Region Illawarra
Locally Grown.

Kiama infant's incredible recovery after shock heart condition discovery

26 September 2026 | By Keeli Dyson

Waiaarangi was diagnosed with a heart condition when she was five months old, but now she's thriving. Photos: HeartKids.

A Kiama family will walk alongside their community in support of children impacted by heart disease and to share their own experience, just months after their baby girl underwent major surgery to save her life.

If you didn't know her story or couldn't see her scar, you would never know that nine-month-old Waiaarangi was born with a terrifying condition.

The baby girl from Kiama had shown symptoms including difficulty feeding and some sweating in her first months of life, but it wasn't until she contracted respiratory syncytial virus (RSV) while on a trip to New Zealand that her family was actually exposed to what was causing her struggles.

"The day that we were due to fly home back to Australia, I ended up taking her into the emergency hospital, just because she was really sick," her mum Kayla Raihe said.

"We found out that she had RSV, but it was a paediatrician who told us, she just said casually, 'Oh, did you know she has a heart murmur?'"

It was the first time it had ever been mentioned to them but, with further investigations, it would quickly lead to the discovery that Waiaarangi had a hole in her heart.

"They did a few more tests, an ECG and a chest X-ray, and then it wasn't until they were doing the echo and the guy was taking quite a while, so that's when we kind of knew that something was bad — you could tell that he was really trying to find the right answers before saying anything to us," Kayla said.

"They were saying she needs to have the surgery as soon as possible because the hole was so large, so initially the plan was to have the surgery in New Zealand."

They were then told that the operation couldn't take place for almost a month due to the RSV and, with approval from the doctors and paediatrician, decided to return to Australia and have the procedure here.

A few weeks later, Waiaarangi underwent open-heart surgery for an Atrial Septal Defect (ASD) and Ventricular Septal Defect (VSD) closure and tricuspid valve repair.

"The surgeon said everything went well, but he said it was a really large hole," Kayla said.

"It was quite a shock when we went back to the hospital to see her, obviously, because she was hooked up to so many things; she had lots of lines in her hands, feet and neck, so it was quite scary."

Waiaarangi has made an incredible recovery and is back to her energetic and happy self.

But Waiaarangi bounced back quickly, with her incredible recovery putting many of Kayla's fears to rest about her leaving hospital.

"When I was thinking about the surgery, that's what I was scared of, taking her home, because she's not in the hospital anymore, so I'm not going to have anyone that's going to be able to help me with her," she said.

"But from about two weeks after surgery, if you never knew that she'd had open-heart surgery, you'd just think she was back to herself."

Since her surgery, Waiaarangi's feeding and weight gain have improved and her symptoms have subsided.

And while she will need check-ups for the rest of her life, the cardiologist has said that she won't need any further surgery.

Throughout this fast and emotional journey, the first-time parents were unaware of what to expect — particularly with no family history of heart conditions that they were aware of.

But HeartKids helped make them aware of a community of families they could look to and lean on.

"I think it's really helpful even just reading all the other families' stories on the website because there's so many different procedures and heart conditions and it's also something that you wouldn't know about unless you could see their scar or someone told you," Kayla said.

"But there's people there that you can see or talk to about things like this.

"If I didn't know about HeartKids, I would've just winged it or gone from what people told me, but there's an organisation out there that knows a lot more than I do, or the people around me, that can help me."

So in October, Waiaarangi's family will take part in Two Feet & A Heartbeat, HeartKids' annual community walk, to mark every milestone and remember every story of those touched by heart disease.

"I'm looking forward to the event and just meeting people that have gone through similar things — if it's not with their kids, then maybe themselves," Kayla said.

The event will run at Hindmarsh Park from 9 am on 25 October, with the community urged to register online by 5 October.

To register or to find out more, visit the Two Feet & A Heartbeat website.

Make us preferred on Google

Free, trusted, local news, direct to your inbox

Keep up-to-date with what's happening in Wollongong and the Illawarra by signing up for our free daily newsletter, delivered direct to your inbox.

Enter your email address

Sign Up

By submitting your email address you are agreeing to Region Group's terms and conditions and privacy policy.