

**2019-20 Federal Budget Submission**

**February 2019**

a charity dedicated to improving lives affected by eosinophilic disorders

[Contact Information 1](#_Toc1067691)

[About ausEE Inc. 2](#_Toc1067692)

[About EGIDs 3](#_Toc1067693)

[Introduction 4](#_Toc1067694)

[Objective 1 5](#_Toc1067695)

[Objective 2 6](#_Toc1067696)

[Conclusion 7](#_Toc1067697)

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# About ausEE Inc.

Founded in 2009, ausEE Inc. is Australia’s only national support and patient advocacy non-profit organisation and registered 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 into eosinophilic disorders in Australia through our Medical Research Fund.

ausEE Inc. is also a stakeholder organization of the Australasian Society of Clinical Immunology & Allergy and Allergy & Anaphylaxis Australia’s National Allergy Strategy, Rare Voices Australia ‘Fair for Rare’ campaign and Internationally a representative on the C-EOS (Coalition of Eosinophil Patient Advocacy Groups) and a patient advocacy group of the Rare Diseases Clinical Research Network (RDCRN) Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR) Contact Registry.

We strive to improve the quality of life for all people living with eosinophilic disorders.

# 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.

The abnormal amounts of eosinophils can occur in the:

* oesophagus (eosinophilic oesophagitis)
* stomach (eosinophilic gastritis)
* duodenum (eosinophilic duodenitis)
* small intestine (eosinophilic enteritis)
* large intestine (eosinophilic colitis)
* throughout the gastrointestinal tract (eosinophilic gastroenteritis)

Eosinophilic Oesophagitis (EoE) is the most common type of EGID. The exact cause of EoE in most individuals is unclear. In some, it appears to be due to an allergy to food(s) and/or aero-allergens. In its most severe form, EoE is a chronic inflammatory condition with can develop into a fibrostenotic condition over time resulting in strictures of the oesophagus.

The symptoms of EoE vary from one individual to the next and can include:

* Feeding difficulty, oral aversion, poor appetite and failure to thrive
* Dysphagia and food impaction
* Nausea, persistent vomiting and retching
* Reflux that does not respond to anti-acid medication
* Abdominal or chest pain

In other types of EGIDs, symptoms depend on which part of the gut is affected (e.g. diarrhoea and bloody stools if the small or large intestine is involved).

Endoscopy and biopsy is the only way to confirm the diagnosis of an EGID and effectively monitor the treatment. There is no cure, but the goal of treatment is to eliminate the eosinophils in the affected area, thereby alleviating symptoms and reducing inflammation.

Treatment options for EoE include:

* Elimination diet/elemental diet
* Antacid medications/Proton pump inhibitors (PPIs)
* Corticosteroids (usually topically administered)
* Oesophageal dilation

EGIDs are chronic diseases that require ongoing monitoring and management.

# Introduction

Thank you for the opportunity to provide a submission for the 2019-20 Federal Budget.

ausEE Inc. supports individuals, families, communities, healthcare professionals and other key stakeholders to ensure that people impacted by an eosinophilic gastrointestinal disorder (EGID) have access to evidence-based information and resources to help them understand and manage their diagnosis and receive the support they need.

EGIDs are chronic allergic disorders that have increased in prevalence, for EoE from 1:10,000 to 1:2,000 in the years since our foundation and as such demand for our services and resources has dramatically increased, however our funding has remained limited. We are entirely volunteer run and rely predominately on donations. We provide our information, patient resources and support free for everyone and do not charge membership fees as we strongly believe that everyone should have access to the information and resources they need to help them on their journey living with an EGID. With Government support there is so much more we can achieve for all people diagnosed with an eosinophilic gastrointestinal disorder.

A total investment from the Federal Government of $80,000 will ensure that people living with EGIDs have the opportunity to receive the information, care and support they need by strengthening our capacity and increasing our reach, efficiency and overall impact.

The funding of these key objectives will ensure a better future for those living with eosinophilic disorders.

Objective 1 Support and Outreach Coordination $50,000

Objective 2 Awareness Projects for Timely Diagnosis $30,000

# Objective 1

**Support and Outreach Coordination**

**Implementation Cost:** $50,000

Living with an EGID greatly impacts on quality of life; physically, socially and mentally. Due to the complexity of these disorders, affected individuals and families can feel very isolated and require a lot of support. ausEE also supports the medical community with the provision of free patient resources to assist them in caring for their patients.

**Objective Activities:**

* Coordination of support networks for those living with an EGID including hosting online support groups and face-to-face support group meetings
* Ensuring the needs of all Australians living with EGIDs have access to support with a focus on increasing our capacity to reach those living in regional and remote locations
* Maintaining web-based information for the purposes of disseminating accurate information on EGIDs and raising awareness for EGIDs
* Managing our 1300 Information phone line
* Production and distribution of patient resources including EGID medical information brochures and children’s books on EGIDs to public and private hospitals, allergy and gastroenterology clinics around Australia (patient resources are reviewed and approved by our Medical Advisory Board of EGID specialists in Australia)
* Further outreach to the health sector to develop networks and partnerships to support adequate patient care pathways
* Providing relevant evidence-based information to medical practitioners (including doctors, nurses and allied health professionals) via Quarterly medical professionals’ newsletters
* Disseminating relevant evidence-based information to individuals, families, communities via social media and through Monthly newsletters
* Conducting a survey of our members on issues (if any) of access to specialist’s care, the role of primary care in managing EGID, particularly for people living in rural and remote areas where there is limited access to specialists with the objective to identify efficiencies and gaps of health services and resulting in the provision of relevant, well-informed information and advice to the Australian Government
* Approaching key stakeholders and healthcare professionals and conduct a round table discussion on the feasibility for developing a Standards of Care and Treatment Guidelines for EGIDs in Australia to improve quality of care for all patients with EGIDs

# Objective 2

**Awareness Projects for Timely Diagnosis**

**Implementation Cost:** $30,000

EGIDs are complex to diagnose and treat and ausEE awareness raising campaigns play an important role to assist in an improved pathway to diagnosis and to provide greater knowledge and understanding of EGIDs and the impact on those affected to the wider community.

**Objective Activities:**

* Developing and promoting awareness campaigns to help people recognize the symptoms of EGIDs and seek appropriate medical advice to reach a timely diagnosis
* Hosting awareness campaigns including National EOS Awareness Week and Feeding Tube Awareness Week with an increased focus on creating more awareness and understanding by the general community, schools and child care services
* Improving the timeliness of patient diagnosis by outreaching to healthcare professionals including gastroenterologists, allergists, dietitians, paediatricians, general practitioners and raising awareness of EGIDs with a focus on increasing our capacity to reach those working in regional and remote locations
* Raising awareness to the medical community about the International Consensus Diagnostic Criteria for Eosinophilic Esophagitis and supporting the translation of relevant research into clinical care practices
* Conducting a survey of our members to identify the barriers (if any) they faced to seek a timely diagnosis, and access to the most effective treatments with the objective to identify efficiencies and gaps of health services and resulting in the provision of relevant, well-informed information and advice to the Australian Government
* Developing a project plan to host our first Australian Patient Conference for individuals living with or families caring for a child with an EGID. EGID Patient Conference will offer information by medical professionals in the field on diagnosis, research, treatment, long term impacts and novel treatments as well as provide networking opportunities, activities for children and young people
* Raising awareness to both patients and healthcare providers and encourage the use of the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR) Contact Registry

# Conclusion

Eosinophilic gastrointestinal disorders (EGIDs), whilst being classified as rare diseases, have increased in prevalence, with EoE, being the most common, now affecting 1 in 2,000 individuals and rising.

The funding investments outlined in this submission will improve the quality of life and overall wellbeing of Australians impacted by EGIDs and has the potential to bring long term savings for the Australian Government.

Investing in these initiatives to raise awareness, define the diagnosis pathway, outreach and support the community about EGIDs, can reduce strain on public healthcare and improve public healthcare services and efficiencies.

Thank you for your consideration.