Take Top 8 challenge
Charity event seeks to raise awareness of rare disease

By CARLY REES

IMAGINE your child turning up their nose at potato chips. Imagine seeing a frown at the suggestion of a chocolate. This is Sarah Gray's reality as her daughter Bella, 8, battles a rare incurable disease.

Eosinophilic oesophagitis is one of a group of conditions known as eosinophilic gastrointestinal disorders which occurs when eosinophils, a type of white blood cell, are found in above-normal amounts within the gastrointestinal track.

When eosinophils accumulate in the gut in response to food and/or airborne allergens they can cause inflammation and tissue damage. A friend's birthday party for Bella means bringing along a packed lunch and if there is a girls' slumber party planned, she heads home in the afternoon.

"She can't have sleepovers at peoples' places, it is just too difficult," Mrs Cray said.

Bella has an anaphylactic reaction to egg, fish and dairy, and suffers from asthma and eczema. She has several other food allergies including wheat, corn and soy.

Because she was not thriving, Bella recently had a gastrostomy feeding device fitted and now receives her nutrition overnight via a pump in two continuous five-hour feeds of 450ml each.

From August 8 to 14, Mrs Gray has organised the first National EOS Week to help raise awareness for the condition.

To really understand the lives of people living with this condition, during the week Mrs Gray encourages people to raise money by taking part in the Top 8 Challenge.

The charity asks that for one day you don't eat milk, eggs, soy, wheat, peanuts, tree nuts or shellfish, foods most people with the condition are allergic to.

"There is no other awareness week in Australia for it, so we wanted to bring attention to it so people will start understanding it," Mrs Gray said.

Bella was four months old when her mother first noticed there was something up because she wasn't thriving.

"It wasn't until she was 18 months old that she was diagnosed with the disorder which, at the time, Mrs Gray had never heard of.

"When she was diagnosed in 2005 there was nothing about it and when you Googled, Wikipedia was the only page that came up," Mrs Gray said.

She said she didn't realise the enormity of the condition because of the lack of information and assumed her daughter would grow out of it.

Mrs Gray soon realised this wasn't the case and she became the voice for the condition, forming the support group ausEE and website www.ausEE.org.

The charity hopes to raise vital funds for medical research into the condition.