

Traci Stanbury interview

South Island Child Health Alliance consumer representative

At one point, Christchurch Hospital's pharmacy saw so much of Traci Stanbury, and thought she spoke medical language so fluently, it assumed she worked at the hospital and offered her a staff discount.

When he was four months old, Traci's son, Ben, suffered heart failure and she was told he had a one in three chance of dying. His heart failure was caused by high blood pressure, a result of undiagnosed autosomal recessive polycystic kidney disease. So began an immersion in the health system that has lasted all the ensuing years.

Ben is now nearly 10, and the oldest child in the country with his condition, which also includes congenital hepatic fibrosis of the liver. He has overcome global developmental delay, he received a liver transplant in 2015 and will need at least one kidney transplant, and probably more, during his lifetime.

Because of her ongoing experience fighting Ben's corner, and the medical knowledge she has learned along the way (including a postgraduate diploma in health sciences, with a masters due for completion next year), Traci could not be better placed to be the first consumer representative on the South Island Child Health Alliance, where she sits alongside clinical leaders, health professionals and others from the five South Island district health boards (DHBs). She took up the role last year, after a three-year term on the Canterbury DHB family advisory council.

'It still feels like I'm giving back, but it's not such a local way of giving back now,' says Traci. 'And it does take longer; it's not such immediate results. Because this is not just impacting my experiences in my local hospital, it's impacting the much wider community across the South Island. It's very satisfying and I do enjoy it.'

Passion and a longevity within the health system are key attributes for a consumer representative, according to Traci.

'I've only ever hung out with the paediatric consumers and they know they're in it for the long haul. Some of them have already done 20 years in the system. Some of them have had children die in the system. And while that's obviously an awful experience, they have been able to give that perspective.'

'They've all got a passion because of how they were treated, whether it was positively or negatively. They want to help other families in the position they were in.'

'It's hard, though. You've got to have the time to do it. Even if you've got the passion, you've still got to show up to meetings every week. Without the commitment, it makes the group very disjointed.'

At the South Island Alliance level especially, another requirement is confidence in your ability to speak up, says Traci, because health professionals can be intimidating with all their qualifications. 'It certainly takes a few meetings to be able to say, "Actually, have you thought about doing this and have you thought about that?"'

'But they value my opinion and will stop in the middle of something and say, "Traci, what do you think from your perspective?"'