

'MY DAUGHTER DIDN'T EAT FOR 10 YEARS'



JEMMA'S RARE CONDITION HAD DOCTORS AT A LOSS, BUT HER DETERMINED PARENTS HELPED FIND A DIAGNOSIS

When Jemma sat down at the family dinner table and refused to eat, she wasn't being rude nor was she being fussy. In fact, her peaches and cream skin and cheeky grin masked a serious health

problem that, until recently, meant the 14-year-old hadn't eaten in over a decade.

"Jemma has Coffin-Siris syndrome, a rare condition causing intellectual disability or delayed development of speech and motor skills," Jemma's mum, Belinda, tells New Idea. "Children also suffer respiratory infections and have trouble feeding."

Sufferers tend to have coarse facial features, a wide and flat nose, as well as underdeveloped tips of the fingers or toes. And Jemma,

as far as they know, is one of just 200 cases worldwide.

From the moment Jemma was born, she constantly struggled to thrive.

"She was diagnosed with eye issues, hearing loss, a cleft palate and a hole in the heart," says Belinda, 39.

The brave little battler had a successful operation to fix the hole in her heart, but her worried mum and dad noticed their little girl wasn't eating.

"I was beside myself. Jemma refused to drink milk and even lick, smell or taste food,"

and her husband, Brendan, welcomed her baby brother into the world. As he thrived, there were small glimmers of hope when Jemma, who was watching Cayden enjoy his puréed food, took her first sip of formula.

"She liked it, but anything else she wouldn't touch," says Belinda.

Jemma continued to be inspired by her little brother. When 1-year-old Cayden took his first wobbly steps, Jemma, aged 5, did too, and then when Cayden smiled for the

"I CHERISH EVERY MEALTIME WITH JEMMA SITTING AT THE TABLE WITH FOOD ON HER PLATE"

Belinda recalls. "Doctors were at a loss as to what was wrong and there was no diagnosis for her – there were no answers as to why she couldn't eat, talk, walk or even smile."

As time passed, Jemma was fed by a tube to fuel her body with much-needed food and nutrients to survive.

"It broke my heart to see her at the dinner table with an empty plate," says Belinda. "Food is a big part of our family's life – when we celebrated Christmas or birthdays, I'd shed a tear that my girl couldn't even enjoy a slice of her own birthday cake."

When Jemma was 4, Belinda

first time, so did his sister.

"I couldn't stop the tears of joy rolling down my cheeks," Belinda remembers.

Then, three years later, when Jemma was 8, she tried custard for the first time – and it even became her staple for two years!

But still without a diagnosis, Belinda and Brendan were desperate to do something to help Jemma – who, despite not being able to eat, talk or walk, was a happy soul and loved jigging around to music on her knees.

Searching endlessly for answers and after numerous visits with doctors and

specialists, it wasn't until Jemma was 10 that a blood test was sent to the US for genetic testing and revealed she had Coffin-Siris syndrome.

"Suddenly, all the pieces of the puzzle fell into place," says Belinda. "One of the symptoms of kids with the syndrome is feeding trouble, so Jemma's aversion to food made sense, but we still didn't know if she'd ever be able to eat properly."

Slowly, Jemma started to try soup and Weet-Bix, and then after more than a decade of missing Christmas dinner, last year she had her first bite of turkey.

"Jemma is still in nappies, has the mental age of a toddler and can't talk," says Belinda. "Her diet is still very limited too, but she's

come a long way when we think back to all those years when she wouldn't eat at all. Now I cherish every mealtime with Jemma sitting at the table with food on her plate. She never gives up and that smile of hers will always light up my world."

By Astha Gupta

• For more information, visit friendinme.org.au.

Parents Belinda and Brendan are proud and relieved that their daughter can finally eat.

For so many years, little Jemma missed out on birthday cakes and Christmas dinners due to her condition.

