from SCID.

If they were in Sri Lanka, there is no way he would have been tested. It was also good timing for the family as there was a clinical trial for SCID to be included in the Newborn Bloodspot Screening test and we happened to be part of it. Since finding out she has a SCID baby, Sumali has joined a network of other parents in similar situations who all work together to help each other and educate the wider community of the importance of early testing.

"The Newborn Bloodspot Screening didn't only save my child's life; it saved my family and my mental health – helped to stop unthinkable pain and suffering of losing a child. I'm so grateful for this test being available and to the doctors and nurses who worked with us to get Kai to where he is today" – Said Sumali

