

CAMBRIDGE RARE DISEASE NETWORK

Company Registration number 09798317

Charity Registration number 1166365

FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2020

CAMBRIDGE RARE DISEASE NETWORK

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REFERENCE AND ADMINISTRATION INFORMATION FOR THE PERIOD ENDED 31 DECEMBER 2020

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

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2020

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

Charity Objectives and Activities

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

Our Vision: A world where people with rare diseases are valued and supported

Our Mission: To create regional networks to improve the rare disease journey

Our Aims:

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

Charity Objects as recorded with the Charity Commission

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

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

Significant activities

Creating Networks to Improve the Rare Disease Patient Journey

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

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

Events, forums and communications

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

Events

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

Regional Community Forum

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

Companies Forum

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

Communications

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

Public benefit

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

Achievement and Performance October 2019 – December 2020

Significant Activities

RAREsummit19

The focus of the autumn season of 2019 was CRDN's 4th RAREsummit held at the Wellcome Genome Campus in Cambridgeshire. The theme of the event was 'Patients as Partners'. We set out to build on the success of our previous Summit, where we demonstrated that personal stories have the power to change hearts and minds and make a real difference. In 2017, our vehicle for personal stories was the

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patient journey poster exhibition; in 2019, we firmly gave patients the stage. The patient voice was central to every talk and panel discussion, highlighting how collaborative partnerships with industry and healthcare professionals result in inspired thinking and better outcomes for all.

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

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

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

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

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

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

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

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

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

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

RAREfest20

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

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

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

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

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

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

Unique Feet Community Group

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

The group continued to flourish despite the complex situation. All original members continued to attend, and membership increased from 12 families and 36 beneficiaries in 2018 to 20 families and 70 beneficiaries during 2020. Most Unique Feet children were added to the COVID 'extremely clinically vulnerable' list, and consequently, families were directed to shield by the Government. We delivered group activities online to keep families connected, active and supported during this challenging and isolating time. These activities included yoga, pottery making, 'Meet the Meerkats' provided by a local zoo and regular social Zoom meetups for parents. Grant funding enabled us to deliver monthly activity bundles filled with cooking, STEM, arts and crafts and gardening activities. Whole families took part and shared their creations via the community social media groups. The parents WhatsApp group, monitored by CRDN, served as a portal for sharing experiences, giving guidance, letting off steam and keeping each other motivated and in good spirits. During periods of lighter restrictions, we met as a group in

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beautiful, therapeutic, outdoor spaces. The local privately run Challis Gardens allowed us to use their space exclusively to give the children a safe place to play and explore freely. Unable to meet to develop their planned dance performance for RAREfest20, the group instead created a series of short films chronicling their lockdown journey as a team. The resulting film was the finale of the RAREfest20 programme and has been watched by hundreds since.

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

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

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

Companies Forum

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

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Other Activities

Rare Disease Day Rare-i-Tea Party

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

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

Communications and Marketing

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

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

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

We invested in professional filming and editing of all RAREsummit19 talks, hackathon and RAREfest20. This wealth of rich content on our newly established YouTube channel and website resources section showcases our work brilliantly. It has led to 60 new subscribers on our YouTube channel and 2760 video

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views compared with 243 views the previous year. Having this resource has increased our ability to educate and raise awareness on a much broader scale.

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

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

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

Partnerships

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

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

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

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

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

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

Financial Review

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

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

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

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

A strategy day will be held in 2021 to review the long term plan and fundraising strategy to achieve sustainable resources and facilitate growth. This will build on the charity's strengths in accessing sponsorship and core funding grants whilst formulating a three year plan to achieve a third of its funding through Companies Forum membership fees and events. The charity is also exploring new opportunities for project-based grants and community fundraising to support its regional community group's growth

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and next steps. During this financial year, CRDN moved to a new accountant. A new trustee with professional financial experience was appointed during 2020 to fill the gap following the resignation of a trustee responsible for this area. The Managing Director is responsible for the day-to-day running of finances, overseen by the Treasurer and trustee signatories during this financial year and payroll, pension payments, and quarterly management accounts undertaken by BCS Accounting based in Shelford, Cambridge, followed by Number Ninja accounting.

Investment Policy

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

Reserves Policy

The charity's management team work to a policy whereby unrestricted funds not committed or invested in tangible fixed assets held by the charity should be a minimum of three months running costs. The present level of cash available to the charity as of 31 December was £130,373.50.

Structure, Governance and Management

Governing Document

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

Trustee Induction and Training

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

Organisation

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

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Pay Policy for Senior Staff

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

Risk Management

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

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

Responsibilities of the Trustees

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

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

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

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

The Trustees are responsible for keeping adequate accounting records sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company. They must ensure that the financial statements comply with the Companies Act 2006. Trustees are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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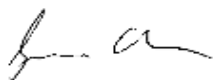
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This report is approved by the Trustees and signed on their behalf by:

Dr Gemma Chandratillake

Chair and trustee

Date 20th July 2021



Organisation Details

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

Registered Company Limited by Guarantee 9798317- Registered on 28th September 2015

Registered Charity number-1166365- Registered on 5th April 2016

Trustees

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

Dr Tim 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 – Rare Revolution Comms (until Sept 2020), Anna Todd (Sept-Dec 2020)

Social media - Vaila Morrison (contracted)

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

IT support – George Nicolau (contracted)

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

CAMBRIDGE RARE DISEASE NETWORK

TRUSTEES ANNUAL REPORT FOR THE PERIOD ENDED 31 DECEMBER 2020

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

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

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

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

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

Independent Accounts Review - Community360

CAMBRIDGE RARE DISEASE NETWORK

STATEMENT OF FINANCIAL ACTIVITIES FOR THE PERIOD ENDED 31 DECEMBER 2020

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

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

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

CAMBRIDGE RARE DISEASE NETWORK

BALANCE SHEET AS AT 31 DECEMBER 2020

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

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

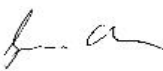
The members have not required the company to obtain an audit in accordance with section 476 of the Companies Act 2006.

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
and signed on their behalf by:

Signed



Dr Gemma Chandrillake

Date

20.07.2021

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 PERIOD ENDED 31 DECEMBER 2020

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.

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

1.2 Going concern

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

1.3 Company status

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

1.4 Income

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

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

Donations are recognised when received. Sponsorship income is recognised in relation to the specific events, such as the 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 PERIOD ENDED 31 DECEMBER 2020

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 PERIOD ENDED 31 DECEMBER 2020

2 Donations and legacies	Unrestricted Funds	Restricted Funds	2020 Total £	2019 Total £
Donations and gifts	11,867	70,979	82,846	66,415
	<u>11,867</u>	<u>70,979</u>	<u>82,846</u>	<u>66,415</u>
TOTAL 2019	<u>62,892</u>	<u>3,523</u>	<u>66,415</u>	
3 Charitable activities	Unrestricted Funds	Restricted Funds	2020 Total £	2019 Total £
Delegate Sales	4,179	-	4,179	18,361
Grants	532	26,366	26,898	46,130
Sponsorship	48,000	-	48,000	110,000
Other	587	-	587	-
	<u>53,298</u>	<u>26,366</u>	<u>79,665</u>	<u>174,491</u>
TOTAL 2019	<u>174,491</u>	<u>-</u>	<u>174,491</u>	
4 Resources expended	Unrestricted Funds	Restricted Funds	2020 Total £	2019 Total £
Staff costs	-	59,651	59,651	11,284
Depreciation	-	-	-	160
Accommodation	62	-	62	178
Admin support	790	11,727	12,517	10,524
Advertising & marketing	120	20,738	20,858	2,951
Accountancy fees	9,906	564	10,470	3,136
Bank fees	93	-	93	64
Consulting	20,412	252	20,664	50,239
Event kits rental	-	-	-	483
General expenses	40	-	40	329
Independent examination	3,426	-	3,426	2,040
Insurance	840	-	840	420
IT software & consumables	1,591	134	1,725	878
Legal expenses	356	-	356	13
Outsources events	-	-	-	2,143
Postage, freight & courier	162	441	603	40
Printed goods	-	-	-	2,049
Selling costs	-	-	-	77
Speaker costs	-	-	-	2,794
Staff training	-	340	340	1,543
Subscriptions	-	382	382	230
Travel	1,242	887	2,129	1,769
Venue & catering	5,683	15,983	21,666	38,873
Website design & admin	-	8,356	8,356	4,830
	<u>44,723</u>	<u>119,456</u>	<u>164,179</u>	<u>137,047</u>
TOTAL 2019	<u>96,182</u>	<u>40,865</u>	<u>137,047</u>	

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2020

5 Staff costs	2020 Total £	2019 Total £
Wages and salaries	58,159	11,000
Pension costs	1,492	284
	<u>59,651</u>	<u>11,284</u>

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

	2020 No.	2019 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 (2019 Nil). During the year, no trustee received any reimbursement of expenses.

6 Debtors	2020 Total £	2019 Total £
DUE WITHIN ONE YEAR		
Trade debtors	10,000	14,632
Prepayments and accrued income	121	17,873
	<u>10,121</u>	<u>32,505</u>

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2020

7 Creditors: amounts falling due within one year	2020 Total £	2019 Total £			
Trade creditors	1,429	2,158			
Other creditors	389	246			
Accruals and deferred income	9,210	23,298			
	11,028	25,702			
8 Deferred income analysis	2020 Total £	2019 Total £			
Deferred income at 1 October 2019	5,420	69,119			
Resources deferred during the year	5,821	5,420			
Amounts released from previous periods	(5,420)	(69,119)			
	5,821	5,420			
9 Statement of funds					
	Balance at 1 October 2019 £	Income £	Expenditure £	Transfers In/out £	Balance at 30 December 2020 £
UNRESTRICTED FUNDS					
General funds - all funds	56,086	65,165	44,723		76,528
RESTRICTED					
National Lottery	1,332	8,930	1,349	-	8,913
Evolution Education Trust (marketing)	26,941	-	24,192	-	2,749
Evolution Education Trust (operations)	48,110	55,200	61,260	-	42,050
Evolution Education Trust (Technology)		10,000	10,000	-	-
CCF	-	3,270	2,839	-	431
Peoples Health Trust	-	3,166	3,166	-	-
Pro-Bono		14,540	14,540	-	-
Unique Feet	-	2,240	2,110	-	130
Total restricted funds	76,383	97,346	119,456	-	54,273
Total funds	132,469	162,511	164,179	-	130,801

Purpose of funds

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

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

CAMBRIDGE RARE DISEASE NETWORK

NOTES TO THE FINANCIAL STATEMENTS FOR THE PERIOD ENDED 31 DECEMBER 2020

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 2020 £	Restricted funds 2020 £	Total 2020 £
Fund balances at 31 December 2020 are represented by:			
Current assets	87,556	54,273	141,829
Creditors: amounts falling due within one year	(11,028)	-	(11,028)
	<u>76,528</u>	<u>54,273</u>	<u>130,801</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) £9,383 (2019: £3,106 for consultancy work. Quotes were obtained, and Prof Barrell was not included in making the decision of placing this piece of work with this provider.

CRDN paid Emily Leslie (wife of Trustee Tim Guillems) £800 (2019: £Nil) for Yoga classes for the Unique Feet group. The decision to use Emily was done at operational level. Emily had previously worked with the Unique Feet Children and the rate paid was a reduced market rate.

In this financial period, CRDN received a restricted grant from Evolution Education Trust for £65,200 (2019: £30,000) One of the trustees of Evolution Education Trust, Dr J S Milner is also a trustee of CRDN.

CAMBRIDGE RARE DISEASE NETWORK

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

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

Respective responsibilities of trustees and examiner

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

It is my responsibility to:

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

Basis of independent examiner's Statement

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

Independent examiner's statement

In the course of my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of the accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair' view which is not a matter considered as part of an independent examination.

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Shelley-Marie Rudling FMAAT AATQB for and on behalf of:
Community360

Winsley's House, High Street, Colchester, Essex



Date 09/09/2021