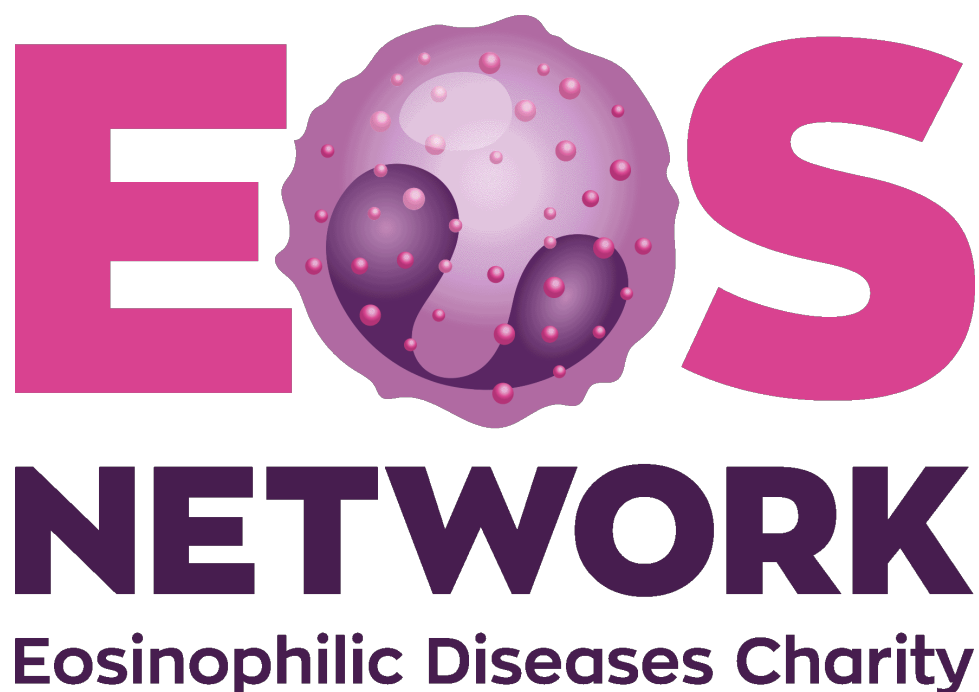




CIO

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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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

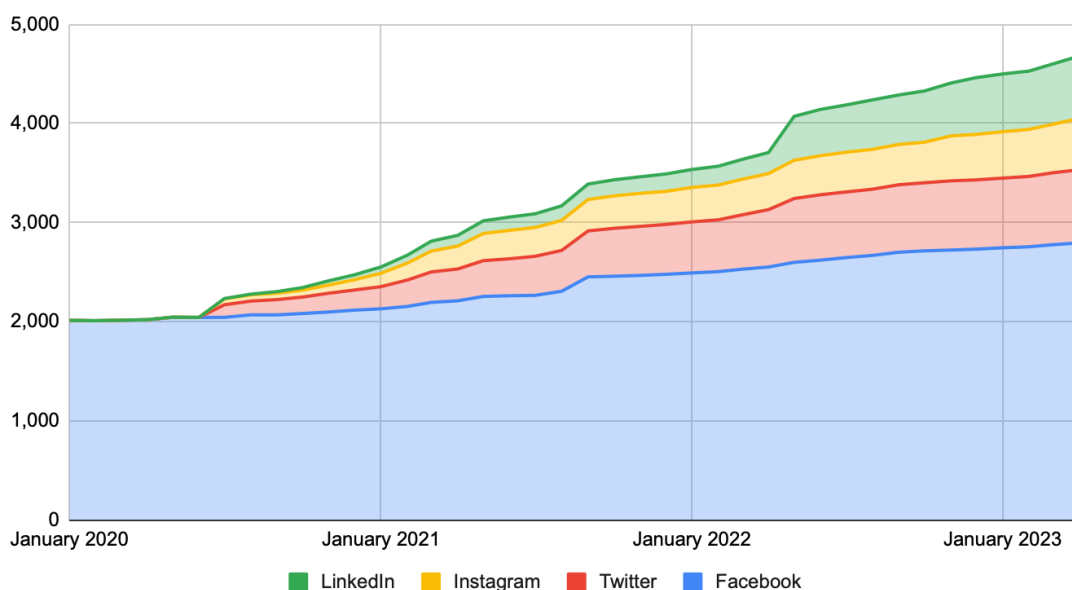
The EOS Network CIO was incorporated on 10th May 2022, as a successor organisation of registered charity 1143267 unincorporated association of the same name.

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.

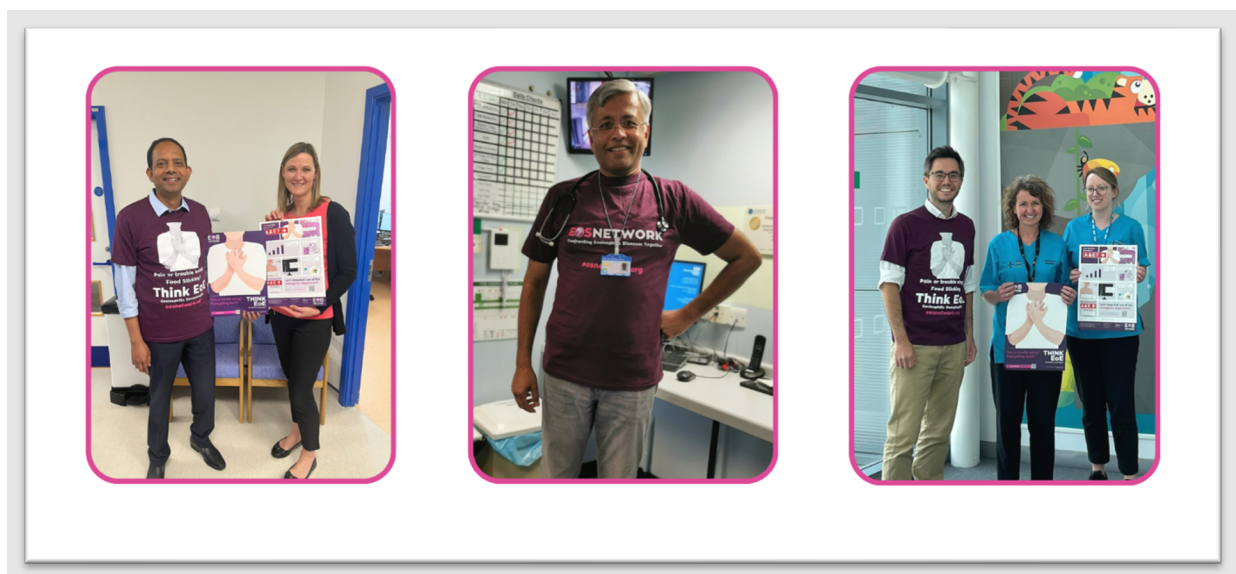
Resources Development

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