

CAMBRIDGE RARE DISEASE NETWORK

Charity Registration number 1166365
FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

CAMBRIDGE RARE DISEASE NETWORK

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CAMBRIDGE RARE DISEASE NETWORK

REFERENCE AND ADMINISTRATION INFORMATION FOR THE YEAR ENDED 31 DECEMBER 2023

Charity number 1166365

Principal Address C/o BCS
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

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 2023

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.

CamRARE is a Cambridge-based charitable incorporated organisation that connects, educates, and supports stakeholders, locally and globally, in rare diseases to improve outcomes for people living with and affected by such conditions.

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. Our 'Unique Feet' community group offers a welcoming environment where families can feel connected, understood and supported, empowering them to be effective advocates;
2. **Raising awareness and facilitating cross-sector collaboration** through a programme of innovative educational and networking events such as RAREfest, RAREsummit and regular smaller events. Collaborating with other organisations to co-host events to reach a more diverse audience;
3. Through our Companies Forum, providing **opportunities for immersive learning and impactful networking** for representatives from pharmaceutical, biotechnology companies, and healthcare organisations operating and guest patient groups in the rare diseases space;
4. Identifying gaps in support, care, education and integration and **facilitating a voice for and access to people with rare diseases** to enable solutions (PPIEP - public and patient involvement, engagement and participation).

Charity Objects, as recorded with the Charity Commission

The relief of sickness of persons with rare diseases, particularly, but not exclusively, by providing support, advice, and information for such persons, their families, carers, and those working with affected individuals.

To advance the education of the public in general on the subject of rare diseases and related syndromes and promote research for the public benefit in all aspects of that subject and publish the useful results thereof.

Public benefit

The trustees have complied with Section 17(5) of the Charities Act 2011. They have had due regard to the guidance on Public Benefit by the Charity Commission when exercising relevant powers and duties.

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Activities

Creating networks to improve outcomes for those living with or affected by rare disease.

In Europe, a rare disease is characterised by affecting fewer than one in 2,000 individuals. Recent findings from the Monarch Initiative, using a computational approach to unify major knowledge bases, suggest there could be more than 10,000 such conditions. Collectively, these diseases impact one in 17 people, amounting to 3.5 million individuals in the UK. Among them, 80% have a genetic origin, 50% affect children, and only 5% have approved treatments. Alarming, about 30% of those with a rare disease do not live past their fifth birthday.

Despite this considerable prevalence, which is equivalent to the number of people in the UK with asthma, and unmet need, each rare condition affects so few individuals that they often go unnoticed and misunderstood by health professionals, researchers, educators, social care providers, and the general public. This lack of awareness frequently results in a “Diagnostic Odyssey,” with an average diagnosis taking 4.8 years and involving consultations with 7.3 physicians. Delays and misdiagnoses are common, compounding the difficulties faced by patients and their families.

Moreover, insufficient awareness hampers patients' access to appropriate care and support in educational and workplace settings, contributing to social isolation and placing a significant burden on caregivers. Despite recent advancements, challenges persist in the diagnosis, treatment development, and coordinated care of rare diseases. A range of mitigating factors are at play: low patient numbers per disease; limited awareness and inadequate training of healthcare professionals; difficulty recruiting enough patients for clinical trials; economic challenges; high treatment costs; reimbursement issues; and incomplete understanding of disease mechanisms.

Therefore, it is crucial to raise awareness that while individual rare diseases affect small numbers of people, their collective impact is substantial and far-reaching. At CamRARE, we are actively forging multi-stakeholder, cross-sector partnerships to educate, support, foster collaboration, and incorporate the patient perspective, aiming to improve outcomes for those affected by rare diseases.

CamRARE 2023 Annual Report

CamRARE's achievements in 2023 reflect our commitment to supporting families, raising awareness, fostering collaboration, and enhancing patient involvement in research. These efforts have delivered clear and quantifiable benefits to a wide range of rare disease stakeholders, laying a solid foundation for future growth and impact. As we move forward, we aim to secure additional funding and partnerships, increase our reach and engagement, and continue building a robust network to improve outcomes for people with rare diseases.

At a Glance: Calendar Events Summary

January:

NIHR Public Partnership Grant: Awarded £111,765.20 to develop a community-led Rare Disease Research Network and online platform, aiming to enhance collaboration and access to research opportunities for rare disease stakeholders.

RAREfest22 Impact Report: Published and disseminated widely to showcase event success, attract future sponsors, and extend outreach. Recordings uploaded to YouTube garnered 5,376 views, demonstrating increased visibility and engagement within the community.

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February

Rare-i-Tea Party: Hosted for 100 members of the regional rare disease community, fostering connections, reducing isolation, and celebrating Rare Disease Day. This event strengthened our network by bringing together families and individuals affected by rare conditions.

March

Clinical Trial Design Innovation: Our Managing Director, Jo Balfour, participated in a panel at the Medidata NEXT biotech conference in London, focusing on innovative clinical trial design. This participation positioned CamRARE at the forefront of discussions on cutting-edge research methodologies.

April

Rare Patient Passport Pilot Study: Launched Phase Two, enrolling over 300 individuals to enhance patient communication and care coordination. The pilot collected valuable data to refine the Passport, improving healthcare interactions for those with rare conditions.

May

Pint of Science Festival: Engaged over 200 attendees through a series of public-friendly events across Cambridge, increasing awareness and understanding of rare disease research and its significance to the broader community.

Spring Companies Forum: Hosted a meeting in London with 20 life sciences companies and research organisations, featuring expert speakers from the Department of Health and Social Care and NHS England, promoting collaboration and sharing insights on the UK Rare Disease Framework.

June

Rare Disease Research Network (RDRN) Project: Began an 18-month project to develop an online platform for patient-centered research. This initiative aims to connect stakeholders and facilitate innovative research partnerships.

Transitions to Adult Care Report: Presented at the Beacon Rare Diseases Showcase, providing insights and recommendations to improve healthcare transitions for young adults with rare diseases.

July

LifeArc Translational Research Challenge: Coordinated the launch event, attended by 300 researchers, and showcased the Unique Feet community's film 'Why We Do Research.' This event highlighted the importance of translational research and strengthened partnerships with key stakeholders.

August

'My Story, My Way' Project: Unique Feet community won NHS Health Inequalities competition funding, supporting a project to capture the stories and perspectives of UF members through photography. This project amplified patient voices and influenced the development of future activities and services.

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Website Development: Collaborated with families and intern Joe to create a new family resources section on our website, offering support on topics such as genetic testing, financial advice, and inclusive activities. This resource is a valuable tool for families navigating rare disease challenges.

September

RDRN Community Advisory Team: Formed with 22 individuals, including expert patients, caregivers, and representatives from patient groups, to guide patient-centered projects and ensure diverse perspectives in research initiatives.

Shelford 5k Fun Run Partnership: Co-hosted the event, enhancing community engagement, raising funds, and increasing awareness of rare diseases within the local community.

October

Cambridgeshire Pinpoint SEND Conference: Recruited three new families to the Unique Feet group, expanding our support network and outreach efforts. This event facilitated connections with regional service providers and legal experts to support future initiatives.

RAREsummit23: Hosted the 5th summit at the Wellcome Genome Campus, attracting 270 stakeholders and featuring groundbreaking sessions such as a rare youth panel and a rare men's fireside chat. The event promoted collaboration and highlighted advancements in diagnosis and treatment.

November

Companies Forum: Convened discussions on the rare disease research landscape, strengthening industry connections and identifying opportunities for collaboration. The forum featured speakers from key organisations like DHSC, NHS England, and Genomics England.

December

'ART-TRANslations' Initiative: Launched in partnership with LifeArc, pairing 20 rare disease researchers with artists to create an art exhibition, raising awareness and fostering dialogue about rare diseases. This initiative will premiere in Spring 2024 and continue to engage audiences at RAREfest24.

Rare Disease International Mirror and Action Group (IMAG) Event: Explored UK-EU collaboration opportunities post-Brexit, expanding CamRARE's network and influence in the international rare disease community.

Strategic Pillars: Key Achievements

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

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

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CamRARE's Unique Feet (UF) community focuses on creating a robust support network for families affected by rare diseases. In 2023, we welcomed 14 new families, increasing our total membership to 172 individuals across Cambridgeshire and the Eastern region. This growth reflects our commitment to reducing isolation and fostering connections among those affected by rare conditions. We organised 39 family activities and eight parent meet-ups, the highest number to date, providing opportunities for families to engage, share experiences, and support one another.

Our NHS-funded 'My Story, My Way' project captured the perspectives and aspirations of our 16+ UF members through photography, influencing the development of future activities and services. Unique Feet families featured in the CamRARE film 'Why We Need Research,' showcased at the LifeArc Translational Research Challenge launch event. Additionally, we launched a redesigned UF impact report and a community-created newsletter, reaching over 80 recipients directly and expanding outreach through social media channels. UF members participated in various advocacy activities, including media features and speaking engagements, raising awareness and amplifying the voice of the rare disease 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.

CamRARE tackled rare disease awareness by promoting engagement and communication among stakeholders through public events and collaborations. The RAREsummit23, held at the Wellcome Genome Campus, was a major highlight, attracting 270 attendees from the UK and globally. The summit featured 60 key opinion leaders, 43 exhibition stands, and sessions exploring cutting-edge themes and innovations. The event was rated positively by 100% of attendees, with 84% meeting new people, underscoring its role in fostering collaboration and networking.

Sponsorships for RAREsummit23 totalled £83,151, with ticket sales raising £9,302. Over 30 volunteers supported the event, contributing to its success. CamRARE also participated in the Pint of Science Festival, engaging over 200 attendees in rare disease research and increasing awareness of its significance. Additionally, the 'ART-TRANslations' initiative paired researchers with artists to create an art exhibition, fostering dialogue and raising awareness about rare diseases. These efforts have successfully enhanced visibility and promoted collaboration across sectors, driving innovation and understanding in the rare disease community.

Education and Youth Engagement

Throughout 2023, CamRARE has been committed to educating and inspiring the next generation of scientists and advocates within the rare disease community. Our efforts included hosting three student interns from Keele University over the summer, who contributed significantly to our projects. Joe, a 5th-year medical student, played a pivotal role in developing a new family resources section on our website and continues to volunteer with us, demonstrating the value of engaging young talent in our mission.

CamRARE also participated in youth education activities, such as exhibiting at the Royal Holloway University Rare Disease Day event, where we inspired Year 11 and 12 students to pursue careers in the life sciences. Additionally, our involvement with the new Cambridge University Rare Disease Society at the Freshers Fair recruited over 60 students to our mailing list, encouraging them to explore volunteering and event opportunities with CamRARE. These initiatives highlight our dedication to nurturing future leaders and raising awareness about the importance of rare disease research and advocacy.

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Pillar Three: Providing a Platform for Immersive Learning and Impactful Networking - 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.

The Companies Forum is a key component of CamRARE's strategy to promote collaboration and innovation in the rare disease sector. In 2023, we hosted two Companies Forum meetings, welcoming 46 representatives from various industries. These meetings facilitated discussions on the UK Rare Disease Framework and the Rare Disease Research Landscape, identifying opportunities for collaboration and innovation.

The Companies Forum engaged stakeholders in initiatives like the LifeArc Translational Research Challenge, promoting translational research efforts and showcasing the potential for impactful solutions. By embedding the patient voice in discussions and providing platforms for networking and knowledge exchange, CamRARE has strengthened industry connections and supported the development of innovative treatments and technology solutions to enhance the lives of rare patients.

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.

CamRARE is committed to integrating patient perspectives into research and healthcare through its PPIEP initiatives. The Rare Patient Passport pilot study, involving over 300 participants, gathered insights to enhance patient communication and care coordination. Initial findings demonstrate that the passport supports better healthcare outcomes, enhances communication between patients and healthcare providers, and promotes patient safety and empowerment.

The Rare Disease Research Network (RDRN) project, funded by a NIHR Public Partnership grant, focuses on creating an online network to foster patient-centered research. We partnered with the Patient Led Research Network to form a community advisory team comprising 22 individuals with lived experiences, guiding the project forward. The RDRN project aims to demonstrate the value of patient-initiated and led research and facilitate collaboration among diverse stakeholders. Through these activities, CamRARE has empowered patients and enhanced their involvement in research and healthcare, advancing its mission to improve outcomes for those affected by rare conditions.

Events Participation Summary

Throughout 2023, CamRARE actively contributed to the rare disease community by attending and participating in key events. Our involvement in events such as the Genomics England Research Conference, the Beacon Rare Diseases Showcase, and the World Orphan Drugs Congress in Barcelona facilitated valuable connections with industry stakeholders, patient organisations, and researchers. These engagements have strengthened our network, expanded our reach, and reinforced our position as a leader in patient-centered research and advocacy.

FINANCIAL REVIEW

The overall net income for 2023 of activity is £223,867 and expenditure £191,845.

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The primary sources of funds for the year came from corporate sponsorship and grant funding, with a growing contribution from community fundraising and donations. Most Companies Forum members paid for their membership through gold and diamond sponsorship packages for RAREfest. The most significant sources of income were RAREfest and grant funding for the new Rare Disease Research Network Project and towards Unique Feet activities. A grant of £10,000 was received from Alexion Astra Zeneca to support the Rare Patient Passport project. Additionally, income from donations saw a significant increase, totaling £40,251.

During this financial year, CamRARE continued to work with accountants Community 360, who have specific charity finance expertise. The Managing Director is responsible for managing finances, overseen by the Treasurer and trustee signatories. Responsibility for payroll, pension payments, and quarterly management accounts lies with Community 360 accounting.

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.

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 running costs. The present level of cash available to the charity as of 31 December 2023 was £229,269.

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. During 2023, three trustees stepped down. Dr Tim Guilleams resigned following 7 years of service as Founder, Chair and Trustee of CamRARE. Ilan Chaitowitz resigned following 3 years and 10 months as charity Treasurer. 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.

Pay Policy

The charity's policy is that Trustees give their time voluntarily and receive no benefit from the charity. One trustee reclaimed minimal travel expenses from the charity in the last financial year. CamRARE now has three employed members of staff. Jo Balfour is the Managing Director (full-time) and continues in her role. Deputy Director (full time), Dr Lesley Booth, came to CamRARE in Sept 2022 from Bowel Research UK and continues in her role.

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A social scientist researcher, she has twenty years of experience working with underrepresented groups. Lindsey Brown has been working freelance for CamRARE since 2017 and joined the team part-time as an employee as Events and Projects Officer. Georgie Windsor was employed in August 2023 to co-lead the PPIE framework for the new Rare Disease Research Network project.

Pay is reviewed annually and benchmarked against salaries for similar charity roles outside of London with consideration given to incoming budgetary concerns. We pay for all other services at agreed contracted rates.

Risk Management

The risks to which CamRARE is exposed are minimal as committed spending and running costs are still relatively low. A financial software package manages its increasing transaction complexity and supports the charity's growth. CamRARE had a very successful year financially, enabling growth and secure employment in the core team. Sustainable funding is in place through Companies Forum, corporate sponsorships, and project grant funding.

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.

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



18 Sep 2024

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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 Sarah Leiter (appointed 05/06/2017)
Dr Gemma Chandratillake (appointed 15/05/2017 - appointed Chair 03/12/2019)
Mrs Susan Berry (appointed 29/07/2019)
Sarah Faircliffe (appointed 03/10/2022)
Emma Green (appointed 03/10/2022)
Loretta MacInnes (appointed 03/10/2022)

Resigned 2023

Dr Tim Williams (appointed 28/09/2015) – resigned 26/07/2023
Jon Green (appointed 03/10/2022) – resigned 26/07/2023
Ilan Chaitowitz (appointed 03/12/2019) – resigned 31/10/2023

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)
IT consultancy - George Nicolau (contracted)
Community Communications – Celia Enderle (contracted)

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

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total £	2022 Total £
<u>Incoming resources</u>					
Incoming resources from generating funds:					
Donations and legacies	2	40,251	-	40,251	15,166
Charitable activities	3	110,441	73,175	183,616	109,835
Total incoming resources		150,692	73,175	223,867	125,001
<u>Resources expended</u>					
Charitable activities	4	120,111	71,734	191,845	123,309
Total charitable expenditure		120,111	71,734	191,845	123,309
Net incoming/(outgoing) resources before transfers		30,581	1,441	32,022	1,692
Net income/(expenditure) for the year/ Net movement in funds		30,581	1,441	32,022	1,692
Fund balances at 1 January 2023		190,770	3,762	194,532	192,840
Fund balances at 31 December 2023		221,351	5,203	226,554	194,532

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BALANCE SHEET AS AT 31 DECEMBER 2023

	Notes	2023 £	2022 £
Current assets			
Debtors	6	91	5,664
Cash at bank and in hand		229,178	195,901
		<u>229,269</u>	<u>201,565</u>
Creditors: amounts falling due within one year	7	<u>(2,715)</u>	<u>(7,033)</u>
Net current assets		226,554	194,532
Total net assets		<u><u>226,554</u></u>	<u><u>194,532</u></u>
Income funds			
Restricted funds	9	5,203	3,762
Unrestricted funds		221,351	190,770
		<u><u>226,554</u></u>	<u><u>194,532</u></u>

Approved by the trustees on the 10th September 2024 and signed on their behalf by:



Emma Green

Date 18 Sep 2024

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 2023

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 International Summit 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.

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NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

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 2023

2 Donations and legacies

	Unrestricted Funds	Restricted Funds	2023 Total £	2022 Total £
Donations and gifts	40,251	-	40,251	15,166
	<u>40,251</u>	<u>-</u>	<u>40,251</u>	<u>15,166</u>
TOTAL 2022	<u>15,166</u>	<u>-</u>	<u>15,166</u>	

3 Charitable activities

	Unrestricted Funds	Restricted Funds	2023 Total £	2022 Total £
Delegate Sales	9,302	-	9,302	7,000
Grants	-	61,675	61,675	8,800
Sponsorship	83,151	-	83,151	91,000
Other	17,988	11,500	29,488	3,035
	<u>110,441</u>	<u>73,175</u>	<u>183,616</u>	<u>109,835</u>
TOTAL 2022	<u>102,035</u>	<u>7,800</u>	<u>109,835</u>	

4 Resources expended

	Unrestricted Funds	Restricted Funds	2023 Total £	2022 Total £
Staff costs	52,646	55,487	108,133	67,002
Activity costs	90	7,943	8,033	-
Accommodation	639	219.00	858	547
Admin support	3,024	3,190	6,214	4,273
Advertising & marketing	1,207	2,578	3,785	12,448
Accountancy fees	1,486	-	1,486	1,237
Bank fees	57	-	57	7
Consulting	-	-	-	3,431
General expenses	652	-	652	132
Equipment hire	180	-	180	7,711
Event costs	13,429	1,000	14,429	350
Independent examination	-	-	-	-
Insurance	460	-	460	528
IT software & consumables	1,360	34.00	1,394	1,012
Legal expenses	186	-	186	-
Postage, freight & courier	1,737	262	1,999	1,024
Staff training	-	-	-	516
Subscriptions	1,645	-	1,645	1,149
Travel	4,799	774	5,573	3,301
Venue & catering	35,263	247	35,510	17,886
Website design & admin	1,252	-	1,252	754
	<u>120,111</u>	<u>71,734</u>	<u>191,845</u>	<u>123,309</u>
TOTAL 2022	<u>104,882</u>	<u>18,427</u>	<u>123,309</u>	

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

5 Staff costs

	2023	2022
	Total	Total
	£	£
Wages and salaries	105,824	65,511
Pension costs	2,309	1,491
	108,133	67,002

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

	2023	2022
	No.	No.
Employees	4	3

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

	2023	2022
	Total	Total
	£	£
DUE WITHIN ONE YEAR		
Trade debtors	-	5,543
Prepayments and accrued income	91	121
	91	5,664

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

7 Creditors: amounts falling due within one year

	2023 Total £	2022 Total £
Trade creditors	831	3,706
Other creditors	1,585	2,867
Accruals and deferred income	300	460
	2,715	7,033

9 Statement of funds

	Balance at 1 January 2023 £	Income £	Expenditure £	Transfers In/out £	Balance at 31 December 2023 £
UNRESTRICTED FUNDS					
General funds - all funds	190,539	150,692	120,111	-	221,120
RESTRICTED					
National Lottery	325	-	325	-	-
Evolution Education Trust (marketing)	3,025	-	3,025	-	-
Life Arc	-	15,000	15,000	-	-
Gillian Stevensons	-	3,660	1,960	-	1,700
CCF	-	3,400	1,675	-	1,725
Alexion	-	10,000	10,000	-	-
Oxford research	-	7,904	7,904	-	-
NIHR RDRN	-	26,351	26,351	-	-
Cole Trust	-	1,000	-	-	1,000
Unique Feet	411	5,860	5,494	-	777
Total restricted funds	3,762	73,175	71,734	-	5,203
Total funds	194,301	223,867	191,846	-	226,323

Purpose of funds

National Lottery - this grant was awarded to support CRDN's regional community group activities and coordination.

Evolution Education Trust (marketing) - the purpose of this grant is to support the complex marketing strategy involved in promoting, delivering and reaching as many people as possible with CRDN's awareness-raising events and education programme. The bulk of the funds cover the cost of a marketing professional, a graphic and web designer and communication/copy-writing professionals to undertake the design of a wide range of marketing materials for print and social media/online, the design and management of our website, the writing and design of our blogs and newsletters and events materials. Funds are also allocated to the printing of marketing materials, paid advertising for events and funding CRDN to attend and exhibit at other events for networking and marketing purposes.

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

South Cambridge District Council - this grant was awarded to support CRDN's regional community group activities and coordination.

10 Analysis of net assets between funds

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Fund balances at 31 December 2023 are represented by:			
Current assets	224,066	5,203	229,269
Creditors: amounts falling due within one year	(2,715)	-	(2,715)
	221,351	5,203	226,554

Restricted funds represent amounts received for specific projects.

11 Related party transactions

In this financial period, CRDN paid BCS (directors are daughter and son-in-law of Trustee Alan Barrell) £Nil (2022: £199) for consultancy work. Quotes were obtained, and Prof Barrell was not included in making the decision of placing this piece of work with this provider.

CRDN paid Emily Leslie (wife of Trustee Tim Guilliams) £Nil (2022: £Nil) for Yoga classes for the Unique Feet group. The decision to use Emily was done at operational level. Emily had previously worked with the Unique Feet Children and the rate paid was a reduced market rate.

In this financial period, CRDN received a donation from Evolution Education Trust for £Nil (2022: £5,000) One of the trustees of Evolution Education Trust, Dr J S Milner is also a trustee of CRDN.

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.