



ausEE

a charity dedicated to improving lives affected by eosinophilic disorders

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## **Eosinophilic gastrointestinal disorders are often misdiagnosed and misunderstood**

- 8-14 August 2021 is National EOS Awareness Week
- Community is invited to take part in the Free From + Allergy ausEE Edition Virtual Show
- New research shows that EGIDs may be highly underdiagnosed

Eosinophilic gastrointestinal disorders (EGIDs) are on the rise and new research shows that they may be highly underdiagnosed. ausEE Inc., Australia's peak national support and patient advocacy organisation for EGIDs is urging people to find out more about these chronic misunderstood diseases during their National EOS Awareness Week (NEOSW), which is running from 8-14 August 2021.

Characterized by eosinophilic infiltration in the gastrointestinal tract, EGIDs are complex allergic inflammatory disorders. The most known type of EGID is eosinophilic oesophagitis (EoE), where the elevated eosinophils are found in the oesophagus, with the estimated prevalence having increased from 1 in 10,000 to 1 in 1,000 people in the 11 years since ausEE's foundation. Until recently, eosinophilic gastritis and/or eosinophilic duodenitis (EG/EoD) were thought to be very rare EGIDs but new evidence indicates that EG/EoD appears to be a lot more common than previously thought and may be a common cause of chronic unexplained gastrointestinal symptoms.

EGIDs are invisible illnesses that can have a significant impact on quality of life. The symptoms of EoE can include, trouble swallowing, choking or gagging on food, regurgitation of foods, abdominal or chest pain and reflux that does not respond to medications. The time taken to receive a diagnosis can vary greatly and sometimes follows a food impaction when food gets stuck in the oesophagus. If EoE is left untreated, around 30-50% of children and adults with EoE will eventually get a food impaction, which may have to be removed in hospital. EoE can cause scarring and narrowing of the oesophagus requiring oesophageal dilation/s.

Symptoms of EG/EoD can include, early satiety, bloating, loss of appetite, diarrhea, abdominal pain/cramping, and nausea/vomiting. These symptoms overlap with other gastrointestinal conditions and therefore people may have been misdiagnosed as having a functional gastrointestinal disorder (FGID), such as irritable bowel syndrome (IBS) without being assessed for EG/EoD, which, like all EGIDs, requires an endoscopy with sufficient biopsies. More research, awareness and education is vital for all EGIDs.

ausEE Inc., is celebrating 10 years of its important annual awareness initiatives, National EOS Awareness Week and Top 8 Challenge day and in an Australian first for EGID awareness and education, they have partnered with Free From + Allergy on a virtual show. Running from Sunday 8 - Saturday 14 August, the free virtual show's impressive program provides 14 video presentations including Laureate Professor Nicholas Talley from the Centre of Research Excellence in Digestive Health discussing the new findings on EG/EoD, international specialist, Professor Evan Dellon from University of North Carolina School of Medicine in Chapel Hill talking about the epidemiology of EGIDs and Olympian, Nicole Hannan who has a daughter with EoE is

sharing her research results on healthcare use, burden of disease and satisfaction with care in paediatric EoE. Also, part of the show is ausEE's Charity Ambassador, Eddie Woo from Wootube who has a son with EoE and Coles Ambassador and former MasterChef, Courtney Roulston is sharing an allergy friendly recipe.

Sarah Gray, President and Founder of ausEE Inc, the peak body for people living with EGIDs is encouraging people to get involved during NEOSW by registering to attend the free virtual show. 'We are so fortunate to have worked with Free From and Allergy to provide this show to our members and the community and are thankful to Coles, the show sponsor and all the presenters for making the event possible.' 'This is an amazing opportunity for people with EGIDs, their family, carers and friends to learn more about their diagnosis and for members of the community who are experiencing symptoms and may have an undiagnosed EGID to have the information to ask their doctor.'

ausEE is here to help and support people through all stages of their journey with an EGID as being diagnosed is just the first step, with the road to receiving a diagnosis, often being a long one. Health care professionals are also urged to participate in the virtual show as more awareness and education is crucial to reduce diagnosis timeframes and improve patient outcomes.

Register for the Free From + Allergy ausEE Edition Virtual Show at [www.freefromallergyshow.com](http://www.freefromallergyshow.com)  
Learn more about NEOSW and support EGID medical research at [www.eosaware.com](http://www.eosaware.com)  
For more information about EGID/EoE and to access free support, visit [www.ausee.org](http://www.ausee.org)

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#### **References:**

<https://allergy.org.au/patients/food-other-adverse-reactions/eosinophilic-oesophagitis>  
<https://medicalresearch.com/author-interviews/eosinophilic-stomach-intestinal-disorders-frequently-misdiagnosed/57455/>  
<https://eosaware.com/auseevirtualshow>

#### **About ausEE Inc.**

Founded in 2009, ausEE Inc. is a national health promotion charity whose mission is to improve the lives of those affected by eosinophilic gastrointestinal disorders by providing support, evidence-based information, resources and campaigning to raise awareness and funds for further research in Australia.

#### **About Free From + Allergy Show**

The Free From + Allergy Show was created to help support those living with allergies and intolerances and connect them with specialists within their field and products that can help them live a better life with their allergy and/or intolerance. Due to COVID, they had to postpone their live events and from last year went virtual, having since successfully produced multiple digital shows raising awareness for allergies, intolerance, coeliac disease, FODMAPs and now EGIDs.

#### **About National EOS Awareness Week and Top 8 Challenge day**

Since 2011, ausEE Inc. has been hosting National EOS Awareness Week to raise awareness for eosinophilic gastrointestinal disorders (EGIDs). This year #NEOSW2021 is being held 8-14 August 2021. The #Top8Challenge is ausEE Inc.'s major fundraising campaign held each year on 8/8 with funds raised going to Australian medical research into EGIDs. During NEOSW on Sunday 8 August, ausEE challenges people to take their Top 8 Challenge by not eating any top 8 common allergenic foods (this means no milk, eggs, wheat, fish, peanuts, tree nuts, soy or shellfish) and don't to help find a cure.