

A person in glasses looking at the camera

Description automatically generatedA person in a blue shirt

Description automatically generatedA picture containing person, indoor, young, boy

Description automatically generatedA person lying on a bed

Description automatically generatedA person looking at the camera

Description automatically generatedA person posing for a picture

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a charity dedicated to improving lives affected by eosinophilic disorders

**2021-22 Pre-Budget Submission**

**January 2021**

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# Introduction

Founded in 2009, ausEE Inc. is Australia’s peak national support and patient advocacy organisation representing 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.

Thank you for the opportunity to provide a submission for the 2021-22 Federal Budget.

ausEE Inc. is a solely volunteer run organisation whose outreach extends to individuals, families, hospitals, healthcare professionals, peak bodies, stakeholders and the wider community. We support the Government and Australians by filling serious gaps in support services, supply information resources for patients and clinicians and provide feedback and advice to Government through written submissions and stakeholder engagement requests that contribute to public policy.

EGIDs are chronic inflammatory disorders characterized by eosinophilic infiltration in the gastrointestinal tract. The most common type of EGID is EoE, where the infiltration is found in the oesophagus, which causes inflammation and can lead to scarring, strictures and narrowing of the oesophagus, putting patients at risk of food impaction. EGIDs are rare diseases, however in EoE the prevalence has rapidly increased from 1 in 10,000 to 1 in 2,000 people and rising in the 11 years since ausEE’s foundation.

EGIDs have a significant impact on health and wellbeing and individuals and families are facing on-going social, financial, education and employment issues because of EGIDs. Additionally, they have an impact on the Australian economy and to date, EGIDs and EoE, which has become a more common chronic disease, have been totally overlooked in national health priorities. Now is the time to act.

Over the years demand for our services and resources has dramatically increased, however we have remained unfunded. Funding is now critical for us to continue to provide the support and services to Australians living with EGIDs. EGIDs 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.

A total investment from the Australian Government of $495,000 over three years will allow for a continuation of services and 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 assist in earlier diagnosis, support for health professional education and awareness from the wider community to provide a better future for those living with EGIDs.

These key objectives were also raised in our submission to the Parliamentary Inquiry into Allergies and Anaphylaxis and discussed at the public hearing and it was disappointing that these important issues and recommendations were not addressed in the Committee’s report ‘Walking the allergy tightrope’. Our continued requests to Government on these important issues for several years have repeatedly not been responded to.

As the public voice for Australians living with an EGID, we thank you for reading our 2021-22 pre-budget submission and for your consideration of our proposal.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Objective | 2021/22 | 2022/23 | 2023/24 | Cost over 3 years |
| 1: Timely Diagnosis | $ 40,000 | $ 38,000 | $ 36,000 | $114,000 |
| 2: Standards of Care | $ 55,000 | $ 50,000 | $ 45,000 | $150,000 |
| 3: Evidence-based Information | $ 30,000 | $ 33,000 | $ 36,000 | $ 99,000 |
| 4: Support Services | $ 20,000 | $ 22,000 | $ 24,000 | $ 66,000 |
| 5: Community Outreach | $ 20,000 | $ 22,000 | $ 24,000 | $ 66,000 |
| Total | $165,000 | $165,000 | $165,000 | $495,000 |

# Objective 1

**Timely Diagnosis**

There is currently no defined referral/diagnosis pathway for EGIDs and a journey to receive a diagnosis varies greatly. A survey of our members conducted in April/May 2019[[1]](#footnote-2) 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 great need to promote clinician awareness of EGIDs, especially to those working in regional, rural and remote locations to improve diagnosis timeframes.

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A diagnosis pathway can reduce unnecessary tests and strain on healthcare services and improve the timeliness of a diagnosis which may result in the need for less invasive treatments.

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It took 16 years to finally get a diagnosis. Even after complaining of constant pain when I swallowed food and having multiple trips to hospital with food stuck in my oesophagus. I now have monthly dilations to try and widen my severely damaged oesophagus.

During the COVID-19 pandemic, there were even further delays reported by our members with temporary suspensions placed on non-urgent elective surgeries which included endoscopies. Endoscopy with biopsies is the only method for diagnosing and reliably monitoring the treatment of EGIDs so these measurers, whilst warranted, understandably negatively impacted on those living with EGIDs.

- Nioka

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. A delayed diagnosis can also contribute to a patient needing more invasive treatments including feeding tubes and oesophageal dilations, one member reporting they’d suffered a tear of the oesophagus due to the extent of long-term inflammation and strictures.

A referral pathway is critical for patients who present with certain characteristics of the disease such as, emergency food impactions (choking episode), children who are failing to thrive or an infant who may be refusing to eat. An effective referral pathway can lead to a timelier diagnosis, less visits to the emergency department and greater care for patients.

**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[[2]](#footnote-3).
* 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.

**Total Investment:** $114,000 over 3 years

# Objective 2

**Standards of care**

People living with an EGID experience many inconsistencies in the care and medical advice they receive to manage their EGID, day-to-day, as outpatients and when accessing emergency care. This varies greatly hospital to hospital, clinician to clinician as there are no National Standards of Care Guidelines in place. In its most severe form, EoE can cause scar tissue/fibrosis in the oesophagus and research[[3]](#footnote-4) 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 were declined a referral to an allergy specialist for my son as our local hospital didn’t have an understanding of how to handle EoE. When we finally had an appointment with a gastroenterologist who is an EoE specialist at the capital city hospital he said he would never have put our son on the treatment he had been put on when he was first diagnosed. Our EoE specialist has now arranged for a new referral to an allergy specialist.

This inconsistency in the information and care provided is a real concern as left untreated EoE can result in long-term tissue damage and chronic inflammation and in EoE, the patient may end up requiring ongoing oesophageal dilations and emergency department visits.

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Some of the issues in the current care provided that have been reported by our members include delay in diagnosis, access to efficient and effective treatments, access to multidisciplinary chronic disease care, inadequate emergency care, variances in frequency of endoscopies and psychological impact on the individual and family unit of living with the disease not being adequately addressed. Issues were also reported in the 2020 publication in Digestive Diseases and Sciences titled ‘EoE Down Under Is Still EoE: Variability in Provider Practice Patterns in Australia and New Zealand Among Pediatric Gastroenterologists’[[4]](#footnote-5).

- Amy

Patients currently have limited opportunity to participate actively in their own EGID management or are feeling like they are having to completely manage their EGID and make decisions on their treatment in some cases without adequate support or guidance from medical professionals who themselves are often ill-equipped, especially those living in regional, rural and remote locations.

EGIDs are 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 which can include dietitians, speech pathologists, occupational therapists and psychologists, 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 and provide patient-centred care for EGIDs. Consistent and equitable care will improve patient outcomes and overall wellbeing of individuals and families.

**Objective Activities:**

* Consultation with ausEE’s Medical Advisory Board[[5]](#footnote-6), additional key healthcare professionals and key stakeholders through the formation of a steering committee including peak medical bodies; ASCIA, GESA, Dietitians Australia 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.
* Develop outreach programs to healthcare professionals including those located in regional, rural and remote Australia.
* 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.
* Investigation and outreach to hospitals on the feasibility of the development of EoE Clinics in all major capital city Australian hospitals, with at a minimum the service including a gastroenterologist, allergist and specialist dietitian. This structure would potentially improve patient outcomes by providing a multi-disciplinary team approach by the one health service which will also reduce duplication and contradictions in medical advice delivered to the patient.

**Total Investment:** $150,000 over 3 years

# 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.

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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.

”

We live in regional Australia where there are no paediatric gastroenterologists, so we need to travel 8 hours by train for endoscopies and appointments. Doctors in our area don’t have any knowledge of anything ‘out of the ordinary’ and would benefit from receiving some evidence-based education.

Before ausEE Inc. was founded there was no information available in Australia on EGIDs to give to patients to explain a diagnosis.

- Peta

We have worked hard over the years consulting with our Medical Advisory Board and collaborating with international specialists and stakeholders to develop quality evidence-based information and resources. However, being an unfunded organisation reliant on volunteers has impacted on our capacity 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 upgraded.

**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 regular medical professionals’ newsletters.
* Disseminating relevant evidence-based information to individuals, families, communities via social media and through regular newsletters.
* Maintaining our National EOS Awareness Week website to provide information on EGIDs to help increase awareness.
* 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.
* Participation and collaboration Internationally with the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR), EGID patient advocacy groups and researchers through EGID Partners.
* Collaboration with peak medical bodies and stakeholders including Australasian Society of Clinical Immunology & Allergy (ASCIA) and Gastroenterological Society of Australia (GESA).
* Managing ausEE’s 1300 Information phone line.

**Total Investment:** $99,000 over 3 years

# 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 regular support. As the only patient support organisation for EGIDs in Australia we play a vital role in providing these support networks to improve patient wellbeing.

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Our support networks provide opportunities for people to connect with other members throughout Australia, enabling greater sense of community through shared experiences.

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It was a long emotional journey to get a diagnosis and has been a long emotional journey since. For me hearing other people’s experiences through ausEE’s support networks made me realise I was not alone and that there are other people out there facing the same struggles, concerns and worries as I do daily. Knowing there were people who understood was the most comforting feeling I could have been given.

With the rapid increase in prevalence of EoE since ausEE’s inception, demand for our support services has been increasing over the years. During the COVID-19 pandemic we have experienced an increase in new members who utilise our support services.

- Jacqui

It is well recognised that the ongoing pandemic is taking a toll on the mental health of the greater population including feelings of isolation, fear of illness, uncertainty for the future and additional strain on finances. These challenges are amplified for people living with a chronic condition like EGIDs. Support from the government is required to ensure the needs of the estimated 13,000 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 high-risk groups such as 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 with implementation of COVIDSafe plans
  + hosting virtual support group chats through Zoom, tailored to parents/carers, teens and adults living with an EGID/EoE
* Targeted outreach to increase awareness about our support networks with a dedicated focus on extending our reach those in regional, rural and remote locations.

**Total Investment:** $66,000 over 3 years

# 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 advocacy organisation providing Australia wide awareness about eosinophilic gastrointestinal disorders, while actively and collaboratively raising awareness for all Australians living with feeding tubes. We do this important outreach as an EGID is one condition where a patient may require a feeding tube to meet their nutritional needs and if they are using elemental formula as a treatment option.

- Jacqui

”

I have found this a very isolating condition due to the public knowledge of this disease being minimal. Friends and family struggle to understand and no one can exactly relate to the daily implications with this condition; the borderline fear of food and fear of certain social situations involving food.

A survey of our members in June-July 2019[[6]](#footnote-7) on the social impact of EGIDs found that families are facing major on-going social, financial and employment issues because 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.
* Promotion of inclusiveness and understanding through general awareness campaigns and empowering individuals and families with evidence-based information.
* Hosting EGID awareness campaigns including our annual National EOS Awareness Week (NEOSW) with the goal of creating more awareness and understanding of the impact of eosinophilic gastrointestinal disorders by outreaching to the general community, schools, childcare services, friends and extended family.
* Hosting Feeding Tube Awareness Week (FTAW) annually with the aim to increase awareness and understanding to the greater community about tube feeding and raise some of the challenges faced and highlight the day-to-day impact on individuals, carers and families. FTAW is about bringing everyone together who has a feeding tube, whatever the reason may be.
* 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.

**Total Investment:** $66,000 over 3 years

# Conclusion

There is a significant social and financial impact of EGIDs not only at the patient level, but on the supporting family and community. 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, helping to provide a better future whilst having the potential to also bring long term savings for the Australian Government.

As Australia’s peak evidence based EGID patient support organisation with 11 years’ experience supporting and advocating for the Australian EGID community, we have the passion, drive, capability and expertise to deliver, however we need the Government’s support. Being a solely volunteer run organisation, our resources have for the long term been limited and with the ever-growing increase in demand for our services, financial support is needed to not only continue but dramatically increase our impact.

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.

Information 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[[7]](#footnote-8).

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.

# Contact Information

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**Websites**

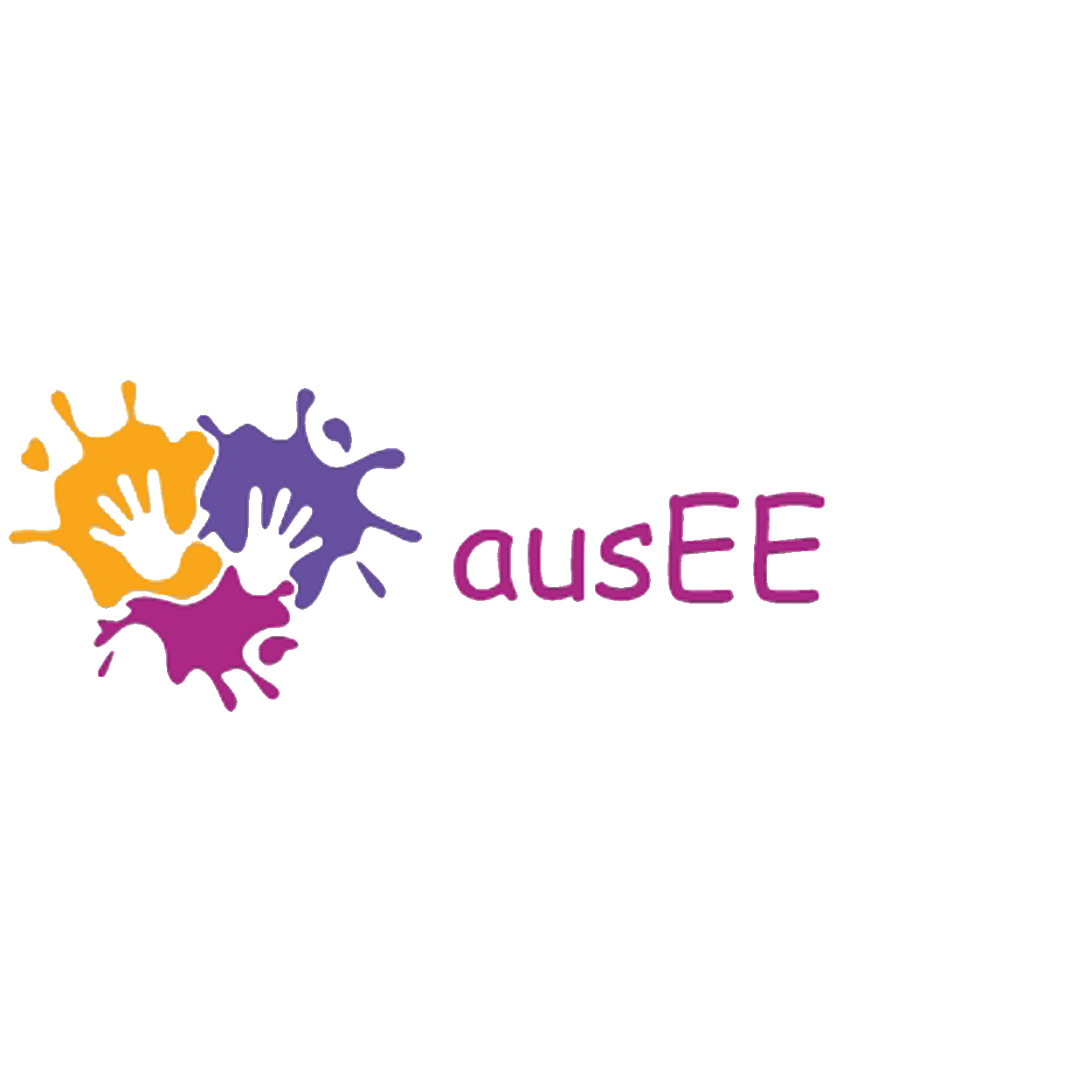
[www.ausee.org](http://www.ausee.org)

[www.eosaware.com](http://www.eosaware.com)

[www.feedingtubeaware.com.au](http://www.feedingtubeaware.com.au/)

**Social Media**

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a charity dedicated to improving lives affected by eosinophilic disorders

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1. Online survey conducted by ausEE Inc. in April/May 2019 on EGIDs. <https://www.ausee.org/survey-results> [↑](#footnote-ref-2)
2. 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-3)
3. 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-4)
4. Sharma, A., Eluri, S., Philpott, H. *et al.* EoE Down Under Is Still EoE: Variability in Provider Practice Patterns in Australia and New Zealand Among Pediatric Gastroenterologists. *Dig Dis Sci* (2020). <https://doi.org/10.1007/s10620-020-06534-6> [↑](#footnote-ref-5)
5. ausEE Medical Advisory Board <https://www.ausee.org/medicaladvisoryboard.htm> [↑](#footnote-ref-6)
6. Online survey by ausEE Inc. in June/July 2019 on the Social Impact of EGIDs. <https://www.ausee.org/survey-results> [↑](#footnote-ref-7)
7. What are Eosinophilic Gastrointestinal Disorders (EGIDs)? <https://www.ausee.org/whatisegid.htm> [↑](#footnote-ref-8)