



ausEE

a charity dedicated to improving lives affected by eosinophilic disorders

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- MEDIA RELEASE -

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## Survey shows impact of eosinophilic gastrointestinal disorders on families

Imagine if food caused pain... nausea... reflux... was hard to swallow or even suddenly became stuck in your oesophagus. That can be the reality for someone living with an eosinophilic gastrointestinal disorder (EGID).

During National EOS Awareness Week, 4-10 August, ausEE Inc. is putting the spotlight on EGIDs and the day-to-day impact living with them has on families.

It is estimated that one in two thousand Australians live with eosinophilic oesophagitis (EoE) which is the most common type of EGID. People living with EGIDs often live with food restrictions which make it hard on physical, emotional and social levels.

A recent survey of more than a hundred people who live with or care for someone with an EGID highlighted the social impact of these inflammatory allergic conditions. 89% of survey respondents said they had difficulty going to a restaurant and 77% reported being anxious about attending social gatherings. A staggering 88% of people found it difficult to go to social occasions/parties/celebrations and sadly, 49% felt they had been left out of a social activity because of their EGID.

The ausEE Inc. survey also found that 90% felt that EGIDs impacted on their food budgets and 81% said that medicines and supplements for EGIDs also had a cost impact for them. 55% of respondents reported that having an EGID or caring for someone with an EGID also impacted on the number of hours they could work and this is significant considering the additional costs families face with food, medicines and supplements.

Whilst it was encouraging to see that 58% of respondents reported they had some support from family and friends, devastatingly, 34% said that they were largely managing on their own with 8% reporting that family and friends sometimes made it harder for them.

Sarah Gray, President of ausEE Inc., the National patient advocacy organisation for eosinophilic disorders said the survey results showed why it's imperative for people living with an EGID to have good support networks in place and why it's important to increase awareness through campaigns like National EOS Awareness Week which incorporates Top 8 Challenge Day on 8 August.

'You can feel very isolated living with an EGID as it is a real challenge to live in a society that focuses so much on food.' says Sarah.

ausEE Inc. provides free support networks and additionally is a source of valuable evidence-based information and practical resources for people living with the chronic disorders.

On the Top 8 Challenge, Sarah says 'We are calling on Australians to spend one day experiencing what it can be like living with an EGID by taking our Top 8 Challenge which is our fundraising and community awareness creating initiative.'

There is no cure for EGIDs and one of the common treatment options is an elimination diet which is tailored to the individual. Whilst some people with an EGID may be able to identify specific food(s) that trigger symptoms, unfortunately most cannot. Some doctors may suggest removing up to 8 common foods allergens (milk, egg, soy, wheat, peanut, tree nut, shellfish, fish) which is the idea behind our Top 8 Challenge.

To take the challenge, the most common allergenic foods are to be removed from your diet on Thursday 8 August and how many you wish to remove is completely up to you. Sarah says, 'You might choose to go only without milk or no wheat and egg or eliminate as many of the top 8 foods you can, up to removing all 8 common food allergens.' 100% funds raised through the Top 8 Challenge go to ausEE's Medical Research Fund which supports Australian medical research. To date ausEE has provided nearly \$100k in medical research grants with the aim being to improve the diagnosis and treatment options for people living with EGIDs and ultimately in search of a cure.

For more information about EGIDs and ausEE's support networks please visit: [www.ausee.org](http://www.ausee.org)

To learn more about the Top 8 Challenge and to take part, please visit: [www.top8challenge.com](http://www.top8challenge.com)

## **Reference**

Online survey completed by 108 people living with EGIDs by ausEE Inc. via Survey Monkey in June-July 2019.

## **About ausEE Inc.**

Founded in 2009, ausEE Inc. is a registered Australian charity dedicated to providing support and information to anyone diagnosed with or caring for someone with an Eosinophilic Gastrointestinal Disorder (EGID) including Eosinophilic Oesophagitis (EoE). We are committed to raising public awareness and supporting the medical community for further research in Australia.

## **About EGIDs**

Eosinophilic gastrointestinal disorders (EGIDs) occur when eosinophils, a type of white blood cell, are found in above-normal amounts within the gastrointestinal tract. Eosinophils are an important cell in your body. It has many roles including defence against parasitic infections (e.g. worms), and involvement in some forms of hypersensitivity and allergy. In some individuals, eosinophils accumulate in the gut potentially in response to drugs, food, airborne allergens and other unknown triggers. This infiltration can cause inflammation and tissue damage. Endoscopy with biopsies are the only way to confirm the diagnosis of an EGID.

**-ENDS-**

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