ausEE EGIDs Survey Results

Summary

There were 157 respondents to the survey from people with eosinophilic gastrointestinal disorders (EGIDs) and from people caring for someone with an EGID. Of these, 57% were female and 43% male. The age at diagnosis ranged from 6 months to 66 years which raises some important questions about onset, timely diagnosis and severity of illness which would be worth exploring in a future survey.

In 89% of cases the diagnosis was Eosinophilic Oesophagitis. The next most likely diagnosis was Eosinophilic Gastroenteritis at 4.4% and Eosinophilic Colitis at 3.6%. This broadly reflects the rates of EGIDs with EoE being the most common form.

Genetic/precision medicine is the subject of significant research globally and offers the promise of treatment and prevention for some people with rare diseases. ausEE recently participated in a research study about consumers and co-design in the genetic/precision medicine research arena (results will be available soon) and familial/genetic patterns of EGIDs requires further exploration as it may offer the potential for better treatments for people with EGIDs and their families in the future. Interestingly however, 87% of respondents to this survey said there was only one person with an EGID in their family and 11% said there were two people in their family.
Most respondents, around 63%, were unsure of any seasonal impacts of EGIDS and the worst and best seasons for EGID were spread pretty evenly across each season. The postcode data collected provide little insight into patterns of EGIDs geographically and only 5% of respondents reported moving address to be closer to services and hospitals.

The symptoms of an EGID flare and strategies to manage flare were remarkably similar between respondents to the survey and are presented in the word clouds below.

**What are the main symptoms experienced by the person with an EGID during a flare?**

- food
- choking
- throat
- loss
- appetite
- vomiting
- swallowing
- pain
- feeling
- nausea
- sore
- Chest
- pain
- Difficulty
- Reflux
- abdominal
- pain
- fatigue
- stuck
- stomach
- pain
- discomfort
- Food
- impaction
- trouble
- swallowing
- chest
- stomach
- cramps
- food
- stuck
- throat
- irritation
- headaches

**How do you treat/manage a flare?**

- avoid
- Hospital
- eat
- meds
- steroids
- strict
- Medication
- food
- elimination
- Flixtotide
- go
- food
- Nothing
- diet
- Increase
- antihistamines
- pain
- rest
- water
- flare
- pain
- relief
- Panadol