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Australian Support Network for Eosinophilic oEsophagitis and related disorders

'...together, we are not alone...'

MEDIA RELEASE

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Charity for rare disorder marks one year

November marks the first birthday since ausEE Inc. the first Australian Support Network for Eosinophilic oEsophagitis (EE or EoE) and related disorders was founded.

EE is just one of a group of diseases called Eosinophilic Gastrointestinal Disorders (EGID) that are often associated with allergies. Symptoms can include nausea, vomiting, reflux, trouble sleeping, failure to thrive, difficulty swallowing and food impactions. The current¹ estimated prevalence of EE is 1–4 cases per 10,000 individuals. There is no cure and most of the children who suffer from an EGID do not eat a normal diet and have severe food restrictions. Some of them can't eat any food at all and are fed through a tube inserted in their stomach.

The diagnosis of an eosinophilic disorder (pronounced ee-oh-sin-oh-fill-ick) 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.

"When I first launched the ausEE website, I don't think I realized the enormity of what I had set out to do" said Sarah Gray, who founded the organization in November 2009.

Since foundation, the charity ausEE Inc. has been endorsed by the ATO as a Deductible Gift Recipient (DGR) and has been fundraising with plans to fund Australian medical research into these disorders in 2011.

Some of the achievements for ausEE during the past 12 months have been the forming of a Medical Advisory Board of six medical professionals in the field and the production of Australia's first medical brochures on eosinophilic gastrointestinal disorders which are being displayed in hospitals.

The charity's website www.ausee.org provides information on the disorders, links and relevant resources including communication forums for members, for which there are now over 100.

"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/>

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