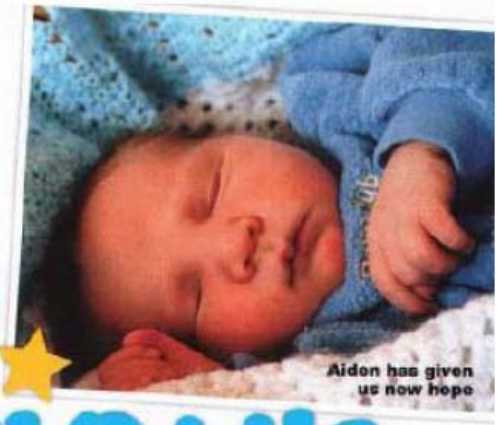
With a daughter battling an incurable illness, optimism was a tough ask for Julie and Shane – until a tiny miracle of hope was born …


Aiden has given us new hope

Our little saviour

I watched the clock all afternoon, waiting for Shane, my partner of three years, to get home from work.

"What are you smiling about?" he asked, as he came through the door of our home in the Melbourne suburbs.

"You're going to be a Dad," I squealed, revealing the pregnancy test kit with its two distinctive pink lines.

Although unplanned, my first pregnancy went well and when little Mikaela was born on October 31, 1999, we felt blessed.

I was bathing her one night when she was six weeks old and, as I lowered her into her baby tub, I kissed her gently on the forehead. But I was surprised when I got a strange taste in my mouth.

"Shane! Mikaela tastes funny!" I shouted. "She's really salty."

Just a few days later we got a call from the hospital saying results were back for a heel test that all bubs get straight after birth.

"I'm afraid there's no easy way to tell you this," the geneticist at The Royal Children's Hospital in Melbourne said. "Mikaela has tested positive for possible cystic fibrosis – a genetic disorder of the lungs and digestive system – and she'll need to come in for further tests. But don't worry; this test isn't always 100 per cent certain."


Shane and me

We were confident in the specialist's words, so I took Mikaela along a week later while Shane, then 32, went to work.

The doctor gently tied an elastic band around her arm and, with electrodes, tested the salt level in her sweat.

"Her salt levels are very high, I'm sorry," she said.

I went home crushed, but I tried to stay positive. The final confirmation of Mikaela's diagnosis the following day was awful.

"She's going to die!" I sobbed down the phone to Shane at work.

"Calm down, darl, I can't understand a word you're saying," he soothed.

"Mikaela is going to die," I repeated.

It was the worst day of our lives. We knew nothing about cystic fibrosis (CF) apart from the fact that it was an incurable and fatal condition.

"I'm coming home now and I'll call the hospital and ask for a second opinion," he said.

We were together for Mikaela's second testing which sadly did not bring us the news we wanted.

"There's been no mistake, it's positive," we were told.

Countless appointments followed over the next three days, including counselling for me and Shane as our learning curve steepened.

"It's a genetic disorder, so both of you must be carriers of the rogue gene," we were told. "Her life expectancy will be about 20 years and there'll be a one-in-four chance any other children you have will also have CF."

Her life expectancy will be about 20 years

We listened hard to every expert, took in every piece of detail and still asked more questions.

One of the things we were taught was how to do physio on our six-week-old bub.

"You need to lie her flat on her back, tap gently on her chest, then her sides, then roll her over and tap some more on her back," the nurse instructed.

"It will help dislodge the mucous from her lungs and clear her airways." The more we learnt about CF, the more horrible the disease sounded.

We had thousands of hopes and dreams for Mikaela. Sports-mad Shane was really looking forward to taking her to his beloved Western Bulldogs games and teaching her how to play golf. He hoped she'd turn out to be a real tomboy.

"Those hopes are crushed now," he said, devastated. "We're only going to have her for a few years."

She became the centre of our world and she was such a credit to us. She never moaned about her physio, she always took her medication without a whimper and to our delight she flourished. At one, she was in the 90th percentile of a healthy child her age.

Despite the 25 per cent chance of CF recurring in a second pregnancy, Shane and I were delighted as well as shocked when we

The girls, Shanae and Mikaela, love their baby brother as much as we do

found out I was expecting again in November 2000, when Mikaela was just over a year old.

But luck was on our side when tests at 11 weeks revealed the new baby did not have CF.

Shanae arrived on July 30, 2001, and Mikaela was rapt to have a little sister.

The pair grew very close, with Shanae learning to talk and walk quickly, keen to keep up with her big sis.

She was a bright little button too, and as Mikaela had to go to hospital every three months, it wasn't long before we had to sit down and explain to Shanae why Mikaela was special.

"Her lungs don't work properly and she needs special tablets and special tickles," I explained.

"Can Daddy do it to me?" Shanae asked when Shane had finished Mikaela's physio one day. So from that day on Shanae had to have her 'special tickles', too.

In December 2004, we moved from Melbourne into the country as we prepared Mikaela for school.

With poor lung function, she would always be at risk of respiratory infections, so the cleaner air and smaller class sizes meant we'd reduce the risk of colds and coughs.

Last year we decided to try for another baby.

"We always said we wanted three kids, so let's do it now," Shane said last July, and I fell pregnant within a week.

We went through the anxious 11-week wait for the test to see if the new baby had CF.

"It's a boy and he's all clear," the doctor gushed when the results came back.

After first expressing disgust about having a little brother – "Eeugh, a boy! Will it mean we have to give up the playroom?" the girls chorused – Mikaela and Shanae got used to the idea as my pregnancy progressed without a hitch.

In February, with only two months to go before my due date, I was relaxing at home when I picked up the newsletter from Cystic Fibrosis Victoria.

"It says here they're looking for volunteers for new research," I said to Shane.

"They need expectant mums of CF kids to donate the cells from the baby's cord. It's the first of its kind in the world, is a free treatment and it could help to find a cure!"

I contacted Professor Bob Williamson, who was leading the research, the next day and volunteered for the trial.

"We haven't got long to organise everything, but you'd be the perfect candidate," Bob said.

We explained it to Mikaela in the simplest of terms.

"That sounds great, Daddy! Does this mean I won't have to do physio and take my tablets anymore?"

"We'll have to see, darling, but I hope so," Shane replied.

The final two months of my pregnancy went as smoothly as the previous seven, but with the added excitement that my new baby boy was going to make medical history in this groundbreaking stem cell trial.

I went into labour at 5.30am on Easter Saturday, April 15, and Aiden was born at 4.24 that afternoon at Werribee Mercy Hospital.

Doctors managed to get 93ml of cord blood which was couriered to Professor Bob Williamson and his team from BioCell, the cord blood bank laboratory.

Aiden was perfectly healthy and as soon as his sisters set eyes on him, they were in love. Even though Mikaela is only six, we believe she's well aware of how much of a saviour Aiden could be for her.

Today, more than three months on, it's a case of waiting in hope for the medical breakthrough that will give Mikaela the chance of a healthy life and a future we thought was never going to be possible.

It's hoped healthy, living tissue can be cultivated from the stem cells which will later be injected into Mikaela, reversing the damage to her lungs and digestive system caused by the CF.

There are no guarantees about Mikaela's future, but we're philosophical and have made a pledge.

If we keep her happy, we'll keep her healthy. If we keep her healthy, we'll buy time. If we buy time, they'll find her a cure.

Julie Barross, 32, Vic.

Mikaela and Aiden share a special bond

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