



a charity dedicated to improving lives affected by eosinophilic disorders

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**2020-21 Pre-Budget Submission**

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**Social Media**

Facebook: [@ausEEInc](https://www.facebook.com/ausEEInc)

Twitter: [@auseeorg](https://twitter.com/auseeorg)

Instagram: [@ausee\_inc](https://www.instagram.com/ausee_inc/)

LinkedIn: [@ausee-inc](https://www.linkedin.com/company/ausee-inc/)

# About ausEE Inc.

Founded in 2009, ausEE Inc. is Australia’s peak national support and patient advocacy organisation representing the estimated 12,000 Australians living with an Eosinophilic Gastrointestinal Disorder (EGID) including Eosinophilic Oesophagitis (EoE).

We are a registered Australia wide charity whose mission is to improve the lives of those affected by EGIDs by providing support, evidence-based information, resources and campaigning to raise awareness and funds for further research in Australia.

ausEE Inc. is solely a volunteer-based organisation whose outreach extends to individuals, families, hospitals, health professionals, peak bodies and all Australians living with an EGID.

Internationally, ausEE is 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).

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.

Eosinophils are an important cell in the body that have many roles including defence against parasitic infections and involvement in some forms of hypersensitivity and allergy. However, in some individuals, eosinophils accumulate in the gut potentially in response to drugs, food, airborne allergens and other unknown triggers and this infiltration can cause inflammation and tissue damage.

In EGIDs, if abnormal amounts of eosinophils are found in different regions it is called:

* 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 where eosinophils are found in the oesophagus with a minimum of 15 eosinophils per high-power field required to make the diagnosis of EoE. 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. The current estimated prevalence of EoE is 1 in 2,000 individuals and rising. EoE affects people of all ages, gender and ethnic backgrounds and in some families, there may be an inherited (genetic) tendency[[1]](#footnote-2).

In its most severe form, EoE may cause scar tissue (called fibrosis) in the oesophagus.

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

* Feeding difficulty
* Difficulty in swallowing foods and/or regularly requiring a drink after eating
* A food suddenly becoming stuck in the oesophagus (called food impaction)
* Nausea, persistent vomiting and retching
* Abdominal or chest pain
* Reflux that does not respond to anti-acid medication
* Failure to thrive (failure to put on or loss of weight) due to inadequate intake

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 with biopsies are the only way to confirm the diagnosis of an EGID and EoE at present. The diagnosis cannot be based upon symptoms alone.

There is no cure for EGID and EoE, but the goal of treatment is to eliminate the eosinophils in the affected area, thereby alleviating symptoms and reducing inflammation to minimal safe levels. Treating specialists should discuss the treatment options with patients/families and tailor treatment to the individual.

Current 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 2020-21 Federal Budget.

ausEE 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 10 years since ausEE’s foundation. They are complex chronic diseases that require ongoing monitoring and management and as such have an increased burden for individuals, carers, healthcare services and the nation. ausEE provides 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. Over the years demand for our services and resources has dramatically increased, however we have remained unfunded, being an entirely volunteer run organisation that is relying predominately on donations from our supporters.

A total investment from the Australian Government of $500,000 over three years will strengthen the capacity, reach and impact of our national non-profit organisation to ensure that patients, families and carers of those with EGIDs receive the appropriate information, optimal care and support they need to improve their quality of life.

The funding of these key objectives will additionally support health professional education and the wider community to provide a better future for those living with EGIDs.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Objective | 2020/21 | 2021/22 | 2022/23 | Cost over 3 years |
| 1: Timely Diagnosis | $ 40,000 | $ 40,000 | $ 40,000 | $120,000 |
| 2: Standards of Care | $ 55,000 | $ 45,000 | $ 40,000 | $140,000 |
| 3: Evidence-based Information | $ 30,000 | $ 30,000 | $ 30,000 | $ 90,000 |
| 4: Support Services | $ 30,000 | $ 30,000 | $ 30,000 | $ 90,000 |
| 5: Community Outreach | $ 20,000 | $ 20,000 | $ 20,000 | $ 60,000 |
| Total | $175,000 | $165,000 | $160,000 | $500,000 |

# Objective 1

**Timely Diagnosis**

A survey of our members conducted in April/May 2019[[2]](#footnote-3) reported the age at diagnosis as ranging from 6 months of age to 66 years of age which highlights some important issues. There is a need to promote clinician awareness of EGIDs, especially to those working in regional, rural and remote locations to improve diagnosis timeframes. With currently no published referral/diagnosis pathway, a journey for patients to receive their diagnosis can vary greatly and a clear pathway can reduce unnecessary tests, minimise strain on other healthcare services and improve the timeliness of patient diagnosis.

Due to the lack of education and awareness of EGIDs by healthcare providers some patients resort to unscientific tests and treatments to seek answers for their ongoing symptoms when they have not been able to receive a diagnosis or have their needs met by mainstream healthcare services. Late diagnosis’s can also contribute to a patient needing more invasive treatments including feeding tubes and oesophageal dilations.

When patients present to emergency departments with a food impaction or after a choking episode or an infant is seen by their GP with persistent failure to thrive and is refusing foods due to discomfort and has multiple food allergies a referral pathway can lead to a timelier diagnosis.

**Objective Activities:**

* Planning and supporting for the development of a referral/diagnosis pathway for EGIDs in Australia by collaborating with Government, healthcare services, key stakeholders and peak medical bodies including Australasian Society of Clinical Immunology & Allergy (ASCIA) and Gastroenterological Society of Australia (GESA).
* Provision of education to the medical community on the International Consensus Diagnostic Criteria for Eosinophilic Esophagitis[[3]](#footnote-4).
* Support for the translation of relevant research into clinical care practices by communicating with key stakeholders and medical professionals.
* Conducting a survey of our members to identify the barriers they faced to seek a timely diagnosis, and access to the most effective treatments with the objective to identify efficiencies and gaps of mainstream health services and resulting in the provision of relevant, well-informed information and advice to the Australian Government.

# Objective 2

**Standards of care**

Those living with an EGID and EoE have expressed their frustration with and issues they have experienced with the many inconsistencies in the care they receive in managing their EGID. This varies hospital to hospital, clinician to clinician with no current National Standards of Care Guidelines in place. In its most severe form, EoE can cause scar tissue/fibrosis in the oesophagus and research[[4]](#footnote-5) has demonstrated that without consistent treatment and ongoing monitoring the clinical, endoscopic, and histologic features of the disease will in most cases remain active.

We surveyed our members in April/May 2018[[5]](#footnote-6) on research priorities and the development of Care and treatment guidelines for eosinophilic disorders was reported by 92% of survey respondents as being the highest priority for them.

Issues faced with the current care patients receive in managing their EGID include delay in diagnosis, access to efficient and effective treatments, poor access to multidisciplinary chronic disease care, inadequate emergency care, frequency of endoscopies, psychological impact of living with the disease not being adequately addressed and having limited ability to participate actively in their own EGID management or feeling they are having to completely manage their EGID and make decisions on their treatment without adequate support or guidance from medical professionals who themselves are often ill-equipped, especially those living in regional, rural and remote locations.

EGID is best managed by a team healthcare approach including a gastroenterologist and allergist/immunologist with support from a GP and/or paediatrician. People with EGID will also benefit from having access to a multidisciplinary team of appropriately skilled allied health professionals, both in the community and in the hospital setting according to need.

The development of Standards of Care Guidelines would substantially benefit healthcare professionals, healthcare institutions and ultimately their patients and is pivotal to achieve best clinical practice for EGIDs as well as influencing and improving quality of care and patient outcomes.

**Objective Activities:**

* Consultation with ausEE’s Medical Advisory Board[[6]](#footnote-7), additional key healthcare professionals and key stakeholders through the formation of a steering committee including peak medical bodies; ASCIA, GESA, Dietitians Association of Australia (DAA) and The Royal Australian College of General Practitioners (RACGP).
* Collaboration with stakeholders from other national peak patient bodies for chronic diseases to knowledge share on Standards of Care Guidelines.
* Develop Standards of Care Guidelines for EGIDs including EoE with extensive coordination from the steering committee to ensure coordinated, efficient, effective and appropriate care to optimise quality of life for people living with an EGID.
* Improve education on EGIDs to healthcare professionals on Standards of Care Guidelines for person-centred care which will additionally provide for greater access to multidisciplinary allied health teams including dietitians, speech pathologists, occupational therapists and psychologists.
* Conducting a survey of our members on issues of access to specialist’s care, the role of primary care in managing EGID, particularly for people living in regional, rural and remote areas where there is limited access to specialists with the objective to identify efficiencies and gaps of mainstream health services and resulting in the provision of relevant, well-informed information and advice to the Australian Government.

# Objective 3

**Evidence-based Information**

ausEE provides evidence-based information on EGIDs to individuals, families, schools, key stakeholders and the general community to help raise awareness and understanding and provide practical resources to assist those impacted with an EGID.

We support the medical community including hospitals, clinics, specialists and allied health professionals by providing free resources to assist them in caring for their patients.

Before our organisation was founded there was no information available in Australia on EGIDs to give to patients to explain a diagnosis. We have worked hard over the years consulting with our Medical Advisory Board and collaborating with International specialists and stakeholders to develop quality resources. However, being an unfunded organisation reliant on volunteers has impacted on our reach due to the costs involved in printing, postage and time restraints and we are not currently able to reach as many as needed. Funding would allow us to outreach to more Australian hospitals and clinics including in regional, rural and remote locations and for our website to be updated to a more sustainable platform.

**Objective Activities:**

* Updating and revising our current website to a new platform and maintaining this web-based information for the ongoing purpose of disseminating accurate information on EGIDs and raising awareness for EGIDs in a user friendly format.
* Continuation of our website HONcode certification assessment as being compliant with the International HONcode standard for trustworthy health information.
* Review and maintain all patient resources on EGIDs in consultation with ausEE’s Medical Advisory Board.
* Publication and distribution of patient resources including patient information folders, fact sheets, children’s books explaining EoE and medical brochures to Australian public and private hospitals, allergy and gastroenterology clinics, medical professionals including an increase in outreach to regional, rural and remote locations.
* 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.
* Maintaining our Feeding Tube Awareness website which provides a platform for links to information and resources for Australians living with a feeding tube and fosters partnerships for resource sharing with other disability and advocacy organisations.
* Managing ausEE’s 1300 Information phone line.

# Objective 4

**Support Services**

Living with an EGID greatly impacts on quality of life; physically, socially and mentally. Due to the complexity of these disorders individuals and families can feel very isolated and require a lot of support. As the only patient support organisation for EGIDs in Australia we play an important role in providing these support networks to improve patient wellbeing.

Our support networks provide opportunities for people to connect with someone else going through similar, someone who 'gets it'. With the rapid increase in prevalence of EoE since our foundation demand for ausEE’s support services has dramatically increased. Support from the government is required to ensure the needs of the estimated 12,000 Australians living with EGIDs are met and that they have access to the support they need.

Funding is requested to allow for the growth required to ensure access to support services and provide for a dedicated focus on increasing our currently limited capacity to reach two target groups, young people and those living in regional, rural and remote locations who often face obstacles to accessing support services.

**Objective Activities:**

* Facilitate, coordinate, manage, monitor and promote peer-led support networks for those living with an EGID including: 
  + online support groups/forums for adults living an EGID and parents/carers of children living with an EGID
  + support group options for teens and young adults
  + support program for children to connect with other children and their siblings
  + face-to-face support group meetings for individuals and families of all ages
* Outreach to regional, rural and remote locations about our support networks.

# Objective 5

**Community Outreach**

EGIDs are complex to diagnose and treat and awareness raising activities are vital 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.

ausEE Inc. is the only patient organisation providing Australia wide awareness about eosinophilic gastrointestinal disorders and additionally we raise awareness for those with feeding tubes as an EGID is one condition where a patient may require a feeding tube to meet their nutritional needs.

A survey of our members in June-July 2019[[7]](#footnote-8) on the social impact of EGIDs found that families are facing major on-going social, financial and employment issues as a result of EGIDs. This highlights the importance of ausEE’s goal to raise further awareness to promote inclusion and inform the community of the simple things that others can do to help their overall wellbeing.

**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 the goal of creating more awareness and understanding by the general community, schools, childcare services, friends and extended family.
* Improving the timeliness of patient diagnosis and patient care pathways by outreaching to healthcare professionals including gastroenterologists, allergists, dietitians, paediatricians, general practitioners and key stakeholders to raise awareness of EGIDs with a focus on increasing our capacity to reach those working in regional, rural and remote locations.
* Promotion of inclusiveness and understanding through general awareness campaigns and empowering individuals and families with evidence-based information.

# Conclusion

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

ausEE advocates for those impacted by EGIDs and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, healthcare and service providers and other peak bodies to Nationally address the issues identified.

Investing in these identified initiatives to define the diagnosis pathway for a timely diagnosis, provide optimal standards of care, evidence-based information, support for those affected and raise awareness with community outreach, can reduce strain on public healthcare and improve healthcare services and efficiencies, ensuring the needs of all Australians living with EGIDs are met whilst having the potential to bring long term savings for the Australian Government.

As Australia’s peak evidence-based EGID patient support organisation with 10 years’ experience supporting and advocating for the Australian EGID community, we have the passion, drive, capability and expertise to deliver. We look forward to working with the Government on the objectives outlined in this submission to improve the quality of life and overall wellbeing of Australians impacted by EGIDs.

Thank you for your consideration.

1. What are Eosinophilic Gastrointestinal Disorders (EGIDs)? <https://www.ausee.org/whatisegid.htm> [↑](#footnote-ref-2)
2. Online survey completed by 157 people conducted by ausEE Inc. via Survey Monkey in April/May 2019 on EGIDs. <https://www.ausee.org/survey-results> [↑](#footnote-ref-3)
3. Updated International Consensus Diagnostic Criteria for Eosinophilic Esophagitis: Proceedings of the AGREE Conference. Dellon, Evan S. et al. Gastroenterology, Volume 155, Issue 4, 1022 - 1033.e10 <https://www.gastrojournal.org/article/S0016-5085(18)34763-2/fulltext> [↑](#footnote-ref-4)
4. No Maintenance, No Gain in Long-term Treatment of Eosinophilic Esophagitis. Dellon, Evan S.

   Clinical Gastroenterology and Hepatology, Volume 17, Issue 3, 397 – 399. <https://www.cghjournal.org/article/S1542-3565(18)30804-8/fulltext> [↑](#footnote-ref-5)
5. Online survey completed by 72 people conducted by ausEE Inc. via Survey Monkey in April/May 2018 on ausEE research priorities. <https://www.ausee.org/survey-results> [↑](#footnote-ref-6)
6. ausEE Medical Advisory Board <https://www.ausee.org/medicaladvisoryboard.htm> [↑](#footnote-ref-7)
7. Online survey completed by 108 people conducted by ausEE Inc. via Survey Monkey in June/July 2019 on the Social Impact of EGIDs. <https://www.ausee.org/survey-results> [↑](#footnote-ref-8)