



**ausEE Inc.**

a charity dedicated to improving lives  
affected by an eosinophilic disease

# Annual Report

2023

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## About Us

Founded in 2009, ausEE Inc. is a registered Australia wide charity and peak national support and patient advocacy organisation representing Australians living with an eosinophilic disease including eosinophilic gastrointestinal diseases (EGIDs). ausEE is predominantly run by volunteers with approximately 3,000 members, extending its outreach to individuals, families, hospitals, health professionals, peak bodies, stakeholders and the wider community.

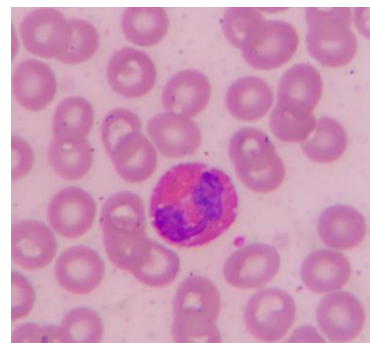


### ACKNOWLEDGEMENT OF COUNTRY

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 play a role in certain medical conditions and immune responses. If a person has too many eosinophils without another known cause, it may be because of an eosinophil-associated disease. The eosinophils build up and can cause inflammation and tissue damage. 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. Eosinophilic oesophagitis (EoE), the most known type of EGID, now has an estimated prevalence of 1 in 1,000. In EoE, the inflammation can lead to scarring, strictures and narrowing of the oesophagus, putting people at risk of food impactions (food getting stuck in the oesophagus).

Eosinophilic diseases are chronic diseases that require ongoing management and monitoring. The symptoms can be debilitating and often cause increased financial burden, social and emotional implications for patients and carers, decreased health-related quality of life and the need for repeated visits to multiple healthcare professionals, emergency departments and hospitals.

## 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 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.

## 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*

**Associate Professor Ajay Sharma** *Paediatric 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 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 honoured to have Eddie Woo ([Wootube](#)) as our Charity Ambassador. Eddie empathizes with the challenges of living with an eosinophilic disease, having experienced its impact firsthand within his own family due to his child having EoE.

### ORGANISATION MEMBERSHIPS

ausEE Inc. is a member of American Partnership for Eosinophilic Disorders, Australian Patient Advocacy Alliance, Connect Groups, Consumers Health Forum of Australia, Continuity of Care Collaboration, Genetic Alliance Australia, Genetic Services Network Victoria, Global Allergy & Airways Patient Platform, National Allergy Centre of Excellence, National Patient Organisation Network, Patient Voice Initiative, Rare Voices Australia and Small Non-Profits Alliance.

## What We Do

Eosinophilic diseases are a complex array of chronic conditions that can significantly impact the quality of life, leading individuals, families, and caregivers to often feel isolated. ausEE is committed to supporting people at every stage of their journey by offering information, resources, and support free for everyone.

We deeply appreciate each member of our community and their contributions to our network. We are also grateful for the generosity of our supporters whose contributions enable us to fulfill our mission. Without their support, we would not be able to provide the assistance that is so crucial to those we serve.

The achievements of ausEE Inc. in 2023 highlight how 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 & Founder, ausEE Inc.



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### 2023 Highlights in Numbers

Our achievements are outlined in six key areas:

**2,587** current subscribers to our monthly members/supporters eNewsletter

**672** subscribers receiving our health professionals eNewsletter


**INFORMATION**



**RESEARCH**

**\$12,788** funds donated to the ausEE Medical Research Fund

**\$19,000** medical research project grants



**2,754** patient resources given to health professionals, hospitals and clinics

**296** children's books on EoE distributed

**RESOURCES**



**ADVOCACY**

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

**265** outreach to organisations, stakeholders, industry and Government submissions prepared



**14,587** followers on ausEE's social media pages

**184** landmarks illuminated for eosinophilic diseases and tube feeding awareness

**AWARENESS**



**SUPPORT**

**3,333** members in ausEE's online support group networks

**12** support group meetings



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

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

## INFORMATION


- ausEE [website](#) (new site launched in September 2023).
- Feeding Tube Aware [website](#).
- Information phone line: 1300 923 043.
- Supporter/Member [eNewsletters](#).
- Health Professionals [eNewsletters](#).
- Attended BioPharmaDispatch Annual Conference held in Sydney, 15 May 2023.
- Participated in a panel at the National Patient Organisation Network (NPO) Member Conference held in Sydney, 15-16 May 2023.
- Presented at the YourTube e-Tradeshaw, 31 May 2023.
- Exhibited at the Gastroenterological Society of Queensland's (GESQ) Noosa Update held in Noosa, 3-4 June 2023.
- Attended the HTAi (Health Technology Assessment International) Annual Meeting held in Adelaide, 24-28 June 2023.
- Exhibited at the Gastroenterological Society of Australia's (GESA) Australian Gastroenterology Week (AGW) held in Brisbane, 3-5 September 2023.
- Exhibited at the Australasian Society of Clinical Immunology and Allergy's (ASCI) Annual Conference held in Sydney, 6-8 September 2023.
- 'Supporting young people to thrive with allergies' session hosted by Eddie Woo, at the Free From + Allergy Show held in Sydney, 21 and 22 October 2023.
- Article published in Source Kids magazine about tube feeding and ausEE's Feeding Tube Awareness Week campaign.
- Contributed to the 'Plain Language Summary of principles for improving the care of people with eosinophil-associated diseases' [publication](#).
- 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 the [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, EP-104IAR study, CROSSING study, Griffith University EoE study and the Southern Cross University EoE study.
- We invited participants to research including Centre for Community-Driven Research's PEEK Rare, Genetic + Undiagnosed Australia 2023 study, The Nathan Centre and Edith Cowan University's Australian Bereaved Parents study, The University of Queensland's Project Plan Review: Tube Feeding Research, Australian College of Applied Professions' The Impact of Parenting a Child with a Food Allergy survey and National Standards for People Living with Allergy - Transition Process from Paediatric to Adult Services survey.
- ausEE Inc. President and researcher at the University of Wollongong, Dr Mercedes Hinchcliff, launched her research project titled 'Health-related quality of life in patients who utilise home enteral nutrition and/or elemental formula in Australia/New Zealand'.
- ausEE Inc. CEO and Founder, Sarah Gray was a co-author on published research; Clinics and Research in Hepatology and Gastroenterology [article](#) 'Early life exposures as risk factors for non-esophageal eosinophilic gastrointestinal diseases', American Journal of Gastroenterology [article](#) 'Frequent report of vitamin deficiencies and use of supplements and complementary/alternative treatment approaches in patients with eosinophilic gastrointestinal diseases', American Journal of Gastroenterology [article](#) 'Telehealth is an acceptable and feasible option for patients with eosinophilic gastrointestinal diseases: data from the online EGID partners cohort' and [AGA Abstract Sa1277](#) 'Extraintestinal symptoms of pain in eosinophilic gastrointestinal diseases'.



### Extraintestinal symptoms of pain in eosinophilic gastrointestinal diseases

Elizabeth T. Jensen, MPH PhD,<sup>1,2,3,4</sup> Xiangfeng Dai, PhD,<sup>3</sup> Chelsea Anderson, PhD MPH,<sup>3</sup> Eilyn Kodroff,<sup>5</sup> Mary Jo Strobel,<sup>6</sup> Amy Zicarelli,<sup>7</sup> Sarah Gray,<sup>8</sup> Amanda Cordell,<sup>9</sup> Gishir Hiremath, MBBS MPH,<sup>10</sup> Evan S. Dellon, MD MPH<sup>1,4</sup>

<sup>1</sup>Department of Epidemiology and Prevention, Wake Forest University School of Medicine; <sup>2</sup>Department of Internal Medicine, Gastroenterology Section, Wake Forest University School of Medicine, Winston-Salem, NC; <sup>3</sup>Center for Gastrointestinal Biology and Disease, Division of Gastroenterology and Hepatology, Department of Medicine; NC <sup>4</sup>Center for Esophageal Diseases and Swallowing, University of North Carolina School of Medicine, Chapel Hill; <sup>5</sup>Campaign Urging Research for Eosinophilic Disease (CURED); <sup>6</sup>American Partnership for Eosinophilic Disorders (APFED); <sup>7</sup>Eosinophilic Family Coalition (EFC); <sup>8</sup>AusEE Inc.; <sup>9</sup>EOS Network; <sup>10</sup>Division of Pediatric Gastroenterology, Hepatology, and Nutrition, Monroe Carell Jr. Children's Hospital at Vanderbilt, Vanderbilt University Medical Center, Nashville, TN

#### Introduction

- Extraintestinal symptoms are well-documented in systemic inflammation-predominant conditions. Eosinophilic gastrointestinal diseases (EGIDs) are associated with features of inflammation and fibrosis.
- Connective tissue disorders, including Ehlers Danlos and Benign Hypermobility Syndrome, are enriched in patients with EGIDs and are associated with musculoskeletal symptoms of pain. While there is a higher frequency of connective tissue disorders in patients with eosinophilic esophagitis (EoE), extra-GI symptoms have not been explored in eosinophilic gastrointestinal diseases (EGIDs).
- **Aim:** To describe and evaluate the differences in the frequency of patient report of joint, leg, and headache pain in EoE and non-EoE EGIDs.

#### Methods

- Data were assembled from EGID Partners (egidpartners.org), an online patient-centered research network developed and implemented by patient advocacy groups (PAGs) and EGID researchers.
- Subjects were recruited via informational emails and through social media, directed messages to EGID patients through medical record patient portals, webinars, and by physicians.
- Adult subjects and caregivers of children (<18 years) completed surveys to document symptoms of leg and joint pain, and the McGill Pain Questionnaire as well as descriptive affective vs sensory pain symptoms. Additionally, subjects reported frequency of headaches, medication use for management of symptoms, and, among adults, severity of headache-associated disability using the Migraine Disability Assessment Test.
- Differences in pain scores between EoE and non-EoE EGID patients were compared using Chi-square tests for differences in distribution of proportions and t-tests for testing differences in means.

#### Results

- We analyzed 94 subjects with EoE (85% >18) and 24 subjects with non-EoE EGIDs (75% >18).
- **Leg pain:** Both EoE and non-EoE EGID subjects described frequent leg pain (60% for EoE and 63% for non-EoE EGIDs) with a mean (std) number of days of leg pain of 1.4 (2.2) and 2.3 (2.7) days, respectively. While no difference was observed in number of days of leg pain (p=0.09), pain severity was higher for non-EoE EGID subjects (p<0.01), and for both affective and sensory pain (p<0.01 for both). For both EoE and non-EoE EGID subjects, pain more frequently initiated concomitantly with or after EGID symptom initiation (Table 1).
- **Joint pain:** For joint pain, 61% of EoE and 67% of non-EoE EGID subjects reported joint pain, with the majority of those indicating that pain started during or after EGID symptom onset. Severity of symptoms was greater for non-EoE EGID patients (p<0.01), as were sensory and affective pain scores (p<0.01) (Table 2).
- **Headache disability:** Among adults, the distribution of headache disability scores for non-EoE EGID subjects was different as compared to subjects with EoE alone, with 17% of non-EoE EGIDs indicating severe disability vs 9% for EoE (p=0.01). A high proportion of both EoE and non-EoE EGID subjects reported taking medications to manage their headaches (Table 3).

	EoE n = 95	Non-EoE EGID n = 24	p
Days per week with pain in legs (mean ± SD) (n=95, 24)	1.4 ± 2.2	2.3 ± 2.7	0.09
Pain severity over prior 7 days (0-10 scale; mean ± SD) (n=97, 24)	1.2 ± 1.8	3.6 ± 2.9	< 0.01
Short-form McGill Pain Questionnaire (mean ± SD)			
Total score	3.6 ± 5.0	11.8 ± 11.2	< 0.01
Sensory sub-score	3.0 ± 4.0	9.5 ± 10.0	< 0.01
Affective sub-score	0.6 ± 1.3	2.2 ± 2.7	< 0.01
Start of leg pain in relation to EGID symptoms - n (%)			< 0.01
Before	11 (14)	1 (8)	
After	20 (26)	5 (28)	
Same time	8 (10)	9 (44)	
N/A (no leg pain)	39 (50)	4 (22)	

	EoE n = 95	Non-EoE EGID n = 24	p
Days per week with pain in joints (mean ± SD) (n=94, 24)	2.7 ± 3.0	3.8 ± 3.2	0.12
Pain severity over prior 7 days (0-10 scale; mean ± SD) (n=96, 19)	1.9 ± 2.0	4.6 ± 3.5	< 0.01
Short-form McGill Pain Questionnaire (mean ± SD)			
Total score	4.1 ± 4.0	13.3 ± 10.7	< 0.01
Sensory sub-score	3.5 ± 4.1	11.0 ± 8.5	< 0.01
Affective sub-score	0.6 ± 1.1	2.3 ± 2.6	< 0.01
Start of joint pain in relation to EGID symptoms - n (%)			0.39
Before	17 (22)	4 (22)	
After	31 (39)	8 (44)	
Same time	9 (11)	4 (22)	
N/A (no joint pain)	22 (28)	2 (11)	

	EoE n = 95	Non-EoE EGID n = 24	p
Days per week with headaches (mean ± SD) (n=95, 24)	1.3 ± 1.8	2.1 ± 2.4	0.06
Days of headaches in the last month (mean ± SD) (n=94, 23)	4.5 ± 6.6	6.4 ± 9.3	0.25
Take prescribed medications for headaches - n (%) (n=85, 22)	9 (11)	5 (23)	0.13
Take over-the-counter medications for headaches - n (%) (n=85, 22)	55 (65)	17 (77)	0.28
Migraine Disability Assessment Test (Adults only) (n=81, 18)			
Mean score (± SD)	7.1 ± 26.5	36.8 ± 81.8	0.01
Grade of severity - n (%)			0.01
I: little or no disability (score 0-5)	66 (83)	9 (50)	
II: mild disability (6-10)	2 (4)	1 (6)	
III: moderate disability (11-20)	4 (5)	5 (28)	
IV: severe disability (21+)	7 (9)	3 (17)	

#### Conclusions

Patients with EGIDs may experience extraintestinal symptoms of leg, joint or headache pain, and these seem to be more prominent with non-EoE EGIDs. Understanding of the underlying factors contributing to these symptoms is needed to guide approaches for mitigating these symptoms.

Funded by an investigator-initiated grant from Takeda and supported by resources from UNC COVID (PI# P30 DK04987). We also acknowledge Allatos and Eliosi as EGID Partners sponsors and thank all patients for participating in EGID Partners.



## RESOURCES

- EGID brochure and fact sheet [patient resources](#).
- EGID information flyer/poster.
- Patient information folders with inserts.
- ausEE information card.
- [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.
- Distributed [The Blend](#) magazine.
- As a Rare Voices Australia partner, co-developed pages on Eosinophilic Gastrointestinal Diseases (EGIDs) and Eosinophilic Oesophagitis (EoE) for the [RARE Portal](#).
- Encouraging 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

- ausEE is a patient advocacy group member of the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR).
- ausEE CEO and Founder, Sarah Gray is on the advisory board of the NHMRC Centre of Research Excellence in Digestive Health.
- Sarah Gray awarded Medal of the Order of Australia (OAM) for service to community health.
- Attended the 2023 EoE Knowledge Exchange with international patient advocacy groups.
- Supporter of the [National Self-Care Charter](#).
- Attended the BMS Patient and Parliament Summit held in Canberra, 17-18 October 2023.
- Liaised with industry about clinical trials and elemental formulas to advocate for timely, affordable access to effective treatments.
- Made a submission to the HTA Review consultation.
- Participated in the Conversations for Change consultation survey.
- Reviewed the Rare Disorders Strategy for Aotearoa New Zealand.
- Reviewed Patient Voice Initiative's 'The Patient Voice Hub'.
- Attended consultations for the National Allergy Council's Shared Care for Allergy Project.
- Submitted comments to the Pharmaceutical Benefits Advisory Committee (PBAC) in support of the change to existing PBS listing for Jorveza.
- Contributed to the development of the 'Bringing Patient Centricity to Life' [white paper](#).

## AWARENESS

- Hosted [Feeding Tube Awareness Week](#) (5-11 February 2023). During #FTAW2023 93 Australian and New Zealand landmarks illuminated purple and blue in support.
- Hosted [National Eosinophilic Week](#) (6-12 August 2023) incorporating [Top 8 Challenge Day](#) on 8/8. During #NEOSW2023 91 landmarks lit up pink and purple around Australia and New Zealand to show their support.
- Collaborated on World Eosinophilic Diseases Day (18 May 2023).
- Supported awareness campaigns including Rare Disease Day, European EoE Day, Dazzle4Rare, World Asthma Day and World Atopic Eczema Day.
- Stories were shared to raise awareness about eosinophilic diseases and tube feeding.
- Raised awareness through articles published in print/online media and radio interviews.
- Exhibited at the Free From + Allergy Show held in Sydney, 21 and 22 October 2023.
- Actively engaged on our social media pages:

[ausEE on Facebook](#)

[ausEE on X/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

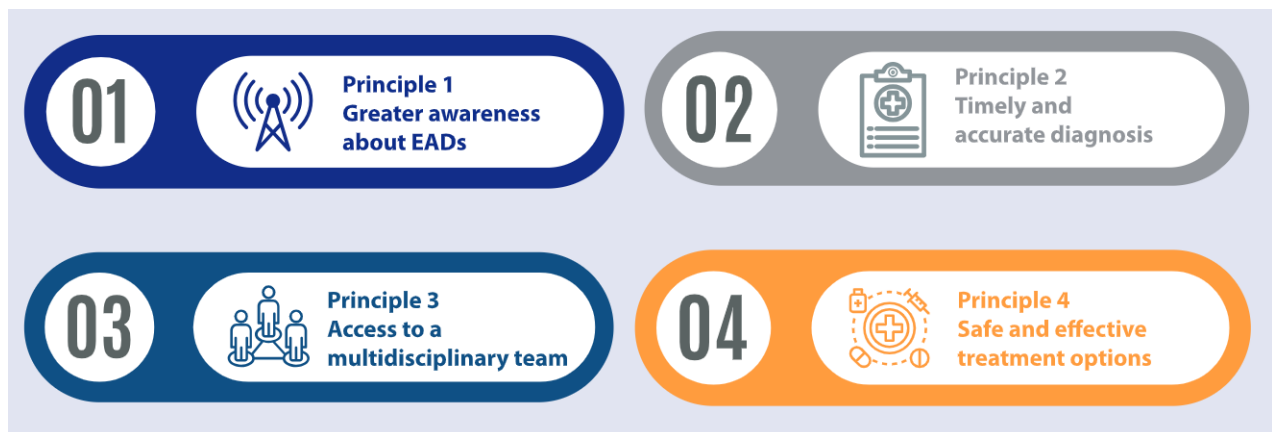
- Online Facebook groups peer support forums:
  - [Eosinophilic Gastrointestinal Disorders Australian Support Network – ausEE](#)
  - [Eosinophilic Gastrointestinal Disorders for Adults – ausEE](#)
  - [Eosinophil-Associated Diseases Australian Support Network – ausEE](#)
  - [AU Tubie Support](#)
- In 2023 we hosted 10 [Virtual Support Group Chats](#) through Zoom as an opportunity for our members to share and 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 Adelaide and Brisbane.
- Supported the tube feeding community through our [feeding tube aware](#) website which shares stories, support options, resources and links.
- Support available through [Livewire](#) for people aged 12-20 living across Australia and New Zealand experiencing hospitalisation, or living with a chronic health condition, serious illness, or disability. Support is available for siblings too.
- 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. collaborated with international patient advocacy groups and health professionals in the development of the [‘Plain Language Summary of principles for improving the care of people with eosinophil-associated diseases’](#) publication. The goal of this charter was to describe the key elements of good quality care, which all people with eosinophil-associated diseases (EADs) deserve, as well as to present an action plan to improve health and overall well-being for people with EADs.

ausEE has issued a request to the Australian Government to adopt the four principles outlined in the charter and support the development and implementation of new initiatives aligned with these principles.



Our government submission outlines the following objectives:

- Standards of Care
- Timely Diagnosis
- Patient Outreach
- Support Services
- Education and Awareness

Individuals affected by EADs encounter difficulties in obtaining timely diagnosis, specialized care, and access to essential information and support. They also experience the effects of limited community awareness. Addressing these unmet needs is crucial for individuals, families, healthcare systems, and society at large.

*Want to work with us to help ausEE achieve these goals?*  
Please register your interest volunteer for ausEE [here](#).

## Fundraising and Donations

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

ausEE Inc. is endorsed by the Australian Taxation Office as a deductible gift recipient. Donations over \$2 are tax deductible. All donations received will help us to achieve our mission to improve the lives of those affected by eosinophilic diseases. We thank our members, supporters and donors who help support us in our mission.

### 2023 FUNDRAISING CAMPAIGNS

2023 Tax Appeal  
 Facebook Fundraisers  
 National Eosinophilic Week / Top 8 Challenge  
[Online Store](#)



### 2023 FUNDRAISING PROGRAMS

ausEE is registered with these fundraising programs:

[Containers for Change](#)  
[Entertainment Memberships](#)  
[Gingerbread Folk](#)  
[Give with Bing](#)  
[Play for Purpose](#)  
[Shopnate](#)



### 2023 DONATION COLLECTION BOXES

Advantage Willsmere Village Pharmacy, Kew, VIC  
 Amcal North Balwyn Pharmacy, Balwyn North, VIC  
 Amcal Tunstall Square Pharmacy, Doncaster East, VIC  
 Casey's Pharmacy, North Balwyn, VIC

### 2023 DONATION PLATFORMS

Our registered fundraising and donation platforms are:

[Benevity](#), [Facebook Fundraisers](#), [GiveNow](#), [MyCause](#), [My Giving Circle](#), [PayPal Giving](#) and [Raisely](#).





## 2023 MEMBER FUNDRAISING

Member/Supporter	Fundraiser Name	Amount Raised
Team Franklin	Top 8 Challenge	\$48
Hayley Dale	Top 8 Challenge	\$84
Bethany Nielsen	Top 8 Challenge	\$100
Olivia Gray	Top 8 Challenge	\$128
Melanie Funk	Top 8 Challenge	\$136
Sara Hodgkinson	Top 8 Challenge	\$229
Jennifer Lee	Top 8 Challenge	\$358
Emily Martin	Top 8 Challenge	\$605
Laura Briggs	Top 8 Challenge	\$675
Sammy Cairnduff	Top 8 Challenge	\$745
Helen Byrne	Top 8 Challenge	\$918
Bethany Davey	Top 8 Challenge	\$1,479
Vanessa Lecky	Top 8 Challenge	\$1,900
Simon Camilleri	Top 8 Challenge	\$3,145
Lamgi's birthday fundraiser for ausEE Inc.	Facebook Fundraiser	\$70
Marion's birthday fundraiser for ausEE Inc.	Facebook Fundraiser	\$250

## 2023 SPECIAL DONOR ACKNOWLEDGEMENTS

Vanessa Lecky	\$1,000.00 Top 8 Challenge - Employer Matched Donation
Swaye Civil Pty Ltd	\$1,150.00 Top 8 Challenge - Donation
Flynn Family	\$1,548.00 Donation to ausEE Medical Research Fund
Thyme Moreton Bay	\$1,670.00 Donation, High Tea and Fashion Parade proceeds



## 2023 DONOR ACKNOWLEDGEMENTS

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

H Boulden	A Dittman	L McDonald
J Briggs	O Fitzsimons	J McLure
K Briggs	O Flower	L McLure
T Buttigieg	S and L Galea	A Meehan
R Buttigieg	A Gomez	P Newman
A Cairnduff	K Gwynne	S Smith
A Camilleri	J Hart	St George Montessori Engadine
Mr and Mrs Coleman	C Jefferies	Sunday Funday Markets
L Davey	D and K Kekatos	J and M Walsh
P Davey	M Kouchis	S Wood
R Davey	V Lecky	S Wright
R Davey		

Thank you to the following donors who made contributions of \$250 or more:

Anonymous	B and M Varghese
-----------	------------------

We gratefully thank the following donors who made contributions of \$500 or more:

BNI Excelsior, Mackay, NQ	J Brailey	D Brandt
J and H Hyde		

Thank you to our monthly donors during 2023:

M Mercer	D Paterson	N Schapowal
K Stock	K Tree	

## 2023 GRANTS

Global Allergy & Airways Patient Platform Communication Grants for:

- World Asthma Day
- World Atopic Eczema Day

Patient Voice Initiative (PVI) Grant to attend HTAi Annual Meeting.



## Our Supporters

In 2023 ausEE Inc. gratefully received support in the form of sponsorships from the following:

### 2023 SUPPORTERS



Diamond



Together we know more.  
Together we do more.

Platinum

sanofi

Gold



Silver



Silver



Silver



Silver

### FTAW 2023 SUPPORTERS



AVANOS



### 2023 PRIZE GIVEAWAY SPONSORS

[Dust Mite Allergy Solutions](#), [OLOE](#), [The Blend](#), [Tubie Fun](#), [Wholesome Blends](#)



Top 8 Challenge Prize Sponsor

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

## Medical Research

### AUSEE MEDICAL RESEARCH FUND

Since 2015, ausEE has been supporting [research projects](#) focused on improving diagnosis, management and treatment options for individuals with eosinophilic diseases. These research grants are made possible through the generous donations of our supporters and our annual Top 8 Challenge fundraising campaign. Each contribution brings us closer to finding a cure.

If you would like to contribute to our Medical Research Fund and support more research projects, please consider making a tax-deductible donation [here](#).

### RESEARCH GRANT AWARDS

In September 2023, ausEE Inc. awarded grant funding of \$9,000 to Nicole Hannan from Southern Cross University for a pilot feasibility trial of Meriva® curcumin phytosome® for adults with eosinophilic oesophagitis (EoE). The purpose of this study is to test two different doses of Curcutex Meriva® Curcumin Phytosome®, a naturally derived herbal product, to determine if it is feasible for the management of EoE in adults. Meriva® is a product containing natural compounds known as curcuminoids from the root of the turmeric (*Curcuma longa*) plant. Curcutex Meriva® Curcumin Phytosome® is registered with our Australian regulatory body, the Therapeutics Goods Administration (TGA). This research is important given little is known about the use, safety and efficacy of Meriva® for EoE. The findings of this study will help to determine if Meriva® is a potential treatment option for people living with EoE that could be examined further through clinical research. This study is being conducted by a team of highly experienced researchers at the National Centre for Naturopathic Medicine (NCNM) from Southern Cross University (SCU).

In October 2023, ausEE Inc. awarded additional grant funding of \$10,000 to Professor Guy Eslick, Professor Mike Jones, Professor Marjorie Walker and Professor Nicholas J. Talley from The University of Newcastle for continuation of their research project titled 'Are disorders of gut-brain interaction (DGBI) due to EGIDs?'. 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. 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. At UEG (United European Gastroenterology) Week in Copenhagen, Professor Nick Talley presented a [poster](#) from this research titled 'Eosinophilic oesophagitis (EoE): Risk factors, relationship with disorders of gut-brain interactions (DGBI), and mortality'.

## Audit Review: ausEE Inc. Annual Financial Statements

### Income and Expenditure Statement for the year ended 30 June 2023

<b>INCOME</b>	<b>2023</b>		<b>2022</b>	
Grants – Other	\$	4,204.14	\$	3,939.98
Donations Received	\$	20,436.24	\$	17,723.94
Non Tax-Deductible Gifts	\$	128.26	\$	195.33
Sales of Goods	\$	5,101.87	\$	5,855.95
Sponsorship & Licensing Fees	\$	71,337.20	\$	40,542.52
Interest	\$	693.14	\$	67.68
Recoupment	\$	292.47	\$	433.64
<b>Total Income</b>	<b>\$</b>	<b>102,193.32</b>	<b>\$</b>	<b>68,763.04</b>
<b>EXPENDITURE</b>				
Advertising & Marketing	\$	428.34	\$	130.37
Assets Purchased <\$5,000	\$	404.68	\$	1,544.50
Audit Fees	\$	330.00	\$	330.00
Bank Fees	\$	8.28	\$	5.96
Client Support Services	\$	2,909.09	\$	946.36
Computer Expenses	\$	2,027.13	\$	934.99
Credit Card Fees	\$	6.76	\$	20.25
Donations Paid (Medical Research Grant)	\$	-	\$	25,000.00
Fees & Permits	\$	-	\$	175.25
Fundraising Expenses	\$	597.98	\$	644.20
Insurance	\$	2,680.92	\$	2,377.53
Membership Fees Paid	\$	337.03	\$	190.91
Postage, Freight & Courier	\$	1,235.50	\$	1,166.32
Printing & Stationery	\$	471.35	\$	448.57
Publications & Information Resources	\$	566.47	\$	3,154.08
Salaries & Wages	\$	54,811.20	\$	23,512.32
Superannuation	\$	5,755.18	\$	2,351.28
Storage Costs	\$	545.44	\$	545.41
Telephone & Internet	\$	233.20	\$	240.51
Training - Development	\$	1,079.94	\$	-
Travel & Accommodation	\$	4,346.03	\$	332.04
Volunteer Costs	\$	1,182.80	\$	332.02
<b>Total Expenses</b>	<b>\$</b>	<b>79,957.32</b>	<b>\$</b>	<b>64,382.87</b>
<b>Current Year Surplus</b>	<b>\$</b>	<b>22,236.00</b>	<b>\$</b>	<b>4,380.17</b>

## Assets and Liabilities Statement ausEE Inc. as at 30 June 2023

<b>Assets</b>	<b>30 June 2023</b>		<b>30 June 2022</b>	
Current Assets				
Cash and Cash Equivalents	\$	129,561.92	\$	106,751.23
<b>Total Current Assets</b>	<b>\$</b>	<b>129,561.92</b>	<b>\$</b>	<b>106,751.23</b>
<b>Total Assets</b>	<b>\$</b>	<b>129,561.92</b>	<b>\$</b>	<b>106,751.23</b>
<b>Liabilities</b>				
Current Liabilities				
Trade and Other Payables	\$	3,969.48	\$	3,035.64
GST Payable	\$	1,760.85	\$	2,119.87
<b>Total Current Liabilities</b>	<b>\$</b>	<b>5,730.33</b>	<b>\$</b>	<b>5,155.51</b>
<b>Total Liabilities</b>	<b>\$</b>	<b>5,730.33</b>	<b>\$</b>	<b>5,155.51</b>
<b>Net Assets</b>	<b>\$</b>	<b>123,831.59</b>	<b>\$</b>	<b>101,595.72</b>
<b>Member's Funds</b>				
Capital Reserve	\$	123,831.59	\$	101,595.72
<b>Total Member's Funds</b>	<b>\$</b>	<b>123,831.59</b>	<b>\$</b>	<b>101,595.72</b>

## Notes to the Financial Statements ausEE Inc. for the year ended 30 June 2023

### 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.

<b>2. Cash on Hand</b>	<b>2023</b>		<b>2022</b>	
Suncorp Account - Medical Research Fund	\$	47,225.10	\$	27,790.76
Suncorp Account - Operational	\$	82,336.82	\$	78,960.47
<b>Total Cash on Hand</b>	<b>\$</b>	<b>129,561.92</b>	<b>\$</b>	<b>106,751.23</b>

<b>3. Trade &amp; Other Payables</b>	<b>2023</b>		<b>2022</b>	
PAYG Withholdings Payable	\$	2,532.00	\$	1,860.00
Superannuation Payable	\$	1,437.48	\$	1,175.64
<b>Total Trade &amp; Other Payables</b>	<b>\$</b>	<b>3,969.48</b>	<b>\$</b>	<b>3,035.64</b>

## **Independent Auditor's Review Report ausEE Inc. for the year ended 30 June 2023**

### **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 2023, 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 2023 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 2023 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.



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Auditor: Rowena Anderson

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

Dated: 17<sup>th</sup> November 2023



## Statement By Members of the Committee ausEE Inc. for the year ended 30 June 2023

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 2023 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:



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Sarah Gray  
CEO, ausEE Inc.

Dated: 3<sup>rd</sup> December 2023



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Mercedes Hinchcliff  
President, ausEE Inc.

Dated: 3<sup>rd</sup> December 2023

# Stories and Feedback

**#MyTubie**



“ We have seen and done so much, and all because we had his tube to keep him healthy and well. We are so very grateful to the incredible little tubie that gave us the opportunity to explore this beautiful country.

**Feeding Tube Awareness Week**  
5-11 February 2023  
feedingtubeaware.com.au

”

- Chloe

**#MyEGID**



“ When you finally get a diagnosis and a doctor tells you that it is the Food that you've been feeding your child that is making him sick, you just feel horrible...to know that what you were doing all along, that you thought was helping your child, was really hurting them.

**National Eosinophilic Week**  
6-12 August 2023  
#EoSavvy

”

- Laura (Ryder's mum)

**#MyTubie**



“ At 11 months of age, Mateo had surgery to have a PEG inserted, and along with that came huge milestone developments in many areas.

**Feeding Tube Awareness Week**  
5-11 February 2023  
feedingtubeaware.com.au

”

- Brittany

**#MyTubie**



“ Hunter and Rory have a special bond because of the feeding tube. From the moment Rory and Hunter met they had an instant connection. Hunter is very special to Rory and the two enjoy spending time together.

**Feeding Tube Awareness Week**  
5-11 February 2023  
feedingtubeaware.com.au

”

- Amanda and Karla

**#MyTubie**



“ I have two children with feeding tubes. Working as a Psychologist alongside being a tubie mum has led me to form a special interest in carer mental health. I am passionate about supporting families of tube fed loved ones as a parent advocate.

**Feeding Tube Awareness Week**  
5-11 February 2023  
feedingtubeaware.com.au

”

- Jess

“ I am fundraising because in November 2022 my Son Ryder was diagnosed with Eosinophilic Oesophagitis (EoE). I want to raise awareness and funds for further research.

**Supporter Spotlight**

**Laura**  
#Top8Challenge



**The taking the top 8 challenge**  
an #EGID23 to raise funds for eosinophilic disease research

**#MyTubie**



“ I have exhausted every option I could before my specialists put in the feeding tube. Doctors don't put in feeding tubes for the fun of it. The feeding tube is saving my life.

**Feeding Tube Awareness Week**  
5-11 February 2023  
feedingtubeaware.com.au

”

- Tayarra

“ Thank you so much for facilitating tonight's call! So good to speak to people who just get it! Lots of us newbies to learn. Very lucky to have all the support. Thank you!

”

- Ramona



**#MyTubie**




“ I struggled to envisage a life without food – the social aspect of eating; the joy of tasting yummy things; the satisfaction you feel after making a tasty dish, sharing it with loved ones and sitting back to enjoy the gastronomical afterglow.

**Feeding Tube Awareness Week**  
5-11 February 2023  
feedingtubeaware.com.au

”

- Juliette

**#MyTubie**



“ Tube feeding has saved Lewis's life; it's never hindered it nor made him different. He is thriving today because of the PEG, giving him freedoms that he was once told were out of his reach.

**Feeding Tube Awareness Week**  
5-11 February 2023  
feedingtubeaware.com.au

”

- Sarah

**#MyEGID**




“ I got diagnosed with eosinophilic oesophagitis (EoE) at age 13 after Mum's chicken tikka got stuck... It's hard and people don't understand so I don't even try to explain.

**National Eosinophilic Week**  
6-12 August 2023  
#EoSavvy

”

- Nick

**#MyTubie**



“ On bad days we are able to use the tube to keep Liv out of hospital which has meant we can have a better quality of life! Liv doesn't allow her tube to define her and loves dancing competitively.

**Feeding Tube Awareness Week**  
5-11 February 2023  
feedingtubeaware.com.au

”

- Kate

**#MyEGID**



“ Before I was diagnosed with eosinophilic colitis (EoC), my stomach was unhappy, cranky, with stabby pain that stopped me in my tracks or made me drop to the ground.

**National Eosinophilic Week**  
6-12 August 2023  
#EoSavvy

”

- Bethany

“ We would like to say a big thanks to everyone at ausEE for their hard work in bringing recognition, education and treatment development to the eosinophilic disease.

”

- Scott & Evonne



“ I was diagnosed with Eosinophilic Colitis (EoC) late last year. There is very little concrete research or reliable information for the rarer types of EGIDs. More research is needed.

**Supporter Spotlight**

**Bethany**  
#Top8Challenge



**The taking the top 8 challenge**  
an #EGID23 to raise funds for eosinophilic disease research

**#MyTubie**



“ Our beautiful boy has gone from taking zero forms of liquid through his mouth to eating up to four puree pouches a day and having up to two hours off his Feeds a day. It has been an incredible long journey to get to this point but seeing Gus thrive has been the biggest achievement.

**Feeding Tube Awareness Week**  
5-11 February 2023  
feedingtubeaware.com.au

”

- Leah

## Contact Information

ausEE Inc.  
PO Box 9923  
Frenchville Qld 4701

**Tel** 1300 923 043

**Email** [admin@ausee.org](mailto:admin@ausee.org)

### Websites

[ausee.org](http://ausee.org)  
[eosaware.com](http://eosaware.com)  
[feedingtubeaware.com.au](http://feedingtubeaware.com.au)

### Social Media

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

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

 [@ausEEorg](https://twitter.com/ausEEorg)

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



**ausEE Inc.**

a charity dedicated to improving lives  
affected by an eosinophilic disease

ABN 30 563 569 016