'My little Bella failed to thrive'

SARAH GRAY, 32, SUPPORT GROUP
FOUNDER, MOUNT COOLUM, QLD

Bella began to fail to thrive at four months of age, before solids were introduced. She was breastfed for 13 months, with me removing milk from my diet when she was about seven months, as we knew then that she couldn’t tolerate dairy. She’d get an immediate rash when we trialled formulas – including the hypo-allergenic varieties.

During this time we saw several doctors, all with different opinions and no answers as to why she wasn’t growing. Then, at 18 months, she was referred to a gastroenterologist for an endoscopy and she was diagnosed with eosinophilic oesophagitis (EE), which occurs when eosinophils, a type of white blood cell, are found in above-normal amounts within the gastrointestinal tract. The eosinophils can accumulate in the gut in response to food and/or airborne allergens and can cause inflammation and tissue damage.

We were given a prescription for Neocate, a formula for infants with cows’ milk allergies, and it has been a huge learning curve ever since. Bella is also anaphylactic to egg, fish and dairy, and suffers from asthma and eczema. She has several other food allergies including to wheat, corn and soy, which are all avoided in her elimination diet.

Her main source of nutrition, until 2010, was from Neocate Advance, which she drank from her favourite sippy cup. The hard bit was getting her to drink enough of it! In December 2010 the decision was made for Bella to have a gastrostomy feeding tube inserted to assist her to gain much-needed weight. Bella is now eight and her six-year-old sister, Olivia, who does not have EE, has outgrown the food allergies she had as a baby. Olivia now only suffers from a rice intolerance.

I have founded ausEE, an EE support network, after many years of feeling isolated and frustrated by the lack of information and support. I aim to reach out to the medical community and other families living with this disorder, because together, we are not alone.

Go to ausEE.org for more information and to support this cause.

WE’D LOVE TO HEAR YOUR STORY!
If you would like to share your story please email it to editorial@poppetgroup.com.au.

Pieces should be 200 to 800 words in length and may be edited for length and clarity.