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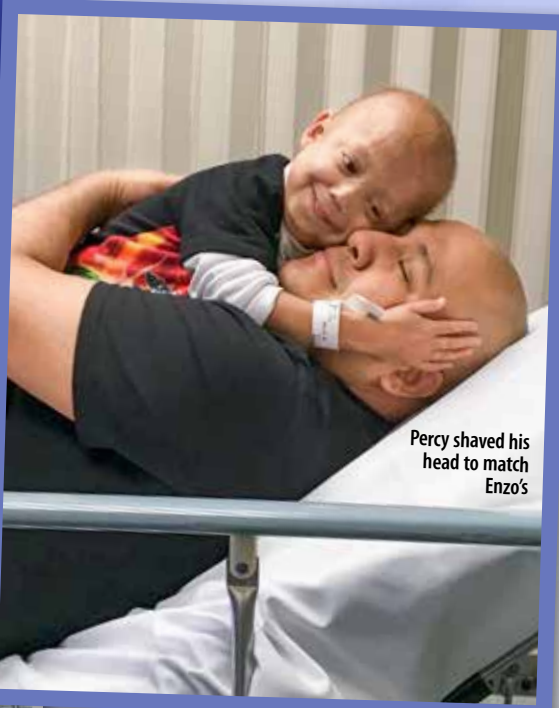
One of Enzo's favourite things is swimming

Battling a rare ageing condition, Catherina's brave boy is one in 20 million Catherina Llontop, Adelaide, SA



Making memories with Mickey Mouse

Me, Enzo and Percy



Percy shaved his head to match Enzo's



Is your child bravely fighting a rare condition? Tell us at tl.features@pacificmags.com.au

Enzo's cheeky spirit shines through in his class photo

OUR RACE AGAINST TIME

Catching a first glimpse of my boy, all my dreams had come true. Longing for a baby for seven years, my husband Percy and I had been considering adoption. But at the last moment, I'd fallen pregnant. 'Boy or girl, they'll be so loved,' I smiled to Percy, before our 20-week scan. Told we were expecting a son, we chose the name Enzo. Everything went smoothly until 30 weeks, when I had to go to hospital with high blood pressure. Admitted for monitoring, we were worried but thankfully I was stable. *Please let everything be okay,* I thought. We'd come so far, we couldn't lose him now. So when Enzo arrived safely and a strong cry pierced the room, it was music to my ears.

Finally, we were mum and dad to this tiny, beautiful boy. At 1.76 kilos and 44cm, Enzo was small, so he was taken to the NICU with Percy by his side. Running between us, Percy showed me videos and photos. 'He's doing well!' he beamed. As I was recovering, I needed a nurse to push me to the NICU in a wheelchair for my first magical cuddle. After that, I couldn't bear to wait for help, so I'd shuffle there by myself. Five long weeks later, we got to take him home. Enzo thrived, but then, at six months, his weight dropped dramatically. 'His skin is getting dry and tough too,' I told Percy.

His paediatrician thought it might be a complication from being premmie, but when Enzo turned one, he still wasn't growing and his skin wasn't baby soft. Referred to a geneticist, he ran tests. 'If Enzo has something, we will find it,' he reassured us. As different conditions were ruled out one by one, Percy and I focused on keeping our little smiler happy. As Enzo's third birthday approached, he was tested for yet another condition – progeria. Extremely rare, it affects just one in 20 million children and causes the body and heart to age rapidly. It means little kids face health problems usually associated with the elderly,

including heart issues. They look older too. From the moment I heard about the condition, my mother's instinct told me this was what Enzo had. Eight weeks later, the three of us sat in the doctor's office for the results. 'The test was positive,' he confirmed gently. 'What can we do?' I asked. But there was no cure or treatment. And Enzo's was the only current case in Australia. *Our precious boy,* I thought, heartbroken. But I refused to cry in front of Enzo. 'A charity in America is running a treatment trial,' the doctor explained, handing us a leaflet. The booklet, from the Progeria Research Foundation (PRF), was a ray of hope. Researchers believed new drugs might slow progeria down for up to two years.

PHOTOS: NEWSPIX/THE PROGERIA RESEARCH FOUNDATION. WWW.PROGERIARESEARCH.ORG/TEAM ENZO PROGERIA/ HOLE IN THE WALL CAMP

PRF was started by the family of Sam Berns, who had progeria and spoke publicly about his life until he passed away aged 17. It aims to find a cure, but relies on donations for funding. *We'll get Enzo on that trial,* I vowed. Leaving the clinic, we kept up a brave face for Enzo. Only after he fell asleep that night did we let ourselves cry. Then, we sprang into action. Calling PRF, we were

given a warm welcome. They agreed to test Enzo in Boston to see if he could join the trial, and they'd even help fund our trip. Seven months later, we flew to the US, stopping off at Disneyland to make some special memories with Mickey Mouse. Then Enzo faced a range of tests, including for his bone density and heart strength, before he was finally accepted on the trial. Aged three, he was one of the youngest children. *It's a race against time,* I realised. Flying home with medicine to protect his heart, only time would tell how well it would work. When Enzo was four, he noticed that his hair had thinned. 'My hair is different,' he said, puzzled. Percy responded by shaving off his own thick hair so they'd

match. With their cheeky sense of humour, they were two peas in a pod. Last year, we flew back to America for more tests and to try a new drug. 'You're so brave,' I told Enzo, as his blood was taken. 'I don't want to be brave,' he admitted, before bouncing back to his happy self. Thankfully, his heart is still healthy, and in three years we'll know more about how the drugs are working. For now, Enzo, six, is a carefree little boy with classmates who always look out for him. Loving and lively, he touches the hearts of everyone he meets. After meeting other children from around the

world through PRF, we feel less alone. Enzo is unique in Australia, but he's special in so many more ways than just his condition. He knows about his heart medicine, and about his hair, but that's all for now. In time, Percy and I will explain more about progeria. We don't know what the future holds, but now we have hope. ● *As told to Sarah Firth To support Enzo's journey, visit teamenzoprogeria.com*

There was no cure or treatment



Enzo lives life to the fullest

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