

CAMBRIDGE RARE DISEASE NETWORK

Charity Registration number 1166365

FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2024

CAMBRIDGE RARE DISEASE NETWORK

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FOR THE YEAR ENDED 31 DECEMBER 2024

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CAMBRIDGE RARE DISEASE NETWORK

REFERENCE AND ADMINISTRATION INFORMATION FOR THE YEAR ENDED 31 DECEMBER 2024

Charity number	1166365
Principal Address	C/o Windsor House Station Court Station Road Great Shelford Cambridge CB22 5NE
Trustees	Dr G Chandratillake Ms. S L Berry Dr S M Leiter Mrs L Macinnes Mrs S Faircliffe Mrs E Green Mr J Andrews
Company Secretary	BSC Cosec Ltd.
Managing Director	Mrs J Balfour
Independent Examiner	Community360 Winsley's House High Street Colchester Essex, CO1 1UG

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

Charity Objectives and Activities

About CamRARE

Cambridge Rare Disease Network (CamRARE) is a platform for change. It is the infrastructure that unites patients, advocates, experts and leaders to address the challenges people face when affected by rare conditions. By sharing knowledge and experience, the journey towards better diagnosis, treatment and support for patients and their families is smoother and more certain.

Our Vision

A world where people with rare diseases are valued and supported.

Our Mission:

We build cross-sector networks to improve outcomes for people with rare diseases.

Our Values:

We put those living with rare conditions at the heart of everything we do. We're creative, innovative and boldly challenge the status quo.

CamRARE's work falls into four broad areas of activity:

1. **Supporting people with and families affected by rare diseases** at a regional level through our 'Unique Feet' community group.
2. **Raising awareness and facilitating cross-sector collaboration** through innovative educational and networking events like RAREfest.
3. **Providing opportunities for immersive learning and impactful networking** for representatives from pharmaceutical, biotechnology companies, and healthcare organisations through our Companies Forum.
4. **Identifying gaps in support and facilitating a voice for people with rare diseases** to enable solutions through Patient and Public Involvement, Engagement and Participation (PPIEP).

Charity Objects, as recorded with the Charity Commission

While individual rare diseases are rare, collectively they are not. There are more than 10,000 such conditions, affecting **one in 17 people**, which amounts to 3.5 million individuals in the UK. The journey for these individuals and their families is fraught with challenges. A lack of awareness among healthcare professionals often leads to a lengthy "Diagnostic Odyssey," with patients waiting over five years for a definitive diagnosis. Once diagnosed, patients face a constant battle to share vital medical information with a wide range of professionals, especially in stressful emergencies.

The burden extends beyond the clinic. In a 2023 survey, **85% of respondents felt that having or caring for someone with a rare condition had negatively impacted their mental health or emotional wellbeing**. This contributes to social isolation and places a significant strain on caregivers. In research, drug development is uncertain, and investigator-led research does not always prioritise questions valued by the patient population.

CamRARE's Solution: Creating Networks to Improve Outcomes

At CamRARE, we are actively forging multi-stakeholder, cross-sector partnerships to educate, support, foster collaboration, and incorporate the patient perspective to improve outcomes for those affected by rare diseases. Our work in 2024 has been a testament to this mission, delivering impactful projects across our four strategic pillars that directly address these profound challenges.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

Strategic Pillars: 2024 Key Achievements & Impact

Pillar One: Supporting Families - Unique Feet (UF) Regional Community

Objective: To build a connected, engaged, and empowered network of individuals affected by rare diseases, providing support and reducing isolation for families.

For families navigating the complexities of a rare condition, our Unique Feet community is a vital lifeline, offering a safe space to share experiences and find support. In 2024, the community continued its steady growth, expanding to **42 active families**.

Our new **Unique Feet Annual Survey**, launched this year, provided crucial insights into the community's needs and our impact. The findings were overwhelmingly positive, with **100% of respondents wishing to continue their membership**.

Key Activities and Impact

- **Improving Quality of Life**

The survey revealed the profound impact of our work. Faced with immense strain, where **55% of parent/carer responders rate their sense of wellbeing as low** and 79% do not get adequate rest or sleep, our community makes a tangible difference. **60% of parents/carers** and **60% of children** with rare conditions **stated that Unique Feet improved their quality of life**.

- **Addressing Complex Needs**

Our families have higher access requirements than most, including sensory needs (58%), quiet spaces (39%), and the crucial need for Changing Spaces toilets (28%), which now guides our future planning.

- **A Full Programme of Events**

From January to August, we offered **31 activities with 168 places filled**, catering to all ages, from our "Little Feet" pre-schoolers to our "Big Feet" young adults. These pre-planned, accessible activities were essential for 97% of families.

- **Financial Pressures**

The annual cost of running Unique Feet is approximately £50,000. With many families facing financial hardship, fully or partially funded activities are essential for 91% of our members. We are grateful for grants received in 2024 from **D'Oyly Carte Charitable Trust (£4000)**, **The Simon Gibson Charity (£5000)**, and **True Colours Trust (£6320)** to support this work.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

Pillar One: Supporting Families
Through the Unique Feet Community

2024 Key Achievements & Impact

The Community at a Glance

Building a connected, engaged, and empowered network for families affected by rare conditions



42
Active families



31
Actives & events

Voices of Impact

"A vital lifeline where families feel seen and supported"



want to
continue
membership



of parents &
children say UF
improved
quality of life



do not get
enough
rest/sleep

Understanding Needs

Listening and adapting
to what matters



58%

Have sensory needs



39%

Need quiet spaces



28%

Need changing places toilets

Accessible Activities for All



£50,000 = Annual running cost
of families rely on
subsidised activities

THE IMPACT OF UNIQUE FEET

- **60%** of parents and **60%** of children say Unique Feet improved their quality of life
- **85%** of families feel it's important to connect with others on a similar journey
- **100%** of members want to remain part of the community

Pillar Two: Raising Awareness and Promoting Cross-Sector Collaboration

Objective: To increase awareness of rare diseases and promote engagement and communication among stakeholders, fostering cross-sector collaboration. 2024 was a landmark year for raising awareness, headlined by our flagship biennial festival, **RAREfest24**, a vibrant and joyful celebration of science, creativity, and community.

Key Activities and Impact

• **RAREfest24 - A Resounding Success:**

Held in November, RAREfest24 brought together over **800 attendees**. The event was described in feedback as "inspiring," "inclusive," "innovative," and a "disability positive space". A remarkable **58% of visitors were attending their first-ever rare disease event**, and **100% rated the festival as 'Excellent' or 'Very Good'**.

◦ One exhibitor beautifully captured its unique spirit: *"What made RAREfest different... is the way stories are told. While there were 'standard' presentations... there were also stories told through music, dance, comedy, art... which was so different and just as impactful".*

◦ From the moving **Rare Youth Monologues** to the joyful **'Hopes & Dreams' performance by our Unique Feet community**, the event put lived experience centre stage. One attendee shared, *"...for the general public to come away buzzing with what you've learned is so empowering!"*.

• **ART-TRAnslations Exhibition:** In partnership with LifeArc, we launched the ART-TRAnslations initiative, pairing 20 rare disease researchers with artists. The resulting exhibition at RAREfest24 was described as "breathtaking," powerfully bridging the worlds of science and emotion. The artwork now features in an online gallery and a 24-month calendar, ensuring its lasting impact.

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2024



RAREfest24: IN NUMBERS

- **>800** Attendees
- **58%** First-time visitors to a rare disease event
- **100%** rated the event 'Excellent' or 'Very Good'
- **96%** learned something new about rare diseases

Pillar Three: Providing a Platform for Immersive Learning – Companies Forum

Objective: To build a network of companies, healthcare professionals, and researchers to develop treatments and technology solutions for rare patients, facilitating impactful collaboration.

In 2024, our Companies Forum meetings explored the drug development cycle from the patient organisation's perspective.

- **May – Collecting Impactful Data:** This session highlighted the immense burden on families to initiate research, illustrated by the story of the NCBRS Foundation, where a father's quest for answers led to the creation of a charity and patient registry 30 years after the condition was first named. Discussions focused on overcoming key barriers for patient groups, such as limited UK funding options for registries.
- **September – Measuring What Matters:** We heard the powerful story of Duchenne UK's fight for access to the drug Translarna. Co-founder Emily Reuben shared her realisation that "*there is something worse than having no treatment: having an effective treatment that is inaccessible due to financial and bureaucratic barriers*". This experience drove the creation of **Project Hercules**, an innovative collaboration uniting competing pharmaceutical companies to build the evidence needed to meet regulatory requirements.
- **December – Driving Patient-Led Research:** The year's final meeting was an immersive experience exploring our newly launched **Rare Disease Research Network (RDRN)**. The session focused on how the RDRN can support patient groups in setting the research agenda and help our industry partners align their work with patient priorities.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

Pillar Four: Patient & Public Involvement, Engagement, Participation (PPIEP)

Objective: To facilitate and provide access to patient voices in research and healthcare settings, ensuring their perspectives are integrated into decision-making processes.

Our PPIEP work has seen phenomenal progress in 2024, with the launch of two transformative, patient-driven initiatives.

Key Activities and Impact:

• **The Rare Patient Passport – A Global Success:** After two years of co-production, we launched a **new, user-friendly version of the passport in March 2024**. Born from our Unique Feet community's need for a tool to communicate vital information in emergencies, the passport addresses a long-standing challenge for patients everywhere. This significant achievement was a true collaborative effort, made possible by the generous support of **Alexion AstraZeneca, which provided a £10,000 grant towards the project**. We are also immensely grateful for the multi-year, pro bono support of the **Costello Medical team, who were instrumental in developing the passport research reports**, and the invaluable contributions of the **many people living with rare conditions and the healthcare professionals who co-produced the passport with us**. Its impact has been global:

- Around **1,900 individual applications** received by the end of the year, according to information from our conversation.
- Passports are in use in **60 countries**.
- Partnerships established with **over 57 patient groups** and discussions underway with over 20 healthcare settings.

• **Launch of the Rare Disease Research Network (RDRN) –Co-created with over 20 adults from the rare disease community, the RDRN is a groundbreaking online platform designed to "turn research on its head" by championing patient-driven research.**

- **Successful Launch:** The platform was **launched at RAREfest24 in November**, with **149 people signing up at the event**, exceeding our initial target of 100. By the end of the year, it had **193 members and 9 research questions**.

- **A Vision for the Future:** The RDRN addresses a critical unmet need. As Allison Watson, CEO of Ring 20 Research & Support, stated, *"This new online network will allow more rare diseases... to be seen and heard in the research space, creating a more equitable field for all... The potential to open up collaboration... is huge...who knows where this may lead?"*.

Our Growing Team

We were delighted to strengthen our core team in 2024 by employing two members of staff who had previously worked with us on a freelance basis. This move builds our internal capacity and secures vital expertise, ensuring we can continue to expand our support for the rare disease community.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

FINANCIAL REVIEW

The overall net income for 2024 of activity is £181,873 and expenditure £231,715.

Key funding for our Unique Feet community in 2024 was secured through grants from the **D'Oyly Carte Charitable Trust (£4000)**, **The Simon Gibson Charity (£5000)**, and the **True Colours Trust (£6320)**. The Rare Disease Research Network was developed with funding from an **NIHR Public Partnership Grant totalling £113,000**. The Rare Patient Passport project was supported by a **£10,000 grant from Alexion AstraZeneca** and pro bono support from **Costello Medical**. Income raised through corporate sponsorship for RAREfest24 and membership of our Companies Forum totalled £65,861 and donations and community fundraising totalled £12,682.

Reserves Policy The charity's management team works to a policy whereby unrestricted funds not committed or invested in tangible fixed assets held by the charity should be a minimum of three months of running costs. The level of cash available to the charity on 31 December 2024 was £178,582.

Investment Policy Aside from retaining a prudent amount in reserves each year, most of the charity's funds are spent in the short term, so there are no long-term investment funds. The management team will review the current investment policy if the funding position changes as the charity evolves.

Structure, Governance and Management

Governing Document CamRARE is a Charitable Incorporated Organisation (CIO) whose only voting members are its charity trustees ('Foundation' Model). The transfer to CIO status was made on 22 September 2022, and the charity works to this updated governing document.

Organisation: The Board of Trustees has no maximum members, and it meets six times a year to administer the charity. During 2024, Dr Sarah Leiter stepped down following 7 years of service as a Trustee to CamRARE. During April, Joseph Andrews was appointed as our Treasurer. We thank all of these trustees for their valuable service to the charity and the community it serves.

Trustee Induction and Training: Newly appointed trustees with little prior knowledge of the role attend CCSV Trustee training. All Trustees have reference to the CamRARE Trustees Handbook for induction.

Pay Policy, Trustees and Staff

The charity's policy is that Trustees give their time voluntarily and receive no financial benefit from the organisation. No Trustees claimed expenses from the charity during the last financial year.

During 2024, CamRARE employed five members of staff. **Jo Balfour** continues in her full-time role as Managing Director. **Lindsey Brown** continues part-time as Events and Projects Officer.

Vaila Morrison was appointed as **Communications and Design Officer** (part-time) after working with CamRARE as a freelancer for two years. **Celia Enderle** joined as **Community Engagement Officer (part-time)** in February 2024, having also previously worked with CamRARE on a freelance basis. Both Vaila and Celia are members of our Unique Feet community and bring valuable lived and professional experience to their roles.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

Georgina Windsor, who was employed in 2023 to co-lead the **PPIE Framework** of our NIHR-funded **Rare Disease Research Network (RDRN)** project, moved on to a new role at the end of the grant-funded period in December 2024. **Lesley Booth**, our Deputy Director, also left CamRARE for a new role in December 2024.

Pay is reviewed annually and benchmarked against salaries for comparable charity roles outside London, with consideration given to the charity's financial position and budget forecasts. All other services are paid at agreed contracted rates.

Risk Management

The risks to which CamRARE is exposed remain minimal, as committed spending and running costs are still relatively low. A dedicated financial software package supports the management of increasing transaction complexity and enables effective monitoring as the charity continues to grow.

CamRARE had a very successful year financially, enabling organisational growth and securing employment for the core team. Sustainable funding is currently supported through income from the **Companies Forum**, **corporate sponsorships**, and **project grant funding**.

However, the charity recognises that competition for grant funding across the voluntary sector is high, and that levels of **corporate sponsorship for RAREfest** have reduced significantly compared with previous years. The Trustees remain mindful of the need to diversify income streams and to continue developing long-term sustainable funding models to mitigate these risks.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing Document

CamRARE is a Charitable Incorporated Organisation whose only voting members are its charity trustees ('Foundation' Model). The transfer to CIO status was made on 22 September 2022 and the charity works to this updated governing document.

Trustee Induction and Training

During 2023, newly appointed trustees with little prior knowledge of the role attended CCSV Trustee training. All Trustees have reference to a CamRARE Trustees Handbook for induction.

Organisation

The Board of Trustees has no maximum number of members, and currently, the seven members administer the charity. The Board meets four times a year. Jon Green also tendered his resignation after taking on new work responsibilities. We thank all of these trustees for their valuable service to the charity and the community it serves.

Responsibilities of the Trustees

The Trustees are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice). They must not approve these financial statements unless they are satisfied that they provide a true and fair view of the state of affairs of the charitable company for that period, specifically regarding its incoming resources and their application.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial reports on a going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company. Trustees are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps to prevent and detect fraud and other irregularities.

This report is approved by the Trustees and signed on their behalf by: Emma Green

Chair and trustee



Date 31 October 2025

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

Organisation Details

Registered Office: c/o BCS, Windsor House, Station Court, Station Road, Great Shelford, CB22 5NE

Registered Charity number – 1166365 - Registered on 5 April 2016 Transferred to Charitable Incorporated Organisation on 28 September 2022

Trustees Current

Dr Gemma Chandratillake (appointed 15/05/2017)
Mrs Susan Berry (appointed 29/07/2019)
Sarah Faircliffe (appointed 03/10/2022)
Emma Green (appointed 03/10/2022 - appointed Chair 23/01/2024)
Loretta MacInnes (appointed 03/10/2022)
Joseph Andrews (appointed 27/04/2024)

Resigned 2024

Dr Sarah Leiter (appointed 05/06/2017 - resigned 31/07/2024)

Management and Operations

Managing Director - Jo Balfour (employed FT)
Deputy Director – Dr Lesley Booth (employed FT)
Events and Projects Officer - Lindsey Brown (employed PT)
Graphic design and communications – Vaila Morrison (contracted - employed PT Feb 2024)
IT consultancy - George Nicolau (contracted)
Community Communications – Celia Enderle (contracted)
Community Engagement Officer - Celia Enderle (employed PT Feb 2024)

Rare Patient Passport report - Costello Medical (pro bono)

Company Secretary - BCS Accounting Ltd Accounting - Community 360 (Jan 2021 - present)

Independent Accounts Review - Community360

CAMBRIDGE RARE DISEASE NETWORK

INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

I report on the accounts of Cambridge Rare Disease Network for the period ended 31 December 2024 which are set out on pages 12 to 19.

Respective responsibilities of trustees and examiner

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act,
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act, and
- To state whether particular matters have come to my attention.

Basis of independent examiner's Statement

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

Independent examiner's statement

In the course of my examination, no material matters have come to my attention 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 the 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 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.

David Courtier FMAAT AATQB for and on behalf of:

Community360

Winsley's House, High Street, Colchester, Essex



Date

31/10/2025

CAMBRIDGE RARE DISEASE NETWORK

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total £	2023 Total £
<u>Incoming resources</u>					
Incoming resources from generating funds:					
Donations and legacies	2	12,682	-	12,682	40,251
Charitable activities	3	72,305	96,886	169,191	183,616
Total incoming resources		84,987	96,886	181,873	223,867
<u>Resources expended</u>					
Charitable activities	4	134,480	97,235	231,715	191,845
Total charitable expenditure		134,480	97,235	231,715	191,845
Net incoming/(outgoing) resources before transfers		(49,492)	(349)	(49,841)	32,022
Previous year adjustment		5,818	-	5,818	-
Transfers between funds		(6,324)	6,324	-	-
Net income/(expenditure) for the year/ Net movement in funds		(49,999)	5,975	(44,024)	32,022
Fund balances at 1 January 2024		221,351	5,203	226,554	194,532
Fund balances at 31 December 2024		171,352	11,178	182,530	226,554

CAMBRIDGE RARE DISEASE NETWORK

BALANCE SHEET AS AT 31 DECEMBER 2024

	Notes	2024	2023
		£	£
		£	£
Current assets			
Debtors	6	8,577	91
Cash at bank and in hand		178,582	229,178
		<u>187,160</u>	<u>229,269</u>
Creditors: amounts falling due within one year	7	<u>(4,630)</u>	<u>(2,715)</u>
Net current assets		182,530	226,554
Total net assets		<u><u>182,530</u></u>	<u><u>226,554</u></u>
Income funds			
Restricted funds	9	11,178	5,203
Unrestricted funds		171,352	221,351
		<u><u>182,530</u></u>	<u><u>226,554</u></u>

Approved by the trustees on the31.October..... 2025 and signed on their behalf by:



Emma Green

Date

31 October 2025

The notes on pages 14-19 form an integral part of these financial statements.

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2024

1 Accounting Policies

1.1 Basis of accounting

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement on Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Cambridge Rare Disease Network meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

There were no significant estimates or judgements made by management in preparing these financial statements.

1.2 Going concern

The trustees have reviewed the financial position of the charity and have a reasonable expectation that the Charity has adequate resources to continue in operation existence for the foreseeable future. Accordingly, the financial statements continue to be prepared on the going concern basis.

1.3 Company status

The Charity is a company limited by guarantee. The members of the Charity are the Trustees named on page 1 and those organisations and individuals who have been invited to become members and where relevant have paid the membership fee. In the event of the Charity being wound up, the liability in respect of the guarantee is limited to £10 per member of the Charity.

1.4 Income

All income is recognised once the Charity has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

Income from government and other grants, whether "capital" grants or "revenue" grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received, and the amount can be measured reliably and is not deferred. Income received in advance of a Conference or provision of other specified service, is deferred until the criteria for the income recognition are met.

Donations are recognised when received. Sponsorship income is recognised in relation to the specific events, such as the RAREsummit or RAREfest. Amounts are included as debtors if owing to the charity at the period end or carried forward in creditors if received in advance.

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

On receipt, donated professional services and facilities are recognised on the basis of the value of the gift to the Charity which is the amount it would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market: a corresponding amount is then recognised in expenditure in the period of receipt.

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2024

1.5 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Charity for particular purposes. The costs of raising and administering such funds are charges against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

1.6 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably.

Expenditure on charitable activities is incurred on directly undertaking the activities which further the Charity's objectives, as well as any associated support costs.

All expenditure is inclusive of irrecoverable VAT.

1.7 Debtors

Trade and other debtors are recognised at the settlement amount after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts.

1.8 Cash at bank and in hand

Cash at bank and in hand includes cash and short-term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

1.9 Liabilities and provisions

Liabilities are recognised when there is an obligation at the Balance Sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably.

Liabilities are recognised at the amount that the Charity anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

1.10 Financial instruments

The Charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

1.11 Cash flow

The financial statements do not include a cash flow statement because the charity, as a small reporting entity, is exempt from the requirement to prepare such a statement under Financial Reporting Standard 1 "Cash flow statements".

1.12 Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income and or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2024

2 Donations and legacies	Unrestricted Funds	Restricted Funds	2024 Total £	2023 Total £
Donations and gifts	12,682	-	12,682	40,251
	<u>12,682</u>	<u>-</u>	<u>12,682</u>	<u>40,251</u>
TOTAL 2023	<u>40,251</u>	<u>-</u>	<u>40,251</u>	
3 Charitable activities	Unrestricted Funds	Restricted Funds	2024 Total £	2023 Total £
Delegate Sales	2,389	-	2,389	9,302
Grants	2,600	86,886	89,486	61,675
Sponsorship	65,861	-	65,861	83,151
Other	1,455	10,000	11,455	29,488
	<u>72,305</u>	<u>96,886</u>	<u>169,191</u>	<u>183,616</u>
TOTAL 2023	<u>110,441</u>	<u>73,175</u>	<u>183,616</u>	
4 Resources expended	Unrestricted Funds	Restricted Funds	2024 Total £	2023 Total £
Staff costs	81,515	37,896	119,411	108,133
Activity costs	-	10,718	10,718	8,033
Accommodation	1,196	-	1,196	858
Admin support	10,367	11,190	21,557	6,214
Advertising & marketing	2,235	3,497	5,732	3,785
Accountancy fees	1,045	-	1,045	1,486
Bank fees	69	-	69	57
DBS Checks	-	108	108	
General expenses	9,643	9,700	19,343	652
Equipment hire	-	-	-	180
Event costs	587	95	682	14,429
Independent examination	300	-	300	-
Insurance	-	314	314	460
IT software & consumables	767	865	1,632	1,394
Legal expenses	-	-	-	186
Postage, freight & courier	413	1,458	1,871	1,999
Subscriptions	734	179	913	1,645
Travel	1,970	1,344	3,314	5,573
Venue & catering	22,491	2,598	25,089	35,510
Website design & admin	1,148	17,273	18,421	1,252
	<u>134,480</u>	<u>97,235</u>	<u>231,715</u>	<u>191,845</u>
TOTAL 2023	<u>120,111</u>	<u>71,734</u>	<u>191,845</u>	

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2024

5 Staff costs	2024 Total £	2023 Total £
Wages and salaries	115,185	105,824
Pension costs	4,226	2,309
	<u>119,411</u>	<u>108,133</u>

The average number of persons employed by the Charity during the year was as follows:

	2024 No.	2023 No.
Employees	<u>4</u>	<u>4</u>

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

No trustee was paid any remuneration during the periods being reported on.

Key management personnel of the charity comprises of the trustees. The trustees have all given their time and expertise without any kind of remuneration or other benefit in kind.

6 Debtors	2024 Total £	2023 Total £
DUE WITHIN ONE YEAR		
Trade debtors	4,971	-
Other debtors	687	-
Prepayments and accrued income	2,919	91
	<u>8,577</u>	<u>91</u>

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2024

7 Creditors: amounts falling due within one year

	2024 Total £	2023 Total £
Trade creditors	1,427	831
Other creditors	2,904	1,585
Accruals and deferred income	300	300
	4,630	2,715

9 Statement of funds

	Balance at 1 January 2024 £	Income £	Expenditure £	Transfers In/out £	Balance at 31 December 2024 £
UNRESTRICTED FUNDS					
General funds - all funds	221,351	90,805	134,480	(6,324)	171,352
RESTRICTED					
True Colours	-	6,320	2,780	-	3,540
Simon Gibson	-	5,000	2,201	-	2,799
RareCare NIHR	-	2,000	2,000	-	-
Gillian Stevensons	1,700	-	1,700	-	-
CCF	1,725	-	1,529	-	196
D'Oyly Carte	-	4,000	1,135	-	2,865
DNU Life Arc	-	10,000	16,000	6,000	-
NIHR RDRN	-	69,566	69,890	324	-
Cole Trust	1,000	-	-	-	1,000
Unique Feet	777	-	-	-	777
Total restricted funds	5,203	96,886	97,235	6,324	11,178
Total funds	226,554	187,691	231,716	-	182,530

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2024

10 Analysis of net assets between funds

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Fund balances at 31 December 2024 are represented by:			
Current assets	175,982	11,178	187,160
Creditors: amounts falling due within one year	(4,630)	-	(4,630)
	<u>171,351</u>	<u>11,178</u>	<u>182,530</u>

Restricted funds represent amounts received for specific projects.

11 Related party transactions

There were no related party transactions in the financial period (2023: £Nil)

12 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the Trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

There are no critical accounting estimates or judgements in the financial statements.