a charity dedicated to improving lives affected by eosinophilic disorders

2016 Annual Report
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About Us

ausEE Inc. is an Australian charity providing support and information to anyone diagnosed with or caring for someone with an Eosinophilic Gastrointestinal Disorder (EGID) including Eosinophilic oEsophagitis (EoE), Eosinophilic Gastritis, Eosinophilic Duodenitis, Eosinophilic Enteritis, Eosinophilic Colitis and Eosinophilic Gastroenteritis.

We are committed to raising public awareness and supporting the medical community for further research into eosinophilic disorders in Australia.

Founded in 2009, ausEE Inc. is a Queensland Incorporated Association (IA38281). We are a registered Charity with the Australian Charities and Not-for-profits Commission (ACNC) and endorsed by the Australian Taxation Office (ATO) as a Deductible Gift Recipient (DGR). We are a National charity and hold fundraising licenses for every state and territory in Australia as required.

Our Cause

Eosinophilic Gastrointestinal Disorders (EGIDs) occur when eosinophils (pronounced ee-oh-sin-oh-fills), a type of white blood cell, are found in above-normal amounts within the gastrointestinal tract. The eosinophils can accumulate in the gut in response to food and/or airborne allergens and can cause inflammation and tissue damage. People living with EGIDs often live with food restrictions which make it hard on physical, emotional and social levels. Endoscopy and biopsy is the only way to confirm the diagnosis of an EGID and effectively monitor the treatment.

There is no cure.
Our Mission

Our mission is to improve the lives of those affected by eosinophilic gastrointestinal disorders by providing support and information and to campaign and raise funds for further research in Australia.

OUR VISION

Our vision is:

- To reach all those affected by eosinophilic disorders in Australia.
- To become the catalyst for further research in the medical field; and ultimately find a cure.
- To become the most prominent eosinophilic support organisation in Australia.

OUR OBJECTIVES

Our objectives are:

- To provide support and information to individuals and families affected by eosinophilic gastrointestinal disorders.
- To improve the quality of life for people with eosinophilic gastrointestinal disorders.
- To create greater public awareness and understanding of eosinophilic gastrointestinal disorders, their impact and appropriate management options.
- To help people recognize the symptoms of eosinophilic gastrointestinal disorders.
- To be a credible source of information to physicians and patients.
- To campaign and raise funds to enable further research to be conducted in Australia for eosinophilic gastrointestinal disorders.
Our Achievements

ausEE Inc. provides valuable information relevant to eosinophilic gastrointestinal disorders through our website to both patients and physicians. Online support is available through our Facebook group forums and we facilitate face-to-face support group meetings.

We strive to improve the quality of life for all people with eosinophilic disorders.

We provide all our information, services and support free for everyone and do not charge membership fees.

The Management Committee of ausEE Inc. is comprised entirely of volunteers and the association has no paid staff.

All donations received help ausEE Inc. to achieve our mission to improve the lives of those affected by eosinophilic gastrointestinal disorders by providing support and information and by funding Australian medical research.

Our achievements are outlined in six key areas:

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

- ausEE website ([www.ausee.org](http://www.ausee.org)) with current HONcode certification
- Information phone line: 1300 923 043
- Monthly Supporter/Member eNewsletters
- Quarterly Physicians eNewsletters
- Co-hosted with My Food Allergy Friends a Free Information Evening on Practical Tips for Living with Allergies and Anaphylaxis
- Exhibited at Medical Conferences: ASCIA 2016 and AGW 2016

RESEARCH

- Awarded The University of Newcastle a grant of $20,000 towards a research project looking to develop new targeted drug delivery therapies through the use of nanotechnology.
- Awarded grant funding of $8,000 to Dr Hamish Philpott, Dr Evan Dellon and Dr Sanjay Nandurkar for the research project 'Antigen presentation and acute inflammation in EoE'.
- Partnered with The Kaleidoscope Project - Engaging Children and Families in Research.
- Actively promoted EduSwell, a study investigating the impacts of a serious illness on a student.
- Supported the Deakin University’s research - Parenting a child with a rare disease: parent mental health and well-being.
- Participated in the National Allergy Strategy’s survey for teens and young adults - Knowledge and Barriers to Allergy Management (KABAM).
- Assisted with the research study ‘Exploring the Experiences of ausEE Members living with Eosinophilic Oesophagitis’. This study was conducted by the Department of Clinical Immunology at Royal Prince Alfred Hospital and included an online survey, 4-day weighed food diary and focus groups.
RESOURCES
- EGID medical brochures
- Patient Information Folders
- A4 information posters
- Charity Information Card
- Children's Books about living with an eosinophilic disorder: 'Meet Arabella', 'Being Henry' and 'Olivia and Kate'
- Donated hand knitted ausEE dolls to gastroenterology clinics in hospitals to be given to kids undergoing endoscopies or surgery for EGID/EoE.
- Distributed Medikidetz Comics on Home Enteral Nutrition.

ADVOCACY
- Continued to support the National Allergy Strategy as a stakeholder organisation.
- Liaised with pharmaceutical companies about the product range of elemental formulas to try to reach the needs of all Australians living with EGIDs.
- Representative on the C-EOS (Coalition of Eosinophil Patient Advocacy Groups)
- Patient advocacy group of the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR)
- Actively involved in the Rare Voices ‘Fair for Rare’ campaign which is in conjunction with the development of a National Rare Diseases Plan.
- Invited to serve on the advisory board of the NHMRC Centre for Excellence titled ‘Centre for Excellence in Neurogastroenterology, Digestive Immunology and Microbiology (CENDIM)’.
- Represented at ‘The Forgotten Ones’ photo exhibition in Melbourne. Kate’s portrait was featured as she has a sibling with a rare disease (Henry).
AWARENESS

- Hosted Feeding Tube Awareness Week (7-13 February 2016)
- Hosted National EOS Awareness Week (7-13 August 2016) (www.eosaware.com)
- Top 8 Challenge Day held on 8/8 each year (www.top8challenge.com)
- Media stories published in print, Podcast and online media
- ausEE YouTube Channels: (ausEE Support Network) (Allergy Friendly)
- Additional social media pages: facebook.com/austallergyfriendlyfinds facebook.com/top8challenge facebook.com/allergyfreecookingontv

SUPPORT

- Online Facebook support forum: www.facebook.com/groups/ausee
- Additional forum for adults diagnosed with an EGID: www.facebook.com/groups/auseeadults
- Official ausEE Group on Livewire for anyone aged between 10 to 20 who is living with an EGID: www.livewire.org.au
- Teen only Facebook support group
- Facebook group for Medical Professionals
- Keep in Touch Program for children (and their siblings) to connect with other children who have also been diagnosed with an EGID via email, Facetime/Skype, or written letters.
- Support Group Meetings held across Australia so that adults, parents, and kids can meet each other face-to-face to share experiences and gain support.
- Support Australian businesses providing products to help those with EGID and allergies through free promotion on Australian Allergy Friendly Finds Facebook page and by running giveaways for our supporters and where possible provide discount offers for our members.
ausEE Boards

**MANAGEMENT BOARD**

**Sarah Gray** – President

**Mercedez Hinchcliff** – Vice President

**Mariya Taylor** – Secretary

**Marion Stock** – Treasurer

**Jason Gray** – Board Member

*Supported by:*

Tim Brock - *Grants and Sponsorships Manager*

Neen Monty - *Marketing Manager*

Kylie Gwynne – *Communications*

**MEDICAL ADVISORY BOARD**

**Professor Pete Smith** (MBBS, BMedSci, FRACP PhD, Allergist & Immunologist)

**Dr Ralf Heine** (MD FRACP, Paediatric Allergist & Gastroenterologist)

**Professor Katie Allen** (MBBS, BMedSci, FRACP PhD, Paediatric Allergist & Gastroenterologist)

**Dr Looi Ee** (MBBS, FRACP, Phd, Paediatric Gastroenterologist)

**Dr Sam Mehr** (MBBS, BMedSci, FRACP, FRCP, Allergist/Immunologist)

**Dr Ajay Sharma** (MBBS, MD, FRACP, Paediatric Gastroenterologist and Hepatologist)

**Wendy Birks** (Paediatric Dietitian - Feeding Clinic & Allergy)

Retiring Member (February 2017):

**Associate Professor Alyson Kakakios** (OAM, MBBS, FRACP, Paediatric Allergist & Immunologist)
Future Goals

DEVELOPMENT OF RESOURCES

We aim to produce additional patient resources to provide information specific to Adults living with eosinophilic disorders. We will also be updating our current resources in 2017.

PATIENT CONFERENCE

We have been continuing to strive towards achieving our goal to host the first Australian Patient Conference for families caring for a child with an eosinophilic gastrointestinal disorder (EGID) or adults themselves living with an EGID.

To host this conference, we will need to receive grant or sponsorship funding which we have been applying for but unfortunately have not yet been successful obtaining.

We have gathered information from similar conferences held in the United States which are hosted by APFED (American Partnership for Eosinophilic Disorders) and CURED (Campaign Urging Research for Eosinophilic Diseases). We will be calling for more volunteers to assist us to make this conference a reality.

VOLUNTEERS

ausEE Inc. is a charity entirely run by volunteers. All of our volunteers are parents of children with an eosinophilic disorder or have an eosinophilic disorder themselves.

The progress and achievements we have made over the years could not have been done without this small group of volunteers. Looking ahead, we hope to attract and retain more volunteer support so that we can achieve more of our goals.
Fundraising and Donations

ausEE Inc. is a registered charity with the 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 help us to provide research, education and information to those people with EGID, their families, friends and the community.

2016 DONATION COLLECTION BOXES

Butcher’s Pharmacy, Kew
Casey’s Pharmacy, North Balwyn
Fish and Chip Takeaway, Mountain Creek
LiveLife Pharmacy, Peregian Springs

2016 FUNDRAISING CAMPAIGNS

National EOS Awareness Week / Top 8 Challenge
Expressions Tea Towel / Gift Shop Sales
Christmas Wish Star Appeal
2016 MEMBER FUNDRAISING

Annette Cairnduff - Sydney’s Big Top 8 Free Morning Tea  
Tricia Hart - Catelyn’s Wish  
Kathleen Hedger - Edmund Rice College – Top 8 Challenge  
Kristin Paterson - Awareness for Andy - Perth City to Surf  
Tracie Sillers – Corporate Volunteer Day

FUNDRAISING PLATFORMS

Our registered fundraising platforms are GiveEasy, GiveMatcher, GiveNow and MyCause.

FUNDRAISING PROGRAMS

We have active fundraising programs with Aid Arena, ARP Mobile Phone Recycling, Bright Star Kids, Entertainment Book, FOLO and The Give Back Campaign.

2016 DONORS

ausEE Inc. would like to acknowledge the following donors who made contributions over $100.

L Avanus  
A Belunek  
S Borazio  
B Bowling  
D Brandt  
D Bridges  
C Burke  
H Calma  
J Chadwick  
Chubb Insurance Company  
K Gwynne

M Hoy  
K McElvogue  
K Stock  
S Walsh  
P Wong  
E Woo  
Donors - Awareness for Andy  
Donors - Lillian’s Top 8 Challenge  
Donors - Food for Reuben Top 8 Challenge  
Donors - Sammy’s Top 8 Challenge
Grants and Sponsorships

In 2016 ausEE Inc. has gratefully received support in the form of grants and sponsorships from the following.

**2016 GRANTS**

Department of Social Services - $1,133 for computer equipment

**2016 PRIZE GIVEAWAY SPONSORS**

Kohoka [www.kohoka.co](http://www.kohoka.co)
My Food Allergy Friends [www.myfoodallergyfriends.com](http://www.myfoodallergyfriends.com)

**2016 SPONSORS**

Happy Tummies – sponsorship of monthly Member/Supporter Newsletters
Nutricia Advanced Medical Nutrition – sponsorship of quarterly Physicians Newsletters
THASC Sales Company Inc. – donation of ausEE branded pens for gift shop and conferences
Medical Research

2016 RESEARCH GRANTS AWARDED

March 2016 - ausEE granted $20,000 of its research funds to support a new study from The University of Newcastle. Laureate Professor Nicholas Talley and his team aim to develop new targeted drug delivery therapies for EoE and EGID through the use of nanotechnology.

November 2016 - ausEE awarded grant funding of $8,000 to Dr Hamish Philpott, Dr Evan Dellon and Dr Sanjay Nandurkar for the research project 'Antigen presentation and acute inflammation in EoE'. This project has the potential to streamline the diagnosis and treatment of patients who present with oesophageal eosinophilia.

INTERNATIONAL RESEARCH

As a patient advocacy group, ausEE supports the Rare Diseases Clinical Research Network (RDCRN) Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR) Contact Registry.

The RDCRN Contact Registry is a way for patients with eosinophilic gastrointestinal diseases and their family members to learn about CEGIR research studies they may be able to join.

This is an international registry. Participation is completely voluntary and you may choose to withdraw at any time. There is no cost to join the Contact Registry.
2016 RESULTS FROM PREVIOUS GRANT RECIPIENT

At the ASCIA 2016 Conference, Mary Agapides from Royal Prince Alfred Hospital presented her poster on the study that ausEE supported with grant funding awarded in 2015.

You can read more about the research below and access the presented publication [online].

An open letter to ausEE

On behalf of the Department of Clinical Immunology at Royal Prince Alfred Hospital we would like to thank ausEE for their kind donation towards research currently underway.

Our research aimed to find alternate methods of diagnosing EoE and the food allergens potentially involved in causing disease. Currently, the only way to diagnose EoE and monitor the success of treatment, is via endoscopy and biopsy. These procedures are expensive, invasive and can be distressing, particularly as EoE patients often require regular testing to monitor their disease. We were specifically focused on blood tests that could be used to aid in the diagnosis of EoE.

We found two proteins circulating in the blood of EoE patients, eosinophilic cationic protein (ECP) and eosinophil-derived neurotoxin (EDN), that were both indicative of disease. The only problem is, these proteins also seem to appear in individuals with other atopic diseases, such as allergic rhinitis, asthma and eczema, conditions also seen in EoE patients. This means ECP and EDN aren’t ideal to use for an initial EoE diagnosis, however, there is potential for these biomarkers to be used to monitor treatment success in EoE patients.

Dietary manipulation is a popular treatment for EoE, however, deciphering which foods are causing disease is often a lengthy and complicated process. We also found a new potential method of “screening” for food allergens in EoE patients which involved looking in the blood for specific IgE reactions to a large panel of foods. This panel identified new potential problem foods in EoE patients, such as egg yolk, chicken, lamb, orange and fruits that are associated with latex allergies. This new method could also be useful in predicting whether dietary treatment is the best option for an EoE patient and if medication should also be considered in controlling their disease. Our research is continuing to validate this method in a larger group of patient.

Mary Agapides and Louise Wienholt
Financial Statements

AUSEE INC. AUDIT REPORT FOR THE YEAR ENDED 30 JUNE 2016

We advise that we have completed the Audit of the books of account of ausEE Inc. for the year ended 30 June 2016. However, before an opinion can be given the following qualification must be noted:-

(1) It is not possible to verify that all monies received have been receipted intact, However, I am satisfied that all monies receipted have been banked intact.

Subject to this qualification, in our opinion:-

(a) The accompanying Financial Statements, which have been prepared from the books and records supplied by the Association, present a true and fair view of the operations of ausEE Inc. as disclosed in the books of account for the year ended 30 June 2016.

(b) The Accounting and other records have been properly maintained.

(c) There is no other matter to be advised to the Committee and members at the Annual General Meeting.

DATED THIS 20th day of October 2016

[Signature]

Karina Stanley MIPA AFA Cdec
COOLUM ACCOUNTANTS
Suite 8/21 Birtwill Street, Coolum Beach
PO Box 1 Coolum Beach QLD 4573
Telephone (07) 5446 2422
## AusEE INC

**PROFIT & LOSS STATEMENT**

**FOR THE YEAR ENDED 30 JUNE 2016**

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<th>NSCOA</th>
<th>INCOME</th>
<th>Amount</th>
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<td>4-1100</td>
<td>Grants — Other (Non Government Elements)</td>
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<td>4-2010</td>
<td>Donations received</td>
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<td>4-2030</td>
<td>Donations (Public Collections)</td>
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<td>4-4010</td>
<td>Sales</td>
<td>761.00</td>
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<td>4-4050</td>
<td>Sponsorship and Licencing Fees</td>
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<td>4-5020</td>
<td>Interest - Unrestricted</td>
<td>714.03</td>
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<td>4-5050</td>
<td>Other / Sundry Income</td>
<td>359.56</td>
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**Total Income**

$16767.60

### LESS EXPENSES

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<td>Bank charges</td>
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<td>6-0300</td>
<td>Donations Paid (Medical Research Grant)</td>
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<td>6-0330</td>
<td>Fees and Permits</td>
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<td>6-0540</td>
<td>Publications and Information Resources</td>
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<td>6-0710</td>
<td>Travel and Accommodation (Conferences)</td>
<td>60.00</td>
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**Total expenses**

$26477.72

**Net Surplus/Deficit**

($9710.12)

Please note: A deficit has been reported for 2015/2016 Financial Year due to the $20,000 medical research grant awarded from our Medical Research Fund.
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<tr>
<td>Opening Balance</td>
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<tr>
<td>Surplus/Deficit</td>
<td>(9710.12)</td>
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<td>$27427.36</td>
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<table>
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<th>Represented By</th>
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<tr>
<td>CURRENT ASSETS</td>
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<tr>
<td>Suncorp Account — Operational 18970</td>
<td>4940.87</td>
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<tr>
<td>Suncorp Account — Medical Research Fund 52725</td>
<td>22486.49</td>
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<td></td>
<td>$27427.36</td>
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</tbody>
</table>
Contact Information

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Australia

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www.asee.org

ausEE

a charity dedicated to improving lives affected by eosinophilic disorders

ABN 30 563 569 016