

Chenelle, Alicia, Simon and Jacinta

PICTURES: NEIL MACKENZIE

Jacinta Hall was a normal, healthy baby – now she’s a helpless five-year-old. Her parents Chenelle Laing and Simon Hall explain how a cruel condition has transformed their darling daughter

Our daughter Jacinta has the most amazing eyes. They’re so expressive, people have commented that they can tell a million stories.

Her eyes have been like that since she was born – but what we didn’t realise is that striking eyes are one of the signs of a cruel condition that transforms little girls from seemingly normal babies and toddlers into helpless children.

It’s lucky Jacinta’s eyes are so expressive – looking into them is mostly how we understand what she wants or how she is feeling because her illness means she can’t tell us.

Jacinta, our second daughter, was born three weeks early after a healthy pregnancy. She was a dream baby who fed and slept well and was always happy.

She developed normally and by the time she was one, she could say a few words. She loved books and would pull them out of the bookshelf to flick through them.

When Jacinta was 14 months old, our Plunket nurse referred her to a paediatrician, as she wasn’t walking yet. We weren’t worried as her older sister Alicia didn’t walk until 17 months. The paediatrician wasn’t too concerned but asked to see Jacinta every two months.

On our third visit, we mentioned Jacinta wasn’t speaking as much as she had been before. She’d also lost some of her ability to use her hands – she no longer picked things up off the floor or turned the pages of books.

The paediatrician had a whole raft of tests done, including an ECG and an MRI. All the results came back normal. We were told Jacinta (aged two by this time) was developmentally delayed but we wondered how her development could have gone so



Our silent angel



Jacinta at 18 months, when her illness was taking hold



With dad Simon and big sis Alicia (right)

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far and then gone backwards. The word "delayed" didn't seem to fit.

Over the next few months, our happy little girl began to change. She started to bang her head against her cot at night, smashing it over and over against the headboard. Sometimes she'd laugh loudly; other times she'd cry inconsolably. During the day she cried constantly. We were no longer worried that she wasn't walking or talking – we only wanted her to be happy and calm again.

This stage eventually passed. But by then she had lost almost all use of her hands and would constantly put them in her mouth. We were confused about what was going on but relieved she seemed happy again.

Jacinta was being helped by the Wellington Early Intervention Trust, which provides therapy for preschoolers with special needs, when one of their therapists attended a seminar on rare neurological disorders. She saw some information on a condition called Rett Syndrome that made her think of Jacinta. She talked to our paediatrician and Jacinta underwent more tests.

In May 2003, when Jacinta was three-and-a-half, she was finally diagnosed as having Rett Syndrome, a developmental disorder caused by a genetic mutation that almost exclusively affects girls. Many RS girls are attractive, with striking eyes. They seem normal when they are born and the first stage, called early onset, is so vague they can be misdiagnosed as having conditions such as autism, cerebral palsy or, like Jacinta, developmental delay.

Stage two – the rapid destructive stage – was responsible for Jacinta's head-banging and crying. She is now in stage three, in which her behaviour is more settled, but she has lost many of her motor skills. She can walk with a walking frame but needs full supervision because her balance is not good. She can't use her arms and she can't talk

'We lost all the dreams we had for our daughter'

but she can make noises. This stage could last for years before she moves on to stage four, where motor skills can deteriorate further. We don't know what the long-term prognosis is. Barring illness or complications, girls with RS usually survive into adulthood.

When we were told what was wrong with Jacinta, it was tough to accept. We lost all the dreams we had for our daughter living the kind of life every parent wants for their children.

But we realised this didn't change who Jacinta was. She was still our Jacinta.

It's difficult to assess Jacinta's intelligence because her inability to talk makes it very hard to carry out traditional tests. But we know she understands everything – we can see it in her eyes. We try to work out what she wants by reading her eyes, facial expressions and body language. It's a guessing game and we only get it right half of the time. It's frustrating for us but that's nothing compared to the frustration she must feel. When we do get it right, her face lights up.

Jacinta went to kindy for two years with the help of a support worker and before she started, we were worried the other kids wouldn't accept her. But they treated her with such love and kindness, it made our hearts melt. They would read her stories, wipe her mouth, put on concerts for her, pull her around in a wagon and do anything they could think of to make her happy.

Jacinta, now five, goes to St Joseph's Catholic School in Upper Hutt and again the children and school community have accepted her for the wonderful girl she is. Children in her class fight over who is going to sit next to her on the mat. They help put her equipment away, push her wheelchair, wipe her face and rub her back when she needs comforting.

We want to raise awareness of Rett Syndrome and let people know we would much rather they asked questions instead of staring. There is nothing to be scared of.

Anyone can see Jacinta is a happy child who laughs a lot. She has taught us so much and will continue to teach us. We think she is very special – she's our silent angel. ●