a charity dedicated to improving lives affected by eosinophilic disorders

2022-23 Pre-Budget Submission

January 2022

AUSEE INC. 2022-23 PRE-BUDGET SUBMISSION

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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 disease, with an established focus on eosinophilic gastrointestinal disorders (EGIDs).

EGIDs are chronic inflammatory diseases characterized by eosinophilic infiltration in the gastrointestinal tract. The most common type of EGID is eosinophilic oesophagitis (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 considered rare diseases, however in EoE the prevalence has rapidly increased from 1 in 10,000 to [1]0.5-1 in 1,000 people and rising in the 12 years since ausEE's foundation. EoE is now the most common cause of food impaction. The incidence of non-EoE EGIDs in Australia is unknown; however, recent research, conducted by our medical advisory board member, Laurette Professor Nicholas J. Talley, has identified they may be highly underdiagnosed. Until recently, eosinophilic gastritis and/or eosinophilic duodenitis (EG/EoD) were thought to be very rare EGIDs but new evidence[2] indicates that EG/EoD appears to be a lot more common than previously thought and may be a common cause of chronic unexplained gastrointestinal symptoms.

ausEE Inc. is a registered Australia wide charity who consistently eases the burden on the Australian healthcare system. Our mission is to improve the lives of those affected by eosinophilic diseases through providing support, evidence-based information, resources, advocacy and by campaigning to raise awareness and funds for further research in Australia. Without the critically needed funds and support of this request, ausEE Inc. is at risk of not being able to deliver our services. Without these services the burden will be shifted back to the public health system.

ausEE Inc. is a predominately volunteer run organisation whose outreach extends to individuals, families, hospitals, healthcare professionals, peak bodies, stakeholders and the wider community throughout Australia. We support the Government and Australians by filling

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[1] Dellon ES. Epidemiology of eosinophilic esophagitis. Gastroenterol Clin North Am. 2014;43(2):201-218. doi:10.1016/j.gtc.2014.02.002 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4019938/

[2] Eosinophilic stomach & intestinal disorders frequently misdiagnosed: https://medicalresearch.com/author-interviews/eosinophilic-stomach-intestinal-disorders-frequently-misdiagnosed/57455/
https://www.gastrojournal.org/article/S0016-5085(21)01011-8/pdf

significant 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 have a significant impact on health and wellbeing. Individuals and families are facing on-going social, financial, education and employment issues because of EGIDs. Historically, EGIDs have been a rare chronic disease, however, the prevalence of EGIDs and EoE is becoming more significant as diagnosis techniques and awareness increase. Globally[3], EoE has rapidly become a major cause of upper gastrointestinal morbidity, but health care costs related to EoE[4] remain poorly documented in Australia. EGIDs have a significant impact on the Australian economy and to date, have been totally overlooked in national health priorities. Now is the time to act.

Over the years demand for ausEE Inc.'s services and resources has dramatically increased, placing a strain on our resources. Funding is now critical for us to continue to provide the support and services to Australians living with eosinophilic diseases. 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. EoE has a high treatment burden for carers and very frequently, we hear stories of families that have had to decrease hours or cease work altogether to care for children and family members who have been diagnosed with an EGID. This impacts not only the individual and immediate family psychosocial wellbeing but also the economy. When members of our community cease or decrease work, they pay less tax, require more significant social benefits as well as requiring medical and social support to manage the chronic disease. This was also reported in an Australian research study[5] on treatment burden and impact on health-related quality of life (HRQoL) for children with EoE and their carers.

A total investment from the Australian Government of $495,000 over three years to support these important objectives, will allow for a continuation of the critical services ausEE provides and the development and implementation of new initiatives. It will also strengthen the

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[3] Jensen ET, Kappelman MD, Martin CF, Dellon ES. Health-care utilization, costs, and the burden of disease related to eosinophilic esophagitis in the United States. Am J Gastroenterol. 2015;110(5):626-632. doi:10.1038/ajg.2014.316 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4590991/

[4] Ransome Ekea, Evan S. Dellon Hospitalization trends and determinants of inpatient costs for eosinophilic esophagitis patients in the United States: results from the Nationwide Inpatient Sample analysis http://www.annalsgastro.gr/index.php/annalsgastro/article/view/5674/5223

[5] Nicole Hannan, BHSc, BSc, Sara S McMillan, PhD, Evelin Tiralongo, PhD, Amie Steel, PhD, Treatment Burden for Pediatric Eosinophilic Esophagitis: A Cross-Sectional Survey of Carers, Journal of Pediatric Psychology, Volume 46, Issue 1, January-February 2021, Pages 100–111, https://doi.org/10.1093/jpepsy/jsaa095

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.

Many of these recommendations and objections were also raised in our submission and public hearing for the Parliamentary Inquiry into Allergies and Anaphylaxis[6] and supports the priorities of the National Strategic Action Plan for Rare Diseases[7] which ausEE was a stakeholder in the development. Furthermore, they align with the aims and principles of the National Preventive Health Strategy 2021-2030[8]. People with an EGID face challenges accessing diagnosis, specialist care, information, support and lack of community understanding and their unmet needs are significant. These must be addressed because the consequences have detrimental impacts on patients, healthcare systems and society.

As the public voice for Australians living with an EGID, we thank you for reading our 2022-23 pre-budget submission and for your consideration of our proposal.

Objective	**2022/23**	**2023/24**	**2024/25**	**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

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[6] ausEE Inc. Submission No. 168 - Parliamentary Inquiry into Allergies and Anaphylaxis https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/Allergiesandanaphylaxis/Submissions

[7] National Strategic Action Plan for Rare Diseases https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases

[8] National Preventive Health Strategy 2021-2030 https://www.health.gov.au/resources/publications/national-preventive-health-strategy-2021-2030

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[9] reported the age at diagnosis as ranging from 6 months of age to 66 years of age which highlights the work that must be undertaken to engage with stakeholders in the medical community to raise awareness of these rare chronic diseases. The findings from research conducted in South Australia and published in August 2021[10] showed that the median duration of symptoms prior to diagnosis of EoE was >1-4 years in childhood-onset disease (44%) and ≥10 years in adult-onset disease (34%).

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 as this has a direct consequence on future quality of life and cost of medical management.

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. Early detection and awareness of risk factors and co-morbidities is critical so that specialist referrals can be made as delayed diagnosis and treatment increases disease burden and severity including risk of permanent damage[11] and poorer long term outcomes.

During the COVID-19 pandemic, there were further delays reported by our members with temporary suspensions placed on non-urgent elective surgeries which included endoscopies. Endoscopy with biopsies is currently 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. ausEE Inc. is hopeful that with increased awareness of EGIDs, further research can be supported to investigate, develop and implement less invasive diagnostic tools.

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[9] Online survey conducted by ausEE Inc. in April/May 2019 on EGIDs. https://www.ausee.org/survey-results

[10] Stephanie Wong et al. Characteristics and progression of childhood-onset and adult-onset eosinophilic esophagitis https://onlinelibrary.wiley.com/doi/10.1111/jgh.15660

[11] Alain M. Schoepfer et al. Delay in Diagnosis of Eosinophilic Esophagitis Increases Risk for Stricture Formation in a Time-Dependent Manner https://www.gastrojournal.org/article/S0016-5085(13)01161-X/fulltext

Due to healthcare providers' lack of education and awareness[12] of EGIDs, 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. The burden this places on medical services when diagnosis is delayed is significantly higher than if someone were to be diagnosed and treated appropriately from the onset of symptoms.

A referral pathway supported by clear referral guidelines, referral criteria, identified recognised specialists, diagnostic criteria and waiting time targets 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. ausEE Inc. seeks to work with stakeholders within the medical community to identify and develop a national referral pathway to increase early intervention thus reducing the impact delayed treatment has on emergency services.

Objective Activities:

- Planning and support for the development of a referral/diagnosis pathway for EGIDs in Australia by collaborating with Government, Healthpathways, 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[13].

- Support for the translation of relevant research into clinical care practices by communicating with key stakeholders and medical professionals.

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[12] Assessing Physicians' Awareness of Eosinophilic Esophagitis on the Treatment and Diagnosis of Patients https://www.omicsonline.org/open-access/assessing-physicians-awareness-of-eosinophilic-esophagitis-on-the-treatment-and-diagnosis-of-patients.pdf

[13] 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

- Conducting research 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 inefficiencies 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

Refer budget supporting documentation for a breakdown of specific activities.

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[14]. 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[15] conducted by our medical advisory board member, Professor Evan Dellon, identified that without consistent treatment and ongoing monitoring the clinical, endoscopic and histologic features of the disease will in most cases remain active, impacting significantly on lifelong quality of life.

This inconsistency in the information and care provided is a real concern. Left untreated EGIDs and 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. This is both painful as well as costly to the individual as well as the medical system. If EoE is left untreated, around 30-50% of children and adults with EoE will eventually get a food impaction[16], which may have to be removed in hospital. A gap in care of ≥2 years in patients with EoE is associated with signs of increased disease activity, and progression to fibrostenosis[17].

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 by our medical advisory board members, Dr Ajay Sharma and Dr Hamish Philpott, titled 'EoE

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[14] ausEE Inc. Submission No. 168 - Parliamentary Inquiry into Allergies and Anaphylaxis – Case Study page 6 https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/Allergiesandanaphylaxis/Submissions

[15] 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

[16] ASCIA Eosinophilic Oesophagitis (EoE) FAQ 2021: https://www.allergy.org.au/patients/food-other-adverse-reactions/eosinophilic-oesophagitis

[17] Nicole C. Chang et al. A Gap in Care Leads to Progression of Fibrosis in Eosinophilic Esophagitis Patients https://www.cghjournal.org/article/S1542-3565(21)01141-1/pdf

Down Under Is Still EoE: Variability in Provider Practice Patterns in Australia and New Zealand Among Pediatric Gastroenterologists'[18].

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, particularly those living in regional, rural and remote locations. Access to a qualified specialist team is crucial and this presents additional challenges, telehealth options should be offered for follow up appointments with dedicated specialists, where appropriate, particularly in rural, regional and remote communities.

EGIDs are best managed by a team healthcare approach[19] including a gastroenterologist and allergist/immunologist with support from a GP and/or paediatrician. This is especially important due to increased risk of and to provide a holistic health care approach to comorbidities[20]. 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. Additionally, a coordinated multidisciplinary transition pathway[21] is needed to ensure young people progress to adult care with the skills to self-manage their condition and advocate independently.

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. It would alleviate the pressure on primary care physicians who are dealing with the “unknown” and provide options

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[18] 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

[19] Evan S. Dellon Cost-effective care in eosinophilic esophagitis https://www.annallergy.org/article/S1081-1206(19)30294-7/fulltext

[20] Chehade M, Jones SM, Pesek RD, et al. Phenotypic Characterization of Eosinophilic Esophagitis in a Large Multicenter Patient Population from the Consortium for Food Allergy Research. J Allergy Clin Immunol Pract. 2018;6(5):1534-1544.e5. doi:10.1016/j.jaip.2018.05.038 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6132253/

[21] E. S. Dellon, P. D. Jones, N. B. Martin, M. Kelly, S. C. Kim, K. L. Freeman, E. P. Dellon, M. E. Ferris, N. J. Shaheen, Health-care transition from pediatric to adult-focused gastroenterology in patients with eosinophilic esophagitis., Diseases of the Esophagus, Volume 26, Issue 1, 1 January 2013, Pages 7–13, https://doi.org/10.1111/j.1442-2050.2011.01315.x

for care when standard practice has been exhausted. Consistent and equitable care will improve patient outcomes and overall wellbeing of individuals and families.

Objective Activities:

- Consultation with ausEE's Medical Advisory Board[22], 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, undertaking a similar approach to Crohn's and Colitis Association's development of the [23]Australian IBD Standards: Standards of healthcare for people with inflammatory bowel disease in Australia.

- 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, through all ages and stages.

- Improve education on EGIDs to healthcare professionals on the developed 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 research of our members on issues of access to specialist's care, appropriative treatments, 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, quality of life, effects on employment/schooling and carer duties with the objective to identify

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[22] ausEE Medical Advisory Board https://www.ausee.org/medicaladvisoryboard.htm

[23] Australian IBD Standards: https://www.crohnsandcolitis.com.au/ibdqoc/australian-ibd-standards/

inefficiencies and gaps of mainstream health services and supports 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 has been successful in countries such as the United States but is not widely used in Australia and would potentially improve patient outcomes by providing a multidisciplinary team approach by the one health service. This will also reduce duplication and contradictions in medical advice delivered to the patient, thus providing streamlined and cost-effective treatment and diagnosis.

Total Investment: $150,000 over 3 years

Refer budget supporting documentation for a breakdown of specific activities.

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 have an important goal to increase our coverage to encompass all eosinophilic diseases by 2025.

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

ausEE is an important conduit for translating and communicating information to our members about accessing relevant health systems including telehealth, My Health Record, Chronic Disease Management plans etc. as the important ‘bridge between’, which is essential to improving health literacy.

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 and for 12 years having been previously reliant on volunteers alone had an impact on our capacity due to the costs involved in resourcing, printing, postage and time restraints and we have not been able to reach as many as needed. Funding would allow us to continue to outreach to Australian hospitals and clinics and potentially increase our reach into regional, rural and remote locations. Additionally, the ausEE website can be upgraded in order to give better provision of accurate and relevant information which is necessary to support people with eosinophilic diseases and their carers to manage the condition.

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 and accessible format.

- Development of new website resource pages with evidence-based information on all rare eosinophilic diseases including collaboration with key stakeholders, Australian and international and ausEE's Medical Advisory Board.
- Development of a new website resource page with information from key stakeholders about access to mental health information and support services to assist people with eosinophilic diseases including Government services. i.e. Mental Health Treatment Plan.
- Development of a new website resource page with evidence-based information on co-morbid conditions of eosinophilic gastrointestinal diseases and promotion awareness campaign to co-morbid conditions disease related patient organisations.
- Continuation of our website HONcode certification assessment as being compliant with the International HONcode standard for trustworthy health information.
- Review, revise 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 feeding tubes 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, support 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[24].

- 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 which supports numerous patients and their carers Australia wide.

Total Investment: $99,000 over 3 years

Refer budget supporting documentation for a breakdown of specific activities.

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[24] EGID Partners https://egidpartners.org/

Objective 4

SUPPORT SERVICES

Living with an EGID greatly impacts on [25]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, and additionally providing support to the tube feeding community, we play a vital role in providing these support networks to improve patient wellbeing.

Our support networks provide opportunities for people to connect with other members throughout Australia, enabling greater sense of community through shared experiences. Effective peer support can help reduce feelings of isolation, anxiety, and stress, as well as increase confidence, independence and self-management.

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.

EoE has a significant impact on quality of life with 31% of EoE patients reporting at least one psychiatric or neuropsychiatric comorbidity, including anxiety and depression[26].

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 are met for the estimated 13,000-26,000 Australians living with EoE, and the thousands who have a non-EoE EGID but are currently undiagnosed.

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[25] Health-Related Quality of Life and Costs Associated with Eosinophilic Esophagitis: A Systematic Review Vincent Mukkada et al. https://www.cghjournal.org/article/S1542-3565(17)30782-6/fulltext

[26] Taft TH, Guadagnoli L, Edlynn E. Anxiety and Depression in Eosinophilic Esophagitis: A Scoping Review and Recommendations for Future Research. *J Asthma Allergy*. 2019;12:389-399 https://doi.org/10.2147/JAA.S193045

Funding is needed 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, individuals/parents/carers managing tube feeding
  - 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 and individuals/parents/carers managing tube feeding
  - increasing the above support networks to cover other eosinophilic diseases
- Targeted outreach to increase awareness about our support networks with a dedicated focus on extending our reach those in regional, rural and remote locations.
- Engagement and consultation with our community to ensure that new initiatives and supports meet their needs.
- Develop and distribute Patient Toolkits to people with EGIDs. These kits will include plain English disease specific information, information on our support networks including access to trusted mental health and medical support services.

Total Investment: $66,000 over 3 years

Refer budget supporting documentation for a breakdown of specific activities.

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 particularly if they are using elemental formula as a treatment option.

A survey of our members in June-July 2019[27] 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.

Targeted, tailored education and awareness campaigns about EGIDs are also necessary for health care professionals in both primary and secondary care to enable timely diagnosis and access to appropriate care.

Objective Activities:

- Develop and promote awareness campaigns to help people recognize the symptoms of EGIDs, seek appropriate medical advice to reach a timely diagnosis i.e. 'Could it be EoE?' 'Have you heard about?'
- Promotion of inclusiveness and understanding through general awareness campaigns and empowering individuals and families with evidence-based information and lived experience i.e. 'My EoE' videos/images series.
- 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 EGIDs by outreaching to the general community, schools, childcare services, friends and extended family.

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[27] Online survey by ausEE Inc. in June/July 2019 on the Social Impact of EGIDs. https://www.ausee.org/survey-results

- 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 to provide support and celebrate the strength it takes to live with and support people who require feeding tubes.

- 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.

- Develop and deliver education and awareness campaigns to health professionals with a ‘Could it be EoE?’ Campaign, an EGID Factsheet, targeted promotions through health provider software e.g. HealthShare, ThinkGP and Australian Doctor Group.

Total Investment: $66,000 over 3 years

Refer budget supporting documentation for a breakdown of specific activities.

Conclusion

There is a significant social and financial impact of EGIDs not only at the patient level, but also supporting their family and the 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 [28]0.5-1 in 1,000 individuals and rising as awareness around the disease increases.

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, up-to-date evidence-based information, support for those affected and raise awareness with community outreach. It can also can reduce strain on public healthcare and improve healthcare services and efficiencies, ensuring the needs of all Australians living with EGIDs are met. Achieving these goals will help to provide a better future for those living with EGIDs, 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 12 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 predominately volunteer run organisation, our resources for long term planning on our existing funding streams, without Government support has been limited. With the ever-growing increase in demand for our services as awareness and diagnosis grows, financial support is needed to not only continue, but to also increase our impact dramatically.

We look forward to working with the Australian 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.

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[28] Evan S. Dellon, Ikuo Hirano, Epidemiology and Natural History of Eosinophilic Esophagitis https://www.gastrojournal.org/article/S0016-5085(17)35971-1/fulltext

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)
- stomach and small intestine (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 1-2,000 individuals and rising. EoE affects people of all ages, gender and ethnic backgrounds and in some families, there may be an inherited (genetic) tendency[29].

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).

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[29] What are Eosinophilic Gastrointestinal Disorders (EGIDs)? https://www.ausee.org/whatisegid.htm

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

ausEE Inc.
PO Box 9303
Pacific Paradise Qld 4564

Tel 1300 923 043
Email admin@ausee.org

Websites
www.ausee.org
www.eosaware.com
www.feedingtubeaware.com.au

Social Media

facebook.com/ausEEInc

instagram.com/ausee_inc

twitter.com/ausEEorg

linkedin.com/company/ausee-inc

ausEE

a charity dedicated to improving lives affected by eosinophilic disorders

ABN 30 563 569 016