CAMBRIDGE RARE DISEASE NETWORK

England & Wales · Charity number 1166365

Details

Other names	CRDN, CamRARE
Status	Registered
Legal form	CIO
Registered	2016-04-05
Register	View on the Charity Commission register

Contact

Address

B C S
5 Station Court
Station Road
Great Shelford
Cambridge
CB22 5NE

Phone	07725039780
Email	info@camraredisease.org
Website	www.camraredisease.org

Activities

Objects: 1) THE RELIEF OF SICKNESS OF PERSONS WITH RARE DISEASES, IN PARTICULAR BUT NOT EXCLUSIVELY BY THE PROVISION OF SUPPORT, ADVICE AND INFORMATION FOR SUCH PERSONS THEIR FAMILIES, CARERS AND THOSE WORKING WITH AFFECTED INDIVIDUALS.2)TO ADVANCE THE EDUCATION OF THE PUBLIC IN GENERAL ON THE SUBJECT OF RARE DISEASES AND RELATED SYNDROMES AND TO PROMOTE RESEARCH FOR THE PUBLIC BENEFIT IN ALL ASPECTS OF THAT SUBJECT AND TO PUBLISH THE USEFUL RESULTS.

Activities: CamRARE makes life easier for those living with rare conditions. Regionally we support affected families through community activities. We connect, educate and collaborate with stakeholders and the public on rare disease research, diagnosis, treatments and care through our platforms RAREsummit, RAREfest, Companies Forum and RDRN. We undertake, support and connect patients with research.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities, Other Charities Or Voluntary Bodies, The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£181,873	£231,715	-	-
2023-12-31	£223,867	£191,845	-	-
2022-12-31	£141,001	£123,309	-	-
2021-12-31	£163,501	£103,210	-	-
2020-12-31	£163,000	£164,000	-	-

Trustees

Name	Role	Appointed
Emma Green	Chair	2022-10-03
Billy Michael Lucas		2025-05-13
Dr Catherine O'Sullivan		2025-03-08
Loretta MacInnes		2022-10-03
Ruth Diazaraque		2025-03-08
Susan Berry		2019-07-29
William Henry Waddington Eldridge		2025-12-09

CAMBRIDGE RARE DISEASE NETWORK

England & Wales - Charity number 1166365

Accounts

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

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

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.

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.

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"

100% want to continue membership

60% of parents & children say UF improved quality of life

79% 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 Activitiies for All

£50,000 = Annual running cost

91% of families rely on subsidised activitities

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.

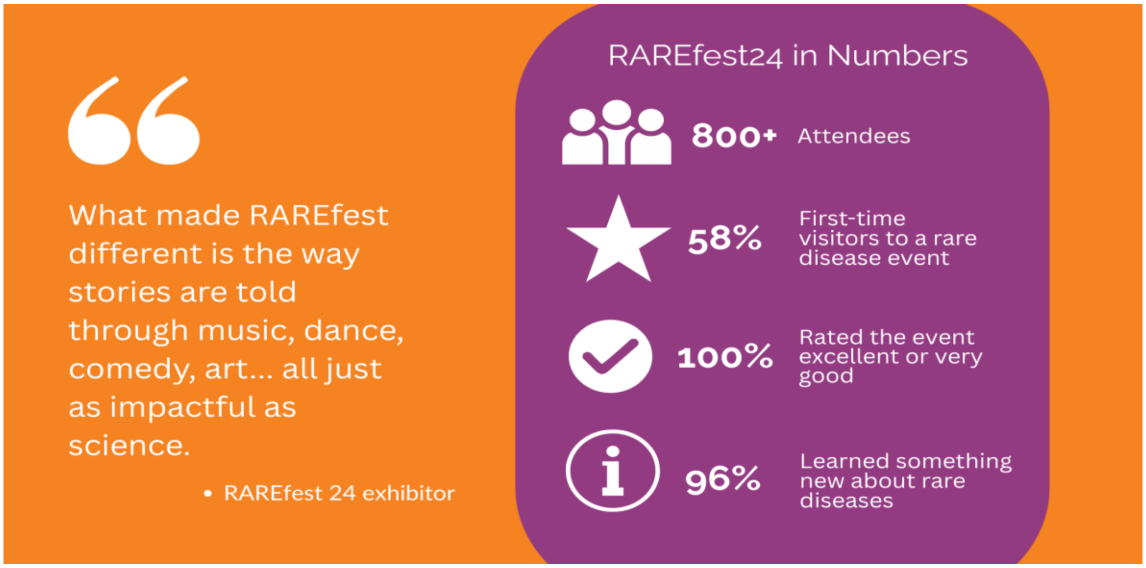
Key Activities and Impact

• **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.



What made RAREfest different is the way stories are told through music, dance, comedy, art... all just as impactful as science.

- RAREfest 24 exhibitor

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.

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.

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.

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.

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

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

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 £
Incoming resources					
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**
Resources expended					
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**

BALANCE SHEET
AS AT 31 DECEMBER 2024

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

Approved by the trustees on the ……31 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.

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 Practise 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.

1.5 Fund accounting

General funds are unrestricted funds which are avaliable 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 objectivies, 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 investements with a short maturity of three months or less from the date of acquistion 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 compcnat 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.

2 Donations and legacies

	Unrestricted Funds	Restricted Funds	2024 Total £	2023 Total £
Donations and gifts	12,682	-	**12,682**	**40,251**
	12,682	**-**	**12,682**	**40,251**
TOTAL 2023	**40,251**	**-**	**40,251**	

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
	72,305	**96,886**	**169,191**	**183,616**
TOTAL 2023	**110,441**	**73,175**	**183,616**	

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
Accomodation	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
	134,480	**97,235**	**231,715**	**191,845**
TOTAL 2023	**120,111**	**71,734**	**191,845**	

5 Staff costs

	2024 Total £	2023 Total £
Wages and salaries	115,185	105,824
Pension costs	4,226	2,309
	119,411	**108,133**

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

	2024 No.	2023 No.
Employees	**4**	**4**

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
	8,577	**91**

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**

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)
	171,351	**11,178**	**182,530**

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.

Accounts

CAMBRIDGE RARE DISEASE NETWORK

Charity Registration number 1166365

FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

CAMBRIDGE RARE DISEASE NETWORK

CONTENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

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

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.

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. Alarmingly, 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.

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.

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.

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.

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.

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 Guilliams 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.

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

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 Guilliams (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 £
Incoming resources					
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**
Resources expended					
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**

CAMBRIDGE RARE DISEASE NETWORK

BALANCE SHEET
AS AT 31 DECEMBER 2023

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

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.

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 Practise 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 Internation 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.

1.5 Fund accounting

General funds are unrestricted funds which are avaliable 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 restrcitions 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 objectivies, 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 investements with a short maturity of three months or less from the date of acquistion 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 compcnat 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.

2 Donations and legacies

	Unrestricted Funds	Restricted Funds	2023 Total £	2022 Total £
Donations and gifts	40,251	-	**40,251**	**15,166**
	40,251	**-**	**40,251**	**15,166**
TOTAL 2022	**15,166**	**-**	**15,166**	

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
	110,441	**73,175**	**183,616**	**109,835**
TOTAL 2022	**102,035**	**7,800**	**109,835**	

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	-
Accomodation	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
	120,111	**71,734**	**191,845**	**123,309**
TOTAL 2022	**104,882**	**18,427**	**123,309**	

5 Staff costs

	2023 Total £	2022 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 No.	2022 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 Total £	2022 Total £
DUE WITHIN ONE YEAR		
Trade debtors	-	5,543
Prepayments and accrued income	91	121
	91	**5,664**

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.

purposes.

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.

CAMBRIDGE RARE DISEASE NETWORK

England & Wales - Charity number 1166365

Accounts

CAMBRIDGE RARE DISEASE NETWORK

Company Registration number 09798317
Charity Registration number 1166365

FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

CAMBRIDGE RARE DISEASE NETWORK

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FOR THE YEAR ENDED 31 DECEMBER 2022

CAMBRIDGE RARE DISEASE NETWORK

REFERENCE AND ADMINISTRATION INFORMATION FOR THE YEAR ENDED 31 DECEMBER 2022

Charity number	1166365
Company number	09798317
Principal Address	C/o BCS Windsor House Station Court Station Road Great Shelford Cambridge CB22 5NE
Trustees	Dr G Chandratillake Dr T Guilliams Ms. S L Berry Dr S M Leiter Mr I M Chaitowitz Mr J Green Mrs S Faircliffe Mrs E Green Mrs L Macinnes
Company Secretary	BSC Cosec Ltd.
Operations Manager	Mrs J Balfour
Independent Examiner	Community360 Winsley's House High Street Colchester Essex, CO1 1UG

Charity Objectives and Activities

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.

About CamRARE

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:

- **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;
- **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;
- Through our Companies Forum, providing **a platform for immersive learning and impactful networking** for representatives from pharmaceutical, biotechnology, and healthcare companies operating and guest patient groups in the rare diseases space;
- Identifying gaps in support, care, education and integration and f**acilitating a voice for and access to people with rare diseases** to enable solutions.

Charity Objects, as recorded with the Charity Commission

1) 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.

2) 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.

Activities

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

In Europe, a rare disease is defined as a condition that affects less than one in 2,000 people. Over 7,000 rare diseases have been identified, collectively affecting one in 17, amounting to 3.5 million people in the UK. Of these diseases, 80 % are genetic in origin, 50 % affect children, and only 5 % have an approved treatment. Some 30 % of those living with a rare disease will die before their fifth birthday. Despite this high prevalence (equivalent to the number of people with asthma in the UK), each condition affects so few people that they tend to be overlooked and misunderstood by health professionals, researchers, education and social care providers and the general public. This lack of awareness and information commonly leads to the “Diagnostic Odyssey”, where it takes an average of 4.8 years and 7.3 physicians to reach the correct diagnosis, and delays and misdiagnoses are common. Poor awareness also impacts patients receiving appropriate care and support in school and the workplace, isolating patients and families, and creating a high social burden of care (Source: Engel et al., JRD, 2013).

Despite advances in recent years, progress in diagnosis, developing treatments and assuring coordinated care continue to prove challenging and are affected by low patient numbers per disease, lack of education in rare diseases for healthcare professionals, difficulty recruiting enough patients for clinical trials, insufficient economic incentives, high cost of treatment, tribulation in reimbursing, low awareness of conditions, and poor scientific understanding of disease mechanisms. It is vital, therefore, to raise awareness that whilst individual rare diseases affect few people, they are collectively common.

At CamRARE, we are building stakeholder networks to educate, support, encourage collaboration and embed the patient voice to improve outcomes for those affected.

Achievement and performance highlights 2022

CamRARE has continued to thrive in 2022 as we emerged more robust than ever from the enforced move to virtual activities and events during 2020 and 2021.

JAN: CamRARE introduced a new activity and events programme and online events calendar with a booking system for our Unique Feet community group.

FEB: Trustees and Managing Director held a Strategy Day and began developing a new strategy for 2023-2027.

FEB: On Rare Disease Day, CamRARE held its annual awareness campaign, sharing stories from families affected by rare conditions. CamRARE and parents from our Unique Feet community joined the East Genomics team to share our work and stories about their experience navigating and receiving a genetic diagnosis. We held our second Rare-i-Tea party for families and the wider community, attended by over 100 people.

FEB: CamRARE took part in a special series of four webinars hosted by the Royal Society of Medicine, sharing the findings of our collaborative ARDENT ‘Making the Unseen Seen: COVID-19 Impact on Rare Diseases’ report.

FEB: In collaboration with US Based Rare Science, CamRARE launched a #RareBearLife hashtag campaign to share everyday stories of life with a rare condition. Each of the children in our Unique Feet community is gifted a bear created by volunteers, through which they share their journey.

MARCH: CamRARE collaborated with Costello Medical and Beacon for Rare Diseases to undertake and publish research on experiences of transitioning from paediatric to adult care for young people living with rare conditions. The resulting report was the culmination of focus groups with young people, their parents and carers, patient groups, and a round table meeting that included healthcare professionals and policy-makers. This report has been referenced in the England Rare Disease Action Plan (Action 21) concerning improving care coordination.

APRIL: CamRARE launched a Staff and Trustees Handbook to support the induction of new team members.

MAY: CamRARE held its 4th Pint of Science Festival series of rare disease research events in Cambridge.

MAY: CamRARE were charity partner at the Anglonordic Life Sciences Summit in London.

MAY: CamRARE supported Cambridge's Next Generation Children's team to organise a Family Day for those families involved in a rapid genome sequencing project for critically ill, undiagnosed children.

FEB - JUNE: CamRARE was honoured to be selected again to participate in Medidata's 'Social Innovation Lab'. A team of 8 of the company's staff helped us undertake research to develop a networking platform proposal to improve future collaborations between patient groups and industry. This social innovation project won a Halo Award.

JUNE: CamRARE held its Companies Forum meeting in person in London and welcomed new companies to the group.

JUNE: Unique Feet families joined Healx for a Wiki-edit-Athon day to create new and improve current Wikipedia entries on their disease.

JULY: CamRARE appointed four new trustees to its Board to help bolster particular skills, areas of experience and influence.

SEPT: CamRARE's team grew. Lindsey Brown, who has worked freelance with the charity since 2017, was employed as Projects and Events Officer, and we welcomed Dr Lesley Booth from Bowel Research UK as Deputy Director. We continued to work with a volunteer team of university students and young people starting in life sciences careers who supported several of our projects.

SEPT: We completed our charity's conversion to a Charitable Incorporated Organisation (so we are no longer a Company Ltd by Guarantee).

NOV: CamRARE held RAREfest22 in person over two days, welcoming over 800 stakeholders and members of the public of all ages to celebrate science, technology, advocacy and the arts in our most successful yet rare disease-inspired festival.

DEC: CamRARE completed the first phase of a Rare Patient Passport project and, with *pro bono* support from Costello Medical, published an initial findings report. Phase two will launch in Spring 2023, inviting 200 diverse people to trial the passport, develop a phase two report, and guide future plans.

DEC: Over 2022, 27 new beneficiaries joined CamRARE's Unique Feet community bringing the total beneficiaries to 117. Members now attend from across Cambridgeshire, Peterborough, Essex, Norfolk, Suffolk and even Hertfordshire. We delivered 39 family activities and eight parent meet-ups, the greatest number of activities to date.

Achievement and Performance January 2022 - December 2022: Significant Activities

Organisational plans

- Hold a strategy day – achieved.
- Develop a new Board meeting reporting framework - achieved
- Grow the staff team by recruiting two employed staff: Deputy Director full-time and Events and Projects Officer part-time – achieved

Strengthen the Trustee Board by developing a Trustee Handbook, a new recruitment system and recruiting four new trustees - achieved

- Convert to a Charitable Incorporated Organisation – achieved
- Creating new trustee working groups for Companies Forum and events – achieved
- Diversify fundraising strategy to include additional grant funding - achieved

Supporting Families: Unique Feet (UF) regional rare disease community

CamRARE is building a regional, connected, engaged, and empowered network of people affected by rare diseases to have a stronger collective voice through the Unique Feet (UF) group. Our community-building activities reduce isolation and give patients and their families the confidence to engage with other stakeholders as experts in their own or their children's health and care.

Highlights for 2022

- Secure grant funding to increase membership and diversity and the number of activities and support offered – achieved from South Cambs District Council Feb 2022.
- Increase number and diversity of community activities – achieved Jan 2022.
- Improve activity promotion and registration through new online calendar and booking system – achieved Jan 2022. CamRARE held a total of 47 community activities for Unique Feet in 2022.
- Increase membership - achieved. Beneficiaries reached 117 in Dec 2022. The number of families involved has grown by 700 % since its formation in 2016, and total beneficiaries have increased by 800 %.
- Introduce 'lead parents' to help oversee activity organisation and management – achieved. Seven lead parents took on new responsibilities for group activities.
- Increase member advocacy activity – achieved.

CamRARE, with grant funding from South Cambridgeshire District Council, along with several smaller donations from Alpkit, Neighbourly, Local Giving, The Cole Charitable Trust and others, have continued to support and grow our regional community of families affected by a rare condition as they emerged from two years of shielding, reduced social contact and increased online activities during the COVID 19 pandemic.

The group has continued to flourish, with all original members continuing to attend as they transition to young adulthood and several younger preschool children joining. Membership increased from 25 families and 90 beneficiaries in 2021 to 36 families and 117 beneficiaries in 2022, totalling 27 new beneficiaries during 2022. Focus has been on improving the organisation, visibility and community leadership of activities. We now have an employed team member who dedicates one day per week to admin, activity logistics and memberships management and a lead Trustee who oversees activity programme development. We have recruited seven parents to activity leader roles, purchased a more sophisticated events management tool for our website, and updated the Unique Feet webpage and membership materials.

We have continued to have a UF parent create a monthly community newsletter with contributions from families circulated to over 60 people and many more via our social media channels. The parents' WhatsApp group continued to serve as a vital portal for sharing experiences, giving guidance, letting off steam and keeping each other motivated and in good spirits.

In-person group activities revolved around beautiful, therapeutic outdoor spaces such as the privately run Challis Gardens and Cambridge Botanic Gardens, providing a safe place to play and explore freely. We introduced activities which families said they would never have the chance to try because of their child's accessibility needs: skiing and sledging at Milton Keynes Snowdome, water sports and climbing at Grafham Water and performing their own dance creation at our RAREfest22 event.

Ambassadors and Advocacy

Unique Feet parents continued being the voice of rare diseases in our community. Notably, families have worked with CamRARE to develop a Rare Patient Passport and be part of a pilot for this. Families have also been involved in a collaborative project exploring children and young people's experience of transitioning to adult care undertaken by Costello Medical, CamRARE and Cambridge-based charity Beacon. This project has involved focus groups with young people, parents, patient groups and health professionals, followed by a multi-stakeholder round table discussion and yielded a report with insights and recommendations published in March 2022. In addition, parents and children have taken part in the Cambridge Children's Hospital Network throughout 2022 to help shape the design of this new hospital.

Families took part in an incredible array of activities this year, including:

- Being the focus of BBC Look East TV and Cambridge Independent news pieces
- Becoming patient voice panel members of NHS East Genomics
- Speaking at East Genomics Rare Disease Day event for Eastern region health care professionals
- Taking part as ambassadors in the 'Next Generation Children's Project' Family Day – a day welcoming families from across the country who had been part of a cutting-edge project to sequence the genome and find a diagnosis for critically ill children.
- Contributing to PharmaForum and PharmaFocus Magazine Patient Insight articles about their rare conditions
- Being members of Cambridge Children's Hospital development forums
- Supporting CamRARE's Rare Patient Passport project
- Taking part in focus groups on transitions from paediatric to adult care
- Taking part in a Healx Wiki-edit-Athon day
- Contributing to CamRARE's 'Rare Disease Day' awareness campaign with stories and social media work
- Working in a self-employed capacity for CamRARE in communications
- Volunteering in the development of Unique Feet Future Strategy
- Volunteering to lead Unique Feet activities
- Supporting the writing of grant applications
- Volunteering at RAREfest22 and Shelford Fun Run
- Fundraising £3000 in 2022

Raising awareness and promoting cross-sector collaboration: Events, forums and communications

At CamRARE, we are challenging the lack of awareness of rare diseases and encouraging all stakeholders to engage and communicate with each other to promote cross-sector working. We hold stakeholder and public-facing events to bring the challenges of the rare disease journey to the fore, provide a platform for engagement, and nurture impactful collaboration.

Royal Society of Medicine Webinar Series - ARDEnt (Action for Rare Disease Empowerment)

The report 'Making the Unseen, Seen' by the ARDENT group, of which CamRARE is a founding member and part of the organising committee, was published on 5 May 2021. It revealed the impact of the pandemic on every stage of the patient journey, from diagnosis to eventual management. It made nine recommendations that should bring patients with rare diseases into the light and make their management more robust for the future. Its findings and recommendations have been shared widely, referred to, and adopted as part of the Department for Health and Social Care UK Rare Disease Framework 2021 and the related Action Plans for England, published in February 2022. The cross-party Public Policy Projects team used the report to inform a 'State of the Nation' report on Rare Diseases.

In February 2022, the ARDENT theme leads, including CamRARE Managing Director, led a series of four webinars exploring each of the report themes in detail with representatives from the group and invited panellists from the rare disease community to give the patient voice.

RAREfest22

The focus of the autumn season was CamRARE's. RAREfest22, a scientific, educational and community-centric event, was back in person after its virtual success in 2020, providing a vast jamboree of opportunities and insights for a community harnessing and wielding its collective voice to drive forward the recognition of the challenges it faces whilst sharing the opportunities and progress that are emerging. RAREfest demonstrated that CamRARE's sharing, multi-disciplinary networking format is an impactful way to impart knowledge and experience and build connections.

Around eight hundred people from 97 different towns and cities across the UK filled the Cambridge Guildhall over the weekend of 25th – 26th November. Alongside adult visitors from all walks of life, children, teenagers, and young adults immersed themselves, wide-eyed and mouths agape, in the many hands-on experiments, science activities, arts and crafts and virtual reality experiences. These exchanges with young people provided valuable feedback for the exhibitor teams. They will hopefully inspire young attendees to become the scientists, researchers, healthcare professionals, innovators, changemakers and carers of the future.

RAREfest22 gave scientists, researchers, patient organisations and companies unique opportunities to interact with the public and engage in meaningful discussion. Many of the 15 speakers, 23 performers, and 100+ people involved in interactive exhibits especially relished the chance to seek the insights and opinions of those with lived experience of rare diseases to understand better their priorities and any concerns they may have to improve their work. One exhibitor said, "*The highlight for me was meeting individuals and caregivers who are affected by a rare disease and gaining knowledge and further understanding.*"

The Friday evening launch 'Strictly Rare' opened its doors for a magical evening. Young people and children living with rare conditions took to the stage in sparkling form to mesmerise the audience with various dance, music and speaker performances. Adults with rare conditions also spoke of their journeys, inviting us to explore the possible through storey telling and stand-up comedy. There was much to reflect on - the joy of listening and learning through a brilliant entertainment programme. To see into the lives of people living with rare conditions and be motivated to learn more. To marvel over how science and the arts can unite perfectly. CamRARE's 'Unique Feet' group explored the frustrations of assumptions, constraints of conformity, the strength of shared experiences and the joy of movement. One healthcare worker said, "*I've just watched the Unique Feet performance. Oh my goodness, it's AMAZING! What a triumph! Still wiping away the tears."*

Saturday's event involved a wonderfully diverse programme of talks, panel discussions and performances ranging from '*Genomics! The Musical*, an expert panel exploring emerging techniques for diagnosing rare diseases, a Cambridge University student sharing what anthropology taught her about her rare diseases and young adults with rare conditions approaching challenging topics like medical gaslighting and mental health through monologues. In the exhibition hall, the atmosphere was electric as people delved into a collection of hands-on, interactive and engaging science, technology, advocacy and art exhibits. People learnt about rare diseases as they peered down microscopes at cells, extracted 'tumours' from play-doh brains, donned virtual reality headsets, indulged in sensory experiences and reflected on the stories told through stunning artwork. All exhibitors excelled themselves in delivering a first-class public engagement experience.

Feedback and Impact

Some 65 % of visitors had never attended a rare disease event before, a considerable achievement to attract such a broad range of the public to engage in a niche topic. An impressive 100 % of visitors rated RAREfest as very good or excellent. 80 % said they were more interested in rare diseases than previously, and 87 % had learnt a lot or a significant amount of new information.

One company exhibitor who had been showcasing microscopy images of brain cancer cell lines and guiding visitors through models of DNA's structure commented, "*We had such a wonderful time exhibiting, and the performances and talks the night before were so thought-provoking. It was so wonderful to be in a room with disabled children celebrating their bodies and the spotlight being on those of us with rare diseases. As a disabled person, I felt seen. Thank you, again, for making it so easy to get involved."*

A mother to a little girl with a rare condition and patient organisation representative captured the breadth of experiences, *"the DNA musical was phenomenal, Little Journey exhibition and team were fantastic, informative, interesting and helpful, as were the Cambridge Children's Hospital. The amount of interaction with the exhibits made for a really interesting day for all the family. The Rare Bears on the CamRARE stand were a real highlight for my daughter."*

And scientists and researchers also got to reflect on the value of hearing from those with lived experience *"My favourite part was when CamRARE parents got to share their heartfelt comments about their experience with a child with a rare disease and the disconnect we, as scientists/researchers, have between the "end users". And a poem in one of the booths even talked about how researchers do not get back to the patient's family and are treated just like "sample sources" rather than real humans with real stories. They were eye-opening, and they made me want to be more careful with my own research work."*

Support
RAREfest is vital to CamRARE's fundraising strategy through sponsorship and donations. RAREfest sponsorship in 2022 totalled £96,000 from 12 funders, up from £66,000 from 7 funders in 2020 - our highest single event sponsorship to date. We also received pro bono support from CambridgePrinting.Com.

We recruited over 30 volunteers to support various aspects of the festival. They included medical and genomics students, industry professionals and our Unique Feet regional community members. Ten of these contributed to the RAREfest 'Through Your Eyes' impact report with written reviews.

Media
The event caught regional media attention and was featured in several Cambridge Independent news articles. All live talks, panel discussions and innovation pitching sessions were recorded and made available on our YouTube channel post event. To date, recordings have been watched 3991 times.

COMPANIES FORUM

CamRARE is building a network of Companies, healthcare professionals and researchers who can improve treatments and create technology solutions to enhance rare patients' lives. We are embedding the patient voice and providing the scaffolding and platforms to help connect these groups and encourage collaborations to flourish.

In 2022 we held two Companies Forum meetings welcoming 46 representatives from companies over the year.

January 2022: At this virtual meeting, a National Institute for Health and Care Excellence (NICE) representative led us through the proposed Innovative Medicines Fund (IMF) concerning rare diseases to support our Forum in responding to the live consultation on these proposals. Thomas Strong - HTA Adviser - Managed Access (Cancer Drugs Fund) at NICE, gave a high-level overview of the IMF proposals. Essentially, they are bringing the non-cancer space in line with what the Cancer Drugs Fund has offered. There is a dedicated fund with dedicated criteria for entry. He explained that IMF would align with the ILAP (Innovative Licensing) Pathway within the regulatory space, and many updates to NICE methods and processes would be happening, all driving earlier access to medicines. Thomas suggested that one of the critical drivers of the IMF is earlier access to medicines for patients. The IMF allows NICE committees to give patients access to the most promising medicines while waiting for additional evidence and a final decision on routine commissioning.

Alexion (Astra Zeneca Rare Diseases), a member of the Forum, shared findings from their white paper on the IMF stemming from their round table cross-sector discussion. A poll during the meeting showed that 92% of attendees agreed or strongly agreed with the purpose of the IMF. Still, feelings were mixed on the operational plans, which led to vibrant discussion, challenges and suggestions on how the IMF would operate.

June 2022: We held the Companies Forum meeting in person at the Royal Society of Medicine. All members agreed that it was great to meet in person again and benefit from the networking aspect of the event. The theme 'How do physicians learn about rare diseases?' was introduced by Dr Will Evans - GP, NIHR Practice Fellow University of Nottingham, Chair of Niemann Pick Disease Group. Dr Evans gave an overview of the findings of recent surveys exploring physicians' knowledge of rare diseases around the world and where they look for rare disease-related information. The presentation highlighted the broad perception by respondents that rare diseases are rarer than they are and are, therefore, not that relevant for many physicians.

The group discussed that Physicians want their rare disease information from world-renowned experts or clinicians, followed by local experts or clinicians and then patient advocates, preferably in case-based or short-lecture-based learning formats. Dr Lucy McKay, CEO of Medics4Rare Diseases, suggested how the life science industry could help by building on existing resources and making resources relevant through real-life scenarios. The group discussed using blended learning for different learning styles, developing 'Just in time' highly targeted resources for specific rare diseases and 'Just in case' resources for rare disease education broadly or broad clinical presentations. All agreed it was essential to put resources in familiar online places using existing infrastructure and in a typical format.

CamRARE was delighted to be chosen by international company Medidata as one of their Social Impact Lab charity partners in 2021. A team of their UK and European staff worked with us pro bono over three months, helping to explore the impact of this partnering event and develop a framework for future events. We look forward to developing this further in 2022 and beyond.

There are 15 current company members of the Forum, three of which joined in 2022. Two patient group representatives are honorary members to provide the patient voice at meetings. In line with our new Strategy for 2023, we will build on and grow this membership and welcome an increasingly diverse group of companies and organisations.

OTHER SIGNIFICANT ACTIVITIES

Communications

CamRARE continued to participate in a wide range of events, editorial and awareness-raising opportunities as speakers, media partners, chairs of panels, interviewees and writers.

Redevelopment and improvement of the CamRARE website continued throughout 2022. In particular, we undertook to improve the user experience for regional families by adding a new Unique Feet activity calendar and booking system and a contact form for new families wanting to join. The majority of further membership enquiries now come via the website.

Development of the CamRARE website has led to 15,023 new users on the platform this year, with over 8,900 page visits during the peak three month marketing activity preceding our RAREfest event.

CamRARE invested in recording and editing all RAREfest22 live talks and panel discussions, creating a legacy of rich content on our YouTube channel and website that showcases our work and continues to deliver impact. This resource has increased our ability to educate and raise awareness on a much broader scale.

Communications continue to be a central part of our work in advocacy, raising awareness, and connecting the broader rare disease community and the public. This year, we continue to have communications officers who are parents of children living locally with a rare condition. They helped shape our social media and regional community communications, ensuring the patient voice is at the heart of our messaging.

Partnerships and Patient Voice

Partnership highlights for 2022 include collaborative projects with AI drug development company Healx, local charity Beacon for Rare Disease, health communications company Costello Medical and clinical trials data specialist Medidata. CamRARE has been delighted to continue collaborations with all of these organisations into 2022 as we strive to develop innovative and collaborative ways to improve the rare patient journey together. In particular, the long term pro bono support of the companies we partner with has enormous value for our community and us in producing high-quality resources for the wider community.

Transitions from Paediatric to Adult Care Research

In 2021, in collaboration with Costello Medical and Beacon, we undertook a series of focus groups and a round table meeting with young people, their families, patient groups and healthcare professionals to strengthen relationships within our regional healthcare network and to understand better the process, challenges and possibilities for development in transitions to adult care for young people living with rare conditions. We were delighted to launch a collaborative report on this project in April 2022. This project and the report are showcased on the CamRARE website, and the report was circulated widely through all of our networks. Our MD delivered a presentation about this project with Costello Medical at Beacon's 'Cambridge Rare Disease Showcase' event in June 2022. The project team was also invited to speak about the project's findings at other rare disease conferences. We continue to work closely with Costello to develop the next phase of this work to pilot one of the recommendations from the report in a healthcare setting.

Rare Patient Passport

We have continued to invest in our Rare Patient Passport project, completing the design of the editable pdf passport, developing pre and post-pilot surveys for users and undertaking a pilot with 30 users. This work followed a series of focus groups with people living with rare conditions, their caregivers and healthcare professionals to understand their unmet needs and preferred passport format and agree on the document's content. With the pro bono support of Costello Medical throughout 2022, we launched a pilot in July with 30 families using the passport in hospital and care settings. This culminated in developing and launching a stage one report on findings and recommendations for next steps. This work has put CamRARE in a solid position to undertake a stage two pilot study with a target group of 200 patients of all ages, living with any rare or undiagnosed condition, from across the UK in 2023. With the support of Medidata through their Social Impact Lab project, we will seek healthcare professionals' views and showcase the Rare Patient Passport project via a newly developed webpage on the CamRARE website in 2023.

Wiki-editathon

In June 2022, five Unique Feet families participated in a Wiki-editthon event with Cambridge company Healx. The day's purpose was to create and update Wikipedia entries on the rare conditions these children live with. Parents joined scientists from Healx for a day of discussion, research and intense creativity as they updated citations and shared lived experiences to improve the information on their disease in this public information platform.

Pint of Science Festival

In May 2022, CamRARE partnered for the 4th year running with the international Pint of Science festival to host two evenings of rare disease-inspired talks for the public. Speakers Prof Giles Yeo and Prof Miguel Constancia delivered exciting and thought-provoking talks on imprinting in studying metabolic diseases and rare genetic causes of obesity. At the same time, CRUK researchers Sigourney Bell and Dr Jessica Taylor challenged rare paediatric brain tumour treatments, taking their research beyond curing to 'curing with kindness', developing treatments with fewer long-term side effects. A team of six volunteers, local students and Healx staff joined our team for two fun, action-packed and inspiring evenings of passionate talks, interactive activities and plenty of audience participation. We attracted our largest POS audience, with 100 people packed into each event. Partnering with the festival allows us to share rare disease research with an engaged public audience and highlight the value of rare disease research in understanding more common diseases.

Other Events

CamRARE had a presence at many other events throughout 2022, including:-

- being charity partners and exhibiting at the Anglo Nordic Life Sciences conference in London, where we had the opportunity to meet companies and investors working in the disease space
- delivering training on getting the best from events for Beacon's Patient Group Training programme
- speaking at the Glasgow Office for Rare Diseases webinar on our rare patient passport project
- helping organise and exhibiting at the Next Generation Children's event at the Welcome Genome Campus
- speaking at the Beacon Cambridge Rare Disease Showcase event and an ALDLife UK conference on transitions from paediatric to adult care
- contributing to round table discussions on the Takeda 'I am Number 17' awareness-raising project
- exhibiting at Beacon's Drug Repurposing conference in London

It is also noteworthy that CamRARE's events rely on the support and collaboration of our many friends and partners throughout the rare disease world. At RAREfestt22, an incredible 61 media partners, including leading rare disease charities from the UK, Europe, and the US, Cambridge-based Wellcome Genome Campus, the Innovation Forum, Front Line Genomics and Babraham Research Institute, and a wide range of companies joined our quest to raise awareness and promote this event.

Overall, CamRARE has continued to deliver clear and quantifiable benefits to a wide range of rare disease stakeholders. We have offered more opportunities for cross-sector collaboration, which are beginning to provide real impact and outcomes. Growth in demand for our local community has seen CAMRARE support an increasing number of families affected by rare conditions. We welcomed more patient groups, companies, and medical and scientific organisations into the network. By refining the delivery of existing projects, whether empowerment, community building, or scientific, the charity has built a robust service offering with a strong reputation for patient engagement.

This progress forms a strong foundation for securing more company funding partnerships and grant funding in 2023 and increase our reach and engagement with rare disease stakeholders and the broader public in the UK and beyond.

Financial Review

The overall net income for 2022 of activity is £141,001

Funds are primarily raised through corporate sponsorship and grant funding with a lesser, but increasing, amount through community fundraising and online donations. Most paying Companies Forum members obtained membership through gold and diamond sponsorship packages for RAREsummit. The most significant contributors to income for this year's charitable activities were for RAREfest and grant funding for Unique Feet activities. We received almost £8,000 in grant funding from South Cambridgeshire District Council, our first successful local government grant.

Strategy Day Feb 2022

On 7 February 2022, five of the six CRDN Trustees and the Managing Director met for a whole day, Strategy Day (facilitated by Julian Lomas of Almond Tree Strategic Consulting), to explore the future strategic direction for the charity. It was agreed that in broad terms, CamRARE's current activities fall under four headings and a growth and funding strategy was decided for each:

1. **Supporting local people with and families affected by rare conditions** (i.e. Unique Feet). Local/regional

Growth - Primary focus on a significant increase in participating families, e.g. through work with local healthcare providers, special schools and promotional activities. Continue to develop provisions and content to meet the needs of members. Restructure (geographically and/or by age groups) as membership grows.

Income and funding potential - Increased grant funding, community fundraising and individual donations.

2. **Educational and networking events** (e.g. RAREfest, RAREsummit and regular smaller events). Regional, national and international

Growth - Primary focus on increasing impact, e.g. through increased collaboration with other stakeholders and developing appropriate hybrid formats to sustain expanded audience reach and facilitate speaker engagement.

Income and funding potential – Continued growth in sponsorship of events. Explore ways to monetise virtual engagement in events.

3. **Networking for representatives from pharmaceutical, biotechnology, and healthcare companies** operating and guest patient groups in the rare diseases space (i.e. Companies Forum). Regional, national and international

Growth – Primary focus on increasing membership (and income). Continue to develop and ensure consistent content to attract more members and meet their needs. Possible increase in number of meetings and/or segmentation of meetings (e.g. to focus on sub-sets of members or specific interests).

Income and funding potential – Increase direct purchases of membership.

4**. Identifying gaps in provision and facilitating a voice** for, and/or access to, people with rare diseases to enable solutions (referred to as "advocacy & access").

Growth - Use a simple prioritisation framework (impacts and costs) to aid decision-making on participation and charging and to support evaluation. Develop options for monetising CamRARE's involvement in such projects (where appropriate).

Income and funding - To be explored further, particularly charging private sector partners for "consultancy" and/or “brokerage” services.

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 during this financial year. 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 work 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 was £210,533

Structure, Governance and Management

Governing Document

At the Strategy Day in Feb 2022, the Board and team decided to apply to become a Charitable Incorporated Organisation whose only voting members are its charity trustees (‘Foundation’ Model). The organisation was a charitable company limited by guarantee, incorporated on 28 September 2015 and registered as a charity on 5 April 2016. The company was established under a Memorandum of Association that established the charity company’s objects and powers and is governed under its Articles of Association. In the event of the company winding up, members must contribute an amount not exceeding £10.

The Board resolved to adopt the revised constitution, an application for CIO status was successful, and the transfer was made on 22 September 2022. If the CIO is wound up, each member of the CIO is liable to contribute to the assets of the CIO such amount (but not more than £1)

Trustee Induction and Training

Some of CAMRARE’s Trustees are involved as board members of other organisations and bring their previous experience and expertise. New trustees with little prior knowledge of the role should attend CCSV Trustee training. Following a revamp of the charity’s equality and diversity policy in 2020, the Board has been committed to ensuring an inclusive, representative and broad group of trustees. In addition, Trustees undertook a skills audit of the Board to identify gaps and how these can be addressed through Trustee recruitment. An output of the strategy day was a new Trustee’s Handbook which outlines the roles and responsibilities of the Board and provides an excellent induction to the work of the charity.

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. The Operations team, consisting of the Chair, one trustee and the Managing Director, meets regularly to facilitate effective operations. CamRARE welcomed four new trustees in 2022 following identifying skills gaps in the strategy day audit.

New trustees appointed were: Loretta Macinnes, Founder, Marketing and Policy Specialist, and Writer. Loretta has lived experience and is an advocate for people with rare diseases and invisible disabilities. We also appointed Emma Green, ClinDev executive and Biotech advisor, Jon Green, CEO of Ionotas and Chair of One Nucleus and Sarah Faircliffe, Legal Director at Bird and Bird.

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. We employed two new members of the staff team in 2022. Jo Balfour is the Managing Director (full-time) and continues in her role. Newly appointed Deputy Director (full time), Dr Lesley Booth, came to CamRARE in Sept 2022 from Bowel Research UK. A social scientist researcher, she has twenty years of experience working with underrepresented groups. Lesley is passionate about education and providing opportunities to educate those who feel excluded or exclude themselves from the systems that should support them. She has an unrivalled understanding of patient and public involvement and engagement processes and growing partnerships with clinicians, researchers and patients. Lindsey Brown has been working freelance for CamRARE since 2017 and joined the team part-time as an employed member of staff as an Events and Projects Officer bringing her wealth of experience and expertise in logistics and events management to support our events programme and the registration process and activities organisation for Unique Feet. Pay is reviewed annually in line with an employee's tenure, changes in the market for talent or 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 successful year financially, enabling growth and employment in the core team. Two-year seed funding from the Evolution Education Trust to cover the full-time job of the Managing Director ended in autumn 2021. We have successfully maintained the required level of income to sustain growth. 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 following applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each fiscal year. Under company law, the Trustees must not approve the financial accounts unless they are satisfied they give an accurate and fair view of the state of affairs of the charitable company for that period - specifically its incoming resources and application of these.

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. They must ensure that the financial statements comply with the Companies Act 2006. 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:

Dr Gemma Chandratillake

Chair and trustee Date 10.8.23

Organisation Details

Registered Office: 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

Resigned 2022

Dr Jonathan Milner (appointed 23/01/2019, resigned 16/05/22)

Dr Ron Jortner (appointed 23/01/2019, resigned 22/06/22)

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 support - George Nicolau (contracted)

Community Communications – Celia Enderle (contracted)

Rare Patient Passport and Transition to adult care reports - 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 2022

I report on the accounts of Cambridge Rare Disease Network for the period ended 31 December 2022 which are set out on pages 19 to 26.

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.

Shelley-Marie Rudling FMAAT AATQB for and on behalf of:
Community360
Winsley's House, High Street, Colchester, Essex Date 11/08/2023

CAMBRIDGE RARE DISEASE NETWORK
STATEMENT OF FINANCIAL ACTIVITIES (INCLUDING INCOME & EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 DECEMBER 2022

	Notes	Unrestricted funds £	Restricted funds £	2022 Total £	2021 Total £
Incoming resources					
Incoming resources from generating funds:					
Donations and legacies	**2**	15,166	-	15,166	11,034
Charitable activities	**3**	118,035	7,800	125,835	152,468
Total incoming resources		**133,201**	**7,800**	**141,001**	**163,501**
Resources expended					
Charitable activities	**4**	104,882	18,427	123,309	103,210
Total charitable expenditure		**104,882**	**18,427**	**123,309**	**103,210**
Net incoming/(outgoing) resources before transfers		**28,319**	**(10,627)**	**17,692**	**60,291**
Transfer between funds		(79)	79	-	-
Previous year adjustment		-	-	-	1,748
Net income/(expenditure) for the year/ Net movement in funds		28,240	(10,548)	17,692	60,291
Fund balances at 1 January 2022		178,531	14,310	192,840	130,801
Fund balances at 31 December 2022		**206,771**	**3,762**	**210,533**	**192,840**

The Statement of Financial Activities includes all gains and losses recognised in the year.

The notes on pages 21-26 form part of these financial statements.

CAMBRIDGE RARE DISEASE NETWORK

BALANCE SHEET
AS AT 31 DECEMBER 2022

		2022		2021	
	Notes	**£**	**£**	**£**	**£**
Current assets					
Debtors	**6**	5,664		6,164	
Cash at bank and in hand		211,901		189,891	
		217,565		196,055	
Creditors: amounts falling due within one year	**7**	(7,033)		(3,215)	
Net current assets			210,532		192,840
Total net assets			**210,532**		**192,840**
Income funds					
Restricted funds	**9**		3,762		14,310
Unrestricted funds			206,771		178,531
			210,533		**192,840**

The Charity was entitled to exemption from audit under section 477 of the Companies Act 2006.

The members have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.

The Trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and preparation of financial statements.

The financial statements have been prepared in accordance with the provisions applicable to entities subject to the small companies regime.

The financial statements were approved and authorised for issue by the Trustees on the 10th August 2023 and signed on their behalf by:

Signed ____________________ Date 10/08/2023

Dr Gemma Chandrtillake

The notes on pages 21-26 form an integral part of these financial statements.

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 Practise 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) and the Companies Act 2006.

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 Internation 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.

1.5 Fund accounting

General funds are unrestricted funds which are avaliable 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 restrcitions 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 objectivies, 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 investements with a short maturity of three months or less from the date of acquistion 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 compcnat 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.

2 Donations and legacies

	Unrestricted Funds	Restricted Funds	2022 Total £	2021 Total £
Donations and gifts	15,166	-	**15,166**	**11,304**
	15,166	**-**	**15,166**	**11,304**
TOTAL 2021	**10,534**	**500**	**11,034**	

3 Charitable activities

	Unrestricted Funds	Restricted Funds	2022 Total £	2021 Total £
Delegate Sales	7,000	-	7,000	15,000
Grants	1,000	7,800	8,800	28,945
Sponsorship	107,000	-	107,000	95,000
Other	3,035	-	3,035	13,523
	118,035	**7,800**	**125,835**	**152,468**
TOTAL 2021	**123,523**	**28,945**	**152,468**	

4 Resources expended

	Unrestricted Funds	Restricted Funds	2022 Total £	2021 Total £
Staff costs	59,564	7,438	67,002	53,371
Depreciation	-	-	-	-
Accomodation	547	-	547	33
Admin support	1,717	2,556	4,273	6,420
Advertising & marketing	8,732	3,716	12,448	27,487
Accountancy fees	1,237	-	1,237	1,655
Bank fees	7	-	7	66
Consulting	3,431	-	3,431	-
General expenses	132	-	132	150
Equipment hire	7,711	-	7,711	-
Event costs	350	-	350	-
Independent examination	-	-	-	-
Insurance	528	-	528	528
IT software & consumables	1,012	-	1,012	1,223
Legal expenses	-	-	-	-
Postage, freight & courier	256	768	1,024	19
Staff training	516	-	516	173
Subscriptions	1,149	-	1,149	493
Travel	3,301	-	3,301	276
Venue & catering	14,427	3,459	17,886	4,145
Website design & admin	264	490	754	7,171
	104,882	**18,427**	**123,309**	**103,210**
TOTAL 2021	**32,054**	**71,157**	**103,210**	

5 Staff costs

	2022 Total £	2021 Total £
Wages and salaries	65,511	52,068
Pension costs	1,491	1,303
	67,002	**53,371**

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

	2022 No.	2021 No.
Employees	**3**	**1**

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.
During the year, Dr Ron Jortner received reimbursement of expenses totalling £Nil (2021: 26.44).

6 Debtors

	2022 Total £	2021 Total £
DUE WITHIN ONE YEAR		
Trade debtors	5,543	6,043
Prepayments and accrued income	121	121
	5,664	**6,164**

7 Creditors: amounts falling due within one year

	2022 Total £	2021 Total £
Trade creditors	3,706	1,614
Other creditors	2,867	1,301
Accruals and deferred income	460	300
	7,033	**3,215**

8 Deferred income analysis

	2022 Total £	2021 Total £
Deferred income at 1 October 2020	-	5,420
Resources deferred during the year	-	-
Amounts released from previous periods	-	(5,420)
	-	**-**

9 Statement of funds

	Balance at 1 January 2022 £	Income £	Expenditure £	Transfers In/out £	Balance at 31 December 2022 £
UNRESTRICTED FUNDS					
General funds - all funds	178,531	133,201	104,882	(79)	206,771
RESTRICTED					
National Lottery	845	-	520	-	325
Evolution Education Trust (marketing)	9,977	-	6,952	-	3,025
CCF	29	-	108	79	-
South Cambridge DC	-	7,500	7,500	-	-
Unique Feet	3,458	300	3,348	-	410
Total restricted funds	**14,310**	**7,800**	**18,427**	**79**	**3,761**
Total funds	**192,841**	**141,001**	**123,311**	**-**	**210,533**

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.

purposes.

Evolution Education Trust (operations) - the purpose of this donation is to fund the full-time employment of the Operations Manager of the charity to allow the charity a period of stability and time to generate more regular sources of income. The funds also fund the Operations manager's training and attendance at relevant conferences and events in order to raise the profile of the charity.

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 2022 £	Restricted funds 2022 £	Total 2022 £
Fund balances at 31 December 2022 are represented by:			
Current assets	213,803	3,762	217,565
Creditors: amounts falling due within one year	(7,033)	-	(7,033)
	206,770	**3,762**	**210,532**

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) £199.48 (2021: £180) 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 (2021: £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 £5,000 (2021: £25,000) One of the trustees of Evolution Education Trust, Dr J S Milner is also a trustee of CRDN.

CAMBRIDGE RARE DISEASE NETWORK

England & Wales - Charity number 1166365

Accounts

CAMBRIDGE RARE DISEASE NETWORK

Company Registration number 09798317
Charity Registration number 1166365

FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2021

CAMBRIDGE RARE DISEASE NETWORK

CONTENTS
FOR THE YEAR ENDED 31 DECEMBER 2021

CAMBRIDGE RARE DISEASE NETWORK

REFERENCE AND ADMINISTRATION INFORMATION FOR THE YEAR ENDED 31 DECEMBER 2021

Charity number	1166365
Company number	09798317
Principal Address	C/o BCS Windsor House Station Court Station Road Great Shelford Cambridge CB22 5NE
Trustees	Dr T Guilliams Dr G Chandratillake Ms. S L Berry Dr J S Milner Dr R A Jortner Dr S M Leiter Mr I M Chaitowitz
Company Secretary	BSC Cosec Ltd.
Operations Manager	Mrs J Balfour
Independent Examiner	Community360 Winsley's House High Street Colchester Essex, CO1 1UG

The trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 December 2020. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts following the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Charity Objectives and Activities

Cambridge Rare Disease Network 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: To create regional networks to improve the rare disease journey

Our Aims:

- Stimulate and nurture cross-sector cooperation and collaboration.
- Make support available for families.
- Raise awareness of the rare disease journey.

Charity Objects as recorded with the Charity Commission

1) 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.

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

Significant activities

Creating Networks to Improve the Rare Disease Patient Journey

In the EU, a rare disease is defined as a condition that affects less than one in 2,000 people. Currently, over 7,000 rare diseases have been identified, which collectively affect one in 17, amounting to 3.5 million people in the UK. Of these diseases, 80 % are genetic in origin, 50 % affect children, and only 5 % have an approved treatment. Despite this high prevalence, each condition affects so few people that they tend to be overlooked and misunderstood by health professionals, researchers, education and social care providers and the general public. This lack of awareness and information commonly leads to the “Diagnostic Odyssey”, where it takes an average of 4.8 years and 7.3 physicians to reach the correct diagnosis, and delays and misdiagnosis are common. Poor awareness also impacts patients receiving appropriate care, support in school and the workplace, leads to isolation for patients and families and creates a high social burden of care (Source: Engel et al., JRD, 2013.

Despite advances in recent years, progress in diagnosis, developing treatments and assuring coordinated care continue to prove challenging and is affected by low patient numbers per disease, lack of education in rare diseases for healthcare professionals, difficulty recruiting enough patients for clinical trials, insufficient economic incentives, high cost of treatment, tribulation in reimbursing, low awareness of conditions and poor scientific understanding of disease mechanisms.

Events, forums and communications

At CRDN, we are challenging this lack of awareness by delivering a range of visionary events and forums and a bold and proactive online communications presence.

Events

We hold stakeholder and public-facing events to bring the challenges of the rare disease journey to the fore, provide a platform for engagement, and nurture impactful collaboration.

Regional Community of People Living with Rare Diseases

We build a regional, connected, engaged, and empowered network of people affected by rare diseases to have a stronger voice collectively. Our community-building activities reduce isolation and give patients and their families the confidence to engage with other stakeholders as experts in their own or their children's health and care.

Companies Forum

We are building a network of Companies, healthcare professionals and researchers who can improve treatments and create technology solutions to enhance rare patients' lives. We are embedding the patient voice and providing the scaffolding and platforms to help connect these groups and encourage collaborations to flourish.

Patient Access

We use our communications strategy to highlight patient stories through a range of online, broadcasting and paper media channels. We engage new audiences through our online media campaigns and our events. We hope to secure additional, continued funding and donations by highlighting our cross-sector, collaborative and proactive approach.

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.

Achievement and Performance January 2021 - December 2021
Significant Activities

Collaborating through COVID and beyond - ARDEnt (Action for Rare Disease Empowerment)

In March 2020, the COVID-19 pandemic turned many of our planmned events and activities on their head, so we reacted swiftly and adapted. Early on, CRDN's Managing Director, Jo Balfour, partnered with Medics4Rare Diseases CEO, DR Lucy McKay and Rare Revolution Founder, Rebecca Stewart to develop and lead on a COVID-19 response group of 30 cross sector advocates, including patient groups, industry, healthcare and policy experts. CRDN's Chair, DR Gemma Chandratilake and trustee Dr Ron Jortner also took part.

The resulting report, 'Making the Unseen, Seen' was published on 5 May 2021 and launched through a multi-stakeholder webinar. The webinar attracted 358 attendees. It revealed the impact of the pandemic on every stage of the patient journey, from diagnosis to eventual management. It catalogues the re-assignment of specialists away from a rare disease, for fear of infection, the closure of clinics, the fracture of coordination of health and social care, and the delay or termination of research, evidence generation and clinical studies. At the same time, the pandemic has accelerated the evolution of remote monitoring, the adoption of telemedicine and a move towards more patient-centric and decentralised clinical trials. The report makes nine recommendations that should bring patients with rare disease into the light and make their management more robust for the future.

Since its publication the ‘Making the Unseen Seen’ report has been downloaded 1329 times from the CRDN website, shared widely with over 50,000 people by the ARDEnt team and their organisations. Its findings and recommendations have been referred to and adopted as part of the Department for Health and Social Care UK Rare Disease Framework 2021 and the related Action Plans for England, published in February 2022 The ARDEnt theme leads, including Jo Balfour from CRDN, have been invited as rare diseases spokespersons on expert panels hosted by pharmaceutical companies Biomarin, Alexion and Takeda and as Patient Experts on the weekly Genetic Alliance UK Patient Empowerment Group which advises government policy on Rare Diseases. In addition, ARDEnt theme leads have been involved in various Department of Health and Social Care expert panels supporting the development of the UK Rare Disease Framework 2021 action plans. The report was used by the cross-party Public Policy Projects team to inform a ‘State of the Nation’ report on Rare Diseases.

Media coverage of the report was widespread and included articles on the healthwareness.co.uk platform, by Frontline Genomics, Raconteur, Media Planet and Rare Revolution Magazine.
ARDEnt is not a formally recognised organisation and therefore has no funding. All contributors take part voluntarily. CRDN successfully commissioned a Cambridge based Medical Communications company who provided £35,000 of pro bono support to create the final report.

RAREsummit21

The focus of the autumn season of 2021 was CRDN’s 5th RAREsummit, held online for the first time, making it more accessible than ever to a global audience. The event was held on a highly visual and interactive platform over one live day and on demand for 30 days following. Building on the huge success of our virtual RAREfest20, RAREsummit21 attracted 48 key opinion leaders from the UK, Europe, the US and Asia, with a shared ambition to improve life's journey for families living with rare conditions. Speakers took part in panel discussions, fireside chats and live pitching sessions, alongside over 38 interactive exhibition stands, short films and posters in an inspirational online gallery. Themes covered during the event included medicines discovery, catalysing treatments for rare diseases, developing innovative ways to provide accessible and trustworthy health information, innovate solutions to rare disease challenges, running clinical trials without placebos, amplifying the patient voice, rare equity and early access programmes.

We pride ourselves on creating unique events that will inspire and challenge the audience. This year we continued our partnership with the Eastern Academic Health Science Network (Eastern AHSN) who had launched a survey at RAREfest20 to ask our patient community what their day to day challenges were. The outcome of that survey was a live innovation 'Dragon's Den' style pitching session at RAREsummit21 which showcased the five best innovation solutions to these challenges as selected by an expert judging panel from 17 unique company entries.

Another new addition to the Summit was a partnership with Medical Communications company Prime Global. They helped us to increase the impact of our showcase Patient Journey poster exhibition by supporting ten patient groups who has previously submitted a poster to our gallery. They worked over 6 months to create new Patient Voice Publications with our patient group contacts to develop a poster which speaks to Pharma and helps the patient group clearly outline their unmet needs and challenges to the industry. We look forward to continuing to work with prime Global to support more patient groups in the future.

Attendees

Three hundred and fifty people gathered from 138 towns and cities across the UK and 24 countries to find a way forward. This attendance was a 94 % increase on our inaugural conference in 2015 and a 32% on RAREsummit19. Some 42% of attendees were patient advocates, 29% from industry, 18% representing academia and 11% healthcare with all attendee groups showing a percentage increase on 2019.

Feedback and Impact

Feedback on the event was consistently positive, 100% of people rating RAREsummit21 as good or excellent, 100% rating the organisation as good or excellent, 100% saying they would recommend it to others and 90% happy that there was a good variety of exhibition stands and posters. One health care professional commented "I've just visited the exhibition and am blown away by the exhibitors I've not been aware of. And I've been involved in paediatric rare disease work for 30 odd years for The British Paediatric Surveillance Unit. Another attendee said "RAREsummit21 has turned my growing curiosity in Rare Disease into a reality where I was both able to connect with some amazing people and be inspired by the passion and activity that is going on throughout this community" and another reported "It was the first time I have attended a RAREsummit representing my patient group, and I have to say it was amazing. I loved the whole set up and platform and I've come away with so many great ideas and resources, met some great people and made some new connections".

Over the duration of the event, we saw 2522 visits to exhibition stands and the poster and film gallery where materials were viewed, downloaded and conversations had between stakeholders.
Over the coming year we will be assessing the longer-term impact of this event in relation to opportunities it has created and collaborations which have emerged.

Support

RAREsummit is a vital element of CRDN's fundraising strategy through sponsorship and ticket sales. Summit sponsorship in 2021 totalled £94,000 from 14 funders, up from £59,000 from 10 funders in 2019 – our highest single event sponsorship to date. Ticket sales were lower at £8,215 as compared to £18,000 in 2019 as we reduced the cost for an online event. We also received significant pro bono support to create the innovation pitching challenge and event from the Eastern Academic Health Science Network.

We recruited over 20 volunteers to support with various aspects of the Summit. They included medical and genomics students, industry professionals and members of our Unique Feet regional community. Ten of these contributed to the RAREsummit21'Through Your Eyes' impact report with written reviews.

Media
The event caught regional media attention and was featured in several Cambridge Independent news articles. All live talks, panel discussions and innovation pitching session were recorded and made available on our YouTube channel post event. To date recordings have been watched 1276 times on the event platform and our YouTube channel.

UNIQUE FEET COMMUNITY

CRDN, with grant funding from Cambridgeshire Community Fund and the National Lottery COVID Fund, along with several smaller donations have continued to respond swiftly and with agility to the emerging COVID -19 pandemic situation for our regional community of families affected by a rare condition.

The group has continued to flourish despite the complex situation. All original members continued to attend, and membership increased from 12 families and 36 beneficiaries in 2018 to 25 families and 90 beneficiaries, totalling 33 new beneficiaries during 2021. Some children are on the COVID 'extremely clinically vulnerable' list, and consequently, families have continued to shield intermittently through the year. We continued to offer group activities online to keep families connected, active and supported during this challenging and isolating time, whilst safely opening up in person activities again. The parents WhatsApp group continued to serve as a vital portal for sharing experiences, giving guidance, letting off steam and keeping each other motivated and in good spirits.

In person group activities revolved around in beautiful, therapeutic, outdoor spaces such as the privately run Challis Gardens and Cambridge Botanic Gardens providing a safe place to play and explore freely.

Ambassadors and Advocacy

Unique Feet parents continued being the voice of rare disease in our community, despite of and in response to the pandemic.
Notably, families have worked with CRDN to develop a Rare Hospital Passport. This resource evolved to support patients with rare diseases, particularly those with communication difficulties, who, in the context of COVID-19, experienced strict limitations on visitors and may find their usual medical team redeployed. We have received pro bono design support from Costello Medical to finalise this and roll out the passport for more general use to the whole rare disease community in 2021.

Families have also been involved in a collaborative project exploring children and young people's experience of transitioning to adult care undertaken by Costello Medical, CRDN and Cambridge based charity Findacure. This project has involved focus groups with young people, parents, patient groups and health professionals followed by a multi stakeholder round table discussion and will yield a report for circulation in early 2022.

Parents and children developed a monthly community newsletter, joined the Cambridge Children's Hospital Network to help shape the design of this new resource, and undertook interviews for several news stories in local papers, pharmaceutical journals, and BBC Look East. Some parents have been speakers at conferences and events to tell their rare disease journey story. We have seen the true impact of building a regional community and the influence these collective voices can have in shaping local health, social care and education policy and will continue to give families a range of platforms to have a voice. Families took part in an incredible array of activity this year including:

- Were the focus of BBC Look East TV and Cambridge Independent news pieces
- Created PharmaForum Magazine Patient Insight articles
- Contributing to an IQIVIA paper on the value of play therapists in commercial and clinical research
- Attended DHSC expert round table on the UK Rare Disease Framework action plans
- LIlluminated Kings College for their child's rare disease celebration day. BBC TV, radio and newspaper coverage
- Piloted an Illumina art project
- Became members of Cambridge Children's Hospital development forums
- Supported CRDN's Rare Hospital Passport project
- Took part of focus groups on transitions to adult care
- Contributed to CRDN's Rare Disease Day awareness campaign with stories and social media work
- Creatied short films 'Rare Disease Day Every Day' which have been viewed 1502 times
- Trialling an app by Thriving.ai – finalist in RAREsummit21 dragons den pitching
- Worked in a self-employed capacity for CRDN in communications
- Volunteered in development of Unique Feet future strategy
- Volunteered in Unique Feet activities
- Volunteered to help with grant applications and fundraising
- Fundraised @£3000 in 2021

COMPANIES FORUM

Companies Forum continued to make progress over the last year. Meetings were held virtually and although we have missed the vibrant networking element of in person meetings, we have been pleased to host some dynamic discussions and activities and welcome new members.

In May we held an inaugural Patient Group and Industry Partnering event which brought together 11 rare disease patient groups alongside 11 companies working in the rare disease space; our goal was to form collaborations towards the development of new treatments. Of the thousands of rare diseases currently identified, around 95% have no treatment, and most of the remaining 5% have limited treatment options. Development of treatments for rare diseases is often hindered by small market size, inadequate sources of information, and low awareness of the conditions. CRDN Companies Forum aims to tackle these issues and contribute to the development of new treatments through creation of the right networks.

The event featured short pitches by patient groups, followed by a series of speed-dating style partnering sessions, where representatives from each patient group and each company had the chance to meet and discuss potential common interests.

One company said this was a great opportunity to hear in very succinct terms what people's needs were" and a patent group reported "we are actively following up with five companies that we were not in touch with before so definitely a success".

Progress is being tracked over time, but early feedback showed that patient groups were collaborating with one company on developing antibodies to help research, another in discussions around the diagnostic odyssey, whilst others were exploring advocacy opportunities.

We were delighted to be chosen by international company Medidata to be one of their Social Impact Lab charity partners in 2021. A team of ten of their UK and European staff worked with us pro bono over three months helping to explore the impact of this partnering event and to develop a framework for future events of this kind. We look forward to developing this further in 2022 and beyond.

In July we held a meeting with a speaker from the MHRA exploring the new ILAP (Innovative Licensing Access Pathway). The new pathway represents a totally new way of thinking and is a truly collaborative approach between the healthcare system, the pharmaceutical industry and patients. The aim is for it to transform the way innovative medicines reach patients in the UK. Partnering with the MHRA and others to build this frictionless pathway to the timely availability of cost-effective medicines is one of the ways NICE is delivering benefits for patients, the NHS and the life sciences industry. The ILAP offers a genuine and significant opportunity to ensure new and innovative products reach patients across the UK, safer and quicker. The event was attended by 15 companies and 20 attendees and a vibrant discussion and debate ensued.

In 2021 we have invested in streamlining membership renewal and have updated our Membership benefits offering. A member's survey was undertaken and partnership development meetings were held with each member company to better understand their needs and wishes in relation to Companies Forum and to inform future development. There are 15 current company members of the Forum, three of which joined in 2021. Two patient group representatives are also honorary members to provide the patient voice at meetings.

OTHER ACTIVITIES

Other events and communications

CRDN continued to take part in a wide range of events, editorial and awareness raising opportunities as speakers, media partners, chairs of panels, interviewees and writers. These events have spanned the pharmaceutical industry, patient groups, healthcare professionals and the public media.

Grant funding from the Evolution Education Trust grant has underpinned a marketing plan over the financial year and supported our efforts to deliver on our charity objectives in a structured, impactful and meaningful way to encourage sustainable growth, reach new audiences, and better engage them. Developing our brand, our website and marketing materials for events has had significant impact. Increased visibility has led to many rich and productive conversations and resulted in increased collaborations and successful sponsorship funding. Online donations to the charity have continued to rise, we have recruited three new Companies Forum members, and £163,501 income has been generated from sponsorship, grants, and donations in 2021.

We continued to redevelop aspects of the CRDN website, creating mini-sites within the central platform for our major events, substantially advancing traffic to the site and event registrations. Work was undertaken to improve the user experience for corporate visitors and local families, to build a more intuitive/searchable resources section, and to showcase the work we do, which will continue into 2022. Development of the CRDN website has led to 12,873 new users on the platform this year, with over 16,000 page visits during the peak three month marketing activity preceding our RAREsummit event.

We invested in recording and editing of all RAREsummit21 live talks and panel discussions creating a legacy of rich content on our YouTube channel and website which showcases our work and continues to deliver impact. This resource has increased our ability to educate and raise awareness on a much broader scale.

Communications continue to be a central part of our work in advocacy, raising awareness, connecting the broader rare disease community and the public. We were delighted to work with two new communications officers this year who are parents of children living locally with a rare condition. They helped shape our social media and regional community communications, ensuring the patient voice is at the heart of our messaging.

Partnerships and Patient Voice

Partnership highlights for 2021 include collaborative projects with the Eastern Academic Health Science Network, Prime Global People, Costello Medical and Medidata, as detailed earlier in the report. We are delighted to continue collaborations with all of these organisations into 2022 as we strive to develop innovative and collaborative ways to improve the rare patient journey together.

We strengthened relationships within our regional healthcare network, undertaking focus groups and holding discussions on patient passports, transitions to adult care and care coordination. We look forward to circulating and finding ways to act on the final report developed by Costello Medical in partnership with CRDN and Findacure charity on transitions, due for publication in early 2022. We are building a meaningful relationship with the Cambridge Children's Hospital development team to ensure the new hospital, due to be built in 2025, meets the needs of children and young people with rare and undiagnosed conditions.

We maintained relationships with corporate partners that have provided pro bono support to CRDN over the year and some financial assistance. Healx, Costello Medical Consulting, InterComm International and Prime Global People have all donated valuable skills, support and time to our work over this year in event planning, report writing and graphic design.

Our Unique Feet families enjoyed supporting Cambridge based diagnostics company Illumina with an art project for Rare Disease Day and we have worked with the company on a short film telling the story of an ultra rare patient group, Ring20 Research and Support, and their collaboration with this tech giant Illumina on a two year project to unravel the Ring20 genome. This project stemmed from CRDN's RAREsummit19 when we invited the charity's CEO to speak and pose the challenge of diagnosis of this complex condition to the audience.

We continued our partnership with PharmaFocus and Pharmaphorum Magazines to bring monthly patient experience stories to their readership. Recently we were delighted to hear that Timothy Syndrome Alliance group in the UK was contacted by a health professional in Australia about a family they had recently diagnosed with this condition after reading the patient insight article in PharmaFocus. The family have now been signposted to the community for support.

We continued to work closely with a range of medical and genomics students from Cambridge University and further afield who supported our Rare Hospital Passport project and RAREsummit21 marketing, communications, and report writing.

Our work relies on partnerships with other stakeholders within our network. We consolidated these friendships during the COVID-19 pandemic to establish the ARDEnt group mentioned earlier in this report which continues to attract new members and interest.

It is also noteworthy that CRDN's events rely on the support and collaboration of our many friends and partners throughout the rare disease world. At RAREsummit21, some 35 media partners, including leading rare disease charities from the UK, Europe and the US, Cambridge based Wellcome Genome Campus and Babraham Research Institute, and a wide range of companies joined our quest to raise awareness and promote this event.

Overall, CRDN has continued to deliver clear and quantifiable benefits to a wide range of rare disease stakeholders. Virtual platforms enabled a global reach for our events programme and communication campaigns. We have delivered more opportunities for cross-sector collaboration, which are beginning to provide real impact and outcomes. Growth in demand for our local community services due to the isolation imposed on many through COVID-19 shielding has seen CRDN support an increasing number of families affected by rare conditions. We welcomed more patient groups, companies, medical and scientific organisations into the network. By refining the delivery of existing projects, whether empowerment, community building, or scientific, the charity has built a robust service offering with a strong reputation for patient engagement.

This progress forms a strong foundation for securing more company funding partnerships grant funding in 2022 and increase our reach and engagement with rare disease stakeholders and the broader public in the UK and beyond.

Financial Review

This is the 6th year of charity activity, and a lot was achieved, despite testing times.

Funding continues to be mainly raised through corporate sponsorship and grant funding with a lesser but increasing amount through community fundraising and online donations. Most paying Companies Forum members obtained membership through gold and diamond sponsorship packages for RAREsummit.

The most significant contributors to income for this year's charitable activities were for RAREsummit and grant funding from the Evolution Education Trust.

A strategy day will be held in early 2022 to review the long term plan and fundraising strategy to achieve sustainable resources and facilitate growth. This will build on the charity's strengths in accessing sponsorship and community activity grants whilst formulating a three year plan to achieve a third of its funding through Companies Forum membership fees and events. The charity is also exploring new opportunities for project-based grants and community fundraising to support its regional community group's growth and next steps. During this financial year, CRDN moved to a new accountant with specific expertise in charity finance. The Managing Director is responsible for the day-to-day running of finances, overseen by the Treasurer and trustee signatories during this financial year. Responsibility for payroll, pension payments, and quarterly management accounts now lies with Community 360 accounting following our move from Number Ninja 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. If the funding position changes as the charity evolves, the management team will review the current investment policy.

Reserves Policy

The charity's management team work 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 was £178,531.

Structure, Governance and Management

Governing Document

The organisation is a charitable company limited by guarantee, incorporated on 28 September 2015 and registered as a charity on 5 April 2016. The company was established under a Memorandum of Association that established the charity company's objects and powers and is governed under its Articles of Association. In the event of the company winding up, members must contribute an amount not exceeding £10.

Trustee Induction and Training

Some of CRDN's Trustees are involved as board members of other organisations and bring their previous experience and expertise. There has been no change in the Trustee team over 2021. New trustees with little prior experience of the role should attend CCSV Trustee training. Following a revamp of the charity's equality and diversity policy in 2020, the board will be exploring how to ensure an inclusive, representative and broad group of trustees at our strategy day. In addition, they will undertake a skills audit of the Board to identify gaps how the can be addressed through Trustee recruitment.

Organisation

The board of Trustees, which has no maximum number of members and is currently seven members administer the charity. The board has continued to meet six times a year. The Operations team, which consists of the Chair, one trustee and the Managing Director, meets more regularly to facilitate effective operations.

Pay Policy for Senior Staff

It is the charity's policy that Trustees give their time voluntarily and receive no benefit from the charity. Minimal travel expenses were reclaimed from the charity by one trustee in the last financial year. CRDN currently has one employed member of staff, the Managing Director. We pay for all other services at agreed contracted rates.

Risk Management

As CRDN is still in its early years, the risks it is exposed to should be at a minimum as committed spend and running costs are still relatively low. However, we expect this to increase in the next couple of years. A financial software package was implemented in 2016 to support the charity's growth, aiming to help manage its increasing transaction complexity.

CRDN had a successful year financially but further work is needed to ensure continued stability and growth in the coming financial year. Two year seed funding from the Evolution Education Trust to cover the full-time employment of the Managing Director came to an end in autumn 2021. Hence, a plan for sustainable funding through Companies Forum, corporate partnerships, and project grant funding to cover this is essential.

Responsibilities of the Trustees

The Trustees (who are also directors of Cambridge Rare Disease Network for the purposes of company law) are responsible for preparing the Trustees' Report and the financial statements following applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each fiscal year. Under company law, the Trustees must not approve the financial accounts unless they are satisfied they give an accurate and fair view of the state of affairs of the charitable company for that period - specifically its incoming resources and application of these.

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 the 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. They must ensure that the financial statements comply with the Companies Act 2006. Trustees are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT
FOR THE PERIOD ENDED 31 DECEMBER 2021

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

Dr Gemma Chandratillake

Chair and trustee Date 15th March 2022

Organisation Details

Registered Office: Bcs Windsor House, Station Court, Station Road, Great Shelford, CB22 5NE

Registered Company Limited by Guarantee 9798317- Registered on 28th September 2015
Registered Charity number-1166365- Registered on 5th April 2016

Trustees

Prof Alan Walter Barrell (appointed 28/09/2015 - resigned 03/12/2019)

Dr Tim Guilliams (appointed 28/09/2015)

Dr Sarah Leiter (appointed 05/06/2017)

Dr Gemma Chandratillake (appointed 15/05/2017 - appointed Chair 03/12/2019)

Dr Ron Jortner (appointed 23/01/2019)

Dr Jonathan Milner (appointed 23/01/2019)

Mrs Susan Berry (appointed 29/07/2019)

Prof Tim Cox (resigned 03/12/19)

Ilan Chaitowitz (appointed 03/12/2019)

Management and Operations

Managing Director – Jo Balfour (employed)

Events and Marketing Executive – Lindsey Brown (contracted)

Graphic and web design – Suzanne Morris (contracted)

Communications support – Creative Warehouse (contracted)

Social media - Vaila Morrison (contracted)

IT support – George Nicolau (contracted)

ARDEnt COVID Impact report - Keele Uni Interns and Intercomm International Ltd (pro bono)

Rare Patient Passport and Transition to adult care reports - Costello Medical (pro bono)

Company Secretary - BCS Accounting Ltd

Accounting - Emma James, Number Ninja (Sept 2020 - Dec 2020), Community 360 (Jan 2021 - present)

Independent Accounts Review - Community360

CAMBRIDGE RARE DISEASE NETWORK

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2021

	Notes	Unrestricted funds £	Restricted funds £	2021 Total £	2020 Total £
Incoming resources					
Incoming resources from generating funds:					
Donations and legacies	**2**	10,534	500	11,034	82,846
Charitable activities	**3**	123,523	28,945	152,468	79,665
Total incoming resources		**134,056**	**29,445**	**163,501**	**162,511**
Resources expended					
Charitable activities	**4**	32,054	71,157	103,210	164,179
Total charitable expenditure		**32,054**	**71,157**	**103,210**	**164,179**
Net incoming/(outgoing) resources before transfers		**102,003**	**(41,712)**	**60,291**	**(1,667)**
Transfer between funds		-	-	-	-
Previous year adjustment		-	1,355	1,355	-
Net income/(expenditure) for the year/ Net movement in funds		102,003	(40,356)	61,646	(1,667)
Fund balances at 1 October 2020		76,528	54,273	130,801	132,469
Fund balances at 31 December 2021		**178,531**	**13,917**	**192,447**	**130,801**

The Statement of Financial Activities includes all gains and losses recognised in the year.

The notes on pages 7-11 form part of these financial statements.

CAMBRIDGE RARE DISEASE NETWORK

BALANCE SHEET
AS AT 31 DECEMBER 2021

	Notes	2021 £	2021 £	2020 £	2020 £
Current assets					
Debtors	**6**	5,771		10,121	
Cash at bank and in hand		189,891		131,708	
		195,662		141,829	
Creditors: amounts falling due within one year	**7**	(3,215)		(11,028)	
Net current assets			192,447		130,801
Total net assets			**192,447**		**130,801**
Income funds					
Restricted funds	**9**		13,917		54,273
Unrestricted funds			178,531		76,528
			192,447		**130,801**

The Charity was entitled to exemption from audit under section 477 of the Companies Act 2006.

The members have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.

The Trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and preparation of financial statements.

The financial statements have been prepared in accordance with the provisions applicable to entities subject to the small companies regime.

The financial statements were approved and authorised for issue by the Trustees on …15.7.22……………
……….. and signed on their behalf by:

Signed ______________________ Date 15.7.22
Dr Gemma Chandrtillake

The notes on pages 7 - 11 form an integral part of these financial statements.

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 Practise 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) and the Companies Act 2006.

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 Internation 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.

1.5 Fund accounting

General funds are unrestricted funds which are avaliable 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 restrcitions 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 objectivies, 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 investements with a short maturity of three months or less from the date of acquistion 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 Tangible fixed assets and depreciation

Tangible fixed assets are initially recognised at cost. After recognition, under the cost model, tangible fixed assets are measured at cost less accumulated depreciation and any accumulated impairment losses. All costs incurred to bring a tangible fixed asset into its intended working condition should be included in the measurement of cost.

Depreciation is charges so as to allocate the cost of tangible fixed assets less their residual value over their estimated useful lives, using the straight-line method.

2 Donations and legacies

	Unrestricted Funds	Restricted Funds	2021 Total £	2020 Total £
Donations and gifts	10,534	500	**11,034**	**66,415**
	10,534	**500**	**11,034**	**66,415**
TOTAL 2020	**11,867**	**70,979**	**82,846**	

3 Charitable activities

	Unrestricted Funds	Restricted Funds	2021 Total £	2020 Total £
Delegate Sales	15,000	-	15,000	4,179
Grants	-	28,945	28,945	26,898
Sponsorship	95,000	-	95,000	48,000
Other	13,523	-	13,523	587
	123,523	**28,945**	**152,468**	**79,665**
TOTAL 2020	**53,298**	**26,366**	**79,665**	

4 Resources expended

	Unrestricted Funds	Restricted Funds	2021 Total £	2020 Total £
Staff costs	4,276	49,095	53,371	59,651
Depreciation	-	-	-	-
Accomodation	33	-	33	62
Admin support	652	5,768	6,420	12,517
Advertising & marketing	22,141	5,346	27,487	20,858
Accountancy fees	300	1,355	1,655	10,470
Bank fees	66	-	66	93
Consulting	-	-	-	20,664
General expenses	77	73	150	40
Independent examination	-	-	-	3,426
Insurance	528	-	528	840
IT software & consumables	963	260	1,223	1,725
Legal expenses	-	-	-	356
Postage, freight & courier	19	-	19	603
Staff training	-	173	173	340
Subscriptions	493	-	493	382
Travel	167	109	276	2,129
Venue & catering	114	4,030.82	4,145	21,666
Website design & admin	2,225	4,946	7,171	8,356
	32,054	**71,157**	**103,210**	**164,179**
TOTAL 2020	**44,723**	**119,456**	**164,179**	

5 Staff costs

	2021 Total £	2020 Total £
Wages and salaries	52,068	58,159
Pension costs	1,303	1,492
	53,371	**59,651**

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

	2021 No.	2020 No.
Employees	1	**1**

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

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.
During the year, Dr Ron Jortner received reimbursement of expenses totalling £26.44
(2020: no trustees/£Nil).

6 Debtors

	2021 Total £	2020 Total £
DUE WITHIN ONE YEAR		
Trade debtors	5,650	10,000
Prepayments and accrued income	121	121
	5,771	**10,121**

7 Creditors: amounts falling due within one year

	2021 Total £	2020 Total £
Trade creditors	1,614	1,429
Other creditors	1,301	389
Accruals and deferred income	300	9,210
	3,215	**11,028**

8 Deferred income analysis

	2021 Total £	2020 Total £
Deferred income at 1 October 2020	5,420	5,420
Resources deferred during the year	-	5,821
Amounts released from previous periods	(5,420)	(5,420)
	-	**5,821**

9 Statement of funds

	Balance at 1 October 2020 £	Income £	Expenditure £	Transfers In/out £	Balance at 30 December 2021 £
UNRESTRICTED FUNDS					
General funds - all funds	76,528	134,056	32,054		178,531
RESTRICTED					
National Lottery	8,913	-	4,368	-	4,545
Evolution Edication Trust (marketing)	2,749	25,000	15,618	-	12,131
Evolution Edication Trust (operations)	42,050	-	48,749	-	- 6,699
CCF	431	-	402	-	29
People's Health	-	845	-		845
Unique Feet	130	3,600	272	-	3,458
Total restricted funds	**54,273**	**29,445**	**69,408**	**-**	**14,310**
Total funds	130,801	163,501	101,462	-	192,840

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. purposes.

Evolution Education Trust (operations) - the purpose of this donation is to fund the full-time employment of the Operations Manager of the charity to allow the charity a period of stability and time to generate more regular sources of income. The funds also fund the Operations manager's training and attendance at relevant conferences and events in order to raise the profile of the charity.

10 Analysis of net assets between funds

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £
Fund balances at 31 December 2021 are represented by:			
Current assets	98,638	13,917	112,555
Creditors: amounts falling due within one year	(3,215)	-	(3,215)
	95,423	**13,917**	**109,340**

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) £180 (2020: £9,383) 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 (2020: £800) 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 restricted grant from Evolution Education Trust for £25,000 (2020: £65,200) One of the trustees of Evolution Education Trust, Dr J S Milner is also a trustee of CRDN.

CAMBRIDGE RARE DISEASE NETWORK

England & Wales - Charity number 1166365

Accounts

CAMBRIDGE RARE DISEASE NETWORK

Company Registration number 09798317
Charity Registration number 1166365
FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2020

CAMBRIDGE RARE DISEASE NETWORK

CONTENTS
FOR THE PERIOD ENDED 31 DECEMBER 2020

CAMBRIDGE RARE DISEASE NETWORK

REFERENCE AND ADMINISTRATION INFORMATION FOR THE PERIOD ENDED 31 DECEMBER 2020

Charity number	1166365
Company number	09798317
Principal Address	C/o BCS Windsor House Station Court Station Road Great Shelford Cambridge CB22 5NE
Trustees	Dr T Guilliams Dr G Chandratillake Ms. S L Berry Dr J S Milner Dr R A Jortner Dr S M Leiter Mr I M Chaitowitz
Company Secretary	BSC Cosec Ltd.
Operations Manager	Mrs J Balfour
Independent Examiner	Community360 Winsley's House High Street Colchester Essex, CO1 1UG

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT
FOR THE PERIOD ENDED 31 DECEMBER 2020

The trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 December 2020. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts following the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

Charity Objectives and Activities

Cambridge Rare Disease Network 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: To create regional networks to improve the rare disease journey

Our Aims:

- Stimulate cross-sector cooperation.
- Make support available for families.
- Raise awareness of the rare disease journey.

Charity Objects as recorded with the Charity Commission

1) 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.

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

Significant activities

Creating Networks to Improve the Rare Disease Patient Journey

In the EU, a rare disease is defined as a condition that affects less than one in 2,000 people. Currently, over 7,000 rare diseases have been identified, which collectively affect one in 17, amounting to 3.5 million people in the UK. Of these diseases, 80 % are genetic in origin, 50 % affect children, and only 5 % have an approved treatment. Despite this high prevalence, each condition affects so few people that they tend to be overlooked and misunderstood by health professionals, researchers, education and social care providers and the general public. This lack of awareness and information commonly leads to the “Diagnostic Odyssey”, where it takes an average of 4.8 years and 7.3 physicians to reach the correct diagnosis, and delays and misdiagnosis are common. This lack of awareness also impacts patients receiving appropriate care, support in school and the workplace, leads to isolation for patients and families and creates a high social burden of care (Source: Engel et al., JRD, 2013.

Despite advances in recent years, progress in diagnosis, developing treatments and assuring coordinated care continue to prove challenging and is affected by low patient numbers per disease, lack of education in rare diseases for healthcare professionals, difficulty recruiting enough patients for clinical trials, insufficient economic incentives, high cost of treatment, tribulation in reimbursing, low awareness of conditions and poor scientific understanding of disease mechanisms.

Events, forums and communications

At CRDN, we are challenging this lack of awareness by delivering a range of visionary events and forums and a bold and proactive online communications presence.

Events

We hold stakeholder and public-facing events to bring the challenges of the rare disease journey to the fore, provide a platform for engagement, and nurture impactful collaboration.

Regional Community Forum

We build a regional, connected, engaged, and empowered network of people affected by rare diseases to have a stronger voice collectively. Our community-building activities reduce isolation and give patients and their families the confidence to engage with other stakeholders as experts in their own or their children’s health and care.

Companies Forum

We are building a network of Companies, healthcare professionals and researchers who can improve treatments and create technology solutions to enhance rare patients’ lives. We are embedding the patient voice and providing the scaffolding and platforms to help connect these groups and encourage collaborations to flourish.

Communications

We use our communications strategy to highlight patient stories through a range of online, broadcasting and paper media channels. We engage new audiences through our online media campaigns and our events. We hope to secure additional, continued funding and donations by highlighting our cross-sector, collaborative and proactive approach.

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.

Achievement and Performance October 2019 – December 2020

Significant Activities

RAREsummit19

The focus of the autumn season of 2019 was CRDN’s 4th RAREsummit held at the Wellcome Genome Campus in Cambridgeshire. The theme of the event was ‘Patients as Partners’. We set out to build on the success of our previous Summit, where we demonstrated that personal stories have the power to change hearts and minds and make a real difference. In 2017, our vehicle for personal stories was the patient journey poster exhibition; in 2019, we firmly gave patients the stage. The patient voice was central to every talk and panel discussion, highlighting how collaborative partnerships with industry and healthcare professionals result in inspired thinking and better outcomes for all.

To encourage collaboration between all attendees, we introduced a hackathon with the aim of cross-sector groups working together to agree on their priorities for the UK's Rare Disease Strategy of the future. It was an honour to have Baroness Nicola Blackwood, then Parliamentary Under-Secretary of State at the Department of Health and Social Care, address the delegates and introduce the hackathon challenge. Teams worked together to develop their priorities and workable solutions. Project ideas were pitched to the whole audience and voted on. The impact of RAREsummit continued beyond the live day with the generation and dissemination of the captures of these hackathon solutions and recommendations in a report shared with Government policymakers.

We were delighted to welcome 259 attendees to the summit, a 73 % increase since our inaugural conference in 2015. We were particularly pleased with the 425 % increase in patient groups represented with 105 attendees from this sector showcasing 20 patient journey posters and hosting 20 exhibition stands amplifying the patient voice and providing opportunities to network amongst a host of rare disease stakeholders. We also saw a remarkable increase of 725 % in health professional attendance – vital in ensuring the medical profession is kept abreast of developments in rare diseases.

Feedback on the event was consistently positive, with 97 % of delegates rating the event as excellent or very good and the same percentage would recommend RAREsummit to others. Interaction and engagement with the event were high, with 70 % of attendees having made positive connections which they planned to follow up. Some 2,262 interactions were logged on the event platform, Glisser, which allowed delegates to post questions on screen, download speaker slides, complete real-time polls and share slides via social media.

It has also been rewarding to track the event's impact on a particular ultra-rare patient group, Ring20 Research and Support. Their CEO presented at the event and posed a challenge to delegates – to find a way to unravel the Ring20 genome, a challenge which whole genome sequencing has yet to crack. As a direct result, this patient group has now entered into a scientific partnership with Illumina Inc, Cambridge based sequencing experts, to unravel the genomes of r(20) patients to identify new cases and develop an effective diagnostic test. The CEO of Ring20 Research and Support said, "We're starting a new international scientific collaboration which evolved from discussions with companies following my being a speaker at your CRDN RAREsummit. It also involves another company who we met through CRDN's invite for me to present at your Companies Forum – so your events have a HUGE amount of value to us!"

RAREsummit is a vital element of CRDN's fundraising strategy through sponsorship and ticket sales. Summit sponsorship in 2019 totalled £59,000 from 10 funders and ticket sales £16,785. We also received £15,558 pro bono support to create the hackathon report from a Health Communications company. The event caught regional media attention and was featured on the 6 o'clock BBC Look East news and generated several local news articles. We commissioned filming all live talks and panel discussions for the first time at one of our events—a definite breakthrough in reaching a wider audience. To date, RAREsummit19 talks recordings have been watched 1445 times on our YouTube channel.

Collaborating through COVID – the formation of ARDEnt (Action for Rare Disease Empowerment)

In March 2020, the COVID-19 pandemic turned many of our planned events and activities on their head, so we reacted swiftly and adapted. Early on, CRDN's Managing Director, Jo Balfour, partnered with two other rare disease charity CEOs to develop and lead on a COVID-19 response group of 30 cross sector advocates, including patient groups, industry, healthcare and policy experts. CRDN's Chair, Dr Gemma Chandratillake and trustee Dr Ron Jortner also took part. The aims were to shed light on the unseen impact of the pandemic on people living with rare conditions, to protect existing services for people living with rare diseases, and to learn lessons.

The team gathered information, insights and evidence on critical themes – diagnosis, care and drug development - then collated a report. This report, 'Making the Unseen Seen' published on 5 May 2021 and launched through a multi-stakeholder webinar, reveals the impact of the pandemic on every stage of the patient journey, from diagnosis to eventual management. It catalogues the re-assignment of specialists away from a rare disease, the fear of infection, the closure of clinics, the fracture of coordination of health and social care, and the delay or termination of clinical studies. At the same time, the pandemic has accelerated the evolution of remote monitoring, the adoption of video calling and virtual appointments. Finally, this report makes nine recommendations that should bring patients with rare disease into the light and make their management more robust for the future.

We were honoured to partner with such a diverse and passionate group of rare disease advocates and experts at a time when our community needed us most. We look forward to continuing this collaboration and influencing the UK's new Rare Diseases Framework implementation plans in 2021.

ARDEnt is not a formally recognised organisation and therefore has no funding. All contributors took part voluntarily. CRDN successfully commissioned a Cambridge Health Communications company that provided £16,000 of pro bono support to create the final report.

RAREfest20

In true 2020 style, RAREfest20 was a virtual feast that sparked curiosity, challenged perceptions, inspired innovation and collaboration and gave a voice to rare disease patients and their families. Planning for a two day in-person RAREfest event to follow on from the award-winning inaugural RAREfest in 2018 had begun in January 2020. Detailed plans were underway when COVID-19 struck and ended any hopes for a face-to-face festival. After several months of exploring virtual platforms, we decided to host RAREfest20 online using an interactive virtual platform. An excellent decision as the platform provided the perfect space for a vibrant, interactive, public-facing event overcoming any concerns regarding safety and dismantling the traditional barriers of travel, affordability and accessibility.

The live programme featured leading scientists, technology experts, patients, and advocates worldwide discussing and demonstrating the latest advances and thinking in rare disease research, treatments, diagnosis, and support. We were delighted to showcase over 50 rare diseases, research projects, tech initiatives and arts projects through 21 interactive exhibits, 25 posters and films and 36 speakers and 18 performers. A particular highlight was the involvement of 28 young people who hosted quizzes, panel discussions, live cookery demos, and our own Unique Feet children's group performance of their 'Chameleons' piece telling the story of their journey as a community through the lockdown.

Attendees were able to develop their knowledge and meet others from the comfort of their own home, lab or office. As a result, we saw over 1000 people attend from 185 towns and cities in the UK and 41 countries globally. An overwhelming 91 % of respondents thought RAREfest20 was very good or excellent, 96 % rated the organisation very good or excellent, 63 % came away feeling even more interested in rare diseases. This was especially pleasing as 41 % of attendees had never attended a rare disease event before. Also, 65 % made good connections with academics, industry, media, investors, patients and the public, proving fruitful for their work. Despite, or perhaps because of the virtual format, interaction and engagement with the event were high. Some 6616 actions took place through the platform, including conversations in chat rooms, downloading resources to swag bags, watching talks and films and posing questions to speakers during live sessions.

Some 63 media partners supported CRDN to undertake an effective three month awareness-raising campaign on social media in the run up to RF20. All live content was recorded and uploaded to the vFairs platform for 30 days and our YouTube channel for future viewing. Media interest included one TV segment, five newspaper articles and 27 blog posts.

RAREfest is a vital source of funding for CRDN and received £10,000 of grant funding and £48,000 of sponsorship from 8 organisations. Tickets were free, and we received £1267 of donations from attendees. We received further pro bono support from three companies, a team of eight students from the Universities of Cambridge and Keele, and an additional 12 volunteers.

We were humbled and proud to win an award at the Pharma Market Europe Awards (PMEA) in Nov 2019 for our inaugural RAREfest. “This year, the judges decided that they wanted to recognise two particular entries that stood out as interesting, fresh and different. Both these entries had great merit beyond the criteria for the categories in which they were entered. They both demonstrated breakthrough thinking and facilitate hope for future care. The two winners of this impressive award were Cambridge Rare Disease Network and Havas Life Medicom for their entry RAREfest, and King’s College London and Four Health for the GLAD I Took Part campaign.” Dr Paul Stuart-Kregor, PMEA chair of judges.

Unique Feet Community Group

In October 2019, the two year grant funding from The People's Health Trust to facilitate the expansion of our ‘Unique Feet’ local community group expired. CRDN secured £13,290 grant funding from Cambridgeshire Community Fund and the National Lottery COVID Fund, along with several smaller donations, allowing us to respond swiftly and with agility to the emerging COVID -19 pandemic situation.

The group continued to flourish despite the complex situation. All original members continued to attend, and membership increased from 12 families and 36 beneficiaries in 2018 to 20 families and 70 beneficiaries during 2020. Most Unique Feet children were added to the COVID ‘extremely clinically vulnerable ‘ list, and consequently, families were directed to shield by the Government. We delivered group activities online to keep families connected, active and supported during this challenging and isolating time. These activities included yoga, pottery making, ‘Meet the Meerkats’ provided by a local zoo and regular social Zoom meetups for parents. Grant funding enabled us to deliver monthly activity bundles filled with cooking, STEM, arts and crafts and gardening activities. Whole families took part and shared their creations via the community social media groups. The parents WhatsApp group, monitored by CRDN, served as a portal for sharing experiences, giving guidance, letting off steam and keeping each other motivated and in good spirits. During periods of lighter restrictions, we met as a group in beautiful, therapeutic, outdoor spaces. The local privately run Challis Gardens allowed us to use their space exclusively to give the children a safe place to play and explore freely. Unable to meet to develop their planned dance performance for RAREfest20, the group instead created a series of short films chronicling their lockdown journey as a team. The resulting film was the finale of the RAREfest20 programme and has been watched by hundreds since.

During this lull in face to face activities, CRDN recruited six students from the Cambridge University Impact Hub to create a five year Unique Feet impact report. Families reported that this opportunity to reflect on the difference the group had made to their family was an uplifting time for them. We were delighted with the resulting report used in funding applications and recruiting new members. The experience led to the group organising a strategy session to discuss and share ideas about future activities and services they would like to see CRDN develop. We will be reviewing and acting on some of these in 2021/22.

Families also worked with CRDN to develop a Rare Hospital Passport. This resource evolved to support patients with rare diseases, particularly those with communication difficulties, who, in the context of COVID-19, experienced strict limitations on visitors and may find their usual medical team redeployed. We have received pro bono design support from Costello Medical to finalise this and roll out the passport for more general use to the whole rare disease community in 2021.

Unique Feet parents continued being the voice of rare disease in our community, despite the pandemic. Parents have developed a new monthly community newsletter, joined the Cambridge Children's Hospital Network to help shape the design of this new resource, and undertook interviews for several news stories in local papers, pharmaceutical journals, and BBC Look East. Some parents have been speakers at conferences and events to tell their rare disease journey story. We are beginning to see the true impact of building a regional community and the influence these collective voices can have in shaping local health, social care and education policy and plan to continue to give families a range of platforms to have a voice.

Companies Forum

Companies Forum has continued to make progress over the last year. In person meetings were held at the Royal Society of Medicine in November 2019 and March 2020 with speakers from Oxford University, NICE, and regulatory bodies, and included a panel of patient experts for the first time. In October 2020, we also held a virtual meeting exploring the impact of the COVID-19 pandemic on clinical trials and opportunities for more patient-centric, decentralised trials for the future. There were 24 attendees at each meeting representing 15 companies and three patient groups. We are delighted that one of these patient groups has developed a promising scientific partnership with a Companies Forum member. Two new companies joined the Forum in 2020, and ten companies continued their membership. We delivered two half-day meetings in 2020, one in person and the other virtually. Recruitment of a more significant number of new companies was hindered by not carrying out our usual networking at live pharma industry events and caution from some companies to invest funds during uncertain times. Plans for 2021 include developing a patient group and industry partnering events to complement the traditional Companies Forum roundtable meetings. We aim to recruit more paying company members to provide a sustainable income source for CRDN and facilitate the development of a paid role to manage the Companies Forum events and develop and nurture corporate partnerships.

Other Activities

Rare Disease Day Rare-i-Tea Party

To mark the annual International Rare Disease Day on 28 February 2020, which seeks to raise awareness about rare diseases amongst the public and policy-makers, CRDN held a public community event. CRDN's Unique Feet group hosted the event, providing fun science and sensory activities, rare disease information stands and films, a quiz and arts activities. A great mix of 130 people attended, including leading rare disease clinicians from Addenbrookes Hospital and several affected families from the local area and from as far afield as Norwich and Hertfordshire. Two local families who attended have since become members of our Unique Feet group.

This awareness-raising event received a £900 grant from National Lottery 25 and raised £500 in cake sales and donations. CRDN further spread the word about rare diseases through 3 regional radio and TV interviews about the event and Rare Disease Day more generally.

Communications and Marketing

CRDN received grant funding from the Evolution Education Trust to develop its communications and marketing programme over the financial year. We have utilised this grant to the max, forging ahead with a breadth and intensity of activity that has projected us into a peak position in the rare disease landscape, regionally and nationally and on the European and world stages. Our unique branding, messaging, and creative approaches to communications have solidified an increase in reach and engagement that stands us in good stead for the next phase of our development.

Although packed away since April 2020, we developed marketing collateral for exhibition purposes enabling CRDN to be very visible and approachable at events for the first time. We hosted exhibition stands at three conferences pre COVID lockdown. Our designer then skillfully adapted our physical collateral for virtual exhibition spaces Q.3 and Q.4. We exhibited at a further three events where we had many rich and productive conversations leading to collaborations and successful sponsorship funding. It has increased online donations to the charity, led to the recruitment of two new paying Companies Forum members, and £135,052 income from sponsorship, grants, and donations to RAREsummit19 and RAREfest20. In 2021/22, we intend to explore additional exhibition options to recruit new members to our Unique Feet community, be visible to prospective funders, and compel new corporate partners to join our Companies Forum.

The funding enabled us to redevelop aspects of the CRDN website. We created mini-sites within the central platform for our major events, substantially advancing traffic to the site and event registrations. We improved the user experience for corporate visitors and local families, built a more intuitive/ searchable resources section, and showcased the work we do, which will continue into 2021/2022. Development of the CRDN website has led to 12729 users on the new platform this year, with over 6403 during the peak three month period in the run up to our RAREfest event where our marketing campaign was most active.

We invested in professional filming and editing of all RAREsummit19 talks, hackathon and RAREfest20. This wealth of rich content on our newly established YouTube channel and website resources section showcases our work brilliantly. It has led to 60 new subscribers on our YouTube channel and 2760 video views compared with 243 views the previous year. Having this resource has increased our ability to educate and raise awareness on a much broader scale.

This grant has enabled us to engage marketing and communications professionals on a part-time consultancy basis. They are involved in day-to-day social media posting, blog writing, newsletters, and the creation of event media packs and schedules. Following the recruitment of communications support from Rare Revolution in August 2019 and ex BBC Reporter Anna Todd in September 2020, we have successfully delivered fortnightly news and blog posts to our website and a monthly newsletter to our now 2175 strong mailing list. During this reporting period, non-profit average open rates, according to our newsletter platform Mailchimp, are 18 %, whereas ours show favourable engagement rates averaging 33.68 %. Our targeted newsletters to segments of our audience are twice as effective. We developed a LinkedIn Company page. In 2020 we scaled up our online presence: we created a CRDN Google Company page with links, events, photos and posts, and this has become the second most popular entry point to our website after direct traffic. We opened an Instagram account and created new graphics for use through this channel to attract a younger and more global audience. We have gained over 900 followers this year and have seen good interaction. We resurrected a dormant closed Facebook group where families share photos of their activities for our Unique Feet families. We use this platform to create Unique Feet events pages.

During the most intense promotional period from 1 September – 1 December for RAREfest20, the CRDN Twitter account increased by 312 followers (7.2 %) to over 5000. Our average post engagement is 166 % better than other non-profits, according to Rival IQ benchmark data 2020. This takes into account retweets, comments, clicking on tweet links and mentions. MR Benchmarks found in 2020 that for every 1000 email subscribers, a non-profit has an average of 806 Facebook followers. CRDN had 1151 Facebook followers and 2175 email subscribers at the end of December 2020. The average non-profit Facebook follower annual growth is 6 % compared to our 28.6 % growth this last year.

The EET grant has underpinned a marketing plan over the financial year and supported our efforts to deliver on our charity objectives in a structured, impactful and meaningful way to encourage sustainable growth, reach new audiences, and better engage them.

Partnerships

We have maintained relationships with corporate partners that have provided *pro bono* support to CRDN over the year and some financial assistance. Healx, Costello Medical Consulting, InterComm International, Havas Life Medicom, Life Science Integrates and SWI:ICH Health have all provided valuable support to our work over this year. Our partnership with Havas Life Medicom resulted in the prestigious Pharma Market Europe Award for RARfest18.

We have continued our partnership with PharmaFocus Magazine to bring monthly patient experience stories to their readership and have developed a new editorial collaboration with Pharmaphorum Magazine. Students from Cambridge University Impact Hub and Keele University Internship programmes bolstered our marketing, communications, and report writing capacity.

Our work relies on partnerships with other stakeholders within our network. We consolidated these friendships during the COVID-19 pandemic to establish the ARDEnt group mentioned earlier in this report.

It is also noteworthy that CRDN's events rely on the support and collaboration of our many friends and partners throughout the rare disease world. At RAREfest20, some 65 media partners, including leading rare disease charities from the UK, Europe and the US, Cambridge based Wellcome Genome Campus and Babraham Research Institute, other major science festivals and a wide range of companies joined our quest to raise awareness and promote this event to the public.

Overall, CRDN has continued to deliver clear and quantifiable benefits to a wide range of rare disease stakeholders. Virtual platforms enabled a global reach for our events programme and communication campaigns. We have delivered more opportunities for cross-sector collaboration, which are beginning to provide real impact and outcomes. Growth in demand for our services due to the isolation imposed on many through COVID-19 shielding has seen CRDN support an increasing number of families affected by rare conditions. We welcomed more patient groups, companies, medical and scientific organisations into the network. By refining the delivery of existing projects, whether empowerment, community building, or scientific, the charity has built a robust service offering with a strong reputation for patient engagement.

This progress will form an excellent basis for a drive to secure more company funding partnerships and long-term grants in 2021 and increase our reach and engagement with rare disease stakeholders and the broader public in the UK and beyond.

Financial Review

This is the 5th year of charity activity, and a lot was achieved, despite testing times. The RAREsummit19 and RAREfest20 events were well supported through sponsorship and attendee ticket sales and donations with positive feedback from a wide range of stakeholders. The overall net income for year 5 of activity is £162,511. The end of the financial year was amended from 30 September 2020 to 31 December 2020 to better align with cash flow relating to significant events. This decision will help avoid the situation we saw in the financial year ending 30 September 2019. Both RAREfest18 and RAREsummit19 occurred within the 12 months, giving an inflated picture of income that year.

Funding continues to be mainly raised through corporate sponsorship and grant funding with a lesser but increasing amount through community fundraising and online donations. Most paying Companies Forum members obtained membership through gold sponsorship packages for RAREfest and RAREsummit, with two standalone membership payments received.

The most significant contributors to income for this year's charitable activities were sponsorship and donations for RAREfest and grant funding from the Evolution Education Trust.

There's no doubt that 2020 was a challenging financial year for CRDN, who, like many charities, saw opportunities to raise funds through grants and community fundraising dwindle, replaced by highly competitive COVID-19 emergency grants. Corporate fundraising also saw a downturn as companies were cautious during this time of uncertainty. While funding became harder to come by, we saw a doubling in demand for our services supporting those affected by rare diseases.

A strategy day will be held in 2021 to review the long term plan and fundraising strategy to achieve sustainable resources and facilitate growth. This will build on the charity's strengths in accessing sponsorship and core funding grants whilst formulating a three year plan to achieve a third of its funding through Companies Forum membership fees and events. The charity is also exploring new opportunities for project-based grants and community fundraising to support its regional community group's growth and next steps. During this financial year, CRDN moved to a new accountant. A new trustee with professional financial experience was appointed during 2020 to fill the gap following the resignation of a trustee responsible for this area. The Managing Director is responsible for the day-to-day running of finances, overseen by the Treasurer and trustee signatories during this financial year and payroll, pension payments, and quarterly management accounts undertaken by BCS Accounting based in Shelford, Cambridge, followed by Number Ninja 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. If the funding position changes as the charity evolves, the management team will review the current investment policy.

Reserves Policy

The charity's management team work 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 was £130,373.50.

Structure, Governance and Management

Governing Document

The organisation is a charitable company limited by guarantee, incorporated on 28 September 2015 and registered as a charity on 5 April 2016. The company was established under a Memorandum of Association that established the charity company’s objects and powers and is governed under its Articles of Association. In the event of the company winding up, members must contribute an amount not exceeding £10.

Trustee Induction and Training

Many of the Trustees are involved as board members of other organisations and bring their previous experience and expertise to CRDN. One Trustee resigned in December 2019 who has provided great insight and experience in rare disease research and paediatric healthcare over the past few years. We are incredibly grateful to Professor Tim Cox from Addenbrookes Hospital and Cambridge University for his support and contribution to the charity’s development. Ilan Chaitowitz was appointed Trustee in December 2019 to provide financial expertise and guidance. The new trustee appointments have helped intensify the board's reach into the various stakeholder groups of the charity. New trustees with little prior experience of the role should attend CCSV Trustee training. Following a revamp of the charity’s equality and diversity policy in 2020, the board will be exploring how to ensure an inclusive, representative and broad group of trustees at our strategy day.

Organisation

The board of Trustees, which has no maximum number of members and is currently seven members administer the charity. The board has continued to meet six times a year. The Operations team, which consists of the Chair, one trustee and the Managing Director, meets more regularly to facilitate effective operations. Jo Balfour, appointed Operations Manager in July 2019, was made Managing Director by the board in July 2020.

Pay Policy for Senior Staff

It is the charity's policy that Trustees give their time voluntarily and receive no benefit from the charity. Minimal travel expenses were reclaimed from the charity by one trustee in the last financial year. CRDN currently has one employed member of staff, the Managing Director. We pay for all other services at agreed contracted rates.

Risk Management

As CRDN is still in its early years, the risks it is exposed to should be at a minimum as committed spend and running costs are still relatively low. However, we expect this to increase in the next couple of years. A financial software package was implemented in 2016 to support the charity's growth, aiming to help manage its increasing transaction complexity.

Many trusts and grant funders halted large and multi-year funding opportunities because of the pandemic. CRDN had submitted several applications for such grants before March 2020, which were cancelled, but successfully obtained several emergency COVID-19 grants to cover project costs in the short term. Robust financial management negated any significant impact of the pandemic. Still, further work is needed to ensure continued stability and growth in the coming financial year. Two year seed funding from the Evolution Education Trust to cover the full-time employment of the Managing Director will come to an end in autumn 2021. Hence, a plan for sustainable funding through Companies Forum, corporate partnerships, and project grant funding to cover this is essential.

Responsibilities of the Trustees

The Trustees (who are also directors of Cambridge Rare Disease Network for the purposes of company law) are responsible for preparing the Trustees' Report and the financial statements following applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).
Company law requires the Trustees to prepare financial statements for each fiscal year. Under company law, the Trustees must not approve the financial accounts unless they are satisfied they give an accurate and fair view of the state of affairs of the charitable company for that period - specifically its incoming resources and application of these.

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 the 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. They must ensure that the financial statements comply with the Companies Act 2006. Trustees are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

Dr Gemma Chandratillake

Chair and trustee Date 20th July 2021

Organisation Details

Registered Office: Bcs Windsor House, Station Court, Station Road, Great Shelford, CB22 5NE

Registered Company Limited by Guarantee 9798317- Registered on 28th September 2015
Registered Charity number-1166365- Registered on 5th April 2016

Trustees

Prof Alan Walter Barrell (appointed 28/09/2015 - resigned 03/12/2019)

Dr Tim Guilliams (appointed 28/09/2015)

Dr Sarah Leiter (appointed 05/06/2017)

Dr Gemma Chandratillake (appointed 15/05/2017 - appointed Chair 03/12/2019)

Dr Ron Jortner (appointed 23/01/2019)

Dr Jonathan Milner (appointed 23/01/2019)

Mrs Susan Berry (appointed 29/07/2019)

Prof Tim Cox (resigned 03/12/19)

Ilan Chaitowitz (appointed 03/12/2019)

Management and Operations

Managing Director – Jo Balfour (employed)

Events and Marketing Executive – Lindsey Brown (contracted)

Graphic and web design – Suzanne Morris (contracted)

Communications support – Rare Revolution Comms (until Sept 2020), Anna Todd (Sept-Dec 2020)

Social media - Vaila Morrison (contracted)

Unique Feet Coordinator – Alison Omand-Lewis (until Dec 2020 – contracted)

IT support – George Nicolau (contracted)

Event photography and film – Sebastian Peters and Ryan Nichols, Ceres Productions (contracted)

ARDEnt COVID Impact report – Keele Uni Interns and Intercomm International Ltd (*pro bono*)

RAREsummit19 Hackathon Report – Costello Medical (*pro bono*)

Marketing support RAREfest20 – Keele Uni Interns, SWI:CH Health, Cam Uni Impact Hub (*pro bono*)

Event planning support RAREfest20 - Havas Life Medicom (*pro bono*)

Accountancy and Company Secretary – BCS Accounting Ltd (until Sept 2020), Emma James, Number Ninja (Sept 2020 – Dec 2020)

Independent Accounts Review - Community360

CAMBRIDGE RARE DISEASE NETWORK

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE PERIOD ENDED 31 DECEMBER 2020

	Notes	Unrestricted funds £	Restricted funds £	15 months to 31 December 2020 Total £	2019 Total £
<u>**Incoming resources**</u>					
Incoming resources from generating funds:					
Donations and legacies	**2**	11,867	70,979	82,846	66,415
Charitable activities	**3**	53,298	26,366	79,665	174,491
Total incoming resources		**65,165**	**97,346**	**162,511**	**240,906**
<u>**Resources expended**</u>					
Charitable activities	**4**	44,723	119,456	164,179	137,047
Total charitable expenditure		**44,723**	**119,456**	**164,179**	**137,048**
Net incoming/(outgoing) resources before transfers		**20,442**	**(22,110)**	**(1,668)**	**103,859**
Transfer between funds		-	-	-	-
Net income/(expenditure) for the year/ Net movement in funds		20,442	(22,110)	(1,668)	103,859
Fund balances at 1 October 2019		56,086	76,383	132,469	28,610
Fund balances at 31 December 2020		**76,528**	**54,273**	**130,801**	**132,469**

The Statement of Financial Activities includes all gains and losses recognised in the year.

The notes on pages 7-11 form part of these financial statements.

CAMBRIDGE RARE DISEASE NETWORK

BALANCE SHEET
AS AT 31 DECEMBER 2020

	Notes	2020 £	2020 £	2019 £	2019 £
Current assets					
Debtors	**6**	10,121		32,505	
Cash at bank and in hand		131,708		125,666	
		141,829		158,171	
Creditors: amounts falling due within one year	**7**	(11,028)		(25,702)	
Net current assets			130,801		132,469
Total net assets			**130,801**		**132,469**
Income funds					
Restricted funds	**9**		54,273		76,383
Unrestricted funds			76,528		56,086
			130,801		**132,469**

The Charity was entitled to exemption from audit under section 477 of the Companies Act 2006.

The members have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.

The Trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and preparation of financial statements.

The financial statements have been prepared in accordance with the provisions applicable to entities subject to the small companies regime.

The financial statements were approved and authorised for issue by the Trustees on ………………………..
and signed on their behalf by:

Signed ______________________ Date 20.07.2021
Dr Gemma Chandrtillake

The notes on pages 7 - 11 form an integral part of these financial statements.

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 Practise 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) and the Companies Act 2006.

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.

These accounts cover a 15 month period due to the change of year end from September to December.

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 Internation 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.

1.5 Fund accounting

General funds are unrestricted funds which are avaliable 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 restrcitions 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 objectivies, 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 investements with a short maturity of three months or less from the date of acquistion 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 Tangible fixed assets and depreciation

Tangible fixed assets are initially recognised at cost. After recognition, under the cost model, tangible fixed assets are measured at cost less accumulated depreciation and any accumulated impairment losses. All costs incurred to bring a tangible fixed asset into its intended working condition should be included in the measurement of cost.

Depreciation is charges so as to allocate the cost of tangible fixed assets less their residual value over their estimated useful lives, using the straight-line method.

2 Donations and legacies

	Unrestricted Funds	Restricted Funds	2020 Total £	2019 Total £
Donations and gifts	11,867	70,979	**82,846**	**66,415**
	11,867	**70,979**	**82,846**	**66,415**
TOTAL 2019	**62,892**	**3,523**	**66,415**	

3 Charitable activities

	Unrestricted Funds	Restricted Funds	2020 Total £	2019 Total £
Delegate Sales	4,179	-	4,179	18,361
Grants	532	26,366	26,898	46,130
Sponsorship	48,000	-	48,000	110,000
Other	587	-	587	-
	53,298	**26,366**	**79,665**	**174,491**
TOTAL 2019	**174,491**	**-**	**174,491**	

4 Resources expended

	Unrestricted Funds	Restricted Funds	2020 Total £	2019 Total £
Staff costs	-	59,651	59,651	11,284
Depreciation	-	-	-	160
Accomodation	62	-	62	178
Admin support	790	11,727	12,517	10,524
Advertising & marketing	120	20,738	20,858	2,951
Accountancy fees	9,906	564	10,470	3,136
Bank fees	93	-	93	64
Consulting	20,412	252	20,664	50,239
Event kits rental	-	-	-	483
General expenses	40	-	40	329
Independent examination	3,426	-	3,426	2,040
Insurance	840	-	840	420
IT software & consumables	1,591	134	1,725	878
Legal expenses	356	-	356	13
Outsources events	-	-	-	2,143
Postage, freight & courier	162	441	603	40
Printed goods	-	-	-	2,049
Selling costs	-	-	-	77
Speaker costs	-	-	-	2,794
Staff training	-	340	340	1,543
Subscriptions	-	382	382	230
Travel	1,242	887	2,129	1,769
Venue & catering	5,683	15,983	21,666	38,873
Website design & admin	-	8,356	8,356	4,830
	44,723	**119,456**	**164,179**	**137,047**
TOTAL 2019	**96,182**	**40,865**	**137,047**	

5 Staff costs

	2020 Total £	2019 Total £
Wages and salaries	58,159	11,000
Pension costs	1,492	284
	59,651	**11,284**

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

	2020 No.	2019 No.
Employees	1	**1**

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

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 (2019 Nil). During the year, no trustee received any reimbursement of expenses.

6 Debtors

	2020 Total £	2019 Total £
DUE WITHIN ONE YEAR		
Trade debtors	10,000	14,632
Prepayments and accrued income	121	17,873
	10,121	**32,505**

7 Creditors: amounts falling due within one year

	2020 Total £	2019 Total £
Trade creditors	1,429	2,158
Other creditors	389	246
Accruals and deferred income	9,210	23,298
	11,028	**25,702**

8 Deferred income analysis

	2020 Total £	2019 Total £
Deferred income at 1 October 2019	5,420	69,119
Resources deferred during the year	5,821	5,420
Amounts released from previous periods	(5,420)	(69,119)
	5,821	**5,420**

9 Statement of funds

	Balance at 1 October 2019 £	Income £	Expenditure £	Transfers In/out £	Balance at 30 December 2020 £
UNRESTRICTED FUNDS					
General funds - all funds	56,086	65,165	44,723		76,528
RESTRICTED					
National Lottery	1,332	8,930	1,349	-	8,913
Evolution Edication Trust (marketing)	26,941	-	24,192	-	2,749
Evolution Edication Trust (operations)	48,110	55,200	61,260	-	42,050
Evolution Edication Trust (Technology)		10,000	10,000	-	-
CCF	-	3,270	2,839	-	431
Peoples Health Trust	-	3,166	3,166	-	-
Pro-Bono		14,540	14,540	-	-
Unique Feet	-	2,240	2,110	-	130
Total restricted funds	**76,383**	**97,346**	**119,456**	**-**	**54,273**
Total funds	132,469	162,511	164,179	-	130,801

Purpose of funds

National Lottery - this grant was received to help with the overall admin and support of the charity.

People's Health Trust - this grant was to develop the regional network and increase the number of families involved in the Unique Feet group and organise activities for these children and families.

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. purposes.

Evolution Education Trust (operations) - the purpose of this donation is to fund the full-time employment of the Operations Manager of the charity to allow the charity a period of stability and time to generate more regular sources of income. The funds also fund the Operations manager's training and attendance at relevant conferences and events in order to raise the profile of the charity.

10 Analysis of net assets between funds

	Unrestricted funds 2020 £	Restricted funds 2020 £	Total 2020 £
Fund balances at 31 December 2020 are represented by:			
Current assets	87,556	54,273	141,829
Creditors: amounts falling due within one year	(11,028)	-	(11,028)
	76,528	**54,273**	**130,801**

Restricted funds represent amounts recived 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) £9,383 (2019: £3,106 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) £800 (2019: £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 restricted grant from Evolution Education Trust for £65,200 (2019: £30,000) One of the trustees of Evolution Education Trust, Dr J S Milner is also a trustee of CRDN.

CAMBRIDGE RARE DISEASE NETWORK

INDEPENDENT EXAMINER'S REPORT FOR THE PERIOD ENDED 31 DECEMBER 2020

I report on the accounts of Cambridge Rare Disease Network for the period ended 31 December 2020 which are set out on pages 15 to 22.

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.

Shelley-Marie Rudling FMAAT AATQB for and on behalf of:
Community360
Winsley's House, High Street, Colchester, Essex Date 09/09/2021