

- FOR IMMEDIATE RELEASE -

How EGID affects me... three lives, one diagnosis

National EOS Awareness Week (6-12 August), is a week that Australian charity ausEE hosts to raise awareness for the little-known allergic disorders called eosinophilic gastrointestinal disorders (EGID), the most common being eosinophilic oesophagitis (EoE), and what it means for the estimated 1 in 2,000 Australians living with them.

Meet 23-year-old Emily. Whilst it's only been a year since she was diagnosed with EoE, this diagnosis wasn't the start of her journey. Living with food allergies all her life, she was only an infant when she first experienced anaphylaxis to peanuts. Her list of allergies has grown to also including almonds, soy, dust mites, dog dander and cat fur. As well as this, she is seafood and gluten intolerant. It was after she choked on a piece of chicken on her 22nd birthday, that results of an endoscopy discovered that she had also been living with the rare allergic disorder, eosinophilic oesophagitis. Experiencing dysphagia (difficulty swallowing), nausea, persistent reflux, abdominal or chest pain and food impaction are all common symptoms of EoE.

Emily says "I just wanted to break down and cry, because every few years it felt like one thing after another. My next thought was, I can't have anything wrong with my throat because I'm a singer." Despite having this new diagnosis and having to learn how to manage it, Emily remains positive. She says, "Here's the thing, you don't get to choose what life throws at you, BUT you do get to choose how you deal with it and what you want for your own life."

Emily, who studies music full time and recently finished her first Opera in Melbourne, is not the only one that is affected by an EGID. In fact, people of all ages share the same diagnosis. 4-year-old Andy from Perth was diagnosed with EoE at the young age of 15 months.

Mother, Kristin, recalls that Andy first started throwing up at around 8 months old and continued to do so frequently. He started having formula and solids and was told that it's normal for babies to have what she now knew was reflux. Then, at his 12-month check-up, his weight wasn't registering in the growth charts and they were referred to a paediatrician. A series of tests were finalized but after X-rays, ultrasounds, blood tests and a barium swallow they had eliminated a lot but still had no answers. It was then at 15 months old, Andy went under anaesthetic for an endoscopy and an EoE diagnosis was confirmed. From that day, he was put on a top 8 elimination diet (which is a common treatment option for EoE) and prescribed an elemental formula to bump up his calorie intake.

Now aged 4, Andy is trialling dairy but still needs to avoid peanuts, tree nuts, corn, fish, bananas and egg, although baked egg is now allowed. Kristin says, "He is still very reluctant to eat foods even when he is now allowed them, or we let him know it's okay to eat, as he has fears of vomiting and being in pain."

To show their support to Andy, his family and friends have formed a team for the Perth City to Surf on 27 August to raise money for medical research into EGIDs. Last year, their team was 87 strong and raised nearly \$9,000 for the cause.

<https://www.mycause.com.au/page/151688/awareness-for-andy-c2s>



a charity dedicated to improving lives affected by eosinophilic disorders

Charity Website: www.ausee.org
Awareness Week Website: www.eosaware.com
Email: admin@ausee.org

10-year-old Sammy from Sydney also lives with EoE. Every day he experiences pain and discomfort because of this disease and it means he is allergic to many foods. This year, Sammy has taken the initiative to drive his project idea to raise awareness for EoE and is running a lemonade stand at his school on Top 8 Challenge day which is held each year during National EOS Awareness Week. He put together his own project plan which was approved by his school Principal. This idea has now been extended to include a virtual lemonade stand and Sammy set up a GoFundMe page with a goal to raise \$800 for research.

(<https://www.gofundme.com/sammys-top-8-lemonade-stand>)

ausEE founder, Sarah Gray, says “It’s important to share stories like these and have support networks in place for people with EGIDs because these disorders are complicated to treat and you can feel very isolated.” “Getting a diagnosis is one journey, then it is often a lengthy process working with your medical team (which commonly includes a gastroenterologist, allergist, paediatrician, general practitioner and dietitian) to help identify your allergic triggers and put together an individualised treatment plan”. Treatment options include diet modification, medications, elemental formula and in some cases a feeding tube may be used to ensure nutritional needs are met. Currently the only way to effectively monitor an EGID is to have a repeat endoscopy and biopsies, and for some patients, this may be required several times a year.

Living with an EGID is hard on physical, emotional and social levels and more research is needed to help patients achieve the best quality of life. “Ultimately, we are searching for a cure” Sarah says of ausEE’s National fundraising campaign, the Top 8 Challenge. “Aside from helping us to raise much needed funds for medical research, the Top 8 Challenge is a way to gain some understanding of what it is like living day in and day out with an EGID”.

All money raised from the Top 8 Challenge goes directly to ausEE’s medical research fund. Sarah says. “After last year’s campaign ausEE was able to award a research grant of \$18,000 to Monash University for an EoE research project and the year before we contributed \$20,000 to The University of Newcastle for an EGID study.”

Top 8 Challenge day is 8 August and involves excluding the top 8 common allergenic foods for the day or for one meal on the day. This means no milk, eggs, wheat, fish, peanuts, tree nuts, soy or shellfish. You can visit their website at www.top8challenge.com to join the challenge, don8 and show your support for people like Emily, Andy and Sammy.

For more information about eosinophilic disorders and ausEE Inc. please visit: www.ausee.org

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