

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

	Page
Reference and Administrative Information	1
Trustees Annual Report	2-14
Statement of Financial Activities	15
Balance Sheet	16
Notes to the financial statements	17-22
Independent Examiner's Report	23

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

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2021

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).

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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 planned 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

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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 Biogen, 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 healthawareness.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.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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
- Lllluminated 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
- Created 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.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

One company said this was a great opportunity to hear in very succinct terms what people's needs were" and a patient 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.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 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.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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 they 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.

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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

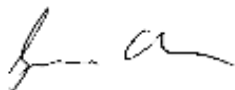
TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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 Guilleams (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

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2021

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

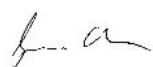
The Charity was entitled to exemption from audit under section 477 of the Companies Act 2006.

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 ...15.7.22.....
.....and signed on their behalf by:

Signed  Date 15.7.22
Dr Gemma Chandrillake

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

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

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 2021

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

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

2 Donations and legacies	Unrestricted Funds	Restricted Funds	2021 Total £	2020 Total £
Donations and gifts	10,534	500	11,034	66,415
	<u>10,534</u>	<u>500</u>	<u>11,034</u>	<u>66,415</u>
TOTAL 2020	<u>11,867</u>	<u>70,979</u>	<u>82,846</u>	
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
	<u>123,523</u>	<u>28,945</u>	<u>152,468</u>	<u>79,665</u>
TOTAL 2020	<u>53,298</u>	<u>26,366</u>	<u>79,665</u>	
4 Resources expended	Unrestricted Funds	Restricted Funds	2021 Total £	2020 Total £
Staff costs	4,276	49,095	53,371	59,651
Depreciation	-	-	-	-
Accommodation	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
	<u>32,054</u>	<u>71,157</u>	<u>103,210</u>	<u>164,179</u>
TOTAL 2020	<u>44,723</u>	<u>119,456</u>	<u>164,179</u>	

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

5 Staff costs

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

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

	2021 No.	2020 No.
Employees	<u>1</u>	<u>1</u>

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
	<u>5,771</u>	<u>10,121</u>

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

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 Education Trust (marketing)	2,749	25,000	15,618	-	12,131
Evolution Education 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.

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

Draft as at 14th July 2022

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.

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)
	<u>95,423</u>	<u>13,917</u>	<u>109,340</u>

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 Guillems) £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.