

EOS Network - Eosinophilic Diseases Charity

England & Wales · Charity number 1198883

Details

Other names	EOS NETWORK, EOS Network, EOS Network - Eosinophilic Diseases Charity
Status	Registered
Legal form	CIO
Registered	2022-05-10
Register	View on the Charity Commission register

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Activities

Objects: THE RELIEF OF SICKNESS AND THE PRESERVATION OF HEALTH AMONG PEOPLE WITH EOSINOPHILIC ASSOCIATED DISEASES, AND BY EXTENSION THEIR FAMILIES AND CARERS, IN PARTICULAR BUT NOT EXCLUSIVELY BY: (A) ADVANCING THE EDUCATION OF THE GENERAL PUBLIC AND THE MEDICAL PROFESSION IN ALL AREAS RELATING TO EOSINOPHILIC ASSOCIATED DISEASES; (B) PROVIDING RELIEF TO AND PROMOTING THE GOOD PHYSICAL AND MENTAL HEALTH OF PERSONS DIAGNOSED WITH EOSINOPHILIC ASSOCIATED DISEASES, AND BY EXTENSION THEIR FAMILIES AND CARERS THROUGH A COMMUNITY HUB AND THE PROVISION OF RESOURCES, ADVICE, GUIDANCE AND EVENTS; AND (C) FUNDING, SHARING AND COOPERATING WITH NATIONAL AND INTERNATIONAL ORGANISATIONS TO SUPPORT MEDICAL RESEARCH INTO THE CAUSES, TREATMENT AND CURE OF EOSINOPHILIC ASSOCIATED DISEASES.

Activities: We provide evidence-based information and support for people with Eosinophilic Associated Diseases, their families and carers; a global platform for clinicians and researchers to connect; and educational resources and events for healthcare professionals. We work with our communities, medical bodies, manufacturers, and funders to improve healthcare services by ensuring the patient's voice is heard.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Throughout England And Wales

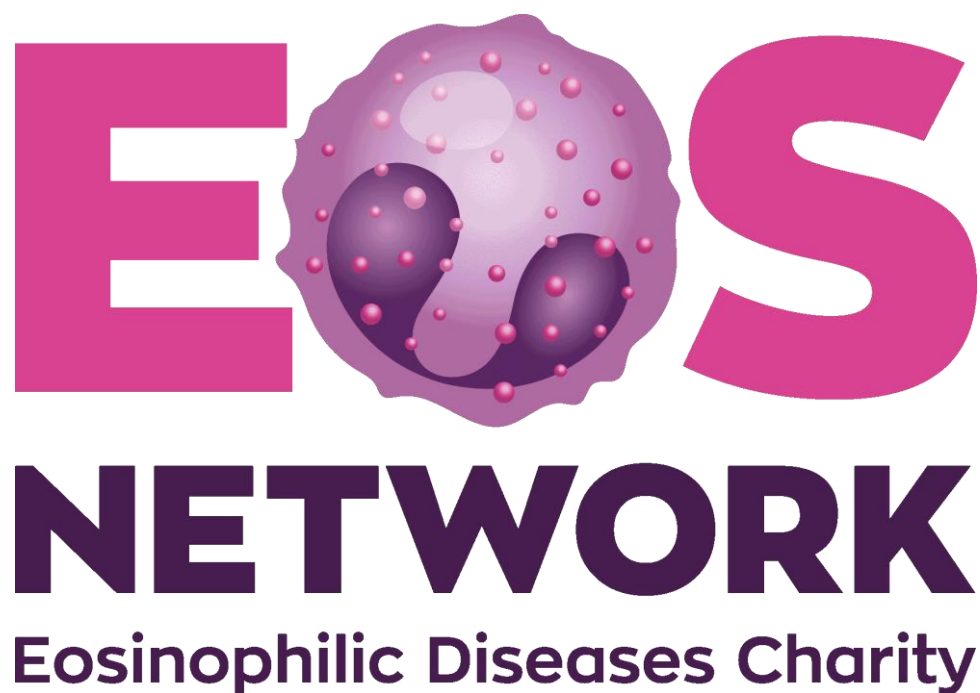
Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£204,479	£205,473	-	-
2024-03-31	£205,688	£238,038	-	-
2023-03-31	£153,670	£77,654	-	-

Trustees

Name	Role	Appointed
Lesley Perkin	Chair	2024-02-02
AMANDA CORDELL		2022-05-06
Bernard McGrath		2022-05-06
DAVID CORDELL		2022-05-06
Mark Boulding		2022-05-06

Accounts



CIO

Trustees report and Financial Statements

for the year

1 April 2024 to 31 March 2025

Registered Charity 1198883

EOS Network – Eosinophilic Diseases Charity

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Welcome from CEO and Founder

This year has been an exciting year of evolution. Having been involved in Eosinophilic advocacy for over 2 decades it felt my journey had made a full circle back to 2010 when much of the understanding of these conditions was still hypotheses. At that time people living with the symptoms knowing they went way beyond the gut but with little or no evidence causing disbelief and lack of recognition.

Fast forward to 2024 with our awareness campaigns, co-authoring of guidelines for Eosinophilic Oesophagitis EoE and advocacy for access to the first approved treatment, recognition of EoE was no longer in question and prevalence doubled to 1 in 700. However, the challenge of 8 years to diagnosis remained raising the question: How do we get people to realise they should seek help earlier for this this silent progressive condition?



Meanwhile our global research partners focus could now begin to move forward into the lesser-known complexities of Eosinophilic gastrointestinal diseases beyond the Oesophagus, and we were delighted to be part of developing the first comprehensive global paediatric to adult medical guideline essential for diagnosis and care.

Our patient representative role within multiple medical institutes and with corporate partners ensured we were able to highlight the latest research as it became available. Research from the revolutionary biological medicines brought new insights. Positive trial results taught us the connection we once hypothesised about was in fact true and Eosinophilic gastrointestinal disease were on the same pathway as Type 2 inflammatory conditions in skin, lung, nasal and other organs. Negative trial data taught us that the Eosinophil is not the only cell causing the problem.

This was a pivotal moment for our community as it confirmed people with Eosinophilic diseases need to be considered in a much more holistic way; understanding now that type 2 inflammatory conditions such as asthma, eczema, rhinitis, allergy, Eosinophilic Oesophagitis and functional gut conditions like IBS may not only coexist but also be associated eosinophilic diseases (EADs).

Here is the circle as all that time ago in 2010 when it was just hypothesis a medical expert and I sat in a hospital canteen and together wrote a leaflet on Eosinophilic associated diseases that today could be backed with robust medical evidence.

With empowering our community to self-advocate and manage their care needs being at the heart of everything we do this new evidence is key to developing our 2025 campaign: recognising and reporting the signs and symptoms of the gut and beyond which are the clues to seeking earlier diagnosis and appropriate cohesive care.

Our work continues to increase awareness, advocate for earlier diagnosis, joined up patient centred care and access to personalised medicines all essential for people to lead healthier better-quality lives

Thank you to our community of lived experience, EOS medical professional network, fundraiser donors and partners experts working together to improve people's lives. We cannot wait to see what is achieved in the coming year.

Amanda Cordell

CEO and Founder

Amanda Cordell

Who we are

EOS Network is the only UK charity focused on improving the lives of the 1 in 700 people and their families affected by lifelong Type 2 Inflammatory Eosinophilic Associated Diseases. We support a growing community of people affected and have established a global healthcare professional network, together we strive to improve awareness, and knowledge to reduce health inequalities for these complex conditions that impact the sufferer and their families.

Our vision

A world where lives are no longer inhibited and controlled by Eosinophilic-Associated Diseases.

Our mission

Is to ensure that every person with an Eosinophilic-Associated Disease receives a prompt, accurate diagnosis, cohesive medical care, and support to live with their condition.

Our Values

We aspire to be well-informed collaborative agents of change, dedicated to improving our Community's future.

We are inclusive, compassionate and devoted to ensuring that everyone should feel respected, empowered and supported in health as a whole person.

Our behaviours

We are driven, open with everyone, and focused on getting results for our community.

We are led by our community's voice in all aspects of our charity's work.



EOS Network – Eosinophilic Diseases Charity

Trustees’ report

For the year ended 31 March 2025

The Trustees present their annual report and financial statements of EOS Network - Eosinophilic Diseases Charity for the period ended 31 March 2025

REFERENCE AND ADMINISTRATIVE INFORMATION

Charity name: EOS Network – Eosinophilic Diseases Charity

Charity Registration Number: 1198883

Trustees: Amanda Cordell
Bernard Michael McGrath
Mark Nicholas Boulding
Philippa Rosemary Dennitts
David Cordell
Lesley Perkin

Bankers: NatWest Bank Plc

Administrative address: Alpenrose
Weeley Road
Great Bentley
Colchester
CO7 8PD

Independent Examiner: Simon Robinson
SAS Accounting Services Ltd
The Colchester Centre
Hawkins Road
Colchester CO2 8JX

EOS Network – Eosinophilic Diseases Charity

Trustees' report (continued)

The Trustees present their Trustees' report and financial statements in accordance with the Charities Act 2011 and the Charity SORP 2005.

1. Structure, governance, and management

- **The governing document**

The Charity EOS Network was constituted as a Charitable Incorporated Organisation (CIO) on 5th May 2022. Evolving from an unincorporated charity registered status since 2012 under registration number 1143267 which was initially started in 2004 as a yahoo patient support group.

30th March 2023 The governing document and name of the Charity was updated to EOS Network – Eosinophilic Diseases Charity for the benefit of increasing public awareness.

Organisational structure and management

EOS Network is governed by its Trustee Board which is responsible for setting the strategic direction of the organisation and the policy of the charity. Trustees meet as a minimum four times per year and review operational, financial and strategic progress at these meetings.

- **Trustees**

The Trustees holding office during the period and up to the date of this report (unless otherwise stated) are:

Amanda Cordell
Bernard Michael McGrath
Mark Nicholas Boulding
Philippa Rosemary Dennitts
David Cordell
Lesley Perkin

- **Recruitment and appointment of Trustees**

The trustees are appointed in accordance with the governing document. Future trustees may be appointed by a resolution of the trustees passed at a meeting of the of the trustees.

- **Trustee induction and training**

Trustees are selected for their expertise that is relevant to the charity, so that a wide knowledge base can be brought to bear on fundraising, finance and administration. Each year the Trustees review their collective ability to fulfil the charity's objectives.

- **Statement of trustees' responsibilities**

Law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the Charity's financial activities during the year and of its financial position at the end of the year. In preparing the financial statements giving a true and fair view, the trustees should follow best practice and:

- i. Select suitable accounting policies and then apply them consistently;
- ii. Make judgements and estimates that are reasonable and prudent;
- iii. State whether applicable accounting standards have been followed, subject to any material departures and explained in the financial statements; and

- iv. Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping accounting records which disclose with reasonable accuracy the financial position of the charity, and which enable them to ensure that the financial statements comply with the Charities Act. They are also responsible for safeguarding the assets of the charity and hence, for taking reasonable steps for the prevention and detection of fraud and other irregularities. They are required to apply the funds of the charity with complete fairness to meet the objects of the charity.

- **Investment powers and policy**

The governing document grants unrestricted powers of investment to the trustees.

- **Risk management**

The Trustees consider the charity is exposed to little risk, but this position is periodically reviewed and documented.

2. Objectives and activities

The objects of the CIO are:

The relief of sickness and the preservation of health among people with Eosinophilic-Associated Diseases, and by extension their families and carers, in particular, but not exclusively by:

(a) **Advancing the education** of the general public and the medical profession in all areas relating to Eosinophilic-Associated Diseases;

(b) **Providing relief** to and promoting the good physical and mental health of persons diagnosed with Eosinophilic-Associated Diseases, and by extension their families and carers through a community hub and the provision of resources, advice, guidance and events; and

(c) **Funding, sharing and cooperating** with national and international organisations to support medical research into the causes, treatment and cure of Eosinophilic-Associated Diseases.

3. Public benefit statement

EOS Network operates for public benefit. The trustees confirm that they complied with the duty in Section 17 of the Charities Act 2011 to have due regard to the general guidance on public benefit, 'Charities and Public Benefit'.

4. Achievement and performance during the period 1st April 2024 to 31st March 2025

The EOS Network CIO was incorporated on 10th May 2022, as a successor organisation of registered charity 1143267 unincorporated association of the same name.

A year of growth in community, patients voice, reach and structure.

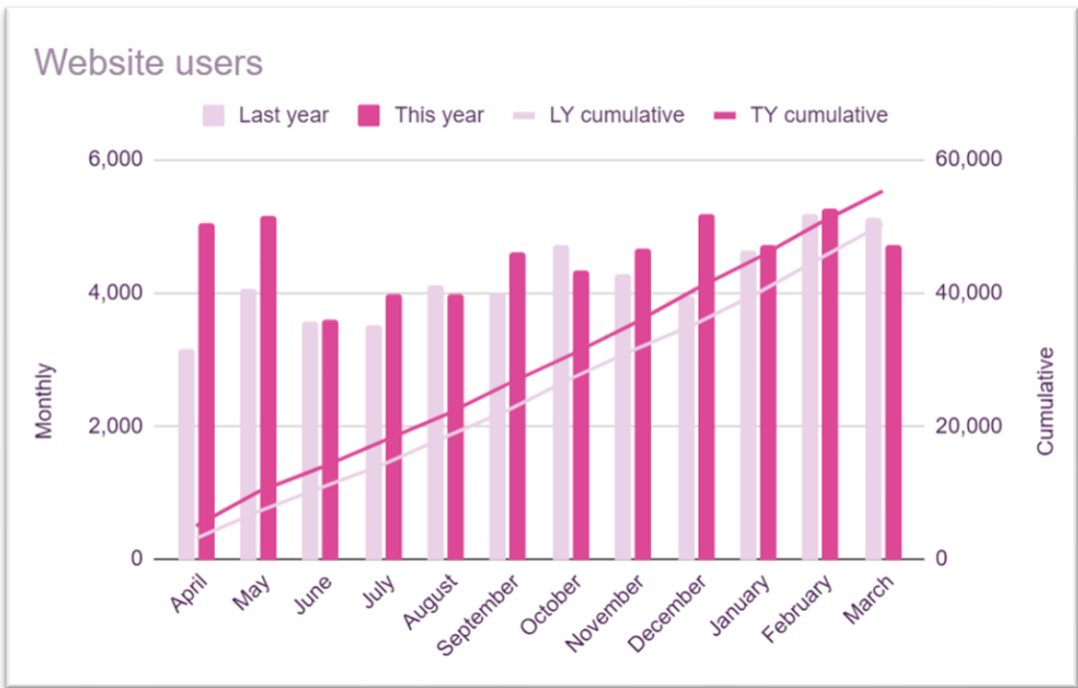
We measured our impact with our Feb 2025 Activities and Feedback Survey* 240 community and professional members participated.

*95% would recommend our services.

*40% survey participants chose to comment on how our services had made a difference – these comments and further statistics are shared throughout our annual report.

*‘Key to fighting this condition is awareness and education - information is power - and your network provides that via multiple avenues.’ **

We published 98 new webpages and gained over 55K new website visitors



- We shared 625 social media posts reaching 180K impressions
- Our social followers reached over 6k a growth of 14%
- Partnerships amplified our EAD awareness to reach millions of people.

Educate, Connect, Empower and Advocate

We provided quality information and practical support for people with Eosinophilic Associated Diseases, their families and carers through our community hub, resources and events.

Our registered patient carer community grew to over 1.1k members

We surveyed our patient/carers community to understand the value we bring. They said that in their experience, we had **empowered** them with knowledge (**77%**), made them feel supported and **less isolated** (**56%**), **connected** them with the **EOS community** (**46%**), and gave them **confidence to ask their doctor questions** (**44%**).

*'Knowledge gained through webinars, speaking to Amanda, the website, news updates, all this has helped with understanding of the disease and empowered us to seek the best treatment and how to live life to the full as possible whilst living with Eosinophilic disease' **

Support

We continued to provide life changing one-to-one telephone or email support to new and existing members.



Inform

76% of survey respondents reported finding our newsletters helpful. With our email campaigns achieving **an average open rate of 62%** - feedback told us how this accessible information has made a difference in people's lives. Key information included seasonal dietary resources, education videos on understanding clinical trials and the latest research news in lay term - read friendly formats. Work began on a series of 6 empowering webinars and community chats due 2025 supported by the National Lottery Community Fund.

Improving Diagnosis

*'EOS Network provided me with the invaluable information I needed to challenge my GP's inaccurate diagnosis of my symptoms. Like many other EOE sufferers, my concerns about my symptoms were dismissed as acid reflux. Without EOS I would have not had the confidence to challenge my GP and fight for better healthcare. Knowing that there is a community of fellow EOE sufferers that I can connect with has been a great comfort to me.' **

*'Helpful to read of others specific experiences with EOE. I have had EOE symptoms for at least 16yrs. Diagnosed, 5yrs ago. I am a retired Med Lab Tech and I had never heard of it prior to my diagnoses.' **

Tools and Resources

We published six real-life community 'Eosinophilic Voices' personal journeys and provided downloadable tools, including adding a new series on clinical trial processes and terminology to our **video educational resources which have received 12 500 views**.



Photo: Community members who participated in Eosinophilic Voices project

'We want to say thank you for all the information and Video Presentations on your website. My adult son has just been diagnosed with EoE, he has a stricture & will commence treatment soon. Your pages and videos are extremely helpful, informative & Supportive, and despite something of a 'scary' diagnosis they are practical & well balanced. We now feel more empowered for when we go back to the specialist next week.'

We held online community meetings for people to meet others facing the same challenges.

What Our Community Said About Our Online Meet Ups

*'In the Community Chat events I've benefited from hearing and sharing experiences with other EOS patients and experts, which I would never have done otherwise. That's immensely helpful not just for reducing any feeling of condition 'isolation' but also for picking up genuine advice on managing the condition' **

*'I found the friendly and accessible web chats really helpful after my diagnosis as it was all new to me. Web based links have also helped me to further my knowledge.' **

*'Having people to speak to with similar issues is priceless' **

A Global Reach In Healthcare and Research

We exhibited and attended numerous medical congresses, expanding our presence and relationships with key institutions far beyond gastro-enterology.

At the European Society of Gastroenterology and Hepatology congress ESPGHAN 2024 we **distributed over 1000 leaflets** and **met with new and existing network members**.



We were delighted to collaborate with attendees and speakers discussing EADs and multisystem allergic diseases at the 2024 conference of the British Society of Allergy and Clinical Immunology (BSACI).



Our CEO networked with leading researchers and clinicians at United European Gastroenterology UEG2024, and EUREOS annual meeting building new collaborative relations to advance our mission.

Work began on a global position paper for Eosinophilic Oesophagitis EOS Growing Professional Network

A further 108 Multidisciplinary Healthcare Professionals (HCPs) became members of EOS Network, and a total of 554 are now receiving regular news and research updates, accessing practical support tools for their clinics, and connecting with each other.

Our HCP newsletters have all achieved opening rates in excess of 50%, which by industry standards is exceptional.

We surveyed our registered HCP community to understand what value EOS Network has brought to them*.

- 68% of respondents said we provide useful tools and services to support their patients
- 45% said we inform them of global research and guidelines
- 42% said that we have expanded their knowledge
- 35% said we have connected them with other healthcare professionals.



Through EOS Network my Dr connected with an international expert which enabled him to diagnose and to treat me successfully and improve my quality of life.

Finding a healthcare professional with the necessary expertise can be very difficult for patients, during this period an additional 25 agreed to be featured on our website 'Find a doctor' map.

"I have received advice on finding specialists in my area which has been invaluable." *

We supported our professional members when peer educating colleagues to improve awareness and implementation of guidelines and were delighted to be invited to exhibit at Broomfield Hospital round table where Gastroenterologist - Dr Rakshit spoke about 'The importance of the district general hospital's role in earlier intervention for EoE in order to avoid fibrous damage caused by delayed diagnosis.'



Representing The Patients Voice

We were invited to join the public affairs committee of European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) and the patient organisations committee of The European Academy of Allergy and Clinical Immunology (EAACI). These relationships enabled us to become the unifying patient voice in EADs across disciplines, institutions, at a national and European level.

We continued to represent our community's voice within British Society for Gastroenterology Hepatology and Nutrition BSPGHAN and the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR). We helped develop a process for ESPGHAN to appraise and endorse patient support materials from PAGs. We began development of a series of webinars for Patients Carers and HCPs on the interconnected symptomatology and pathology of EADs, looking beyond their own specialisms, these are due to be delivered in 2025.

We advocated to our industry partner Sanofi to co-develop a new educational resource 'Could it be EoE?' This collaboration brought together our patient group colleagues from around the globe to highlight the holistic signs and symptoms experienced by our communities. This tool will be used to raise awareness of the silent but progressive clues among the public and all clinical services to reduce diagnosis times and improve cohesive care.

COULD IT BE EOE? THE SIGNS AND SYMPTOMS

Eosinophilic esophagitis (EoE) is a chronic and progressive disease that can occur at any age.¹ EoE is caused by an underlying inflammation, which can damage the esophagus (the tube that takes food from your mouth to your stomach).

Often linked with a personal or family history of allergy-related conditions, its signs vary widely and can affect the entire body. People can experience one, some, or all EoE symptoms, which may vary depending on age. As EoE is a silent condition, understanding behaviors that help people with EoE cope with symptoms (both consciously and unconsciously) is important.

This guide will help you better understand the possible associated symptoms of EoE and common coping mechanisms to look out for.

EoE recurring symptoms and associated conditions vary in each person:

- Headaches, a runny or blocked nose (allergic rhinitis)²
- Feeling like there is a lump in your throat when there is nothing there, getting food stuck in your throat, and experiencing pain and difficulty when swallowing^{3,4}
- Chest pain, ranging from mild tightness to severe⁵
- Persistent cough, tight chest, wheezing, and/or asthma⁶
- Reflux or food regurgitation, vomiting, nausea, stomach pain and a burning sensation or coughing when eating or lying down (heartburn)^{7,8}
- Allergic-related conditions like food allergies and dry itchy skin (eczema)⁹
- Joint pain affecting flexibility, or experiencing some form of connective tissue diseases⁴

In responses to EoE-associated symptoms, people may display these signs and eating behaviors as coping mechanisms:

- Must avoid contact with allergic triggers like certain types of food, animals, dust, molds, or pollen¹⁰
- Cutting food into small pieces¹¹
- Drinking a lot of liquid or using extra sauces when eating to help food go down¹²
- Eating extra slowly or regularly taking longer to eat than others¹³
- Avoiding pills and foods with a certain texture, activities that involve food, or substituting solids with blended or pureed foods¹⁴
- Chewing food excessively¹⁵

Living with EoE can impact daily life:

- Feelings of anxiety, frustration, concern or depression¹⁶
- Avoiding social activities with others, especially when food is involved¹⁷
- Needing to reduce working hours or to stop working entirely¹⁸
- Feeling fatigued or tired¹⁹
- Not gaining weight as expected or losing weight which may lead to malnutrition²⁰

The symptoms and coping mechanisms of EoE can look a little different in children and adolescents.

- Selective or "picky" eating²¹
- Trouble sleeping²²
- Missing school days²³
- Not gaining weight as expected, losing weight and potentially failing to thrive or malnutrition²⁴
- Stomach aches, and sometimes, regurgitating food or vomiting²⁵

If you recognise these signs, symptoms and behaviours, talk to your doctor about EoE. Find additional information and support at EOS Network – Eosinophilic Diseases Charity

www.eosnetwork.org
UK Registered Charity No. 1196883

SCAN HERE

Supported by **sanofi** | **REGENERON** | Developed in collaboration with **EOS NETWORK** | **Apfed** | **ALLERGY UK** | **ALLERGY SOCIETY** | **ALLERGY SOCIETY** | **ALLERGY SOCIETY**

1. Mastoridis, D. (2020) Eosinophilic Esophagitis. Retrieved September 2024, from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7101011/>.
2. Johnston, D. T. (2020) Eosinophilic esophagitis: a review. *Journal of Allergy and Clinical Immunology*, 145(5), 1311-1318. <https://doi.org/10.1016/j.jaci.2020.08.008>.
3. Kaur, A., et al. (2020) Documenting the journey of patients with eosinophilic esophagitis and the impact of the disease on patients and their caregivers: A cross-sectional, qualitative, British study. *Advances in Therapy*, 37(4), 443-450. <https://doi.org/10.1007/s12325-020-01453-3>.
4. Saito, Y., et al. (2020) Eosinophilic esophagitis: a review. *Journal of Allergy and Clinical Immunology*, 145(5), 1311-1318. <https://doi.org/10.1016/j.jaci.2020.08.008>.
5. Alenzi, D. (2017) A review of eosinophilic esophagitis: triggers or heaven's fire? *Journal of Allergy and Clinical Immunology*, 140(1), 1-10. <https://doi.org/10.1016/j.jaci.2016.09.008>.
6. Hwang, J., et al. (2020) Eosinophilic esophagitis: a review. *Journal of Allergy and Clinical Immunology*, 145(5), 1311-1318. <https://doi.org/10.1016/j.jaci.2020.08.008>.
7. Lior, H., et al. (2020) Eosinophilic esophagitis: a review. *Journal of Allergy and Clinical Immunology*, 145(5), 1311-1318. <https://doi.org/10.1016/j.jaci.2020.08.008>.

This resource was developed both as a poster and leaflet and made available online and in hard copy, we plan to distribute throughout 2025/26.

Supporting Research For Better Diagnostic Tools

We convened focus groups, for example on the [QuBIE capsule sponge](#) clinical trial (picture right) which could make EoE diagnosis much less invasive, to give patients a voice in their treatment. We represented the patients experience in the SWALLOW feasibility study with Catherine Sykes.



We featured researchers such as leading [expert Prof Marc Rothenberg](#) (picture below), [Molly Shook](#) and in our podcasts, video and website discussing the future of diagnostics and treatments for Eosinophilic Associated Diseases.

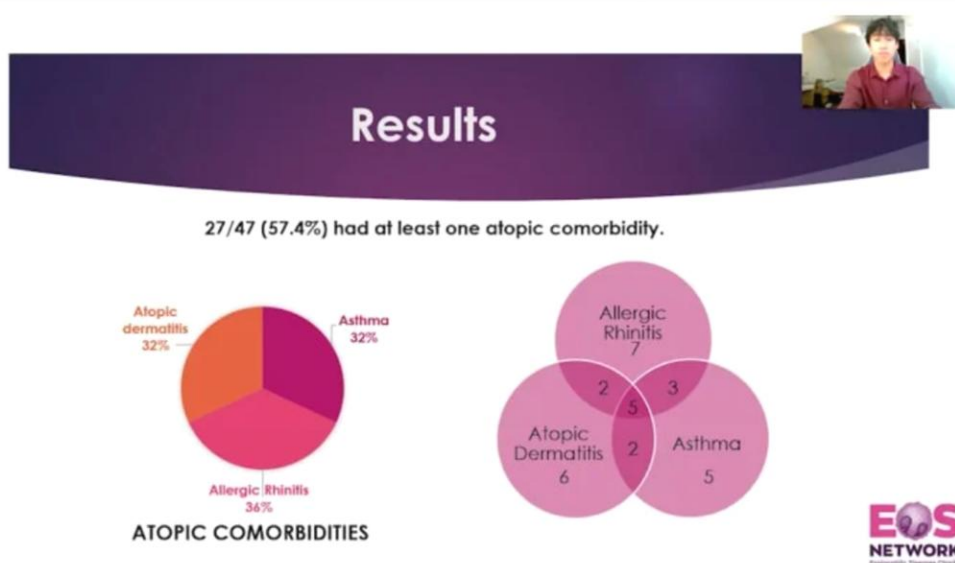


EOSNETWORK
Eosinophilic Diseases Charity

I wanted to give you a round of applause for what you are doing with your organisation. Thank you very much to all your supporters and members who advance the field and call attention of the right people to this important disease in an effort to improve those suffering from it.

Supporting Research for Holistic EAD Care

As per our community's request, we expanded our global research news to cover allergic: skin, lung, nasal and gut, type 2 inflammatory conditions. Inviting [William Fong](#) and members of our network to present their studies.



Dr. William Fong is presenting the study results, which highlight the presence of comorbidities.

Bringing the patients voice to medical research publications and care guidelines

We are proud to have co-authored 5 publications and abstracts highlighting and evidencing the challenges faced by our community:

1. Segmental overlap is common in eosinophilic gastrointestinal diseases and impacts clinical presentation and treatment.

Ketchem CJ, Jensen ET, Dai X, Anderson C, Kodroff E, Strobel MJ, Zicarelli A, Gray S, Cordell A, Hiremath G, Dellon ES. Dis Esophagus. 2025 Jan 7;38(1):doaf011. doi: 10.1093/dote/doaf011. [PMID: 40036388](#); [PMCID: PMC12187587](#).

2. Swallowed topical steroid therapy for eosinophilic oesophagitis in children: practical, evidence-based guidance by the BSPGHAN Eosinophilic Oesophagitis Working Group.

Chan J, Flynn DM, Gordon M, Parmar R, Moolenschot K, Jackman L, Gaynor E, Epstein J, Cordell A, Kannappan H, Furman M, Thompson J, Gasparetto M, Auth MKH. BMJ Paediatr Open. 2024 May 23;8(1):e002467. doi: [10.1136/bmjpo-2023-002467](#). PMID: [38782481](#); [PMCID: PMC11116858](#).



Marcus Auth (above) presenting at European Society for Paediatric Gastroenterology Hepatology and Nutrition

3. Baseline survey on the management of paediatric eosinophilic oesophagitis in the UK and Ireland from the BSPGHAN EoE working group

Regas C, May G, Chan J, et al OC10 Frontline Gastroenterology 2024;15:A8. [DOI: 10.1136/flgastro-2024-bspghan.10](#)

4. Health professionals survey of transition service in eosinophilic oesophagitis in UK – a BSPGHAN EoE Working group initiative

Parmar RS, Moolenschot K, Cordell A, et al OC11 Frontline Gastroenterology 2024;15:A8-A9. [DOI: 10.1136/flgastro-2024-bspghan.11](#)

5. Frequent report of vitamin deficiencies and use of supplements and complementary/alternative treatment approaches in patients with eosinophilic gastrointestinal diseases.

Cameron BA, Jensen ET, Dai X, Anderson C, Kodroff E, Strobel MJ, Zicarelli A, Gray S, Cordell A, Hiremath G, Dellon ES. Ther Adv Rare Dis. 2025 Mar 14;6:26330040251326928. doi: [10.1177/26330040251326928](#). PMID: [40094151](#); [PMCID: PMC11907540](#).

We continued to provide patient perspective review comments for the latest guidelines in Eosinophilic Gastrointestinal Diseases including the development of the first paediatric – adult Non EoE Lower EGIDs international guideline.

Growing A Sustainable Organisation

Our team

As per our strategic plan we have grown our team to include a part time dedicated fundraising officer.

New and existing volunteers played a vital role in our work providing lived experience, personal work or life skills and expert medical or scientific advice. We identified to maximise this opportunity going forward it is essential that more core staff are employed to support and sustain a positive voluntary experience.

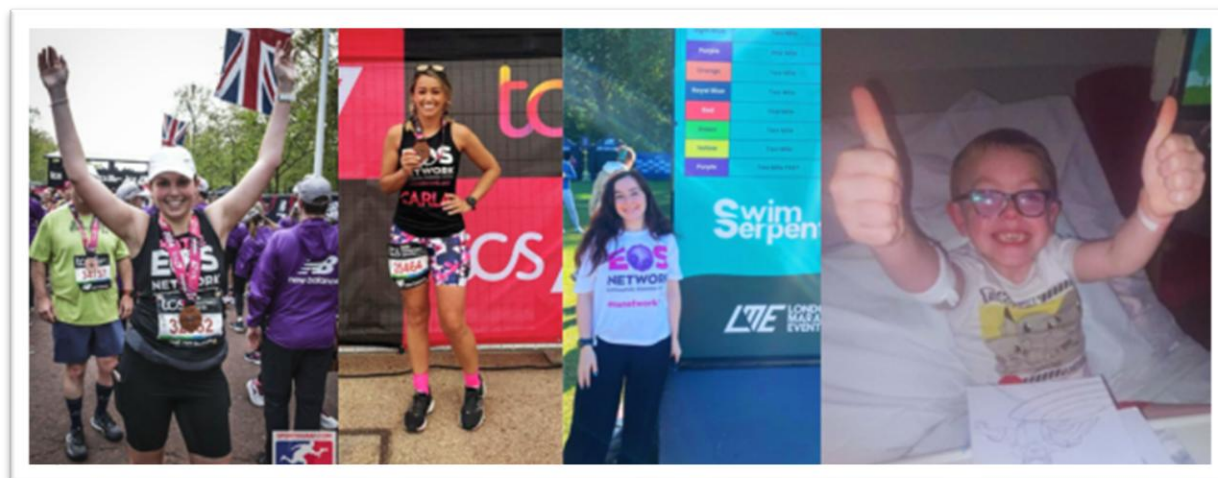
Our Systems

We further developed our community relations management CRM to optimise our communications, support and community engagement. We trialled several workflow programmes to optimise our small but mighty team's time and efficacy. We successfully completed our annual external I.T, GDPR and security review.

Fundraising

Having our new fundraiser Karen in post has enabled us to develop additional fundraising tools and challenge opportunities including holding a dedicated fundraising workshop.

We thank our fundraisers: London Marathon runners Katie and Carla, Serpentine Swimmer Florence, The Junior Great North Run participant William and our generous community of donors who together raised a total of £10,434.



Development of our CRM will enable us to improve our donor journey ensuring we can inform people of the difference their generosity has made.

As per our fundraising strategy we submitted 14 fundraising applications to trusts and foundations and were grateful to have successfully received awards in this period from The National Lottery Community Fund and Fowler Smith and Jones (FSJ Charities). Further applications were submitted to employ a part time administrator and community projects officer to support our team in line with the exponential growth in demand for services and complexity of our mission we await their outcome.

Corporate partners and pro bono services or gifts in kind relations continued to play an essential role in our funding we thank Astra Zeneca, Sanofi - Regeneron, Bristol Myers Squibb, Dr Falk Pharma, Google, Microsoft and Pillsbury Winthrop Shaw Pittman LLP for their support in achieving our mission.

Listening to our Community

The needs of the people affected by Eosinophilic associated diseases are at the heart of our mission. We connect and learn from our communities' voices through many channels including:

- Website forms and contact enquiries
- Phone and email 1 to 1 support services
- Online events
- In person meetings
- Social media platforms
- In event polls and after event feedback surveys
- Focus groups and surveys



The valuable insights gained from these sources alongside our Feb 2025 impact and feedback survey will help shape our future activities.

6. Financial review

i. Results for the year ending 31 March 2025

Income for the year was £204,479 (2024: £205,688) which includes £70,245 (2024: £127,921) in respect of donated services an equivalent amount is included resources expended. Expenditure for the year was £205,473 (2024: £238,038) resulting in a deficit of £994 (2024: £32,350) and with reserves of £43,666 brought forward from 1st April 2024 reserves at 31st March 2025 were £42,673

We are **thankful for** the continued dedicated **support of volunteers, community fundraisers and** the generosity of our **donors and corporate sponsors** without whom our achievements would not have been possible.

Grants and Donations were gratefully received from the following supporters: The National Lottery, Google, Microsoft, Pilsbury Winthrop Shaw and Pittman LLP, Astra Zeneca, Regeneron – Sanofi, Bristol Myers Squibb, Dr Falk Pharma UK and FSJ.

i. Reserves

The Trustees' policy on reserves requires that reserves shall be used for the following purposes:

to provide fixed and working capital; to provide for future contingencies; and to provide a base for future development to deliver the charity's strategic objectives.

The charity has financial reserves that can be a combination of restricted and unrestricted reserves. Restricted reserves are funds that have been given for a specific charitable purpose.

The Trustees consider that the available reserves (i.e. liquid and readily realisable assets, excluding restricted funds represented in these assets) should be maintained in a range between three and six months of operational expenditure.

The Trustees also recognise that owing to the need for resources to be used to finance planned expansion, there may be periods when reserves cannot be maintained within these limits, however sufficient reserves shall be maintained to cover known commitments. The reserve levels required under the reserves policy will be kept under review.

7. Future Plans for 2025-26

During 2023-24, we refreshed the strategy which had been in place since 2021. Much has changed during this time, as EoE has become better recognised, and research has highlighted the interconnectivity of many eosinophilic associated diseases (EADs), within and beyond the gastrointestinal tract. Our new strategy will address the following key issues:

1. Emerging scientific evidence in EADs is yet to be translated into robust clinical evidence

There is growing recognition in specialist/research centres, of the complexity of eosinophilic-associated disease models. This needs to be corroborated in robust clinical evidence, to drive changes in routine practice.

2. Multi-disciplinary care has not yet caught up with advances in scientific understanding of EADs

Our understanding of eosinophilic-associated diseases is improving. We now know that some patients experience multiple EADs affecting different body systems, while many others are affected by concomitant diseases (often atopic), which can be important flags for prompt diagnosis and also require treatment. However, this raises the bar of effective ongoing multi-disciplinary leadership and collaboration in traditional specialty-based healthcare provider structures.

3. Our patient-carer community needs far more than just information about their chronic disease

To live their best lives in existing healthcare systems, patients and carers need to be able to self-advocate. This requires skills and support structures, as well as information about their EADs and the concomitant conditions which should trigger appropriate investigations by HCPs.

4. Our recent growth in reach and capacity necessitates increased sustainable funding

To reach more people and drive greater change, we have invested in paid staff and need to be able to maintain that commitment. Furthermore, to make full use of the opportunities we have unlocked (especially with our CRM system), we need to increase our funding as well as ensuring it is sustainable.

We have set four new strategic goals to address these issues, which we will work towards in 2024-26:

Goal 1: Improve real world EAD impact evidence

We will gather more data from patients and HCPs, on the experience, diagnosis and treatment of EADs and concomitant diseases, with a gastro-intestinal component, in a structured way and on a global scale. Developing robust multiple systemic diseases evidence, to improve patient outcomes through holistic understanding, research, treatments and practices.

2025/26 priority activities for Goal 1

1. Continue to maintain and develop EOS Network community registration CRM data and participate in collaborative projects
2. Develop patient registry project plan and secure funding
3. Recruit a steering committee to map the registry's key aims, scope, content, control and management
4. Select a suitable provider, to build the patient registry
5. Form a robust plan to secure ongoing patient registry funding

Goal 2: Build Bridges

We will foster models of multi-disciplinary collaboration between specialties and across paediatric and adult services, to improve diagnosis and management of EADs which have a gastro-intestinal component, and concomitant diseases.

2025/26 priority activities for Goal 2

1. Advocate for standardised optimal cohesive care and research within medical bodies and other stakeholders as official EAD patient representation
2. Deliver a pilot project using electronic health care records to demonstrate the massive underdiagnosis of EoE in the UK and develop tools to transform it
3. Expand our website content on EADs and concomitant diseases
4. Run a webinar series for HCPs on the interconnected symptomatology and pathology of EADs, looking beyond their own specialisms
5. Plan a conference on leading/achieving system change for EADs management in both adult and paediatric services

Goal 3: Empower patients & carers

We will empower patients and carers living with EADs which have a gastro-intestinal component to get what they need from their healthcare providers.

2025/26 priority activities for Goal 3

1. Provide educational information for EAD patients/carers on their disease and the relevance of any concomitant symptoms, through a leaflet and our website
2. Develop a practical tool to help patients communicate the overall picture of their symptoms to their HCPs
3. Run a patient/carer community event (in person or online) to connect people, deepen their understanding of how to navigate the challenges of their healthcare system, and launch our new resources
4. Focus Eosinophilic Awareness Month on raising awareness amongst patients, carers and HCPs of EADs and concomitant diseases
5. Recruit a paid Community Projects Officer to maximise the reach and impact of these initiatives, and provide increased personalised support to patient/carer Community members

Goal 4: Increase sustainable funding

We will increase and diversify our income and make it more sustainable.

2025/26 priority activities for Goal 4

1. Allocate specific staff resource to increase our level of targeted fundraising activity
2. Diversify our fundraising efforts to include Trusts & Foundations, and Community fundraising
3. Deepen and broaden our engagement with actual/potential pharmaceutical company funders

4. Seek multi-year funding commitments to enable longer term projects such as our Registry.

Approved by the Trustees on 29/9/25

and signed on their behalf by

Chair of Trustees

Amanda Cordell

A handwritten signature in black ink, appearing to read 'A Cordell', written in a cursive style.

Treasurer and Trustee

Bernard McGrath

Bernard Michael McGrath

EOS Network – Eosinophilic Diseases Charity

Statement of Financial Activities

For the year ended 31 March 2025

	Note	2025 Unrestricted £	2025 Restricted £	2025 Total £	2024 Unrestricted £	2024 Restricted £	2024 Total £
Incoming resources							
Income resources from generated funds:							
Voluntary income							
Donations		10,273	-	10,273	9,162	-	9,162
Grants		100,000	-	100,000	65,000	-	65,000
Trusts and Foundations		2,000	19,986	21,986	-	-	-
Donated services	2	70,245	-	70,245	127,921	-	127,921
Other income		1,975	-	1,975	3,605	-	3,605
Total incoming resources		184,493	19,986	204,479	205,688	0	205,688
Resources expended							
Cost of generating funds	7	24,563	-	24,563	8,576	2,530	11,106
Charitable activities	8	100,085	10,040	110,125	98,318	-	98,318
Governance	9	540	-	540	693	-	693
Donated services	2	70,245	-	70,245	127,921	-	127,921
Total resources expended		195,433	10,040	205,473	235,508	2,530	238,038
Net movement in funds		(10,940)	9,946	(994)	(29,820)	(2,530)	(32,350)
Reconciliation of funds							
Funds brought forward 1 April 2024		43,666	-	43,666	73,486	2,530	76,016
Funds carried forward at 31 March 2025		32,727	9,946	42,673	43,666	-	43,666

EOS Network – Eosinophilic Diseases Charity

Balance Sheet as at 31 March 2025

	Note	March 2025 £	March 2024 £
Fixed Assets	5	1,295	2,591
Current assets			
Bank		43,733	40,622
Debtors		1,127	2,854
		<u>44,860</u>	<u>43,476</u>
Creditors		(3,482)	(2,401)
Total assets less current liabilities		41,378	41,075
Net Assets		<u><u>42,673</u></u>	<u><u>43,666</u></u>
Income funds			
Unrestricted		32,727	43,666
Restricted funds		9,946	-
Balances carried forward		<u><u>42,673</u></u>	<u><u>43,666</u></u>

These financial statements were approved by the board

and signed on its behalf by

Chair of Trustees

Amanda Cordell



Treasurer and Trustee

Bernard McGrath



Date: 29/9/25

Charity Number 1198883

The notes on pages 24 to 26 form an integral part of these financial statements

EOS Network – Eosinophilic Diseases Charity

Notes to the financial statements

For the year ended 31 March 2025

Accounting policies

I. Basis of preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice for Charities (SORP 2025), (Second Edition, effective January 2019), the Charities Act 2011 and applicable accounting standards (FRS102).

i. Accounting convention

The accounts are prepared under the historical cost convention.

ii. Donations receivable

Donations are credited to income when received.

iii. Tangible fixed assets and depreciation

Individual fixed assets costing £250 or more are capitalised at cost.

Depreciation is provided at rates calculated to write-off the cost less residual value of each asset over its expected useful life, as follows:

IT equipment – 33% straight line

2. Donated services

During the period the Charity received pro-bono legal services and a google grant to the value of £70,245 (2024: £127,921) which are shown within incoming resources under donated services in the statement of financial activities. An equivalent amount of expenditure of £70,245(2024: £127,921) is shown under resources expended within the statement of financial activities.

3. Payments to Trustees

During the year Amanda Cordell a Trustee, in her capacity as Chief Executive, received remuneration of £54,126 (2024: £48,464) . This employment was approved by the Charity Commission.

4. Governance

Trustees received no remuneration in their role as trustees.

5. Tangible Fixed Assets

	Computers & Equipment £
Cost	
As at 1 April 2024	3,887
Additions	-
At 31 March 2025	<u>3,887</u>
Depreciation	
As at 1 April 2024	1,296
Provided during year	<u>1,296</u>
At 31 March 2025	<u>2,592</u>
Net book value	
At 31 March 2025	<u>1,295</u>
At 31 March 2024	<u>2,591</u>

6. Analysis of Staff Costs

	March 2025 £	March 2024 £
Wages and salaries	99,217	79,159
Social Security costs	5,031	3,220
Pension costs	<u>2,267</u>	<u>1,822</u>
	<u>106,515</u>	<u>84,201</u>

No employee received remuneration amounting to more than £60,000 in either year.

Pension costs

The charity operates a defined contribution pension scheme. The scheme and its assets are held by independent managers. The pension charge represents contributions due from the company and amounted to £2,267 (2024: £1,822)

7. Cost of Raising Funds

	March 2025 £	March 2024 £
Staff costs	23,481	8,888
Fundraising costs	1,082	2,129
Training	-	89
	<u>24,563</u>	<u>11,106</u>

8. Resources Expended

			March 2025 Total	March 2024 Total
	Charitable Activities	Support Costs		
	£	£	£	£
Staff costs	83,034	-	83,034	75,313
Conferences	9,635	-	9,635	3,702
Community Events	1,440	-	1,440	-
Depreciation	1,296	-	1,296	1,296
IT Systems	-	5,591	5,591	10,676
Insurances	-	375	375	1,195
Administration costs	-	3,818	3,818	1,799
Subscriptions	-	2,734	2,734	2,463
Web-site	2,005	-	2,005	1,874
Training	197	-	197	0
	97,607	12,518	110,125	98,318

			March 2024 Total
	Charitable Activities	Support Costs	
	£	£	£
Staff costs	75,313	-	75,313
Conferences	3,702	-	3,702
Depreciation	1,296	-	1,296
IT Systems	8,701	1,975	10,676
Insurances	-	1,195	1,195
Administration costs	1,400	399	1,799
Subscriptions	1,021	1,442	2,463
Web-site	1,874	-	1,874
	93,307	5,011	98,318

9. Governance

	March 2025 £	March 2024 £
Independent Examination	540	540
Trustee Training	-	153
	540	693

EOS Network – Eosinophilic Diseases Charity

Independent Examiner's Report to EOS Network on the accounts for the year ending 31 March 2025 (Charity No: 1198883).

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ending 31 March 2025 set out on pages 22-26.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all applicable Directions by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed: *Simon Robinson*

Date: 01/10/2025

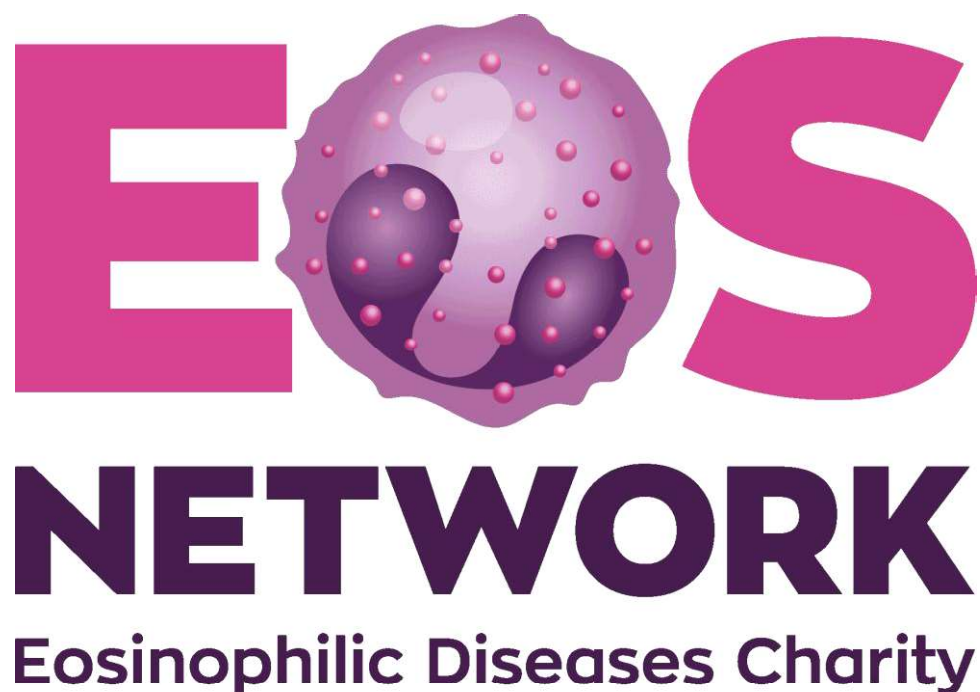
Relevant professional qualification(s) or body

Address:

Simon Robinson
SAS Accounting Services Ltd
The Colchester Centre
Hawkins Road
Colchester CO2 8JX

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Accounts



CIO

Trustees report and Financial Statements

for the period

1 April 2023 to 31 March 2024

Registered Charity 1198883

EOS Network – Eosinophilic Diseases Charity

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Balance Sheet	17
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Independent Examiner's report	21

EOS Network – Eosinophilic Diseases Charity

Trustees’ report

For the period ended 31 March 2024

The Trustees present their annual report and financial statements of EOS Network - Eosinophilic Diseases Charity for the period ended 31 March 2024

REFERENCE AND ADMINISTRATIVE INFORMATION

Charity name: EOS Network – Eosinophilic Diseases Charity

Charity Registration Number: 1198883

Trustees: Amanda Cordell
Bernard Michael McGrath
Mark Nicholas Boulding
Philippa Rosemary Dennitts
David Cordell
Lesley Perkin (joined 2nd February 2024)

Bankers: NatWest Bank Plc

Administrative address: Alpenrose
Weeley Road
Great Bentley
Colchester
CO7 8PD

Independent Examiner: Simon Robinson
SAS Accounting Services Ltd
The Colchester Centre
Hawkins Road
Colchester CO2 8JX

EOS Network – Eosinophilic Diseases Charity

Trustees' report (continued)

The Trustees present their Trustees' report and financial statements in accordance with the Charities Act 2011 and the Charity SORP 2005.

1. Structure, governance, and management

- **The governing document**

The Charity EOS Network was constituted as a Charitable Incorporated Organisation (CIO) on 5th May 2022.

30th March 2023 The governing document and name of the Charity was updated to EOS Network – Eosinophilic Diseases Charity for the benefit of increasing public awareness.

Organisational structure and management

EOS Network is governed by its Trustee Board which is responsible for setting the strategic direction of the organisation and the policy of the charity. Trustees meet as a minimum four times per year and review operational, financial and strategic progress at these meetings.

- **Trustees**

The Trustees holding office during the period and up to the date of this report (unless otherwise stated) are:

Amanda Cordell
Bernard Michael McGrath
Mark Nicholas Boulding
Philippa Rosemary Dennitts
David Cordell
Lesley Perkin (joined 2nd February 2024)

- **Recruitment and appointment of Trustees**

The trustees are appointed by the governing document. Future trustees may be appointed by a resolution of the trustees passed at a meeting of the of the trustees.

- **Trustee induction and training**

Trustees are selected for their expertise that is relevant to the charity, so that a wide knowledge base can be brought to bear on fundraising, finance and administration. Each year the Trustees review their collective ability to fulfil the charity's objectives.

- **Statement of trustees' responsibilities**

Law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the Charity's financial activities during the year and of its financial position at the end of the year. In preparing the financial statements giving a true and fair view, the trustees should follow best practice and:

- i. Select suitable accounting policies and then apply them consistently;
- ii. Make judgements and estimates that are reasonable and prudent;
- iii. State whether applicable accounting standards have been followed, subject to any material departures and explained in the financial statements; and
- iv. Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping accounting records which disclose with reasonable accuracy the financial position of the charity, and which enable them to ensure that the financial statements comply with the Charities Act. They are also responsible for safeguarding the assets of the charity and hence, for taking reasonable steps for the prevention and detection of fraud and other irregularities. They are required to apply the funds of the charity with complete fairness to meet the objects of the charity.

- **Investment powers and policy**

The governing document grants unrestricted powers of investment to the trustees.

- **Risk management**

The Trustees consider the charity is exposed to little risk, but this position is periodically reviewed and documented.

2. Objectives and activities

The objects of the CIO are:

The relief of sickness and the preservation of health among people with Eosinophilic-Associated Diseases, and by extension their families and carers, in particular, but not exclusively by:

(a) **Advancing the education** of the general public and the medical profession in all areas relating to Eosinophilic-Associated Diseases;

(b) **Providing relief** to and promoting the good physical and mental health of persons diagnosed with Eosinophilic-Associated Diseases, and by extension their families and carers through a community hub and the provision of resources, advice, guidance and events; and

(c) **Funding, sharing and cooperating** with national and international organisations to support medical research into the causes, treatment and cure of Eosinophilic-Associated Diseases.

3. Public benefit statement

EOS Network operates for public benefit. The trustees confirm that they complied with the duty in Section 17 of the Charities Act 2011 to have due regard to the general guidance on public benefit, 'Charities and Public Benefit'.

4. Achievement and performance during the period 1st April 2023 to 31st March 2024

The EOS Network CIO was incorporated on 10th May 2022, as a successor organisation of registered charity 1143267 unincorporated association of the same name.

In 2020 the trustees identified five **Critical Success Factors (CSFs)** as the core charity's strategy.

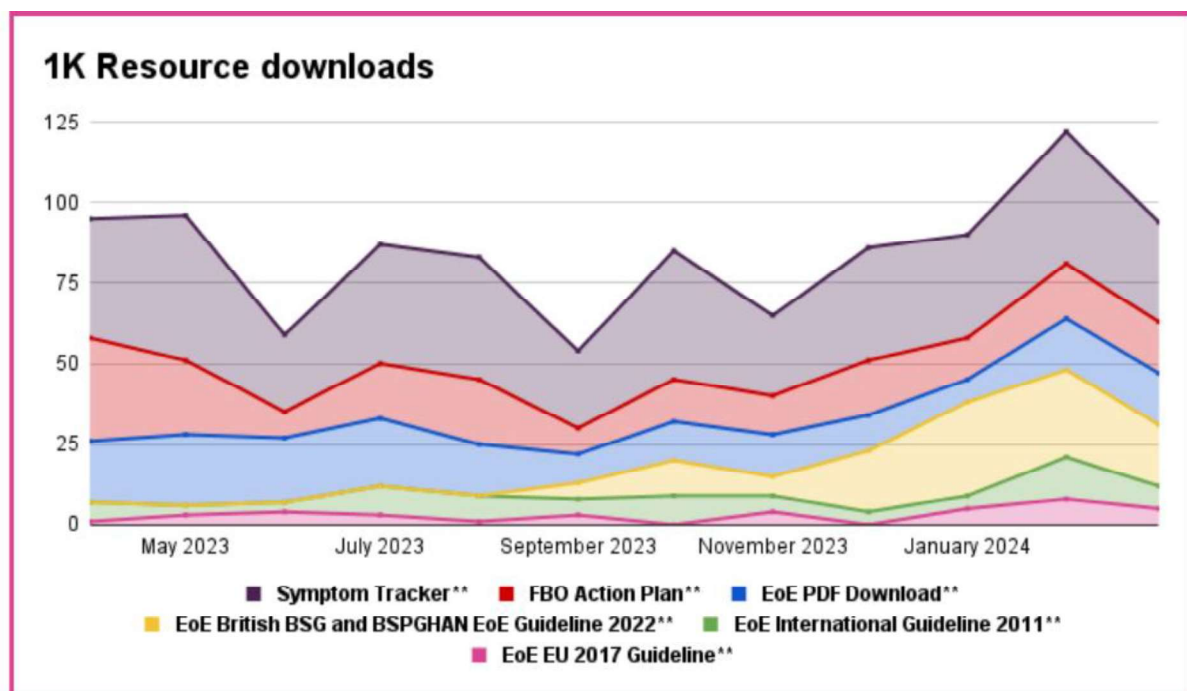
Some notable achievements are listed below, grouped by Critical Success Factor.

1) Enable patients to engage with the right HCPs at the right time, make shared decisions about their treatment, and self-manage when appropriate

With our Communications Officer in post, we were able to provide consistent social media and grow our web presence substantially. We shared **665 media posts, reaching 83,000 users** and gaining 805 new followers.

Our Ambassador, professional footballer Sean Goss, was featured in our Eosinophilic Awareness Month content, and has given confidence to young people and adult members of our community, about what is achievable when EoE is well-managed.

Despite analytical updates to Google and other service providers reducing reportable data we were delighted to see continued growth in demand for our services demonstrated with **46K new website visitors and over 1000 downloads**.



April 2023-March 2024 downloads statistics, Google Analytics

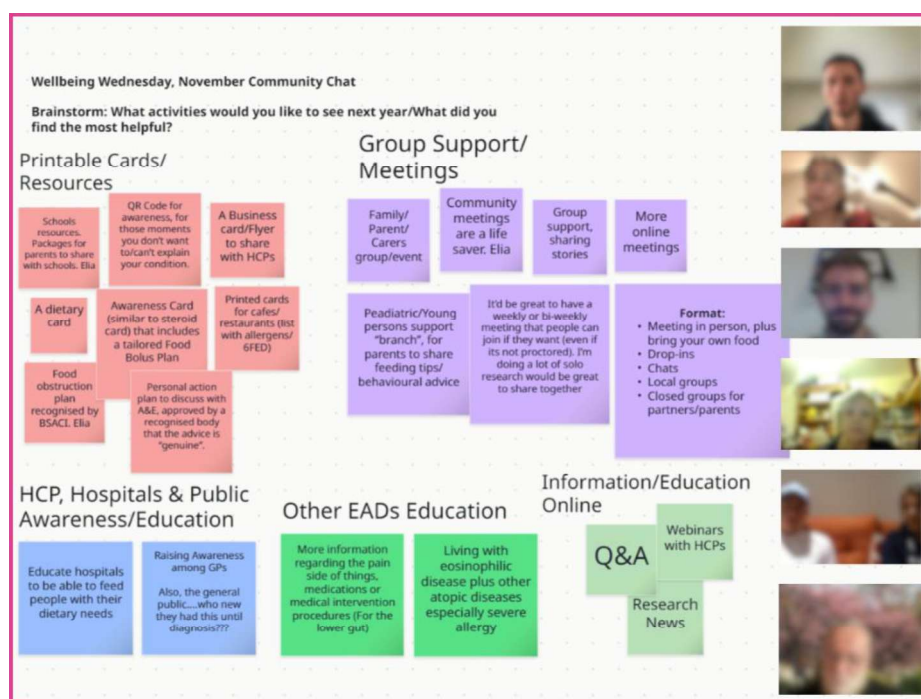
We kept the interest of new and old visitors by publishing **40 new pages on our website**, sharing six community 'Eosinophilic Voices' personal journeys, providing downloadable tools and links to our **video educational resources which received 7500 views**. Empowering our community to live well with their diseases and enabling the confidence to advocate for themselves.



Community members participated in Eosinophilic Voices project

We continued to provide one-to-one telephone support to new and existing registrants. This was supplemented by regular community newsletters that achieved up to **an open rate of 58% and a click-through rate of 38%** - way exceeding industry norms.

During our regular social Community Online Chat sessions, members were able to meet others living with the same challenges, build friendships and continue to shape the focus of our strategy using a new collaborative tool to gather **insights on our community's needs**.



Wellbeing Wednesday: November Community Chat. Working collaboratively with community

2) Educate multiple stakeholders to shorten time to diagnosis and improve long term management

The focus of our Eosinophilic Awareness Month activity was our **'Think EoE' campaign**. Alongside intensive social media communications for healthcare professionals, we distributed information packs designed for frontline professionals who are non-specialists and may not always consider the possibility of eosinophilic disease in the patients they see. Half of these packs were distributed by volunteers from our community, educating professionals and empowering the community at the same time.



One of our fundraisers and advocates, Penny, disseminating Info Packs

Our CEO is now in demand from the professional community as a co-author and was named as such in six publications during the year, including practical, evidence-based guidance by the BSPGHAN (British Society for Paediatric Gastroenterology, Hepatology and Nutrition) Eosinophilic Oesophagitis Working Group on swallowed topical steroid therapy for eosinophilic oesophagitis in children. We also **collaborated with BSPGHAN on surveying issues with transition from paediatric to adult services**, a point at which effective long-term management can break down.

We deepened our relationships with multiple healthcare companies with treatments in development which may be of benefit to our community, to ensure that their trials design, regulatory approval plans and medical education support were appropriate to meet the needs of patients.

With huge variance of available treatments depending on the patient's location, we continued to advocate to multiple stakeholders and providers to improve global access for all affected.

3) Standardise care by fostering multidisciplinary collaboration which adequately addresses the practical needs and expectations of patients, and advocating for access to evidence based treatments

Our **professional publications activity** during the year included a number of topics supporting multi-disciplinary management, including alternative treatment approaches, and frequency of vitamin deficiencies.

Capitalising on the publication of the EoE BSG / BSPGHAN Guidelines, we advocated to the clinical community for accelerated standardisation of appropriate care, so that patients receive a prompt accurate diagnosis and the treatment which is right for them.

We **attended 24 professional meetings worldwide**, either in person or virtually, including CEGIR, BSACI, UEG, BSPGHAN, NICE, ERNICA, EUREOS, Beacon, Genetic Alliance and CVST.



***Speaking with established healthcare professionals and young trainees
working in the field of eosinophilic diseases***

We **enabled the communities voice in ongoing research** to improve diagnostic and management sponge on a string test for EoE through Patient Participation and Involvement Focus Groups in collaboration with Cytel.



Sarah Killcoyne demonstrating sponge-on-a-string testing device during our QuBIE Study meeting

We recruited a new Trustee, Lesley Perkin, who has decades of experience of working in the NHS to improve the effectiveness of multi-disciplinary working, and will guide our activity in this area.

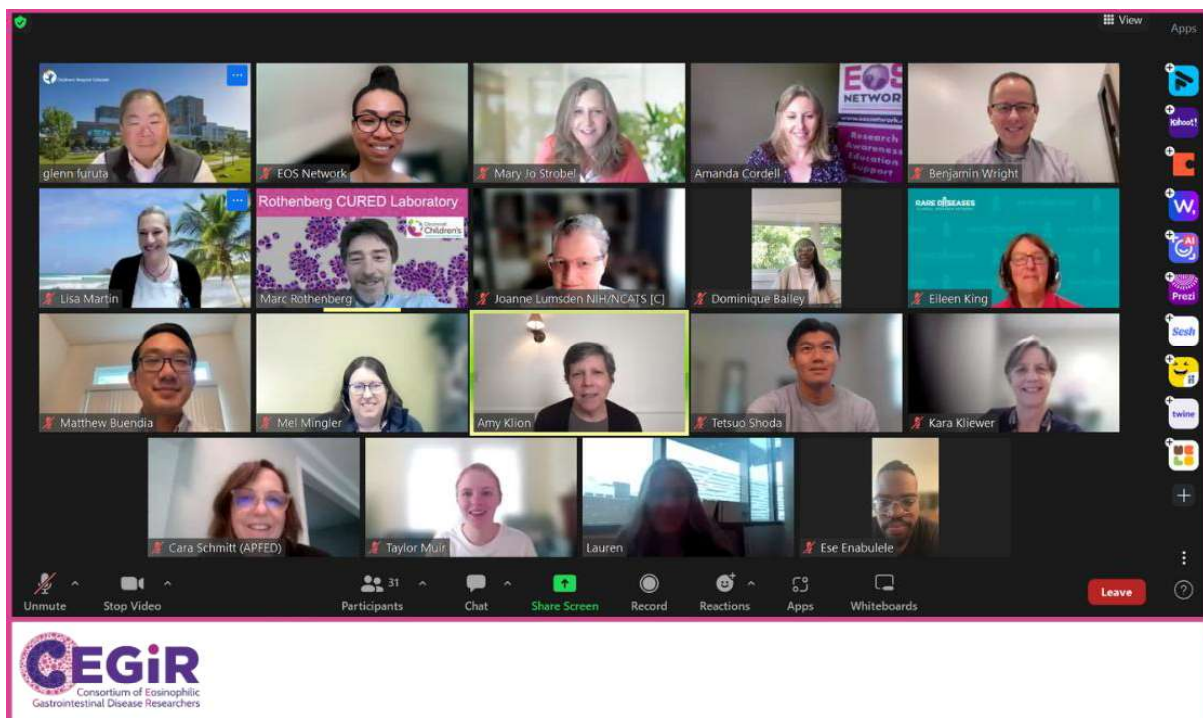
We **collaborated with other patient organisations** and leading clinicians around the world to identify unmet needs for high quality care among people living with Eosinophilic-Associated Diseases. We partnered in developing and disseminating a multi patient advocacy organisation awareness video produced for the first agreed **World EOS Day 18th May**

As patient advocates, we attended a round table meeting organised by the company Sanofi on improving patient access to innovative medicines.

4) Cascade recognition and understanding of lower EGIDs from centres of excellence (primarily in the US) to multidisciplinary communities

Eosinophilic Gastrointestinal Diseases of the lower gut ('Lower EGIDs') are less common and currently less well understood and defined than EoE, but we continued to make them a priority, as patients' needs can be even more acute and under-served.

We attended regular meetings of CEGIR, the leading global consortium for exchanges about lower EGIDs, and **cascaded research news to our EOS professionals' network**. We also used CEGIR information to develop a set of patient-friendly FAQ answers on topics requested by our community.



One of the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR) meetings with healthcare professionals and patients advocates representatives

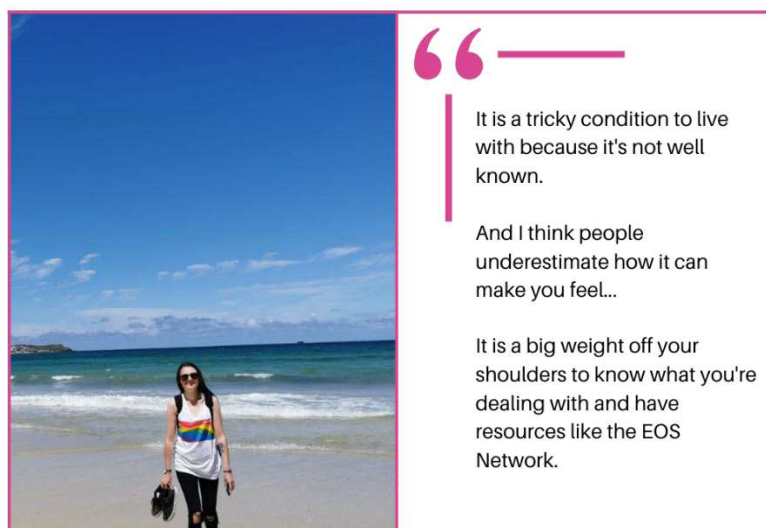
Published our first podcast with guest speaker from Cincinnati Centre for Eosinophilic Diseases making the subject of **research in genetics for EGIDs** available to our community.

Our CEO co-authored a publication on early life exposures as risk factors for non-oesophageal eosinophilic gastrointestinal diseases through EGID partners data collection.

We continued to engage with a number of pharmaceutical companies with products in development which show possible promise for lower EGIDs, to ensure that lower EGIDs are included in their clinical trial and medical education programmes relating to the spectrum of Eosinophilic-Associated Diseases (EADs).

5) Expand our resourcing and develop our organisation, to maximise the explosive growth in opportunities to improve patient experience and outcomes

During the period, we migrated our registration records to **our new CRM system which went 'live'**. This will transform our ability to provide tailored information and support to our patient and professionals communities, with the quality we have always provided, but also at the scale at which we now work. This also enables us to provide improved consistent support to our valued fundraisers, volunteers and donors.



EOS Network Community Support - Becky's Quote

We also **transitioned to Microsoft 365 and Adobe Creative Cloud**, which will enable our growing team to work together to produce high quality content more quickly.

With thanks to our supporters Bristow's LLP, Dechert LLP and Pilsbury Winthrop Shaw and Pittman LLP for providing the valuable donated in-kind legal services during the development of new systems and GDPR policy.

We gratefully recruited several **new volunteers**, bringing lived experience of eosinophilic diseases along with fresh skills in campaigning, fundraising, design and events management.

We increased our income significantly (see Financial Review section 5), diversifying our income sources which makes our financial position more resilient. Our community fundraising grew substantially, which not only brings in additional funds, but also allows us to grow our profile.

6. Financial review

i. Results for the period

Income for the year was £205,688 which includes £127,921 in respect of donated services an equivalent amount is included resources expended. Expenditure for the year was £238,038 resulting in a deficit of £32,350 and with reserves of £76,016 brought forward from 2023 reserves at the end of the year were £43,666



EOS Network Fundraisers and Volunteers

We are **thankful for** the continued dedicated **support of volunteers, community fundraisers and** the generosity of our **donors and corporate sponsors** without whom our achievements would not have been possible.

Grants and Donations were gratefully received from the following corporate supporters: Google, Dechert LLP, Bristow's LLP, and Pilsbury Winthrop Shaw and Pittman LLP, Astra Zeneca and Dr Falk Pharma.

i. Reserves

The Trustees' policy on reserves requires that reserves shall be used for the following purposes:

to provide fixed and working capital; to provide for future contingencies; and to provide a base for future development in order to deliver the charity's strategic objectives.

The charity has financial reserves that can be a combination of restricted and unrestricted reserves. Restricted reserves are funds that have been given for a specific charitable purpose.

The Trustees consider that the available reserves (i.e liquid and readily realisable assets, excluding restricted funds represented in these assets) should be maintained in a range between three and six months of operational expenditure.

The Trustees also recognise that owing to the need for resources to be used to finance planned expansion, there may be periods when reserves cannot be maintained within these limits, however sufficient reserves shall be maintained to cover known commitments. The reserve levels required under the reserves policy will be kept under review.

7. Future Plans for 2024-26

During 2023-24, we refreshed the strategy which had been in place since 2021. Much has changed during this time, as EoE has become better recognised, and research has highlighted the interconnectivity of many eosinophilic associated diseases (EADs), within and beyond the gastrointestinal tract. Our new strategy will address the following key issues:

1. Emerging scientific evidence in EADs is yet to be translated into robust clinical evidence

There is growing recognition in specialist/research centres, of the complexity of eosinophilic-associated disease models. This needs to be corroborated in robust clinical evidence, to drive changes in routine practice.

2. Multi-disciplinary care has not yet caught up with advances in scientific understanding of EADs

Our understanding of eosinophilic-associated diseases is improving. We now know that some patients experience multiple EADs affecting different body systems, while many others are affected by concomitant diseases (often atopic), which can be important flags for prompt diagnosis and also require treatment. However, this raises the bar of effective ongoing multi-disciplinary leadership and collaboration in traditional specialty-based healthcare provider structures.

3. Our patient-carer community needs far more than just information about their chronic disease

To live their best lives in existing healthcare systems, patients and carers need to be able to self-advocate. This requires skills and support structures, as well as factual information about their EADs and the concomitant conditions which should trigger appropriate investigations by HCPs.

4. Our recent growth in reach and capacity necessitates increased sustainable funding

To reach more people and drive greater change, we have invested in paid staff and need to be able to maintain that commitment. Furthermore, to make full use of the opportunities we have unlocked (especially with our CRM system), we need to increase our funding as well as ensuring it is sustainable.

We have set four new strategic goals to address these issues, which we will work towards in 2024-26:

Goal 1: Improve real world EAD impact evidence

We will gather more data from patients and HCPs, on the experience, diagnosis and treatment of EADs and concomitant diseases, with a gastro-intestinal component, in a structured way and on a global scale. Developing robust multiple systemic diseases evidence, to improve patient outcomes through holistic understanding, research, treatments and practices.

2024/26 priority activities for Goal 1

1. Continue to maintain and develop EOS Network community registration CRM data and participate in collaborative projects
2. Develop patient registry project plan and secure funding
3. Recruit a steering committee to map the registries key aims, scope, content, control and management
4. Select a suitable provider, to build the patient registry
5. Form a robust plan to secure ongoing patient registry funding

Goal 2: Build Bridges

We will foster models of multi-disciplinary collaboration between specialties and across paediatric and adult services, to improve diagnosis and management of EADs which have a gastro-intestinal component, and concomitant diseases.

2024/26 priority activities for Goal 2

1. Advocate for standardised optimal cohesive care and research within medical bodies and other stakeholders as official EAD patient representation
2. Deliver a pilot project using electronic health care records to demonstrate the massive underdiagnosis of EoE in the UK and develop tools to transform it
3. Expand our website content on EADs and concomitant diseases
4. Run a webinar series for HCPs on the interconnected symptomatology and pathology of EADs, looking beyond their own specialisms
5. Plan a conference on leading/achieving system change for EADs management in both adult and paediatric services

Goal 3: Empower patients & carers

We will empower patients and carers living with EADs which have a gastro-intestinal component to get what they need from their healthcare providers.

2024/26 priority activities for Goal 3

1. Provide educational information for EAD patients/carers on their disease and the relevance of any concomitant symptoms, through a leaflet and our website
2. Develop a practical tool to help patients communicate the overall picture of their symptoms to their HCPs

3. Run a patient/carer community event (in person or online) to connect people, deepen their understanding of how to navigate the challenges of their healthcare system, and launch our new resources
4. Focus Eosinophilic Awareness Month on raising awareness amongst patients, carers and HCPs of EADs and concomitant diseases
5. Recruit a paid Community Officer to maximise the reach and impact of these initiatives, and provide increased personalised support to patient/carer Community members

Goal 4: Increase sustainable funding

We will increase and diversify our income and make it more sustainable.

2024/26 priority activities for Goal 4

1. Allocate specific staff resource to increase our level of targeted fundraising activity
2. Diversify our fundraising efforts to include Trusts & Foundations, and Community fundraising
3. Deepen and broaden our engagement with actual/potential pharmaceutical company funders
4. Seek multi-year funding commitments to enable longer term projects such as our Registry.

Approved by the Trustees on 13-12-24
and signed on their behalf by

Chair of Trustees

Amanda Cordell



Treasurer and Trustee

Bernard McGrath



Bernard McGrath (Dec 13, 2024 15:32 GMT)

EOS Network – Eosinophilic Diseases Charity

	Note	Mar-24 Unrestricted £	Mar-24 Restricted £	Mar-24 Total £	Mar-23 Unrestricted £	Mar-23 Restricted £	Mar-23 Total £
Incoming resources							
Income resources from generated funds:							
Voluntary income							
Donations		9,162	-	9,162	18,817	-	18,817
Corporate funding		65,000	-	65,000	37,500	-	37,500
Donated services	2	127,921	-	127,921	52,299	-	52,299
Other income		3,605	-	3,605	-	-	-
Other -transfer from EOS Network		-	-	-	42,524	2,530	45,054
Total incoming resources		205,688	0	205,688	151,140	2,530	153,670
Resources expeneed							
Cost of generating funds	8	8,576	2,530	11,106	1,060	-	1,060
Charitable activities		99,011	-	99,011	24,295	-	24,295
Donated services	2	127,921	-	127,921	52,299	-	52,299
Total resources expended		235,508	2,530	238,038	77,654	0	77,654
Net movement in funds		(29,820)	(2,530)	(32,350)	73,486	2,530	76,016
Reconciliation of funds							
Funds b/fwd 1 April 2023		73,486	2,530	76,016	-	-	-
Funds carried forward at 31 March 2024		43,666	0	43,666	73,486	2,530	76,016

EOS Network – Eosinophilic Diseases Charity

Balance Sheet as at 31 March 2024

	Note	March 2024 £	March 2023 £
Fixed Assets	5	2,591	
Current assets			
Bank		40,622	76,016
Debtors		2,854	-
		<u>43,476</u>	<u>76,016</u>
Creditors		(2,401)	-
Total assets less current liabilities		41,075	76,016
Net Assets		<u><u>43,666</u></u>	<u><u>76,016</u></u>
Income funds			
Unrestricted		43,666	73,486
Restricted funds		-	2,530
Balances carried forward		<u><u>43,666</u></u>	<u><u>76,016</u></u>
Unrestricted Funds			
General Fund		73,487	
Current year		-32,351	
Restricted Funds		<u>2,530</u>	
		<u><u>43,666</u></u>	

These financial statements were approved by the board
and signed on its behalf by

Chair of Trustees

Amanda Cordell



Treasurer and Trustee

Bernard McGrath

Bernard McGrath

Bernard McGrath (Dec 13, 2024 15:32 GMT)

Date: 13-12-24

Charity Number 1198883

The notes on pages 18 to 20 form an integral part of these financial statements

EOS Network – Eosinophilic Diseases Charity

Notes to the financial statements

For the year ended 31 March 2024

1) Accounting policies

I. Basis of preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice for Charities (SORP 2025), (Second Edition, effective January 2019), the Charities Act 2011 and applicable accounting standards (FRS102).

i. Accounting convention

The accounts are prepared under the historical cost convention.

ii. Donations receivable

Donations are credited to income when received.

iii. Tangible fixed assets and depreciation

Individual fixed assets costing £250 or more are capitalised at cost.

Depreciation is provided at rates calculated to write-off the cost less residual value of each asset over its expected useful life, as follows:

IT equipment – 33% straight line

2) Donated services

During the period the Charity received pro-bono legal services and a google grant to the value of £127,921 which are shown within incoming resources under donated services in the statement of financial activities. An equivalent amount of expenditure of £127,921 is shown under resources expended within the statement of financial activities.

3) Payments to Trustees

During the year Amanda Cordell a Trustee, in her capacity as Chief Executive, received remuneration of £48,464 and reimbursed expenses of £463.69 This employment was approved by the Charity Commission.

4) Governance cost

Trustees received no remuneration in their role as trustees.

5) Tangible Fixed Assets

	Computers & Equipment £
Cost	
Additions	3,887
At 31 March 2024	<u>3,887</u>
Depreciation	
Provided during year	1,296
At 31 March 2024	<u>1,296</u>
Net book value	
At 31 March 2024	<u>2,591</u>

6) Staff Costs

Analysis of Staff Costs

	2024 £	2023 £
Wages and salaries	79,159	13,482
Social Security costs	3,220	1,442
Pension costs	1,822	-
	<u>84,201</u>	<u>14,924</u>

No employee received remuneration amounting to more than £60,000 in either year.

Pension costs

The charity operates a defined contribution pension scheme. The scheme and its assets are held by independent managers. The pension charge represents contributions due from the company and amounted to £1,822 (2023: Nil)

7) Cost of Raising Funds

	£	2023 £
Staff costs	8,888	-
Fundraising costs	2,129	1,060
Training	89	-
	<u>11,106</u>	<u>1,060</u>

8) Resources Expended

				2024	2023
	Charitable Activities	Support Costs	Governance Costs	Total	Total
	£	£	£	£	
Staff costs	75,313			75,313	14,924
Conferences	3,702			3,702	1,050
Depreciation	1,296			1,296	-
IT Systems	8,701	1,975		10,676	3,930
Insurances		1,195		1,195	900
Administration costs	1,400	399		1,799	2,181
Subscriptions	1,021	1,442		2,463	583
Web-site	1,874			1,874	-
Independent Examination			540	540	540
Training			153	153	187
	93,307	5,011	693	99,011	24,295

	Charitable Activities	Support Costs	Governance Costs	2023 Total
	£	£	£	£
Staff costs	14,924			14,924
Conferences	1,050			1,050
IT Systems	3,930			3,930
Insurances	900			900
Administration costs	2,181			2,181
Subscriptions	583			583
Independent Examination			540	540
Training	187			187
	23,755	0	540	24,295

EOS Network – Eosinophilic Diseases Charity

Independent Examiner's Report to EOS Network on the accounts for the period to 31 March 2024 (Charity No: 1198883).

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the period ended 31 March 2024 set out on pages 16-20.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all applicable Directions by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed: *S Robinson MAAT*
S Robinson MAAT (Dec 16, 2024 13:27 GMT)

Date: Dec 16, 2024

Relevant professional qualification(s) or body

Address:

Simon Robinson
SAS Accounting Services Ltd
The Colchester Centre
Hawkins Road
Colchester CO2 8JX

Appendix 1

Co Authored Publications 1st April 2023 – 31st March 2024

Joseph Chan, Diana M Flynn <https://bmjpaedsopen.bmj.com/content/8/1/e002467>, Morris Gordon, Raj Parmar, Kerry Moolenschot, Lucy Jackman, Ed Gaynor, Jenny Epstein, Amanda Cordell, Hema Kannappan, Mark Furman, Julie Thompson, Marco Gasparetto, Marcus K H Auth

Swallowed topical steroid therapy for eosinophilic oesophagitis in children: practical, evidence-based guidance by the BSPGHAN Eosinophilic Oesophagitis Working Group *BMJ Paediatrics Open* 2024;8:e002467. doi: [10.1136/bmjpo-2023-002467](https://doi.org/10.1136/bmjpo-2023-002467)

Cameron, Brenderia A. MS1,*; Jensen, Elizabeth T. MPH, PhD2; Dai, Xiangfeng PhD1; Anderson, Chelsea PhD, MPH1; Kodroff, Ellyn3; Strobel, Mary Jo4; Zicarelli, Amy5; Gray, Sarah6; Cordell, Amanda7; Hiremath, Girish MBBS, MPH8; Dellon, Evan S. MD, MPH1. S469

Frequent Report of Vitamin Deficiencies and Use of Supplements and Complementary/Alternative Treatment Approaches in Patients with Eosinophilic Gastrointestinal Diseases. *The American Journal of Gastroenterology* 118(10S):p S341-S342, October 2023. | DOI: [10.14309/01.aig.0000951516.88383.f5](https://doi.org/10.14309/01.aig.0000951516.88383.f5)

Venkatesh, Rajitha D. MD1; Hiremath, Girish MBBS, MPH2; Dai, Xiangfeng PhD3; Anderson, Chelsea PhD, MPH3; Kodroff, Ellyn4; Strobel, Mary Jo5; Zicarelli, Amy6; Gray, Sarah7; Cordell, Amanda8; Dellon, Evan S. MD, MPH3,*; Jensen, Elizabeth T. MPH, PhD9. S464

Telehealth Is an Acceptable and Feasible Option for Patients with Eosinophilic Gastrointestinal Diseases: Data From the Online EGID Partners Cohort. *The American Journal of Gastroenterology* 118(10S):p S339, October 2023. | DOI: [10.14309/01.aig.0000951496.13588.06](https://doi.org/10.14309/01.aig.0000951496.13588.06)

Elizabeth T. Jensen, Xiangfeng Dai, Ellyn Kodroff, Mary Jo Strobel, Amy Zicarelli, Sarah Gray, Amanda Cordell, Chelsea Anderson, Girish Hiremath, Evan S. Dellon.

Early life exposures as risk factors for non-esophageal eosinophilic gastrointestinal diseases, *Clinics and Research in Hepatology and Gastroenterology*, Volume 47, Issue 7, 2023, 102170, ISSN 2210-7401, <http://dx.doi.org/10.1016/j.clinre.2023.102170>.

David J Jackson , Praveen Akuthota , Rebeca Andradas , Albert J Bredenoord , Amanda Cordell , Sarah Gray , Joyce Kullman , Sameer K. Mathur , Ian Pavord , Florence Roufosse , Christian Rubio, Irena Clisson Rusek, Dagmar Simon, Mary Jo Strobel & Tonya Winders

Plain Language Summary of principles for improving the care of people with eosinophil-associated diseases Received 22 Dec 2022, Accepted 06 Apr 2023, Published online: 17 May 2023 <https://doi.org/10.2217/imt-2022-0312>

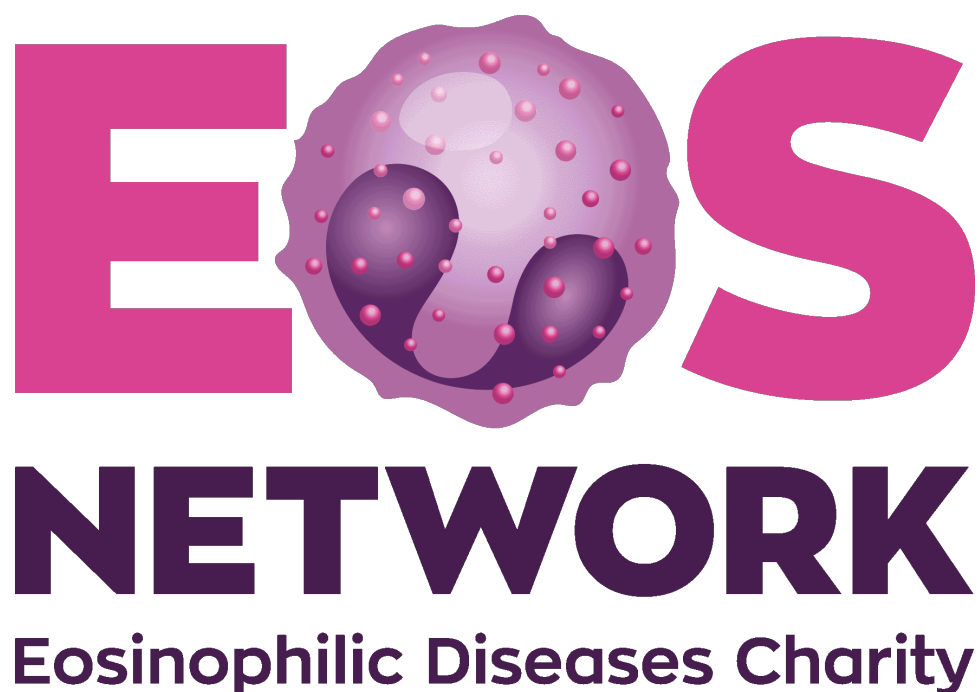
Ryan Alexander, Karthik Ravi, Blake A. Kassmeyer, Ryan J. Lennon, David A. Katzka, Margaret H. Collins, Jeffrey A. Alexander

Sa1277 Extraintestinal symptoms of pain in eosinophilic gastrointestinal diseases AGA Abstract April 2023 DOI: [10.1016/S0016-5085\(23\)01810-3](https://doi.org/10.1016/S0016-5085(23)01810-3)

EOS Network - Eosinophilic Diseases Charity

England & Wales - Charity number 1198883

Accounts



CIO

Trustees report and Financial Statements

for the period

10 May 2022 to 31 March 2023

Registered Charity 1198883

EOS Network – Eosinophilic Diseases Charity

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Balance Sheet	16
Notes to the Financial Statements	17
Independent Examiner's report	18

EOS Network – Eosinophilic Diseases Charity

Trustees’ report

For the period ended 31 March 2023

The Trustees present their annual report and financial statements of EOS Network - Eosinophilic Diseases Charity for the period ended 31 March 2023

REFERENCE AND ADMINISTRATIVE INFORMATION

Charity name: EOS Network – Eosinophilic Diseases Charity

Charity Registration Number: 1198883

Trustees: Amanda Cordell
Bernard Michael McGrath
Mark Nicholas Boulding
Philippa Rosemary Dennitts
David Cordell

Bankers: NatWest Bank Plc

Administrative address: Alpenrose
Weeley Road
Great Bentley
Colchester
CO7 8PD

Independent Examiner: Simon Robinson
SAS Accounting Services Ltd
The Colchester Centre
Hawkins Road
Colchester CO2 8JX

EOS Network – Eosinophilic Diseases Charity

Trustees’ report (continued)

The Trustees present their Trustees’ report and financial statements in accordance with the Charities Act 2011 and the Charity SORP 2005.

1. Structure, governance, and management

- **The governing instrument**

The Charity EOS Network was constituted as a Charitable Incorporated Organisation (CIO) on 5th May 2022.

30th March 2023 The governing instrument and name of the Charity was updated to EOS Network – Eosinophilic Diseases Charity for the benefit of increasing public awareness.

Organisational structure and management

EOS Network is governed by its Trustee Board which is responsible for setting the strategic direction of the organisation and the policy of the charity. Trustees meet as a minimum four times per year and review operational, financial and strategic progress at these meetings.

- **Trustees**

The Trustees holding office during the period and up to the date of this report (unless otherwise stated) are:

Amanda Cordell
Bernard Michael McGrath
Mark Nicholas Boulding
Philippa Rosemary Dennitts
David Cordell

- **Recruitment and appointment of Trustees**

The trustees are appointed by the governing instrument. Future trustees may be appointed by a resolution of the trustees passed at a meeting of the of the trustees.

- **Trustee induction and training**

Trustees are selected for their expertise that is relevant to the charity, so that a wide knowledge base can be brought to bear on fundraising, finance and administration. Each year the Trustees review their collective ability to fulfil the charity’s objectives.

- **Statement of trustees’ responsibilities**

Law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the Charity’s financial activities during the year and of its financial position at the end of the year. In preparing the financial statements giving a true and fair view, the trustees should follow best practice and:

- i. Select suitable accounting policies and then apply them consistently;
- ii. Make judgements and estimates that are reasonable and prudent;
- iii. State whether applicable accounting standards have been followed, subject to any material departures and explained in the financial statements; and
- iv. Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping accounting records which disclose with reasonable accuracy the financial position of the charity, and which enable them to ensure that the financial statements comply with the Charities Act. They are also responsible for safeguarding the assets of the charity and hence, for taking reasonable steps for the prevention and detection of fraud and other irregularities. They are required to apply the funds of the charity with complete fairness to meet the objects of the charity.

- **Investment powers and policy**

The governing instrument grants unrestricted powers of investment to the trustees.

- **Risk management**

The Trustees consider the charity is exposed to little risk, but this position is periodically reviewed and documented.

2. Objectives and activities

The objects of the CIO are:

The relief of sickness and the preservation of health among people with Eosinophilic-Associated Diseases, and by extension their families and carers, in particular, but not exclusively by:

(a) **Advancing the education** of the general public and the medical profession in all areas relating to Eosinophilic-Associated Diseases;

(b) **Providing relief** to and promoting the good physical and mental health of persons diagnosed with Eosinophilic-Associated Diseases, and by extension their families and carers through a community hub and the provision of resources, advice, guidance and events; and

(c) **Funding, sharing and cooperating** with national and international organisations to support medical research into the causes, treatment and cure of Eosinophilic-Associated Diseases.

3. Public benefit statement

EOS Network operates for public benefit. The trustees confirm that they complied with the duty in Section 17 of the Charities Act 2011 to have due regard to the general guidance on public benefit, 'Charities and Public Benefit'.

4. Achievement and performance during the period 10th May 2022 to 31st March 2023

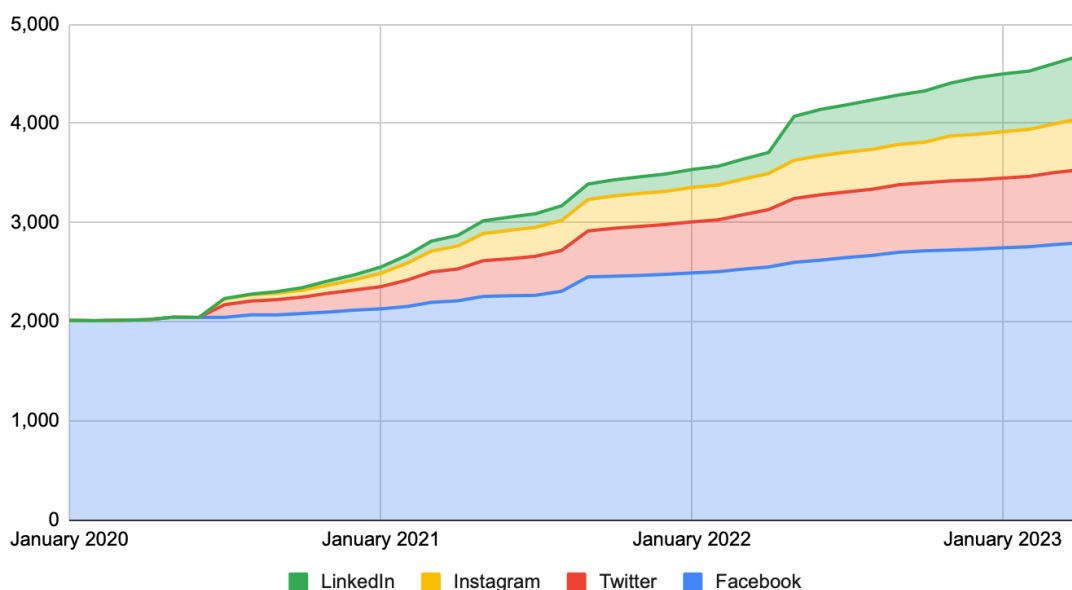
The EOS Network CIO was incorporated on 10th May 2022, as a successor organisation of registered charity 1143267 unincorporated association of the same name.

In 2020 the trustees identified five **Critical Success Factors (CSFs)** as the core charity's strategy.

Some notable achievements are listed below, grouped by CSF.

1. Enable patients to engage with the right HCPs at the right time, make shared decisions about their treatment, and self-manage when appropriate

Social followers



The starting point to empower patients is to reach and engage with them. Our community reach continued to grow rapidly, with **over 3500 new visitors to our website per month**, 4700 social media followers, over 700 registered patients and carers and ongoing collaboration with other Patient Advocacy Groups for Eosinophilic Diseases around the world.



“As a footballer, the main thing is recovery and eating well... I didn't know what EoE was. I was speaking to doctors, and we couldn't get to the bottom of it. Diagnosis was a big weight off my shoulders”.

Sean Goss, a professional footballer and EOS Network Ambassador

We introduced professional footballer Sean Goss of Motherwell FC as our new **Ambassador**. Sean's story has given confidence to members of our community, about what is achievable when EoE is well-managed.

Community Support

We continued to provide one-to-one telephone support to new and existing registrants, which reached the capacity limit of our volunteer team as our community continued to grow.

We held online community chat support meetings giving patients and their families an opportunity to connect and engage with others who had lived experience of their physical and mental health challenges.

Clinical Trials Community Educational Event Series

With growing opportunities for people with Eosinophilic Diseases to participate in clinical trials we identified that our community had a need to understand what this means so they could make informed decisions.

With thanks to speaker support from Synexus Clinical Research we conducted **free patient and carer interactive webinars** on understanding Clinical Trials. The aim of the project was to equip our community's to be able to ask the necessary questions before deciding if participating in a trial would be right for them.

The sessions covered: What is a clinical trial, types of clinical trials, benefits and risks and how to get involved. The training sessions have proved to be a transformative experience, turning interest into confidence, and empowering our community to engage in clinical trials actively.

100%

attendees were confident enough to explore clinical trials by the end of the events.

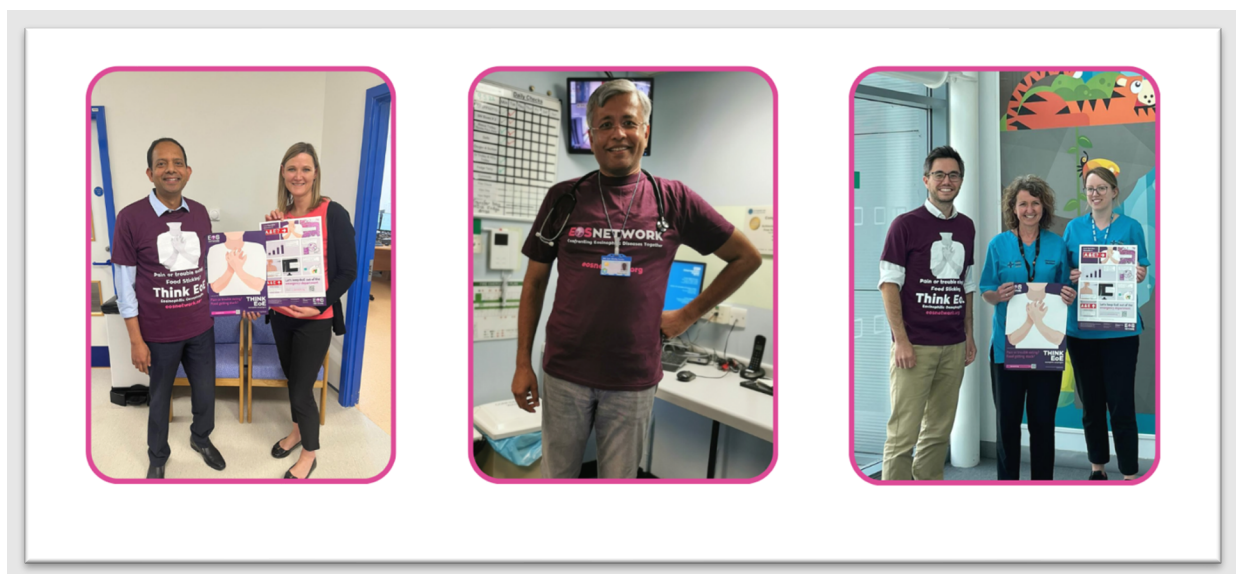
Resources Development

We plan to make this information a free public resource on our website within the next 12 months.

We also grew the number of Healthcare Professionals (HCPs) participating in the 'Find a HCP' map on our website to 185, a key resource for a rare disease with limited availability of clinical expertise.

We expanded the amount of information for patients about Eosinophilic Conditions and their treatment, on our website, and published regular newsletters.

1. Educate multiple stakeholders to shorten time to diagnosis and improve long term management



We were excited to see hospitals roll our “Think EoE” resources to increase awareness, reduce people’s symptom-to-diagnosis time, and direct them to EOS Network for support.

Awareness Campaign

We launched a **‘Think EoE’ awareness campaign** informing GPs, and A & E staff, supplying patients’ support resources to hospitals around the country, which we hope will further support the different areas where patients are being lost in the system.

We deepened our relationships with 12 healthcare companies with treatments in development which may be of benefit to our community, to ensure that their trials design, regulatory approval plans and medical education support were appropriate to meet the needs of patients.

With huge variance of available treatments depending on the patient's location, we continued to advocate to multiple stakeholders and providers to improve global access for all affected.

BSPGHAN Working Group Participation And Guidelines Development

As members of the BSPGHAN British Society of Paediatric Gastroenterology Hepatology and Nutrition Eosinophilic Oesophagitis working group, we represented the patients voice in development of patient centric clinical care and disease management tools. We also exhibited at their annual meeting increasing awareness and providing patient and HCP resources to 100 doctors and dietitians to improve earlier diagnosis through recognition of the symptoms presented in children.



BSPGHAN EoE Working Group at BSPGHAN 2023 Annual Meeting

2. Standardise care by fostering multidisciplinary collaboration which adequately addresses the practical needs and expectations of patients, and advocating for access to evidence based treatments

In Jun 2022, we attended and exhibited at the British Society for Gastroenterology - BSG Live Annual Meeting, where the long-awaited joint **BSG - BSPGHAN Guidelines** for diagnosis and care of EoE were launched. EOS Network has provided the patient's voice for these guidelines, alongside an EoE patient and 17 multidisciplinary paediatric and adult experts, covering gastroenterology, dietetics, allergy, and pathology. Our chair and founder Amanda Cordell is a named author in this publication of the first UK clinical guidance for EoE.

Higher Quality Care Advocacy

Capitalising on the publication of these Guidelines, we advocated to the clinical community for accelerated standardisation of appropriate care, so that patients receive a prompt accurate diagnosis and the treatment which is right for them.

We publicised an important new tool from CEGIR The Consortium for Eosinophilic Gastrointestinal Researchers, the **Index of Severity for Eosinophilic Oesophagitis (I-SEE)**. The I-SEE scoring system

can be completed at routine clinic visits and will help guide practitioners by standardising care, as well as improving benchmarking in future clinical studies

We collaborated with other patient organisations and leading clinicians around the world to identify unmet needs for high quality care among people living with Eosinophilic-Associated Diseases. A **charter** was developed and accepted for publication in an international medical journal and publicised during **2022 Eosinophilic Awareness week** and the launch of the 18th May an international day of Eosinophilic disease recognition.

3. Cascade recognition and understanding of lower EGIDs from centres of excellence (primarily in the US) to multidisciplinary communities

Eosinophilic Gastrointestinal Diseases of the lower gut ('Lower EGIDs') are less common and currently less well understood and defined than EoE, but we continued to make them a priority, as patients' needs can be even more acute and under-served. We attended **regular meetings of CEGIR**, the leading global consortium for exchanges about lower EGIDs, and cascaded research news to our EOS professionals' network.

Our Network grew to include 429 Healthcare Professionals in 43 Countries



We continued to engage with a number of **pharmaceutical companies** with products in development which show possible promise for lower EGIDs, to ensure that lower EGIDs are included in their clinical trial and medical education programmes relating to the spectrum of Eosinophilic-Associated Diseases (EADs).

We promoted the use of the **International Consensus for EGID nomenclature** and important publication that as members of CEGIR we represented the patients voice alongside the 91 world leading experts in this field. This is a crucial step in standardising the evidence to develop essential guidelines for lower EGIDs

4. Expand our resourcing and develop our organisation, to maximise the explosive growth in opportunities to improve patient experience and outcomes

During the period, we transitioned the assets and activities of the previous unincorporated charity to the new CIO.

In 2021/22, our unincorporated predecessor charity had reluctantly had to restrict our social media strategy, web development, patient and HCP information/tools/support due to limited human resources and funds available.

During 2022/23, we laid foundations to build a professionally staffed and managed organisation:

- Changed our legal status, to a Charitable Incorporated Organisation
- Grew our financial resources to enable us to employ staff
- Recruited to two key paid staff roles: CEO and Communications Officer
- Acquired IT equipment for our new staff, thanks to the generosity of our corporate sponsor GeTech
- Expanded our suite of policies
- Transitioned to a new online accounting system
- Appointed new bankers and identified suitable accounts in which to hold reserves
- Continued the development of a Customer Relationship Management (CRM) system
- Made frequent use of Dechert LLP as our legal advisors, for whose donated support we are most grateful



l-r: Olena Filatova (Communications Officer), Amanda Cordell (EOS Network's CEO and Founder), Mark Boulding (Trustee), exhibiting at the Annual BSPGHAN Meeting, 2023.

5. Financial review

i. Results for the period

Income for the period was £153670 which includes £45054 being the transfer assets from the unincorporated charity. Expenditure of £77654 resulting in a surplus of £76016.

We are **thankful for** the continued dedicated **support of volunteers, community fundraisers and** the generosity of our **donors, corporate sponsors, and the trusts/foundations** D'Oyly Carte Charitable Trust, FSJ and Masonic Hall without whom our achievements would not have been possible.



“After getting a diagnosis for EoE we reached out to EOS Network for support, the information we received helped me make informed treatment choices with my doctor. My family and I were also so grateful to meet others in the EOS community and to know I was not the only one living like this.”

Fergus's family, "Team Rice", organised a 24-hour Indoor Cycle Challenge, completing 1363 km and raising £1555. Their viral social media coverage increased public awareness.

Grants and Donations were gratefully received from the following corporate supporters: Dechert LLP, Astra Zeneca, Sanofi – Regeneron, Dr Falk Pharma, Allakos, Bristol Myers Squibb and Avir Pharma.

ii. Reserves

The Trustees' policy on reserves requires that reserves shall be used for the following purposes: to provide fixed and working capital; to provide for future contingencies; and to provide a base for future development required to deliver the charity's strategic objectives.

The charity has **financial reserves** that are a combination of restricted and unrestricted reserves. Restricted reserves are funds that have been given for a specific charitable purpose.

The Trustees consider that the available reserves (i.e., liquid and readily realisable assets, excluding restricted funds represented in these assets) should be maintained in a range between three and six months of operational expenditure.

They also recognise that owing to the need for resources to be used to finance planned expansion, there may be periods when reserves cannot be maintained within these limits, however sufficient reserves shall be maintained to cover known commitments. The reserve levels required under the reserves policy will be kept under review.

6. Plans for 2023-24

With increasing prevalence figures now reaching 1 in 1500 people suffering from an Eosinophilic Disease, we are currently only reaching a fraction of all UK patients with EGIDs who would benefit from our support.

As we increase our capacity to meet demand, we will vigorously continue to grow and empower our patient and carer community, via multiple social media and internet search channels, as well as word of mouth and HCP referrals.

We will also further **expand our content offering** for patients and carers and engage with a patient youth community to develop support for patients transitioning between paediatric and adult services when things can go badly awry.

We plan to hold at least one **national in-person community event**, connecting people living their disease so they can share their experiences and learn from others.

We will also **advocate** to Health Technology Assessment (HTA) bodies, including NICE and the Scottish Medicines Consortium (SMC), to ensure that new and existing **drug treatments** which can benefit our community are made available to them. Specifically, in light of new clinical evidence and USA approval of the first biological treatment for EoE we will advocate for; EU/UK access for Dupilumab® Jorveza® to be endorsed by NICE for maintenance and not just acute treatment of the chronic condition EoE and EU/UK access for Dupilumab®.

Recognising that Eosinophilic Diseases across multiple organ systems may co-exist and be inter-related, we will **participate in international initiatives to characterise the spectrum of Eosinophilic-Associated Diseases**. We will also expand our focus on the better understanding of and diagnostic consensus for **lower EGIDs**, so these complex and highly debilitating conditions are not left behind as the management of EoE improves. We will also expand our website content relating to these areas.

Internally, we anticipate 2022/23 will be a pivotal year of transition for the charity and will require further expansion of the staff team 2023/24 to support our growing EOS patient and carer community and develop an EOS youth community voice.

We plan to **formally close the unincorporated charity** and transfer its assets to the new CIO (charity number 1198883), registered on 10th May 2022). This new CIO will, inter alia, be able to enter into contracts in its own name, for example funding agreements and contracts of employment.

We will **implement our new CRM system**, commensurate with the scale and complexity of our communities and stakeholders.

We will **develop additional policies**, including ones for recruitment, fundraising, risk assessment, complaints and whistleblowing.

Underpinning the transition must be a substantial growth in income. We will continue to **seek funding from a variety of sources**, including trusts and foundations, to avoid over-reliance on any one funder or category. However, we recognise that the current climate for voluntary donor funding is difficult, and likely to remain so as many funders prioritise the cost-of-living crisis over more chronic albeit equally challenging problems.

Counterbalancing this is the emergence of several pharmaceutical products which represent a step-change in the effectiveness of treatments for Eosinophilic Conditions including EGIDs. Whilst we shall always remain steadfastly independent in everything we do and say, we recognise and welcome the fact that our patient and carer community, and the pharmaceutical companies active in the field of EADs, share a common interest in ensuring that patients receive a prompt diagnosis, the right treatment for them and support to live with their condition.

We are therefore predicating our income model on the expectation of significant unrestricted grants from industry in the forthcoming period.

Approved by the Trustees on 20th Nov 2023

and signed on their behalf by

Chair of Trustees

Amanda Cordell

A handwritten signature in black ink, appearing to read 'A Cordell', written in a cursive style.

Treasurer and Trustee

Bernard McGrath

Bernard Michael McGrath

EOS Network CIO

Statement of Financial Activities For the period to 31 March 2023

	Note	Mar-23 Unrestricted £	Mar-23 Restricted £	Mar-23 Total £
Incoming resources				
Income resources from generated funds:				
Voluntary income				
Donations		18,817	-	18,817
Corporate funding		37,500	-	37,500
Donated services	2	52,299	-	52,299
Other -transfer from EOS Network	3	42,524	2,530	45,054
Total incoming resources		151,140	2,530	153,670
Resources expended				
Cost of generating funds				
Cost of generating funds		1,060	-	1,060
Charitable activities		24,295	-	24,295
Donated legal services	2	52,299	-	52,299
Total resources expended		77,654	0	77,654
Net movement in funds		73,486	2,530	76,016
Funds carried forward at 31 March 2023		73,486	2,530	76,016

EOS Network CIO

Balance Sheet as at 31 March 2023

	March 2023 £	
Current assets		
Bank	76,016	
Net Current Assets		76,016
Total assets less current liabilities		76,016
Net Assets		<u>76,016</u>
Income funds		
Unrestricted		73,486
Restricted funds		2,530
Balances carried forward		<u>76,016</u>

EOS Network

Notes to the financial statement

For the period ended 31 March 2023

1) Accounting policies

I. Basis of Preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice for Charities (SORP 2015), (Second Edition, effective January 2019), the Charities Act 2011 and applicable accounting standards (FRS 102).

II. Accounting convention

The accounts are prepared under the historical cost convention.

III. Donations receivable

Donations are credited to income when received.

2) Donated services

During the period the Charity received pro-bono legal services to the value of £52,299 which is shown as expenditure in these financial statements under Donated legal services within Resources Expended. An equivalent amount of income £52,299 is shown as Donated services within Incoming resources.

3) Transfer from EOS Network

On 3 March 2023 the assets of EOS Network (Unincorporated Charity 1143267) were transferred to EOS Network – Eosinophilic Diseases Charity (CIO 1198883). Cash assets of £45,054 transferred to Eosinophilic Diseases Charity (CIO 1198883) are shown within the SOFA under incoming resources.

4) Payments to Trustees

During the period Amanda Cordell a Trustee, in her capacity as Chief Executive, received remuneration of £11,808 and reimbursed expenses of £316. This employment was approved by the Charity Commission.

5) Governance costs

Trustees received no remuneration as their role as trustees.

EOS Network

Independent Examiner's Report to EOS Network on the accounts for the period to 31 March 2022 (Charity No: 1198883).

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the period ended 31 March 2023 set out on pages 15-17.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all applicable Directions by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Simon Robinson

Signed:

21 / 11 / 2023

Date:

Relevant professional qualification(s) or body

Address:

Simon Robinson
SAS Accounting Services Ltd
The Colchester Centre
Hawkins Road
Colchester CO2 8JX