

# Stanthorpe boy fights setbacks

Emma Boughen | 3rd Jul 2015 3:00 PM



(Robbie Milne before surgery to correct his cleft palate. Photo Emma Boughen)

ALMOST 12 months ago the Stanthorpe Border Post brought you the story of little fighter Robbie Milne.

The now 19-month-old was born with a cleft palate and shortly after birth was diagnosed with Ring 18 disease, which affects the way his brain develops, slowing down his growth.

Last we saw Robbie he was seven months old and had just undergone surgery to correct his lip.

Since then Robbie and his family have undergone three more major invasive surgeries.

In that time Robbie has also forged ahead in his therapy with Granite Belt Support Services, helping his speech and teaching him basic functions like sitting up and squatting.

His next visit to the doctors will be in nine months time to catch up with the cleft palate team, but more confronting than not knowing what will come of that meeting said mum Jen Reading was the prospect that government funding which allows Robbie to attend therapy sessions with GBSS will be lost to him under a restructure next year.

"We won't be able to afford to keep sending him," she said.

At her 19 week scan, doctors told Jen and Robbie's dad Nick that their baby had extensive facial defects.

The pair was asked to consider whether his future quality of life would be worth continuing the .

Doctors then recommended an amniocentesis to find out more about their baby's condition but Jen declined as there was a one-in-200 chance she could miscarry.

"I was already a one-in-700 chance to be carrying a child with a cleft palate, so I decided to just take whatever was to come," Jen said.

For eight months Jen burdened herself with the guilt of causing Robbie's cleft palate, before making the game-changing phone call to support group CleftPals.

"Making that phone call was the best thing I ever did, the woman I spoke to voiced all of the concerns and dark thoughts I'd had but never said out loud to anyone," Jen said.

"There is no known cause of cleft palate, I know now it wasn't my fault."

Soon after birth Robbie was taken to the intensive care unit with breathing difficulties. Jen described this day as one of the hardest of her life.

She was told he had hyperprolactinemia which meant his pituitary gland didn't produce growth hormones, adrenalin and lacked testosterone.

To top it all off he was also diagnosed with Ring 18 disease - a condition so rare there are only two case studies of people with the genetic disorder who have survived into adulthood.



(At just 19 months old Robbie Milne has undergone 19 major surgeries. Photo Emma Boughen / The Bush Telegraph)

The condition has many side effects including delayed speech, missed milestones, mild hearing loss due to a narrowing of his ear canal and delayed reflexes meaning that when he falls he doesn't put out his hands to break a fall.

"He usually has a lot of bruises," Jen said.

The hardest part for Nick was that doctors couldn't say what the future held for his son.

"It was so confronting seeing him that way, they weren't even sure if he was a boy or a girl," Nick said.

"We were concerned what kind of life he would have and how other kids would treat him but it was just like 'suck it up princess' and in the end everyone has been so welcoming."

At four months old Robbie had an operation to correct his lip; at nine months old he underwent surgery to correct his palate; earlier this year he had eye surgery to correct his lazy eye; and just six weeks ago he had surgery to find and bring down his testes.

"I wouldn't change Robbie for the world but I wouldn't wish this on anyone else," Jen said.

Robbie will be on medication for the rest of his life including a growth hormone injection which has to take six days a week.

Even a broken bone could be life threatening if he doesn't receive his emergency injection in time.

His next major operation will be at nine years old to take hip from his bone to create a palate in the roof of his mouth.

Despite it all though Jen considers herself one of the lucky ones.

"Spending weeks in intensive care is a real eye-opener."

When Jen returned home to normal life with Nick and Robbie's older sister Lily, reality set in as did a bout of post natal depression.

To pull herself out it, Jen signed on to be a fundraiser with Jeans for Genes day.

"It gave me something else to focus on and I feel like I'm doing something good for children with a wide range of conditions."

With just a month to go until Jeans for Genes day coming up on August 7, Jen has started her fundraising efforts again.

The Stanthorpe State High School has come on board, as has Robbie's day care family who will host a morning tea fundraiser.

Any organisations, school or persons interested in helping out contact Jen at 0404 759 483.