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/territory in Australia as required.

OUR CAUSE

Eosinophilic Gastrointestinal Disorders (EGIDs) occur when eosinophils (pronounced ee-oh-sin-oh-fils), a type of white blood cell, are found in above-normal amounts within the gastrointestinal tract. In some individuals, eosinophils accumulate in the gut potentially in response to drugs, food, airborne allergens and other unknown triggers. This infiltration can cause inflammation and tissue damage.

Eosinophilic Oesophagitis (EoE) is the most common type of EGID. The current estimated prevalence of EoE is 1 in 2,000 individuals and rising.

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. EGIDs are chronic diseases that require ongoing monitoring and management.

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.
Charity Ambassador

2018 Australia's Local Hero, mathematics teacher for the NSW Department of Education and TV Host of Teenage Boss, Eddie Woo has become an Australian household name and we were excited to announce him as our Charity Ambassador in July 2018.

Eddie Woo has been inspiring students across the globe through his YouTube channel, Wootube. Eddie joined ausEE Inc., as our Charity Ambassador to help raise awareness for EGIDs, a cause close to his heart.

Eddie is a proud father with three children who all live with some form of allergic disease. This includes asthma, eczema and multiple immediate food allergies. One of them has an EGID, namely, eosinophilic oesophagitis (EoE). This has caused Eddie’s child to live with symptoms such as difficulty swallowing, vomiting, stomach pain and ‘failure to thrive’.

“The difficulties are every day. Eating itself has become a really difficult experience, because eating was associated with an incredible amount of discomfort and pain just to squeeze food and drink down. In addition, there is a social aspect to food that is very difficult for others to understand. Since relationships are often formed through mealtimes, our children have had to struggle with having a complex and cautious relationship to even the simplest social gatherings.” - Eddie Woo

Eddie has been teaching for 11 years and in 2012 when a student of his had Pancreatic cancer, he felt the urge to help as much as possible and started to record all of his lessons and post them on YouTube. It was astounding to see the amount of views, and his Wootube channel now has more than 557k subscribers and over thirty-one million views.

These videos are now helping people around the world not only understand maths but find joy in maths. For our ausEE members who have high schoolers, this extra assistance with maths has been invaluable for their students as many have experienced the impact living with a chronic illness can have on school work.
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 our volunteers are parents of children with an eosinophilic disorder or have an eosinophilic disorder themselves.

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) with HONcode certification
- Information phone line: 1300 923 043
- Monthly Supporter/Member eNewsletters
- Quarterly Physicians eNewsletters
- Exhibited at Medical Conferences:
  - Gastroenterological Society of Qld (GESQ Update 2018) held in Noosa
  - Australasian Society of Clinical Immunology and Allergy (ASCIA 2018) held in Canberra
  - Gastroenterological Society of Australia’s Australian Gastroenterology Week (AGW 2018) held in Brisbane

RESEARCH

- Awarded grant funding of $25,000 to Dr Jeremy Rosenbaum of Paediatric Gastroenterology Victoria to help facilitate EoE research projects and improve quality of care.
- We supported a research project titled ‘Genomics Research and Involving People’ by researcher Jack Nunn from the Centre for Health Communication and Participation (La Trobe University) and the Public Health Genomics Program at Monash University. Our members were invited to learn more about genomic research and share their views and perspectives about who should be involved in shaping the future of this research.
- ausEE supported Nicole Hannan from Griffith University’s research project titled ‘Exploring healthcare use, burden of disease and satisfaction with care in paediatric eosinophilic oesophagitis.’ This research involved completing an online survey answering questions exploring quality of life and experiences in the healthcare system for paediatric EoE.
RESOURCES

- EGID medical brochures
- Patient Information Folders
- A4 information posters
- Charity Information Card
- Infographic on What is an EGID
- Eosinophilic disorders explained downloadable resource
- 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.
- Representative on the C-EOS (Coalition of Eosinophil Patient Advocacy Groups)
- Patient advocacy group of the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR)
- Nominated in the 2018 Queensland Community Achievement Awards.
- Liaised with pharmaceutical companies about pipeline medications for EGIDs to enquire about clinical trial opportunities and the product range of elemental formulas to ensure people with EGID have timely access to the most effective treatments to improve their quality of life.
- Submitted feedback on the Food Standards Australia New Zealand (FSANZ) Proposal P1044, Plain English Allergen Labelling (PEAL) proposal.
- Partner organisation of Rare Voices Australia (RVA) and represented by Kylie at the 2018 RVA National Rare Diseases Summit and by Lee and Emily at the RVA Future Rare Disease Advocates workshop.
AWARENESS

- Hosted Feeding Tube Awareness Week (4-10 February 2018) (www.feedingtubeaware.com.au)
- Hosted National EOS Awareness Week (5-11 August 2018) NEOSW Infographic (www.eosaware.com)
- Top 8 Challenge Day held on 8/8 each year (www.top8challenge.com)
- Member stories shared to raise awareness
- Stories published in print and online media
- Supported awareness campaigns including Rare Disease Day, World Allergy Week
- Represented by Bella in the Queen’s Baton Relay - GC2018 Commonwealth Games
- ausEE YouTube Channel
- Active on social media:
  - www.facebook.com/auseeinc
  - www.twitter.com/auseeorg
  - www.instagram.com/ausee_inc
  - www.linkedin.com/company/ausee-inc
  - www.pinterest.com/ausee
- Additional social media pages:
  - facebook.com/austallergyfriendlyfinds
  - facebook.com/top8challenge
  - facebook.com/allergyfreecookingontv

SUPPORT

- Online Facebook support forum: www.facebook.com/groups/asee
- Additional forum for adults with an EGID: www.facebook.com/groups/aseeadults
- Official ausEE Group on Livewire for anyone aged between 12 to 20 who is living with an EGID: www.livewire.org.au
- 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 allergy friendly food and products to help those with EGID and allergies through free promotion on our Australian Allergy Friendly Finds Facebook page.
ausEE Boards

**MANAGEMENT BOARD**

**Sarah Gray** – President

**Mercedez Hinchcliff** – Vice President

**Mariya Taylor** – Secretary

**Kristin Paterson** – Treasurer

**Kylie Gwynne** – Board Member

*Thank you to outgoing Treasurer: Marion Stock*

*Facebook Groups Admins and Moderators:*
  Tracie Sillers
  Anna Edwards
  Sarah Gray
  Mercedez Hinchcliff

*ausEE is also supported by:*
  ausEE Inc. Committee Members
  Knitted dolls volunteers
  ausEE Inc. Volunteers

**MEDICAL ADVISORY BOARD**

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

**Dr Looi Ee** MBBS, FRACP, PhD, Paediatric Gastroenterologist

**Dr Sam Mehr** MBBS, BMedSci, FRACP, FRCPA, Allergist & Immunologist

**Dr Hamish Philpott** MBBS, MRCP, FRACP, PhD, Gastroenterologist & Hepatologist

**Dr Jeremy Rosenbaum** MBBS (Hons), FRACP, Paediatric Gastroenterologist & Hepatologist

**Dr Ajay Sharma** MBBS, MD, FRACP, Paediatric Gastroenterologist & Hepatologist

**Wendy Birks** Paediatric Dietitian - Feeding Clinic & Allergy
Future Goals

STANDARDS OF CARE GUIDELINES

We have been seeking funding to develop Standards of Care Guidelines for EGIDs which would be written with extensive coordination and consultation from medical professionals and key stakeholders. We surveyed our members in April/May 2018 and Care and Treatment Guidelines for Eosinophilic Disorders was an area of the highest priority for survey respondents. Achieving this goal would substantially benefit healthcare professionals, institutions and ultimately their patients.

MEMBER CONFERENCE

Hosting a Member/Patient Conference has been one of our goals for several years. In June/July 2018 we surveyed our members and 95% of respondents said they wanted to see us host a Member Conference. This conference would offer information by medical professionals in the field on diagnosis, research, treatment, long term impacts and novel treatments as well as provide networking opportunities for our members. We will continue to seek funding to achieve this goal.

MEDICAL CONFERENCES

ausEE would like to further outreach to the medical community by attending more Australian medical conferences including in the field of dietetics and paediatrics for the opportunity to distribute our resources and raise awareness. We also aim to attend international conferences like those hosted by APFED (American Partnership for Eosinophilic Disorders) and CURED (Campaign Urging Research for Eosinophilic Diseases) to increase our networks and knowledge.

VOLUNTEER GROWTH

ausEE Inc. is a charity entirely run by volunteers. 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 improve lives affected by an EGID, particularly by funding vital research and by providing much needed support and information to families, friends and the community. We are thankful to our members and supporters for supporting us in our mission.

2018 DONATION COLLECTION BOXES

Advantage Willsmere Village Pharmacy, Kew, VIC
Casey’s Pharmacy, North Balwyn, VIC
LiveLife Pharmacy, Peregian Springs, QLD

2018 FUNDRAISING CAMPAIGNS

National EOS Awareness Week
Top 8 Challenge
Gift Shop Sales
Giving Tuesday
Christmas Appeal

2018 FUNDRAISING PROGRAMS

We are registered with the following fundraising programs; ARP Mobile Phone Recycling, Bright Star Kids, Cashrewards, Entertainment Book, FOLO, Play for Purpose and Shopnate.

2018 FUNDRAISING PLATFORMS

Our registered fundraising platforms are GiveEasy, GiveNow, MyCause, My Giving Circle and PayPal Giving.
## 2018 MEMBER FUNDRAISING

<table>
<thead>
<tr>
<th>Member/Supporter</th>
<th>Fundraiser Name</th>
<th>Amount Raised</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Cairnduff &amp; K Gwynne</td>
<td>Kylie &amp; Annette’s Wedding</td>
<td>$7,500</td>
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<tr>
<td>A Cairnduff &amp; K Gwynne</td>
<td>Sammy’s Top 8 Free Cookie Stand</td>
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<tr>
<td>M Cunningham</td>
<td>Top 3 Challenge for Alaina</td>
<td>$350</td>
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<tr>
<td>M Goel</td>
<td>Support ausEE for Arya</td>
<td>$590</td>
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<tr>
<td>N Hannan</td>
<td>Charlie (aka The Captain) Top 8 Challenge</td>
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<tr>
<td>Hedger Family</td>
<td>Edmund Rice College Year 12 Fundraising</td>
<td>$800</td>
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<tr>
<td>M Homan</td>
<td>Melissa’s Top 8 Challenge</td>
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<tr>
<td>T Lukasz</td>
<td>Lenny’s Slime Stall</td>
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<td>B Padbury</td>
<td>Oaklee Padbury’s Top 8 Challenge</td>
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<tr>
<td>K Paterson (Team Andy)</td>
<td>‘Swim for Andy’ Rottnest Channel Swim</td>
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<tr>
<td>K Paterson (Team Andy)</td>
<td>‘Awareness for Andy’ HBF Run for a Reason</td>
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<tr>
<td>M Stock</td>
<td>In Memory of Irwin Johnson</td>
<td>$140</td>
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<tr>
<td>B Varghese</td>
<td>Lorraine Lea Linen Fundraiser</td>
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<tr>
<td>A Wilson</td>
<td>DoTERRA ‘Essentially Sandals’ Fundraising</td>
<td>$2,000</td>
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2018 DONOR ACKNOWLEDGEMENTS

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

M Allison       M Cunningham       S Kelly       D Robinson
K Andrews       J Dejoode         B Lee         P Rogers
P Anthony       A Coulston        L Langley     R Russell
L Avanus        L Dillon          M Lincoln      S Ryan
E Baxter        B Edgar           J Lo Cascio   R Singh
J Bellicicanta  N Elliott         D Lovell      St Patrick's School Year 6
O Best          P Finkelstein      P Macdonald   T Sutherland
L Bond          P Flynn           K Mercer      K Szerdahelyi
J Bowland Curtis L Fong            R Moir        B Varghese
B Bowling       A Friends         S Moore       K Taylor
D Brandt        S Glover          R Osadnik     B Townsend
D Bridges       C Godfrey         S Page        C Tropiano
C Burke         L Goss            B Pamphilon   J Walsh
A Cairnduff     S Goss            B & G Paterson J Wangmann
S Cairnduff     K Gwynne          K Paterson    L Williams
V Christie      K Hill             A Peltola     K Wong
J Clarke        G Homan           C Pruscino    E Woo
A Clarkson      Jen and Kath      R Richardson  M Young
J Cook          N Johnson          S Riethoff    W L Yu

Thank you to our Monthly Donors:
K Stock         A Triglone

Donations of $500 or over were gratefully received from:
Anzac Charity Canteen      Tom Calma      Edmund Rice College     Kathryn Refshauge
Adam Barralet               Michael Chapple  David Hickmott

Thank you to these supporters who generously donated $1,000 or over:
Kay Van Norton           Amanda Wilson

Special Acknowledgement: Emma and Tony Olsen (Flor-Hanly) generously donated $5,000 to our Medical Research Fund in support of their son Lee.
Grants and Sponsorships

In 2018 ausEE Inc. received support in the form of grants and sponsorships from the following:

2018 GRANTS
Grill’d Local Matters – February 2018 - $100
My Giving Circle – June 2018 - $100, December 2018 - $500

2018 PRIZE GIVEAWAY SPONSORS
Anne Braaten-Pow – Norwex Consultant
Balance Photography
Eddie Woo’s Wonderful World of Maths
Happy Tummies
My Food Allergy Friends
No Nasties Makeup Natural Play Makeup for Kids
The Good Cake Co.

2018 MEMBER DISCOUNT OFFERS
AllergEnd
Friendly Bites
Happy Tummies
Jellyfish Mattresses
MedBag

2018 SPONSORS
Abbott - Sponsorship of Awareness Campaigns
AllergEnd - Sponsorship of monthly Member/Supporter Newsletters
Halyard – Sponsorship of 2019 Feeding Tube Awareness Week
Happy Tummies – Sponsorship of monthly Member/Supporter Newsletters and Top 8 Challenge
Nutricia – Sponsorship of quarterly Physicians Newsletters and Awareness Campaigns
Medical Research

ausEE Inc. has funded nearly $75,000 in medical research grants since 2015 that aim to improve the diagnosis and treatment options for people living with eosinophilic gastrointestinal disorders. Physician or researchers wanting to conduct a clinical trial or undertake medical research into EGIDS can apply for a medical research grant any time of the year by completing a Research Grant Application available on our website.

2018 RESEARCH GRANTS AWARDED

June 2018 – ausEE awarded grant funding of $25,000 to Dr Jeremy Rosenbaum of Paediatric Gastroenterology Victoria to help facilitate EoE research projects and improve quality of care.

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.

2018 RESEARCH PUBLICATIONS

Dr Hamish Philpott presented several posters at Australian Gastroenterology Week (AGW) Conference in Brisbane in September 2018. You can view his research publications, including the results from studies that were supported by an ausEE Medical Research Grant from his research profile here.
Financial Statements

AUSEE INC. AUDIT REPORT FOR THE YEAR ENDED 30 JUNE 2018

We advise that we have completed the Audit of the books of account of ausEE Inc. for the year ended 30 June 2018. 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 2018.

(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 7th day of September 2018

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
<table>
<thead>
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<th>NSCOA</th>
<th>INCOME</th>
<th>2018</th>
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<td>4-2030</td>
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<td>4-5020</td>
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<td>6-0680</td>
<td>Telephone &amp; Fax Charges &amp; Internet</td>
<td>$ 255.57</td>
<td>$ 249.84</td>
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<td>6-0730</td>
<td>Volunteer Costs</td>
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<td><strong>Total Expenses</strong></td>
<td><strong>$ 30,927.26</strong></td>
<td><strong>$ 34,639.71</strong></td>
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<td><strong>Net Surplus</strong></td>
<td><strong>$ 4,859.29</strong></td>
<td><strong>$ 6,997.81</strong></td>
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# Balance Sheet

**AusEE INC**  
**Balance Sheet**  
**As at 30 June 2018**

<table>
<thead>
<tr>
<th>NSCOA</th>
<th>Members Funds</th>
<th>2018</th>
<th>2017</th>
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<td>3-1000</td>
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<td>3-2000</td>
<td>Surplus/Deficit</td>
<td>$4,859.29</td>
<td>$6,997.81</td>
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$39,284.46 $34,425.17

**Represented by**  
**Current Assets**

<table>
<thead>
<tr>
<th>NSCOA</th>
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<td>1-1110</td>
<td>Suncorp Account - Medical Research Fund</td>
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<td>1-1120</td>
<td>Suncorp Account - Operational</td>
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<td>1-1160</td>
<td>PayPal Account</td>
<td>$15.52</td>
<td>$41.65</td>
</tr>
</tbody>
</table>

$39,284.46 $34,425.17
Feedback

WHAT OUR MEMBERS ARE SAYING...

‘I remember when my now 3.5yr old was diagnosed and the appointment with her paediatric gastroenterologist after talking in depth about it all she gave me a pamphlet and wrote down your web address on the back of it with instructions to go on there and read up on it all. Your website and Facebook groups have been such a light for us in this journey. Thank you!’ - Kristin

‘ausEE is a wealth of information and support.’ - Donna

‘Myself and 3yr old both have EoE. ausEE has made us not feel alone in this journey.’ - Jess

‘The ausEE group has been such a support and reading other people's stories has provided great insight and valuable information.’ – Kirrilie

‘I’ve found so much useful information from ausEE and even just the feeling of support and we are not alone in this since our son’s diagnosis. So thankful for the ausEE group!’ – Claire

‘I ordered your Children’s books and the package arrived on my son’s first day of kindergarten, he has responded so well to his special gifts. He normally does not like to talk much about his health, and especially to others. He has requested to read the books over and over, he is asking lots of questions, even told his grandparents and teachers about his friends Bella and Henry! I want to thank everyone at ausEE for helping my son feel loved, supported and comfortable to not be ‘the same’. Having your package that was filled with so much love has made a difference in our lives.’ – Lachelle
Contact Information

ausEE Inc.
PO Box 9303
Pacific Paradise Qld 4564
Australia

Tel 1300 923 043
Email admin@asee.org
www.asee.org

ausEE
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