



ausEE Inc.

a charity dedicated to improving lives
affected by an eosinophilic disease

Annual Report

2022

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About Us

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 diseases (EGIDs).

Founded in 2009, ausEE Inc. is an Australia wide health promotion charity, registered with the Australian Charities and Not-for-profits Commission and endorsed by the Australian Taxation Office as a deductible gift recipient.



ausEE Inc. is predominately a volunteer run organisation whose outreach extends to individuals, families, hospitals, health professionals, peak bodies, stakeholders and the wider community.

ACKNOWLEDGEMENT OF COUNTRY

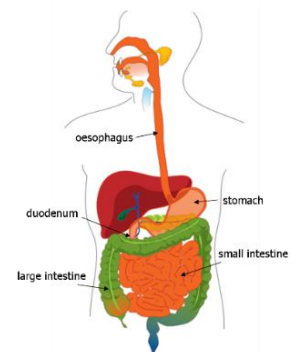
In the spirit of reconciliation, ausEE Inc. acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

WHAT ARE EOSINOPHILIC DISEASES?

Eosinophils are a type of white blood cell that have a role in immune system responses to medical conditions such as infections, inflammation, and allergies. If a person has too many eosinophils without another known cause, it may be because of an eosinophilic disease. The diagnosis depends on where in the body the eosinophils are found.

In eosinophilic gastrointestinal diseases (EGIDs) the eosinophils are found in increased numbers in the gastrointestinal tract. The most known type of EGID is eosinophilic oesophagitis (EoE), where the eosinophilic infiltration is in the oesophagus. This can cause inflammation that can lead to scarring, strictures and narrowing of the oesophagus, putting people at risk of food impactions (food getting stuck in the oesophagus). An endoscopy with biopsies is required to confirm the diagnosis of an EGID.

The current estimated prevalence of EoE is 1 in 1,000-2,000 individuals and rising. EGIDs are chronic diseases that require ongoing management and monitoring with endoscopies and repeat biopsies. There is no cure and more research is needed.



Our Mission

ausEE's 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.



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OUR VISION

ausEE's vision is:

- To reach all those affected by eosinophilic diseases in Australia.
- To be the catalyst for further research in the medical field; and ultimately find a cure.
- To be the peak eosinophilic diseases organisation in Australia, a trusted place for people to turn to for support and information.

OUR OBJECTIVES

ausEE's objectives are:

- To improve the quality of life for people with eosinophilic diseases and other associated conditions.
- To help and support anyone diagnosed with or caring for someone with an eosinophilic disease and other associated conditions.
- To be a reliable and trusted source of information on eosinophilic diseases and other associated conditions.
- To develop, distribute and promote education, information and resources on eosinophilic diseases and other associated conditions.
- To create greater public awareness and understanding of eosinophilic diseases and other associated conditions and their impact.
- To engage in advocacy on behalf of people living with eosinophilic diseases and other associated conditions.
- To encourage, initiate, assist and support research into eosinophilic diseases and other associated conditions.
- To collaborate, partner and otherwise join with other persons or organisations, including research institutions and commercial entities in order to advance the objectives.
- To raise funds to enable the furtherance of these objectives.

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Who We Are

BOARD MEMBERS

Mercedes Hinchcliff – President

Mariya Taylor – Secretary

Kristin Paterson – Treasurer

Kylie Gwynne – Board Member

Sarah Gray – Board Member

ausEE Inc. is also supported by committee members and volunteers.

Facebook Groups Admins and Moderators: Tracie Sillers, Sarah Gray and Mercedes Hinchcliff.

MEDICAL ADVISORY BOARD

Laureate Professor Nicholas J. Talley AC *Professor of Medicine and Neurogastroenterologist*

Professor Pete Smith *Allergist and Immunologist*

Associate Professor Hamish Philpott *Gastroenterologist and Hepatologist*

Dr Looi Ee *Paediatric Gastroenterologist and Hepatologist*

Dr Sam Mehr *Paediatric Allergist, Immunologist and Immunopathologist*

Dr Jeremy Rosenbaum *Paediatric Gastroenterologist and Hepatologist*

Dr Ajay Sharma *Paediatric Gastroenterologist and Hepatologist*

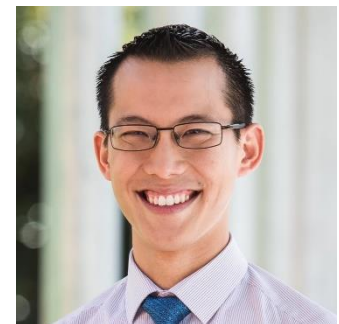
Dr Vicki McWilliam *Clinical Allergy Dietitian and Researcher*

Wendy Birks *Paediatric Dietitian*

Professor Evan S. Dellon *Professor of Medicine and Gastroenterologist (International Member)*

CHARITY AMBASSADOR

We are proud to have Eddie Woo ([Wootube](#)) as our Charity Ambassador. Eddie understands the impact living with an eosinophilic disease can have on the individual and family unit as he has a child with EoE.



ORGANISATION MEMBERSHIPS

ausEE Inc. is a member of American Partnership for Eosinophilic Disorders (APFED), Australian Patient Advocacy Alliance (APAA), Australian Patient Organisation Network (APON), Connect Groups, Consumers Health Forum of Australia (CHF), Genetic Alliance Australia, Genetic Services Network Victoria (GSNV), Global Allergy & Airways Patient Platform (GAAPP), Rare Voices Australia (RVA) and Small Non-Profits Alliance.

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What We Do

Eosinophilic diseases are a complex set of conditions that are chronic and usually life-long. The debilitating symptoms and day-to-day management of these diseases can significantly affect quality of life and individuals, families and carers often feel very isolated. ausEE is here for people through all stages of their journey and proudly provides all information, services, resources and support free for everyone.

We value each and every one of our members and their contribution to our network and the generosity of our supporters who are helping us to achieve our mission. Without them, we could not do what we do.

Highlights of what ausEE Inc. has accomplished in 2022, demonstrate that, together, we are making a difference. These achievements are outlined in six key areas:

- Information
- Research
- Resources
- Advocacy
- Awareness
- Support

Thank you for your support!

Dr Mercedez Hinchcliff
President, ausEE Inc.



Ms Sarah Gray OAM
CEO, ausEE Inc.



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2022 Highlights in Numbers

Our achievements are outlined in six key areas:

2,390 INFORMATION
current subscribers to our monthly members/supporters eNewsletter

617
subscribers receiving our health professionals eNewsletter



RESEARCH

\$18,509

funds donated to the ausEE Medical Research Fund



\$25,000

medical research project funded

2,890 RESOURCES
patient resources given to health professionals, hospitals and clinics

149

children's books on EoE distributed



ADVOCACY

19

partner organisations/stakeholder projects ausEE Inc. is a member of



251

outreach to MPs, organisations, industry and Government submissions prepared

13,694 AWARENESS
followers on ausEE's social media pages

27,626

visits to ausEE's websites



SUPPORT

3,075

members in ausEE's online support group networks



13

virtual support group meetings

Thank you for your support. Together we are making a difference!

ausee.org

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INFORMATION

- ausEE [website](#)
- Feeding Tube Aware [website](#)
- Information phone line: 1300 923 043
- Supporter/Member [eNewsletters](#)
- Health Professionals [eNewsletters](#)
- Hosted FTAW 2022 [Virtual Education Program](#) featuring 14 education and information videos.
- Educational [video](#) from Paula Dunn and Lorna Hastings on 'Myth Busting EoE Clinical Trials'.
- Exhibited at medical conferences; Gastroenterological Society of Queensland (GESQ) Update held in Noosa, Australasian Society of Clinical Immunology and Allergy (ASCIA) held in Melbourne and Gastroenterological Society of Australia's (GESA) Australian Gastroenterology Week (AGW) held in Sydney.
- Distributed patient resources to health professionals attending Dr Falk Pharma forums on eosinophilic oesophagitis (EoE).
- Exhibited at The International Rare Disease Showcase virtual event.
- Presented 'Insights into ausEE Inc. and Australian Allergy Friendly Finds' at [the Free From + Allergy Living Free From Virtual Event](#).
- Disseminated information from the Consortium of Eosinophilic Gastrointestinal Disease Researchers ([CEGIR](#)), including answers to research questions raised by our patient community and through the [RDCRN](#) Rare Research Report.

RESEARCH

- ausEE is a patient advocacy group partner of [EGID Partners](#), an international collaboration.
- ausEE is a partner of [Join Us](#) online register.
- ausEE supports research by sharing about [clinical trials](#) our members and followers may be eligible for including the CC-93538 study, VOYAGE study and AstraZeneca Eosinophilic Gastritis and/or Gastroenteritis study.
- Invited our members to assist in linguistic validation projects from TransPerfect for clinical trial development.
- We invited our members to participate in SUCCEED Child Feeding Alliance research projects on what makes feeding care brilliant.
- ausEE invited our members and followers to participate in research surveys including Southern Cross University's 'Exploring biomedical and complementary medicine use in adults with eosinophilic oesophagitis (EoE)', CRE in Digestive Health's 'Digestive Health and Wellness Survey', Children's Health Queensland's 'The impact of EoE on diet and families survey' and the 'Rare Disease Awareness, Education, Support and Training (RAReST) Project' health professionals survey.
- Participated in the Patient Voice Initiative (PVI) and CaPPRe research project on patient groups interactions with the pharmaceutical industry.
- ausEE CEO and Founder, Sarah Gray was a co-author on research articles published in [Advances in Therapy](#), [American Journal of Gastroenterology](#), [Gastroenterology AGA Abstracts](#) and [The Journal of Allergy and Clinical Immunology](#).

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RESOURCES

- EGID medical brochure [patient resource](#)
- EGID fact sheet
- Patient information folders with inserts
- A4 information flyer/poster
- ausEE information card
- EGIDs explained resource
- [Children's books](#) about living with an eosinophilic disease; 'Meet Arabella', 'Being Henry' and 'Olivia and Kate'.
- Hand knitted ausEE dolls donated to hospitals and clinics for kids undergoing endoscopies or surgery for EGID/EoE.
- Allergy friendly recipe book in development.
- Distributed Medikidz comic books on home enteral nutrition.
- Distributed [The Blend](#) magazine.
- Promoting the use of the [ASCIA Action Plan for EoE](#) and [ASCIA Management Plan for EoE](#).
- Raising awareness about the [Best practice guidelines](#) for anaphylaxis prevention and management in children's education and care services and schools which includes EoE information.



ADVOCACY

- Made a submission to the Therapeutic Goods Administration (TGA) consultations on Repurposing medicines and the Priority Review pathway for biologicals.
- Made submissions to the revised National Medicines Policy consultations.
- Submitted comments to the Pharmaceutical Benefits Advisory Committee (PBAC) in support of Alfamino HMO (amino-acid based formula).
- ausEE is a patient advocacy group member of the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR).
- As a partner of Rare Voices Australia, participated in the National Rare Disease Summit, RARE Portal consultation and RAREST Project (Stream 3) consultation.
- ausEE is a member of the Continuity of Care Collaboration (CCC).
- ausEE CEO and Founder, Sarah Gray is on the advisory board of the NHMRC Centre of Research Excellence in Digestive Health.
- Attended a Patient Advocacy Exchange meeting on eosinophil-associated diseases with international patient advocacy group leaders and health professionals.
- Attended the Shaping Healthcare Together roundtable held in Sydney.
- Liaised with industry about clinical trials and elemental formulas to advocate for timely, affordable access to effective treatments.
- First PBS listed medication for EoE was listed on the Pharmaceutical Benefits Scheme (PBS) from 1 May 2022 for adults with EoE.

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AWARENESS

- Hosted [Feeding Tube Awareness Week](#) (6-12 February 2022) - [FTAW Infographic](#).
- Hosted [National EOS Awareness Week](#) (7-13 August 2022) incorporating [Top 8 Challenge Day](#) on 8/8 - [NEOSW Infographic](#). During #NEOSW2022 47 landmarks lit up pink and purple around Australia and New Zealand.
- Collaborated on the first World Eosinophilic Diseases Day (18 May 2022).
- Supported awareness campaigns including Rare Disease Day, European EoE Day, World Asthma Day and World Eczema Day.
- Member stories shared to raise awareness including participating in the VIVA! Communications national [EoE media campaign](#).
- Raised awareness through articles published in print/online media and radio interviews.
- Actively engaged on our social media pages:
[ausEE on Facebook](#)
[ausEE on Twitter](#)
[ausEE on Instagram](#)
[ausEE on LinkedIn](#)
[ausEE on YouTube](#)
- Additional ausEE social media pages:
[Australian Allergy Friendly Finds on Facebook](#)
[Australian Allergy Friendly Finds on Instagram](#)
[Top 8 Challenge on Facebook](#)
[Allergy Free Cooking on TV on Facebook](#)



SUPPORT

- Online Facebook peer support forums:
facebook.com/groups/ausee
facebook.com/groups/auseeadults
- In 2022 we hosted 13 [Virtual Support Group Chats](#) through Zoom as an opportunity for our members to share/hear stories, chat and support each other. We host group chats for adults, parents/carers and teens living with EGIDs, individuals/families living with an eosinophil-associated disease (non EGID) and individuals/families managing tube feeding.
- We hosted support group dinner meetings in Melbourne and Sydney.
- Supported the tube feeding community through our [feeding tube aware](#) website which shares stories, support options, resources and links.
- ausEE Group on [Livewire](#) for young adults aged between 12-20 living with an EGID.
- ausEE is a member of the Rare Disorders NZ [Rare Disorder Collective](#).
- Supported businesses providing allergy friendly foods and products to help those with EGIDs and allergies through free promotion on our Australian Allergy Friendly Finds Facebook and Instagram pages and support our followers by sharing products, places, resources, recipes and tips to help them on their journey.

Future Goals

ausEE Inc. was proud to collaborate with leading international patient advocacy groups and treating clinicians to develop a landmark Patient Charter for Eosinophil-Associated Diseases (EADs). Published in *Advances in Therapy* journal in April 2022, '[Improving Care in Eosinophil-Associated Diseases: A Charter](#)', describes the key elements of good quality care, which all people with EADs deserve, and presents an ambitious action plan to improve health and overall well-being for people with EADs. ausEE urges healthcare professionals, hospitals, and policymakers to adopt the principles outlined in the charter and we continue to advocate to the Australian Government through [pre-budget submissions](#) for their support to help achieve these important goals.

People with Eosinophil-Associated Diseases (EADs) face challenges accessing diagnosis, specialist care, information, support and experience the impact of lack of community understanding. Their unmet needs are significant and these must be addressed because the consequences have detrimental impacts on individuals, families, healthcare systems and society.

Our call to the Australian Government addresses the objectives outlined below:

- **TIMELY DIAGNOSIS**
- **STANDARDS OF CARE**
- **INFORMATION RESOURCES**
- **SUPPORT SERVICES**
- **COMMUNITY OUTREACH**

4 Key Principles

Developed by leading patient advocacy groups and treating clinicians, the Patient Charter for EADs outlines a set of **4 key rights** which people living with these conditions should expect from their care

Principle 1
People with EADs, their support networks, HCPs, and the public must have greater awareness and education about EADs.
Targeted education and awareness programs for HCPs to drive timely diagnosis, as well as patient education campaigns and resources

Principle 2
People with EADs must receive a timely, accurate diagnosis.
Establish clear referral guidelines and an easily accessible registry of EAD experts from whom patients are more likely to receive a clear, accurate, and timely diagnosis

Principle 3
All people with EADs must have access to an appropriate multidisciplinary team (MDT), when necessary.
Increase use of telemedicine, disease management smartphone apps, and home diagnostic kits or biomarker monitoring, as well as increased electronic record-sharing across a patient's MDT

Principle 4
People with EADs must have access to safe and effective treatment options without unnecessary regulatory delays.
Robust global treatment guidelines need to be developed or updated to reflect new treatment options, which address the underlying causes of the disease

Want to work with us to help ausEE achieve these goals?

Please register your interest to be an ausEE volunteer [here](#).

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Fundraising and Donations

ausEE Inc. is a registered charity with the Australian Charities and Not-for-profits Commission (ACNC) and a registered charity in Queensland (CH1899), New South Wales (CFN/21530), ACT (L 19000791), Victoria (59406), South Australia (CCP2998), Western Australia (CC21779) and Tasmania (C/31).

Donations to ausEE Inc. over \$2 are tax deductible. All donations received will help ausEE Inc. to achieve its mission, particularly by funding vital research and support, bringing hope and care to individuals and families living with an eosinophilic disease. We thank our members, supporters and donors who help support us in our mission.

2022 DONATION COLLECTION BOXES

Advantage Willsmere Village Pharmacy, Kew, VIC
Casey's Pharmacy, North Balwyn, VIC

2022 FUNDRAISING CAMPAIGNS

National EOS Awareness Week / Top 8 Challenge
Online [Gift Shop](#) sales
2022 Tax Appeal
Facebook Fundraisers
Giving Tuesday
2022 Christmas Appeal
Christmas Gingerbread Folk Online Fundraiser

2022 FUNDRAISING PROGRAMS

ausEE is registered with these fundraising programs:
[Bright Star Kids](#), [Containers for Change](#), [Entertainment Memberships](#),
[Gingerbread Folk](#), [Give with Bing](#), [Play for Purpose](#) and [Shopnate](#).

2022 FUNDRAISING PLATFORMS

Our registered fundraising platforms are:
[Benevity](#), [Facebook Fundraisers](#), [GiveNow](#),
[MyCause](#), [My Giving Circle](#), [PayPal Giving](#) and [Raisely](#).



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2022 MEMBER FUNDRAISING

Member/Supporter	Fundraiser Name	Amount Raised
Vanessa Lecky	Top 8 Challenge	\$2,558
Claire Kosac	Top 8 Challenge	\$2,292
Alysia Camilleri	Top 8 Challenge	\$2,006
Jennifer Lee	Top 8 Challenge	\$1,063
Harry Funk	Top 8 Challenge	\$944
Sammy	Top 8 Challenge	\$593
Jordan Falzon Burns	Top 8 Challenge	\$584
Elsbeth Dove	Top 8 Challenge	\$382
Steven Kennington	Top 8 Challenge	\$326
Bella Gray	Top 8 Challenge	\$248
Bethany	Top 8 Challenge	\$145
Olivia Gray	Top 8 Challenge	\$120
Bini Varghese	Top 8 Challenge	\$50
Belinda Camilleri	Top 8 Challenge	\$48
Rozanna's birthday fundraiser	Facebook Fundraiser	\$100
Ella's birthday fundraiser	Facebook Fundraiser	\$30

“
My son Dominic suffers from EoE so I want to help raise funds for this cause which is close to my heart. Hopefully one day there will be a cure and/or more treatment options for those who are affected by EGIDs.
”



Supporter Spotlight

Alysia
#TOP8CHALLENGE




Supporter Spotlight

Lecky Family

“
I am participating in the Top 8 Challenge and fundraising, as research into EoE will hopefully bring some hope for a better future for my sweet boy.
”



Supporter Spotlight

Elsbeth
#TOP8CHALLENGE



“
I am fundraising for research to find a cure or better treatments for EoE. By the way, 8 is my favourite number!
”



Supporter Spotlight

Harry
#TOP8CHALLENGE




Facebook Fundraisers

Celebrate with us and support our mission to improve lives affected by eosinophilic diseases

“
I'm taking the Top 8 Challenge for my sister, Bella. I fundraise for medical research to give hope for a brighter future for everyone living with eosinophilic diseases and their families.
”



Supporter Spotlight

Olivia
#TOP8CHALLENGE



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2022 DONOR ACKNOWLEDGEMENTS

ausEE Inc. would like to thank the following donors who made contributions of \$100 and over:

A Bartolo	G Heinrich	T and A Lia
M Bieleny	M Hinchcliff	H Macdonald
C Burke	R Honeyfield	R McCrohan
R Buttigieg	K Jackson	J McLure
A Cairnduff	D Keirs	L McLure
L and J Camilleri	K Kekatos	C Pashley
Z Condos	S Kekatos	K Paterson
E Dove	N Kohler	N Petrie
N Elliott	T Kosac	C Squires
D Falzon	V Layton	J Turmine
R Farrugia	V Lecky	J Walsh
A Gomez	J Lee	A Wilson
K Gwynne	P Lee	P Wood

We gratefully thank the following donors who made contributions of \$250 or more:

J Beddow	D Brandt	Swaye Civil Pty Ltd
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Thank you to our monthly donors during 2022:

M Mercer	K Stock	K Tree
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Special Acknowledgements:

Sarah Marchetti	\$ 516 Donation to ausEE on behalf of their wedding guests
Flynn Family	\$1,032 Donation to ausEE's Medical Research Fund
Vanessa Lecky	\$1,254 Top 8 Challenge - Employer Matched Donation
Anonymous	\$2,000 Top 8 Challenge - Donation
Emma and Tony Olsen (Flor-Hanly)	\$5,000 Donation to ausEE's Medical Research Fund

2022 GRANTS

Department of Social Services - Volunteer Grant

Global Allergy & Airways Patient Platform Communication Grants for:

World Asthma Day, World COPD Day, World Eczema Day and World Lung Day

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Sponsorships

In 2022 ausEE Inc. gratefully received support in the form of sponsorships from the following:

2022 SUPPORTERS



Diamond



Together we know more.
Together we do more.

Gold



Silver

FTAW SPONSORS



2022 PRIZE GIVEAWAY SPONSORS

Facebook giveaways:

[Charlie's Safe Treat Box](#), [Eddie Woo](#), [Sunpita/No Worries Lollies](#) and [The Good Food Trolley](#).



Top 8 Challenge Prize Sponsor



2022 Christmas Fundraiser Prize Sponsor

2022 MEMBER DISCOUNT OFFERS

Join our support groups to find out more about offers from: [AllergEnd](#), [Happy Tummies](#), [Jellyfish Mattresses](#), [MedBag](#) and [Subo Products](#).

ausEE Inc. does not endorse or promote products or services. The content of our resources are not influenced by our supporters and sponsors and they have no input into their development.

Medical Research

AUSEE MEDICAL RESEARCH FUND

ausEE has been funding [medical research projects](#) since 2015 that aim to improve the diagnosis and treatment options for people with EGIDs. These research grants wouldn't be possible without generous donations from our supporters and through our yearly [Top 8 Challenge](#) fundraising campaign. Medical research takes us one step closer to a cure.

To help us fund more research projects, please make a tax deductible donation to our Medical Research Fund [here](#).

RESEARCH GRANT AWARD

In June 2022, ausEE awarded grant funding of \$25,000 to Professor Guy Eslick, Professor Mike Jones, Professor Marjorie Walker and Professor Nicholas J. Talley from the NHMRC Centre for Research Excellence in Digestive Health and The University of Newcastle.

This study aims to assess the relationship between eosinophilic gastrointestinal disorders (EGIDs) and disorders of gut-brain interaction (DGBI). Disorders of gut-brain interaction (DGBI) include Functional Dyspepsia, Irritable bowel Syndrome, and Rumination Syndrome. The project will involve obtaining General Practice (GP) patient data from the United Kingdom, the data comes from 'The Health Improvement Network' (THIN) database, which represents 6% of the UK population. The research team hope to use this data to identify the overall relationships between EGIDs and DGBIs.

This study may identify important new links between EGIDs and DGBIs that had not been previously reported. This may provide new information on the mechanisms by which eosinophils induce pathology and lead to new novel options for future treatment.

Health professionals and/or researchers wanting to undertake medical research into eosinophilic diseases are invited to apply for a grant from ausEE by completing a [Research Grant Application](#).



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EGID PARTNERS

ausEE is a patient advocacy group partner of EGID Partners, a global online cohort of patients (adults with an EGID and parents and caregivers of children with an EGID). It is a way to conduct clinical research through surveys over time, not just as a one-off project. Unlike other registries, EGID Partners engages patients to help guide research. People without EGIDs are also encouraged to join so data can be compared.

In May 2022, 'Early life exposures as risk factors for eosinophilic gastrointestinal diseases: A pilot study from an online patient-centered research network' poster was presented at Digestive Disease Week (DDW) annual international gastroenterology meeting and subsequently published in the [Gastroenterology](#) journal.

In October 2022, 'High Burden of Disease and Associated Costs for Eosinophilic Gastrointestinal Diseases: Results From an Online Patient-Centered Research Network' poster was presented at the American College of Gastroenterology (ACG) Annual Scientific Meeting and published in [The American Journal of Gastroenterology](#).

If you'd like to find out more and join this research community, please visit egidpartners.org.

AUSEE AND UOW RESEARCH PROJECTS

During 2022, Dr Mercedes Hinchcliff, a researcher at the University of Wollongong (UOW) and President of ausEE Inc., commenced her research project titled 'Health-related quality of life in patients who utilise home enteral nutrition and/or elemental formula in Australia/New Zealand. The [survey](#) for this study was launched in February 2023.

In June 2022, Dr Mercedes Hinchcliff from the UOW and ausEE, collaborated with members of ausEE, our medical advisory board, researchers and consumers to submit a Medical Research Future Fund (MRFF) Consumer-Led Research Grant proposal titled 'The Co-creation of a Treatment Decision Support Tool (TDST) for Eosinophilic Gastrointestinal Diseases (EGIDs)'. Unfortunately we were not successful in receiving grant funding and we will continue to seek opportunities to progress this project which aims to assist patients to make critical decisions about their healthcare and improve patient outcomes.

Early life exposures as risk factors for eosinophilic gastrointestinal diseases: A pilot study from an online patient-centered research network

Elizabeth T. Jensen, MPH PhD^{1,2}; Xiangling Dai, PhD²; Elynn Kodoff³; Mary Jo Strobel⁴; Amy Zcarwall⁵; Sarah Gray⁶; Amanda Corbell⁷; Girish Hiremath, MBBS MPH¹; Evan S. Dellon, MD MPH¹

Introduction

- Early life exposures, including in the prenatal and perinatal periods and in the first year of life, have been shown to increase risk of development of eosinophilic esophagitis (EoE).
- It is unclear whether similar exposures are associated with development of other non-EoE eosinophilic gastrointestinal diseases (EGIDs).
- We aimed to assess the association between (parental, maternal, and early life factors and development of non-EoE EGID).

Methods

- Study design:** Case-control pilot study based in EGID Partners (egidpartners.org), an online patient-centered research network designed and implemented by patient advocacy groups (PAGs) and EGID researchers and launched in 2020 (Fig 1).
- Subjects:** Recruited via email and social media, identified messages to EGID patients through medical record patient portals, websites, and by physicians. Adults (≥18 years) with EGIDs, non-EGID adult controls, and those same groups but for caregivers of children <18 years of age enrolled.
- Data:** Subjects completed surveys on demographics, disease and medical history, and early life exposures using our Early Life Exposures Questionnaire. This was previously developed and includes detailed questions of maternal and child exposures.

Results

- We analyzed 61 non-EoE EGID patients (mean (SD) age 20 (15) years; 67% female; 50% white; 80% with an atopic condition; mean (SD) 7.4 (8.8) years of symptoms prior to diagnosis).
- Of the EGIDs, 14 had eosinophilic gastroenteritis (EGE), 19 had eosinophilic enteritis (EE), 8 had eosinophilic colitis (EC), and 22 had multiple sites of disease; additionally, 30 had esophageal involvement.

Figure 1: EGID Partners website

Table 1: Early life exposures in non-EoE EGIDs

Exposure	Non-EoE EGID (n=61)	Non-EGID (n=100)	P-value
Maternal smoking during pregnancy	12 (19.7%)	18 (18.0%)	0.87
Maternal smoking in first year of life	15 (24.6%)	22 (22.0%)	0.78
Maternal smoking in 1-5 years of life	10 (16.4%)	15 (15.0%)	0.89
Maternal smoking in 6-10 years of life	10 (16.4%)	15 (15.0%)	0.89
Maternal smoking in >10 years of life	13 (21.3%)	15 (15.0%)	0.21
Maternal alcohol during pregnancy	10 (16.4%)	15 (15.0%)	0.89
Maternal alcohol in first year of life	15 (24.6%)	22 (22.0%)	0.78
Maternal alcohol in 1-5 years of life	10 (16.4%)	15 (15.0%)	0.89
Maternal alcohol in 6-10 years of life	10 (16.4%)	15 (15.0%)	0.89
Maternal alcohol in >10 years of life	13 (21.3%)	15 (15.0%)	0.21
Maternal antibiotic use during pregnancy	10 (16.4%)	15 (15.0%)	0.89
Maternal antibiotic use in first year of life	15 (24.6%)	22 (22.0%)	0.78
Maternal antibiotic use in 1-5 years of life	10 (16.4%)	15 (15.0%)	0.89
Maternal antibiotic use in 6-10 years of life	10 (16.4%)	15 (15.0%)	0.89
Maternal antibiotic use in >10 years of life	13 (21.3%)	15 (15.0%)	0.21
Maternal antibiotic use in pregnancy, first year of life, 1-5 years of life, 6-10 years of life, and >10 years of life	10 (16.4%)	15 (15.0%)	0.89
Maternal antibiotic use in pregnancy, first year of life, 1-5 years of life, 6-10 years of life, and >10 years of life	10 (16.4%)	15 (15.0%)	0.89
Maternal antibiotic use in pregnancy, first year of life, 1-5 years of life, 6-10 years of life, and >10 years of life	10 (16.4%)	15 (15.0%)	0.89
Maternal antibiotic use in pregnancy, first year of life, 1-5 years of life, 6-10 years of life, and >10 years of life	10 (16.4%)	15 (15.0%)	0.89

Conclusions

- We identified preliminary associations between certain early life exposures and non-EoE EGID, including pregnancy complications, NICU admission, and antibiotic in infancy.
- While confirmation of these results in a larger sample size is needed, this will be possible as EGID Partners grows continues to grow.
- Future investigations into the role of early life exposures in development of non-esophageal EGID pathogenesis and its overlap with EoE is warranted.

References

High burden of disease and associated costs for eosinophilic gastrointestinal diseases: Results from an online patient-centered research network

Evan S. Dellon, MD MPH^{1,2}; Xiangling Dai, PhD²; Elynn Kodoff³; Mary Jo Strobel⁴; Amy Zcarwall⁵; Sarah Gray⁶; Amanda Corbell⁷; Girish Hiremath, MBBS MPH¹; Elizabeth T. Jensen, MPH PhD^{1,2}

Introduction

- Data regarding health care-related costs and the burden of disease for non-EoE eosinophilic gastrointestinal diseases (EGIDs) are lacking, particularly from the patient perspective.
- We aimed to determine the patient-reported health care burden of disease and costs related to care for non-EoE EGIDs.

Methods

- Study design:** Case-control pilot study based in EGID Partners (egidpartners.org), an online patient-centered research network designed and implemented by patient advocacy groups (PAGs) and EGID researchers and launched in 2020 (Fig 1).
- Subjects:** Recruited via email and social media, identified messages to EGID patients through medical record patient portals, websites, and by physicians. Adults (≥18 years) with EGIDs, non-EGID adult controls, and those same groups but for caregivers of children <18 years of age enrolled.
- Data:** Subjects completed surveys on demographics, disease and medical history, and a burden of disease questionnaire. The instrument reported patient-reported healthcare utilization over the prior year related to health care visits and procedures, as well as out-of-pocket expenditures.

Results

- We analyzed 58 non-EoE EGID patients with health care utilization data (mean (SD) age 20 (15) years; 50% female; 67% white; 80% with an atopic condition; mean (SD) 7.4 (8.8) years of symptoms prior to diagnosis).
- Of the non-EoE EGID cases, 13 had eosinophilic gastroenteritis (EGE), 11 had eosinophilic enteritis (EE), 8 had eosinophilic colitis (EC), and 22 had multiple sites of disease; additionally, 37 had esophageal involvement.

Figure 1: EGID Partners website

Table 1: Non-EoE EGID costs overall, and by adult patient compared to caregiver of the pediatric patient

Health care utilization	Non-EoE EGID (n=58)	Non-EGID (n=100)	P-value
Total number of health care visits	12,000 (12,000)	12,000 (12,000)	0.001
Number of visits to:			
- Gastroenterologist	1,000 (1,000)	1,000 (1,000)	0.001
- Hospital doctor	1,000 (1,000)	1,000 (1,000)	0.001
- Hospitalist	1,000 (1,000)	1,000 (1,000)	0.001
- Outpatient clinic	1,000 (1,000)	1,000 (1,000)	0.001
- Urgent care	1,000 (1,000)	1,000 (1,000)	0.001
- Emergency	1,000 (1,000)	1,000 (1,000)	0.001
- Other	1,000 (1,000)	1,000 (1,000)	0.001
Number of procedures	1,000 (1,000)	1,000 (1,000)	0.001
Number of hospitalizations	1,000 (1,000)	1,000 (1,000)	0.001
Number of emergency visits	1,000 (1,000)	1,000 (1,000)	0.001
Number of out-of-pocket costs	1,000 (1,000)	1,000 (1,000)	0.001

Conclusions

- Patients with non-EoE EGIDs experience a high health care burden, with frequent health care encounters, hospitalizations, and out-of-pocket costs (median of \$1000/year).
- Both adult and pediatric patients must maintain awareness of the substantial burden of costs to EGID patients, including challenges for parents to manage their disease given these costs.
- Future investigations should include costs of out-of-pocket costs, such as the ones listed here, when burden of disease is assessed.

References

AUSEE INC. – 2022 ANNUAL REPORT

Audit Review: Annual Financial Statements

Income and Expenditure Statement ausEE Inc. for the year ended 30 June 2022

INCOME		2022		2021
Grants – Other	\$	3,939.98	\$	-
Donations Received	\$	17,723.94	\$	13,740.71
Non Tax-Deductible Gifts	\$	195.33	\$	96.85
Sales of Goods	\$	5,855.95	\$	2,415.42
Sponsorship & Licensing Fees	\$	40,546.52	\$	39,666.93
Interest	\$	67.68	\$	148.49
Recoupment	\$	433.64	\$	-
Total Income	\$	68,763.04	\$	56,068.40
EXPENDITURE				
Advertising & Marketing	\$	130.37	\$	77.90
Assets Purchased <\$5,000	\$	1,544.50	\$	-
Audit Fees	\$	330.00	\$	330.00
Bank Charges	\$	5.96	\$	4.82
Client Support Services	\$	946.36	\$	-
Computer Expenses	\$	934.99	\$	1,075.90
Credit Card Fees	\$	20.25	\$	8.73
Donations Paid (Medical Research Grant)	\$	25,000.00	\$	3,000.00
Fees & Permits	\$	175.25	\$	57.60
Fundraising Expenses	\$	644.20	\$	349.36
Insurance	\$	2,377.53	\$	2,382.20
Membership Fees Paid	\$	190.91	\$	155.00
Postage, Freight & Courier	\$	1,166.32	\$	851.53
Printing & Stationery	\$	448.57	\$	530.65
Publications & Information Resources	\$	3,154.08	\$	606.40
Salaries & Wages	\$	23,512.32	\$	-
Superannuation	\$	2,351.28	\$	-
Storage Costs	\$	545.41	\$	519.94
Telephone & Internet	\$	240.51	\$	284.24
Travel & Accommodation	\$	332.04	\$	-
Volunteer Costs	\$	332.02	\$	149.04
Total Expenses	\$	64,382.87	\$	10,383.31
Current Year Surplus	\$	4,380.17	\$	45,685.09

AUSEE INC. – 2022 ANNUAL REPORT

Assets and Liabilities Statement ausEE Inc. as at 30 June 2022

Assets	2022		2021	
Current Assets				
Cash and Cash Equivalents	\$	106,751.23	\$	96,950.55
Total Current Assets	\$	106,751.23	\$	96,950.55
Liabilities				
Current Liabilities				
Trade and Other Payables	\$	3,035.64	\$	-
GST Payable	\$	2,119.87	\$	-
Total Current Liabilities	\$	5,155.51	\$	-
Net Assets	\$	101,595.72	\$	96,950.55
Member's Funds				
Capital Reserve	\$	101,595.72	\$	96,950.55
Total Member's Funds	\$	101,595.72	\$	96,950.55

Notes to the Financial Statements **ausEE Inc. for the year ended 30 June 2022**

1. Summary of Significant Accounting Policies

The financial statements are special purpose financial statements prepared in order to satisfy the financial reporting requirements of the Associations Incorporation Act Queensland. The committee has determined that the association is not a reporting entity.

The financial statements have been prepared on an accruals basis and are based on historic costs and do not take into account changing money values or, except where stated specifically, current valuations of non-current assets.

The following significant accounting policies, which are consistent with the previous period unless stated otherwise, have been adopted in the preparation of these financial statements.

Cash on Hand

Cash on hand includes cash on hand, deposits held at call with banks, and other short-term highly liquid investments with original maturities of three months or less.

Revenue and Other Income

Revenue is measured at the fair value of the consideration received or receivable after taking into account any trade discounts and volume rebates allowed. For this purpose, deferred consideration is not discounted to present values when recognizing revenue.

Interest revenue is recognised using the effective interest method, which for floating rate financial assets is the rate inherent in the instrument. Dividend revenue is recognised when the right to receive a dividend has been established.

Grant and donation income is recognised when the entity obtains control over the funds, which is generally at the time of receipt.

If conditions are attached to the grant that must be satisfied before the association is eligible to receive the contribution, recognition of the grant as revenue will be deferred until those conditions are satisfied.

All revenue is stated net of the amount of goods and services tax.

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2. Cash on Hand	2022		2021	
Suncorp Account - Medical Research Fund	\$	27,790.76	\$	45,696.43
Suncorp Account - Operational	\$	78,960.47	\$	51,202.61
PayPal Account	\$	-	\$	51.51
Total Cash on Hand	\$	106,751.23	\$	96,950.55

3. Trade & Other Payables	2022		2021	
PAYG Withholdings Payable	\$	1,860.00	\$	-
Superannuation Payable	\$	1,175.64	\$	-
Total Trade & Other Payables	\$	3,035.64	\$	-

Independent Auditor's Review Report ausEE Inc. for the year ended 30 June 2022

Report of the Financial Report

We have reviewed the accompanying financial report, being a special purpose financial report of ausEE Incorporated, which comprises the statement of financial position as at 30 June 2022, the statement of comprehensive income, notes, comprising a summary of significant accounting policies and other explanatory information, and the responsible entities declarations.

Committee's Responsibility for the Financial Report

The committee of ausEE Inc. is responsible for the preparation and fair presentation of the financial report, and has determined that the basis of preparation described in Note 1 is appropriate to meet the requirements of ausEE Inc. and is appropriate to meet the needs of the members. The committee's responsibility also includes such internal control as the committee determines is necessary to enable the preparation and fair presentation of a financial report that is free from material misstatement, whether due to fraud or error.

Auditor’s Responsibility

Our responsibility is to express a conclusion on the financial report based on our review. We have conducted our review in accordance with Australian Auditing Standards on Review Engagements ASRE 2415 Review of a Financial Report: Company Limited by Guarantee under the ACNC Act, in order to state whether, on the basis of the procedures described, we have become aware of any matter that makes us believe that the financial report does not satisfy the requirements of Division 60 of the ACNC Act including: giving a true and fair value of the registered entity's financial position as at 30 June 2022 and its performance for the year ended on that date; and complying with the Australian Accounting Standards and the Australian Charities and Not-for-profits Commission Regulation 2013 (ACNC Regulation). ASRE 2415 requires that we comply with the ethical requirements relevant to the review of the financial report.

A review of a financial report consists of making enquiries, primarily of persons responsible for financial and accounting matters, and applying analytical and other review procedures. A review is substantially less in scope than an audit conducted in accordance with Australian Auditing Standards and consequently does not enable us to obtain assurance that we would become aware of all significant matters that might be identified in an audit. Accordingly, we do not express an audit opinion.

Independence

In conducting our review, we have complied with the independence requirement of the ACNC Act. We confirm that the independence declaration required by the ACNC Act, which has been given to the responsible entities of Strength Potential Incorporated would be in the same terms if given to the responsible entities as time of this auditor's report.

Conclusion

Based on our review, which is not an audit, we have not become aware of any matter that makes us believe that the financial report of ausEE Incorporated does not satisfy the requirements of Division 60 of the Australian Charities and Not-for-profits Commission Act 2012 including:

1. giving a true and fair view of the registered entity's financial position as at 30 June 2022 and of its financial performance for the year ended on that date; and
2. complying with Australian Accounting Standards to the extent described in Note 1, and Division 60 of the Australian Charities and Not-for-profits Commission Regulation 2013.



Auditor: Rowena Anderson

Auditor’s address: Coastal Accountants & Advisors, 8/21 Birtwill Street, Coolum Beach QLD 4573

Dated: 9th November 2022

Statement By Members of the Committee ausEE Inc. for the year ended 30 June 2022

The committee has determined that the association is not a reporting entity and that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 2 to the financial statements. In the opinion of the committee the financial report:

1. Presents fairly the financial position of ausEE Inc. as at 30 June 2022 and its performance for the year ended at that date.
2. At the date of this statement, there are reasonable grounds to believe that ausEE Inc. will be able to pay its debts as and when they fall due.

This statement is made in accordance with a resolution of the committee and is signed for and on behalf of the committee by:



Sarah Gray
CEO, ausEE Inc.

Dated: 27th November 2022



Mercedes Hinchcliff
President, ausEE Inc.

Dated: 27th November 2022

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Member Stories and Feedback

#MyEoE



“
EoE has also triggered my anxiety because I'm not sure what causes my EoE, or what could trigger a flare up, or if my next impaction will see me hospitalised again.”

- Jamie



National EOS Awareness Week
7-13 August 2022


EOSaware
ausEE Inc.

“
My little 4-year-old Chloe is really into her 'Meet Arabella' book and keeps asking to meet the real Bella! It's really helped explaining her EoE to her with her being able to see there is a "big girl" just like her and she's not alone - thank you!”

- Vanessa



#MyEoE



“
Concerningly, there appears to be a low understanding of EoE among some healthcare professionals. When I visit a GP for example, and request an EoE medication, they often don't know what I'm talking about.”

- Andrew



National EOS Awareness Week
7-13 August 2022

EOSaware
ausEE Inc.

#MyEoE



“
You become so scared to eat food. You over-think not only what you can eat, but when, and where you can eat. You take a sip of water with every little bite of food. Then you start to think about potentially ending up in hospital while simply trying to eat something.”

- Andrew



National EOS Awareness Week
7-13 August 2022

EOSaware
ausEE Inc.

“
I really enjoyed all the presentations from Feeding Tube Awareness Week. As a mum of a fairly new NG tube fed 1yo I found it really interesting and gave me lots of links to resources that I never knew existed.”

- Kerri



#MyEoE



“
Prior to my EoE diagnosis, my husband and I used to love going out to restaurants and exploring new foods. But this isn't possible anymore. Life's just not the same.”

- Nadia



National EOS Awareness Week
7-13 August 2022

EOSaware
ausEE Inc.

#MyEoE



“
Prior to being diagnosed with eosinophilic oesophagitis, I thought the feelings and sensations that I had long been experiencing when eating, were normal.”

- Sinead



National EOS Awareness Week
7-13 August 2022

EOSaware
ausEE Inc.

“
ausEE Inc. has been instrumental in providing our family with resources and knowledge, as well as a community of others who are also navigating the disease, to come to terms with how it can impact someone's quality of life.”

- Jessica



#MyEoE



“
I was out celebrating my 50th birthday when I got some steak lodged in my throat. I was trying to vomit to remove the blockage from my throat – which is what I would normally do when that occurred.”

- James



National EOS Awareness Week
7-13 August 2022

EOSaware
ausEE Inc.

AUSEE INC. – 2022 ANNUAL REPORT

Contact Information

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Websites

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feedingtubeaware.com.au

Social Media



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ausEE Inc.

a charity dedicated to improving lives
affected by an eosinophilic disease

ABN 30 563 569 016

