



MEDIA RELEASE

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Mum forms support network for daughter's rare disorder

A Sunshine Coast mother, Sarah Gray, has formed the first Australian support network for people living with Eosinophilic oEsophagitis (EE or EoE), (pronounced ee-oh-sin-oh-fill-ick) the disorder her 6 year old daughter Bella suffers from.

EE is characterized by elevated levels of eosinophils in the oesophagus (the tube that connects the mouth to the stomach). Eosinophils are a type of white blood cell which can grow in an uncontrolled manner and attack the gastrointestinal system. Symptoms can be (but are not limited to) nausea, vomiting, diarrhoea, abdominal pain, reflux, trouble sleeping, failure to thrive, difficulty swallowing and food impactions.

EE is just one of a group of diseases called Eosinophilic Gastrointestinal Disorders (EGID) that are often associated with allergies. The current¹ estimated prevalence of EE is 1–4 cases per 10,000 individuals. These disorders can only be diagnosed by an endoscopy and biopsy; a diagnosis cannot be made on symptoms alone. The most common medication used is steroids, along with dietary management, to control inflammation and suppress the eosinophils; there is NO CURE. To determine the treatment plan these children may undergo several endoscopies a year.

For most of her life, Bella has been relying on a special elemental formula to get the nutrition she needs as she is allergic to most foods. As this formula is unpleasant in taste, many children with EE require a feeding tube to meet their daily nutritional requirements; fortunately Bella is able to tolerate this formula orally. She is also able to eat certain foods such as rice and potato, but only in small amounts. Due to her significant allergies when she eats other foods, her body reacts, causing nausea, abdominal pain, reflux, eczema and hives. Some children with EE are solely dependent on the elemental formula and are unable to tolerate any foods at all.



“From when Bella was first diagnosed over 5 years ago, we have struggled to find other parents dealing with the same issues and have often felt isolated. There are support organisations operating in the US, Canada and UK but until now there has been no support for Australian’s living with these disorders” said Sarah.

“The aim of ausEE is to provide support and information to anyone diagnosed with or caring for someone with an Eosinophilic Gastrointestinal Disorder (EGID) including Eosinophilic oEsophagitis (EE or EoE), Eosinophilic Gastritis, Eosinophilic Enteritis, Eosinophilic Colitis and Eosinophilic Gastroenteritis.”

“We are also dedicated to raising public awareness for Eosinophilic disorders in Australia as there is so little information available about the disease that patients often suffer for a number of years before a diagnosis is made.”

The non-profit organisation’s website www.ausee.org provides information on the disorders, links to medical articles and other relevant resources including communication forums for members who join the site (free membership).

The diagnosis of an eosinophilic disorder is life-altering, in addition to the serious physical signs and symptoms; it is a challenge to live in a society that focuses on food. Bella Gray knows only too well how difficult it can be.

“By providing support, information and awareness, we hope ausEE can make a difference to the lives of kids and adults living with these disorders” said Sarah.

For more information, please visit ausEE website www.ausee.org

¹source: <http://www.allergy.org.au/content/view/168/1/>