

SCID Member Stories – Henry, NSW



On the 11th May, 2021 we welcomed our handsome little man, Henry. We were settling into life as a family of four, discussing whose eyes he had, what colour his hair would be and if he was going to look like his big brother. At three weeks of age, we received a call that Henry's newborn screening results were abnormal. Within 48 hours we were seeing the Pediatric Immunologist at the Hospital and soon realised his abnormal results were something more serious.

Henry was diagnosed with Severe Combined Immune Deficiency (SCID), the most serious kind of primary immunodeficiency. This means that Henry has no T-cells, the most important cells in the immune system, that protect against infection. This leaves Henry incredibly susceptible to illness and can be life threatening. We were also told he would require a haematopoietic stem cell transplant (aka bone marrow transplant) before three months of age to survive. A lot to reconcile when looking at your perfectly healthy three-week-old baby. Despite a daunting diagnosis, we are optimistic about treatment and feel very fortunate to have access to this lifesaving transplant. We are also very grateful to have access to the newborn screening for primary immunodeficiencies in NSW. If Henry had been born in another state without this newborn screening, it would be a very different story for us.

Since his diagnosis, we have been isolating to minimise the risk of infection for Henry. This has meant a lot of change for our family, including dad stopping work indefinitely. Henry's big brother and social butterfly was also taken out of daycare and has been isolated from his friends. And mum who has had to take it in her stride on top of all the postpartum pressures of being a new mum.

We relocated to Sydney in July for four months while Henry receives a lifesaving stem cell transplant (yes, right in the middle of a COVID lockdown). Henry's dad, was chosen as his stem cell donor while his mum, continues to breastfeed Henry while in hospital. After a week of chemotherapy, Henry received his stem cell transplant at the end of July. In some positive news, Henry was recently discharged from hospital, day 14 post-transplant because he has made such good progress.



