One year to diagnose disorder

IT was a year of trying alternate methods to settle her often inconsolable baby that Mercedes Hinchcliff was told her son had Eosinophilic Oesophagitis. The rarely known disorder was first identified 30 years ago and renders its carriers with some disabling symptoms.

"Some people can go their whole lives without realising why they always feel sick," Ms Hinchcliff said.

At one day old Henry would not stop screaming and Ms Hinchcliff was told that he probably had colic or wind and it would pass. After returning to her Woonona home she took him to the doctor at six weeks and was told he suffered from reflux and was given medication. Six weeks later they tried another medicine.

"His bowel movements would cause blisters and bleeding. He would claw at his chest day and night and draw blood from scratching so much," she said.

Ms Hinchcliff changed her own diet to see if that would help, tried every type of medicine for colic she could find and after receiving no more than two hours of sleep any night, took him to Treallian House.

"He really screamed the most at night, which was when he was not distracted and had time to realise he was really in pain," she said.

At 11 months he was admitted for a sleep study that revealed he woke 30 times in an hour.

"That's when doctors finally took notice," she said.

From there he went to a gastrology paediatrician who diagnosed him with the form of Eosinophilic Gastrointestinal Disorder (EGID). "It's been really tough, and once it was identified we had to take away all of his food," she said.

People with any form of EGID have an allergic reaction to protein and out of the 27 foods Henry has had introduced during their 'food challenges' in the past year, two have been a success.

"He can eat pears and carrot and he had the worst reaction to rice," Ms Hinchcliff said.

Henry's main staple is formula and he wakes up every three hours because he is so hungry.

Like any allergy to food the long-term prognosis is unknown but the method of assessing the status of the disorder is invasive.

"We will be going in for our fifth visit to see what the level of eosinophils in the oesophagus is - we are aiming for zero.

Since having to learn so much about EGID, Ms Hinchcliff has helped establish a NSW network for people dealing with the disorder while raising funds and awareness through www.aussee.org.

The only way to have it diagnosed in children is through an endoscopy or biopsy.

On Saturday, December 4 ausEE will host 'A Day in the Park' that will feature a jumping castle, barbecue and face painting from 8am at Stuart Park in Wollongong as a way to raise awareness and funds to help the cause.