

Features

Silver lining to parents' struggles

JULIE KAIO

To describe Sarah and Jared Chisnall's struggle to ensure their four children get the best possible start in life as 'tough', is a true understatement.

Parenting for many can be a day-to-day strain – but the Chisnall's labour of love is a constant battle.

Their eldest child, daughter Lucia 8, suffered severe brain damage as a toddler and now has the cognitive ability of a two year old.

And last year, their son Tobin, 4, a twin, was struck down with the same rare auto immune disorder that impacted Lucia so cruelly.

Add in to the mix, their healthy children Darci, 6, and Tobin's twin, Milah, and the Chisnall's family dynamic is hugely demanding. "There is no rest, no respite, it can be extremely difficult," Sarah said. "In the last year or so, it's just been horrendous, we've been really stressed out, and been sick."

In desperation for some time out, she approached Pukekohe-based Franklin Silver Lining Trust, which provides locals facing adversity with special breaks away.

The trust has come to their rescue and gifted the couple a weekend away in Taupo – without the children, precious time alone they both genuinely crave – and physically need.

"It's just such a relief, and something to look forward to," Sarah said. "Even just getting the recognition that it's hard work... the trust is amazing, they are local people truly concerned about others in our community."

This is the second retreat the Chisnalls have received from the Franklin Silver Lining Trust.

The first came after Lucia fell ill in 2010 when a viral infection triggered the rare condition they would discover in Tobin six years later. Acute necrotizing



Lucia Chisnall, now 8, suffered brain damage as a toddler when she was struck down with a rare auto immune disorder.



Tobin Chisnall is on the road to recovery. To see Tobin's thank you message to those who supported him during his illness, log on to youtube.com/watch?v=Wi8Gg4UR2JE

encephalopathy is a genetic disorder where the immune system goes into overdrive, attacking the virus – but also healthy brain cells.

In Lucia's case, the damage to her brain was catastrophic.

"It was severe, 40 per cent of her brain was affected through hemorrhage and inflammation," Sarah said.

"She was nothing, she was just a body, she was blind, she couldn't eat, she couldn't move."

Today Lucia is active, but, says Sarah, has a low quality of life. "She has a lot of meltdowns that she can't control, limited vision, and is like a two to three year old."

So rare is her condition, Sarah and Jared have little clue to what their eldest child's future holds.

But they are determined to do what they can to improve her ways of life. "You can't give up on your kid."

In August last year, Tobin succumbed to the same condition. The twins were in the care of



Sarah and Jared Chisnall are looking forward to a break, courtesy of the Franklin Silver Lining Trust.

Sarah's mother while the Chisnalls were on a rare break away in Queenstown.

"Tobin lost consciousness – he went to sleep on the kitchen floor – that's very strange for a three-year-old boy. My mother took him straight to hospital."

Sarah and Jared caught the first flight out of Queenstown and when they arrived at Starship,

their little boy was fighting for his life in intensive care. Being told it was the same condition as Lucia's was devastating.

"I don't know if you've ever felt your heart break – but it is just horrible," Sarah said. "They basically said he was giving them less signs than Lucia had given, and had less chance of survival."

"They took him off the

ventilator and they said it would be up to 24 hours and he would go, he would die. Everyone was there. He breathed, and we said we wanted to take him home."

Remarkably and against all odds little Tobin fought back from death and started to recover, amazing his family and his medical team.

Today, Tobin is almost fully recovered. He can ride a bike, attends kindy, and when he goes to school next year, he won't need a teacher aid. He is however blind in one eye, and has trouble controlling his emotions – but functions as a 'normal' boisterous four year old boy.

The family are immensely thankful for their son's recovery, but their struggle continues with Lucia's high needs. They have set up a Give-a-Little page to help fund her expensive medication, medical cannabis, which is contributing to improve their daughter's quality of life.

See givealittle.co.nz/cause/lucia

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