

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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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

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

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 **facilitating 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.

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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.

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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.

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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 Alpkitt, 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.

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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

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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

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dance, music and speaker performances. Adults with rare conditions also spoke of their journeys, inviting us to explore the possible through story 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."*

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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.

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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.

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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-editathon 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

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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 Wellcome 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 RAREfest22, 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.

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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”

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

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.

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

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;

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

- 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.

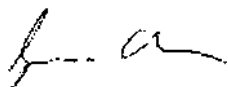
The Trustees are responsible for keeping adequate accounting records sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company. They must ensure that the financial statements comply with the 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

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)

Mrs Susan Berry (appointed 29/07/2019)

Ilan Chaitowitz (appointed 03/12/2019)

Sarah Faircliffe (appointed 03/10/2022)

Emma Green (appointed 03/10/2022)

Jon Green (appointed 03/10/2022)

Loretta MacInnes (appointed 03/10/2022)

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

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 £
<u>Incoming resources</u>					
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
<u>Resources expended</u>					
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

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

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

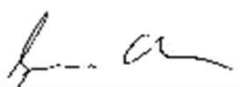
The members have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.

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


Dr Gemma Chandrillake

Date

10/08/2023

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

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

1 Accounting Policies

1.1 Basis of accounting

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement on Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) 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 International Summit or RAREfest. Amounts are included as debtors if owing to the charity at the period end or carried forward in creditors if received in advance.

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

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

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

1.5 Fund accounting

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

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

1.6 Expenditure

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

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

All expenditure is inclusive of irrecoverable VAT.

1.7 Debtors

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

1.8 Cash at bank and in hand

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

1.9 Liabilities and provisions

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

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

1.10 Financial instruments

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

1.11 Cash flow

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

1.12 Taxation

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

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

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	-	-	-	-
Accommodation	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	

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

5 Staff costs

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

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

	2022 No.	2021 No.
Employees	<u>3</u>	<u>1</u>

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

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

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

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
	<u>5,664</u>	<u>6,164</u>

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

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.

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

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.