

Company no. 05460413
Charity no. 1110661

**Rare Chromosome Disorder Support
Group**

Report and Audited Financial Statements

31 March 2021

Rare Chromosome Disorder Support Group

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Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2021

Company number 05460413

Charity number 1110661

Registered office and operational address The Stables
Station Road West
Oxted
Surrey
RH8 9EE

Trustees Trustees, who are also directors under company law, who served during the year and up to the date of this report were as follows:

Helen Campbell	Chair
Isobel Hindle	Trustee
Edna Knight, MBE	Founder, Life President, Trustee
Gillian Manvell	Trustee
Shwetha Ramachandrappa	Trustee
Sophie Sainty	Trustee
Benjamin Stern	Trustee
James Toop	Trustee
Fiona de Zoete	Trustee

Chief executive officer Beverly Searle, PhD

Company secretary Craig Mitchell MInstF (Dip)

Patrons Professor Dian Donnai, UK
Professor Jean-Pierre Fryns, Belgium
Professor Judith Hall, Canada
Baroness Pauline Neville-Jones, UK
Professor Albert Schinzel, Switzerland

Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2021

Bankers

Charities Aid Foundation
Kings Hill
West Malling
Kent
ME19 4TA

Lloyds Bank
PO Box 545
Faryners House
25 Monument Street
London
EC3R 8BQ

United Trust Bank
1 Ropemaker Street
London
EC2Y 9AW

Yorkshire Building Society
Yorkshire House, Yorkshire Drive
Bradford
BD5 8LJ

Virgin Money plc
Jubilee House
Gosforth
Newcastle-upon-Tyne
NE3 4PL

Auditors

Godfrey Wilson Ltd
Chartered accountants and statutory auditors
5th Floor, Mariner House
62 Prince Street
Bristol
BS1 4QD

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Welcome to Unique's annual report for 2020-21, a year of unprecedented uncertainty, during much of which our focus was on navigating the effects of the Covid-19 pandemic. As we present this report, we are able to look forward with increasing hope to a future in which we can all return to something approaching normality.

The rarity of individual chromosome and gene disorders means families often feel very isolated and alone. With national lockdowns, shielding and social distancing due to Covid-19, this has been felt more acutely than ever this year. Families were faced with crucial services like short breaks, clubs and therapies being closed or severely curtailed, removing a vital social outlet and a break from caring. Many families approached us this year feeling alone, distressed and worried about whether their child's chromosome or gene disorder meant they were more susceptible to catching Covid-19 or likely to face more severe symptoms. Others just needed a sympathetic, listening ear to help them cope with the physically and emotionally draining days of round-the-clock care with no break.

As trustees, we were therefore faced with the double whammy of increasing demand, with the nature and scope of the help families needed changing significantly, and uncertainty around income, with fundraising severely curtailed. Our frontline services were under real pressure but we were very conscious of the need to control costs as we faced the likelihood of falling income with a dwindling number of potential income streams. In the event, our financial performance, detailed in this report, was more positive than we had dared hope. Our member families and supporters responded magnificently, rallying to the cause, donating, fundraising where they could and continuing to raise awareness. We are hugely grateful to them all. We are also very proud of the way in which our staff team responded with a flexible and professional approach to ensure our services to families continued unabated, with some staff agreeing to be furloughed to help protect the charity.

Another key focus for trustees this year has been the future leadership of the charity. Our Chief Executive Officer, Dr Beverly Searle, is taking a well-earned retirement in August 2021, after more than 30 years of dedicated service to Unique, 22 years leading the charity. This is a period in which Unique developed from a small group of families looking for support from each other - to over 24,000 families in over 110 countries. Beverly guided us from the pre-internet age to a charity engaging with members via social media but she still often staffs the phone lines and is often the first contact people have with someone who understands their anxiety and distress.

Beverly's combination of professional knowledge with personal experience as a mother to Jenny, who had a rare chromosome disorder, made her such a wonderful leader and mentor. We all owe her a huge debt of thanks for the transformation of Unique and the strong position she leaves us in - we have survived the pandemic in a strong financial position, we are seen within the genetics community as a leading voice for families and are a charity with huge potential. A great many families have contacted us to express their gratitude for the huge difference Beverly has made to their lives. Trustees and staff alike will greatly miss Beverly, but we are delighted to have appointed Dr Sarah Wynn as our new interim CEO. Sarah joined Unique's staff 14 years ago and many of you will already have met or spoken with her. She will be co-leading the charity with our COO, Craig Mitchell and as trustees, we are extremely confident that our future will be as bright as our past 22 years have been. One of Sarah's first tasks as CEO will be to work with Craig and the trustees on our next operating strategy, to be published later this year to take us through the next 3-5 years.

Thank you for reading this annual report and for your interest in Unique and our work. Please do contact us if you have any questions or would like to support us.

Helen Campbell, Chair of trustees

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

The trustees present their report and the audited financial statements for the year ended 31 March 2021.

Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with current statutory requirements, the Memorandum and Articles of Association and the Statement of Recommended Practice - Accounting and Reporting by Charities (effective from January 2019).

Aims and objectives

At Unique, we support anyone affected by and living with a rare chromosome or single gene disorder (RCD) associated with intellectual disability/developmental delay as a minimum. These complex, naturally-occurring conditions are present at birth, lifelong and cause severe medical issues, behavioural problems, developmental delay, learning and/or physical disabilities. They can be extremely life-limiting, sometimes life-threatening and currently there is no cure.

Those with RCDs have parts of one or more of their chromosomes or genes missing, added or rearranged, or in the case of rare gene disorders a change has occurred in a single gene. Many will be totally reliant on their parents and carers throughout their lives, needing round-the-clock care. Others are relatively mildly affected, only diagnosed when trying to have children of their own and facing distressing issues including problems conceiving, stillbirth and multiple miscarriages.

Unique's mission is to inform, support and network to alleviate the isolation of those affected and their families and to raise public awareness. We aim to do this by:

- providing information and support to anyone affected by and dealing with RCDs;
- relieving the isolation of those affected and their families;
- promoting and participating in research; and
- acting as an umbrella organisation for all RCDs.

Diagnostic technology such as DNA sequencing has developed rapidly, meaning ever smaller changes, such as those affecting a single gene, can be detected. As a result, many more people now receive a diagnosis of a rare chromosome or single gene disorder. For example, the rate of those with a learning disability being diagnosed with a RCD has increased from 7% before 2008 to 40% today.

Individual disorders are often very rare, some reported in no more than a handful of cases worldwide, some quite literally 'unique'. However, collectively it is estimated that up to 1 in every 100 babies has a rare chromosome or gene disorder and the rapid growth in numbers being diagnosed means our specialist help is needed now more than ever.

One parent recently described receiving a diagnosis of a RCD for their child as like a "sledgehammer blow", shattering all the hopes and dreams you had for your child. A rare condition with very uncertain outcomes and lots of complex terminology means they inevitably have lots of questions. Many go unanswered though, adding to their overwhelming distress and sense of desperate isolation. This is where Unique (and very often only Unique), can help.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Our activities - support, information and networking

To meet our aims and objectives, we have developed three main strands of our work:

1. Supporting families

Having received a diagnosis for their child or family member, parents and carers often come to us feeling upset and confused, struggling to make sense of what they've been told. Some adults also come to us having received a diagnosis for themselves later in life.

Unique's Listening Ear telephone and email help service is staffed by an experienced team, able to empathise with them, explain complex terms and what the diagnosis means. We also go through what the future may hold for their child, including the health and other issues they are likely to face and the help they could need, before providing a more detailed response tailored to their child's specific RCD.

Our **Family Support Officer** is on hand to welcome families and provide a pack of resources and we use our confidential database as a basis for our Family Matching Service, linking families living with similar disorders and/or symptoms and daily challenges for mutual support. Some then meet in person and attend our events such as Family Days and Study Days, coming together with professionals and other families to learn about genomics and establish informal support networks. These events will re-start and continue as government Covid-19 guidelines allow.

2. Specialist information

Through our **Unique Information Project**, we have compiled and published family-friendly guides to hundreds of specific rare chromosome and gene disorders. Based on empirical data from Unique member families as well as information gleaned from specialist medical literature, all are independently verified by specialist professionals in genomics and related fields who volunteer their time. Going beyond the purely medical, they cover other relevant topics including learning, development and behaviour. With many newly-emerging disorders, this work is ongoing and vital as many parents and carers tell us how valuable the guides were in helping them understand their child's rare condition.

Alongside the disorder-specific guides are our '**practical guides**' for families, covering issues such as communication, sleep, feeding, coping with challenging behaviour and what happens once you've received a diagnosis.

The **Unique database/patient registry** forms the bedrock of all this. It contains rich data provided by our member families, including medical information as well as data about our members' behavioural, social, educational and developmental issues. It is used anonymously to inform researchers, geneticists and other professionals and by our staff to guide families and produce our information resources.

3. Networking and awareness-raising

With Rare Chromosome and Gene Disorders relatively poorly understood, raising awareness, particularly among professionals and the wider public is key. We have forged strong relationships with geneticists and other professionals and work closely with other organisations, including charities, policy-makers and umbrella bodies, to increase knowledge and understanding and raise the profile of RCDs generally.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

By giving presentations, attending networking events, sitting on advisory boards and steering groups Unique staff reach a range of diverse audiences, including policy makers, medical and other professionals, funders and family members. We have a network of over 200 local volunteer contacts, many of them parents themselves, who help signpost families to local services and resources and a huge number of professionals volunteer their time to help us. We are also very active on social media, with large and growing audiences on Facebook, Instagram and Twitter to promote our work, fundraise and raise awareness. We also have several secret groups for families, providing supportive, moderated environments for private discussion, mutual support and empathy.

Response to Covid-19

As we moved into April 2020, the UK had just gone into its first lockdown due to the Covid-19 pandemic. Trustees immediately took steps to protect the charity and mitigate against the resulting constraints on our operations and fundraising efforts. Our office was closed with all staff moved to home-working and an emergency budget drawn up, with various 'worst case scenario' forecasts and their impact on cash-flow through to the financial year end. With income likely to be adversely affected, not least because fundraising events such as the London Marathon were already being postponed or cancelled altogether, we negotiated a rent reduction on our office space which has continued throughout the year and began work to reduce costs such as postage and printing. Key staff, working with our trustee who has responsibility for IT, quickly identified and implemented a solution for sending secure, encrypted email to member families. This helped to streamline operations, reduce costs of posting out database forms and uphold Covid-19 secure practice for example.

We were able to furlough some staff, fully at first and then flexibly as the furlough scheme allowed. Our aim at all times was to protect frontline operations to ensure those who needed us were able to access the same excellent level of service and receive the help they needed. Trustees are hugely grateful to all staff for their flexibility and professionalism during a difficult period as we continually kept our entire cost base under review. Trustees and senior staff met monthly, via Zoom, specifically to discuss financial matters, keep the emergency budget updated and take action where necessary to ensure the charity was best placed to 'weather the storm'.

As the pandemic developed, we dedicated a page on our website to provide ongoing, up to date Covid-19 guidance and self-isolation resources to help families. Many were contacting us as they were struggling in lockdown, feeling incredibly isolated as their short breaks (respite) and other services were closed.

Our achievements during 2020-21

Families in need of more support than ever...

With genetics and other services closed or significantly curtailed, the number of newly-diagnosed families coming to us during the year was slightly down on the previous year. However, we found that those new and existing families approaching us for help needed much more detailed input from our team, largely due to Covid-19. In general, they were more stressed and more worried about issues such as their family member's susceptibility to Covid-19, whether the known symptoms of Covid-19 might be more severe in those with RCDs, particularly those associated with respiratory conditions and asking for guidance about whether they should be shielding. This significant change in the nature of the enquiries we received increased the pressure on our frontline staff and we are very proud of the calm and professional way they responded.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

During the year, to support families and others we:

- welcomed and helped 1,863 new member families;
- responded to 8,762 emails from family members in need of help;
- answered over 300 telephone calls, many from distressed parents reaching out for help;
- responded to 1,680 enquiries from professionals and others, needing specialist assistance; and
- received more than 1,000 messages asking for help via our social media channels.

In the coming year, we expect the nature of the enquiries received by our frontline team will return to something closer to 'normal' levels, with fewer Covid-19-related queries. As genetics services also return to normal, the number of new families coming to us is also set to increase very rapidly as the backlog of families waiting for genetic testing is tackled by the NHS.

Unique's specialist information – another milestone reached

This year we reached a significant milestone with the publication of our 300th disorder-specific information guide. These guides, available free of charge through our website or in print format via our helpline team, each cover a different rare chromosome or single gene disorder. Many of these are quite literally world firsts, there is no other such resource covering the breadth and depth of information about these rare conditions.

During the year, our team published:

- 19 brand new guides to specific rare chromosome and single gene disorders, including those on 5q14 duplications and 15q14 deletions, for which there was significant demand;
- 3 significant updates to existing information guides, providing brand new information to help those affected and their families;
- 51 more translated guides to help those for whom English is not their first spoken language, with translations undertaken by expert volunteers into other languages including Chinese, French, German, Russian and for the first time, Georgian; and
- 9 different rare chromosome and gene disorders were covered in brand new 'my chromosome story' picture books.

In addition to our disorder-specific information guides, we publish more generic 'practical guides' for families. These cover highly relevant topics which cross over and feature with many different RCDs, causing huge challenges which families tell us they face every day. These include sleep issues, problems with communication, challenging behaviour, dental problems, toileting and continence issues and many more. This year we published new guides covering:

- Self-Isolation during Covid (published in April 2020 and revised and updated in January 2021);
- Bereavement and Loss – resources for coping, especially with the loss of a child; and
- 'Uniquely Different' – guide to birth Uniqueness and conditions developing in the early years.

We also continued our rolling database update programme. This project aims to ensure that all those many thousands of member families and professionals for whom we hold data are contacted to ensure we have the most up to date data for them and their affected family member and that they are happy for us to retain it. We have now contacted more than 2,100 of our member families. The data they provide is used to publish our information guides, provide tailored response to those needing help, assist with research and further our collective knowledge.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Networks built, families helped, awareness raised

With awareness and understanding of rare chromosome and gene disorders generally remaining relatively low, our work to raise awareness is as crucial as ever. Despite the constraints brought by the Covid-19 pandemic, we have continued to build strong relationships with medical and other professionals working in genomics and related areas, for the benefit of the families we support. Some notable achievements to networking and raising awareness this year included:

- Our CEO Dr Beverly Searle sat on the Dept. of Health and Social Care Rare Disease Policy Board, ensuring our families' voices were heard as part of the UK's Rare Disease Framework;
- We participated in the EXPRESS Study (Optimising Exome PREnatal Sequencing Services), looking at fetal exome sequencing for pregnancies where severe anomalies have been identified and a clinical geneticist believe a single gene disorder is the likely cause;
- Dr Searle gave online teaching sessions to postgraduate students on Imperial College's MSc Genomic Medicine course. Students included GPs, Consultant Paediatricians and other relevant professionals. She also presented to students on a postgraduate paediatrics course at the University of Brighton Medical School, about the challenges families face;
- We presented at The Royal Society of Medicine's "Genomics Revolution" event for non-geneticist clinicians, organised and chaired by one of Unique's trustees, Consultant Geneticist Dr Shwetha Ramachandrappa;
- Dr Sarah Wynn was selected for the Public and Patient Voice position for NHS England Genomic Test Directory for Rare and Inherited Diseases. This includes making recommendations for new tests and input to the roll-out of the new whole genome sequencing service;
- Our COO, Craig Mitchell continued to represent Unique and our families on the steering group of the Cerebra/Cardiff University project 'Improving Mental Health in Children with Rare Genetic Conditions';
- Dr Searle presented to the Westminster Health Forum policy conference on 'Improving patient involvement in disease specific research areas', an event chaired by Unique Patron Baroness Pauline Neville-Jones;
- Dr Wynn is a committee member of the British Society for Genetic Medicine (BSGM) and was on two Working Parties involved in producing two sets of new practice guidelines (to be published in late 2021) to Genetic Testing of Children and Prenatal Genetic/Genomic testing; and
- Our Information Officer, Arti Patel, gave presentations to diverse audiences including genomic counselling students, geneticists and spoke about Unique and our response to Covid-19 to professionals at Great Ormond Street Hospital as part of their 'Grand Rounds'.

We continued to work closely with other organisations, including Genetic Alliance UK and Rare Disease UK, virtually and face to face (where permitted). We took part in the All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions, with a particular focus on the impact of Covid-19 on those affected by these conditions. We also continued to be an active participant in Rare Disease UK's patient empowerment group meetings, representing Unique families to put their perspective across.

In addition, our social networks continued to go from strength to strength, helping inform and support existing families, ensuring new families can find us and get help and raising awareness among the wider public. Our public Facebook page now has more than 37,000 followers and our Twitter followers increased to more than 7,000. In addition, we have worked hard to develop our Instagram and now have over 5,000 followers.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Digital remains key to our awareness raising efforts and our e-news emails were sent out every 3-4 months to more than 20,000 recipients. All these included items covering the main strands of our work: information, networking and support, benefitting families and professionals alike.

Due to Covid-19 and the UK's lockdown, we were unable to hold our usual awareness week in June 2020, but we did hold a 'Funday Friday' with quizzes, a mindfulness session, various challenges and other activities over Zoom. We were able to bring lots of families together, albeit remotely, as they struggled with the isolation brought by lockdown and the fact that their vital respite/short breaks services were closed or severely curtailed.

Public benefit

The trustees confirm their due regard for the Charity Commission guidance on public benefit in reviewing Unique's aims, objectives and activities undertaken, planning future strategy and setting policy. As the UK's only charity working in the specific field of RCDs, throughout this report we detail the ways in which we help beneficiaries, providing specialist information as well as softer support.

For the wider public benefit, Unique has actively supported the development and roll-out of the new Genomic Medicine Service, building on the NHS contribution to the 100,000 Genomes Project, to provide families with a diagnosis of a rare disease. During the year, Dr Searle also participated in the DHSC's Rare Disease Policy Board as a patient representative, not least feeding back the many challenges due to the Covid-19 pandemic of rare disease patients. The genomics and rare disease expertise gained from these initiatives will benefit more mainstream areas of medicine, e.g. cardiology and respiratory medicine, deliver personalised medicine and stimulate research.

Infrastructure

Trustees and staff continue to ensure Unique's infrastructure is fit for purpose. We have a trustee with specific responsibility for IT and retain the services of a specialist IT company. Data security is paramount, with sensitive medical information accessed and processed by staff on a hierarchical, 'need to know' basis. All data are processed in accordance with the Data Protection Act 2018 and General Data Protection Regulation (GDPR). As our offices remained closed throughout the year, we put secure systems in place to allow staff to work securely from home and also reduce postal expenditure by contacting families more securely by encrypted email.

Volunteers

With our offices closed, opportunities for volunteers were a little more limited this year, but we are hugely grateful to the large number of people who continued to help us during a challenging year. These included:

- More than 200 local volunteer contacts, on hand to support families in their local area;
- Over 30 geneticists and other professionals, verifying our information guides prior to publication;
- At least 50 expert volunteers who translated our information guides into a variety of languages;
- A number of others assisting in areas such as marketing and promotional activities; and
- Voluntary fundraising undertaken by lots of our members and supporters.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Financial review 2020-21

Income

Our total income for the year is £357,247, an increase of just over 10% on the previous year, although without exceptional items such as the government's furlough grants, this would have been a decrease of approximately £5,000. It is also considerably down on the £391,978 received in 2018-19. We are very pleased that income held up relatively well, despite a very challenging year for all charities, with lots of significant fundraising events postponed or cancelled altogether.

Unrestricted income was £316,811 (previous year: £313,192), including unrestricted grants and furlough scheme grants of £73,614. Restricted income was £40,436. The high proportion of unrestricted income, much of which comes directly or indirectly through our member families, affords us greater flexibility when planning future strategy as well as increased confidence, as funds can be directed where we as trustees feel they would have the greatest impact for beneficiaries. Our restricted income this year included a one-off grant towards our helpline as we tried to cope with the increased demand from existing families concerned particularly about the impact of Covid-19 on their affected child.

Expenditure

As the pandemic took hold and the UK's national lockdown began in March 2020, trustees met with senior staff to formulate an emergency budget for the coming year. In the unprecedented and extremely uncertain environment, we assumed a worst-case scenario and throughout the year reduced expenditure accordingly, whilst protecting key, frontline services. Our total expenditure for the year is £299,685, a decrease of just over 10%. As the challenging and uncertain climate continued, trustees and senior staff continued to meet virtually on a monthly basis to discuss the financial performance and ensure we could take a proactive approach. We are proud of the way staff were able to maintain the excellent level of service to families that has been our hallmark over many years.

Level of reserves

It is our policy to hold a minimum level of free reserves equating to four months' average operating costs for the previous year. With expenditure for 2020-21 being lower than in a 'normal' year, this would equate to minimum reserves of £95,000, but we feel it is appropriate to set a minimum requirement of the higher figure of £105,000, which is the same as the previous year and more closely reflects our budgeted expenditure for this year. This will be reviewed again in April 2022.

The future

Our current 5-year operating strategy comes to an end this year and trustees have charged Sarah Wynn (Incoming CEO) and Craig Mitchell (COO) with drafting the strategy for the coming years, to present to trustees. We have made huge progress with our aims in the current plan, for example for the charity to undergo a digital upgrade, to improve our efficiency and to provide enhanced networking opportunities for families. It is likely that the current uncertain operating environment will continue for the foreseeable future but as ever, the needs of our beneficiaries will be paramount in our future strategy and operating plans.

Structure, governance and management

The trustees delegate day-to-day management of the charity's activities to Dr Beverly Searle, CEO. From September 2021, Dr Sarah Wynn will take over as Interim CEO and will co-lead the charity with Craig Mitchell (COO). Unique currently employs ten staff, including the CEO, three of whom are full-time and seven part-time. Craig Mitchell (COO) is also Company Secretary.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Corporate and social responsibility and sustainability

Our policy is to seek all members of our communities who may be affected by a RCD irrespective of race, religion, sexuality, marital status or culture. We are an equal opportunity employer. During the year, we became a member of '**Breaking Down Barriers**', a network of over 40 organisations working to improve the lives of diverse and marginalised communities, so that they have equal access to health services.

During the year, all our staff worked exclusively from home due to Covid-19, only visiting the office when absolutely necessary and communicating mainly via VOIP. This all helped to minimise costs and our carbon footprint. Four of our part-time staff worked exclusively from home prior to the pandemic and moving forward we will explore whether 'hybrid' working for staff, combining working in the office with working from home, could be an effective way of working, for the benefit of the charity and our staff team.

Management of risk

Unique's risk register, containing the major financial, operational, reputational and other potential risks to the charity, to which the charity could be exposed, is regularly reviewed and updated. The CEO and COO take operational responsibility for this, overseen by trustees. A disaster recovery plan is in place, with appropriate contingency plans as operating conditions and/or performance change. The trustees aim to meet formally three times per year, with senior staff present, with the charity's financial position kept under review at each meeting. During this year, trustees and senior staff met more frequently (monthly until January), with a particular focus on the charity's financial position.

Compliance and training

Given the importance to our work of personal and sensitive medical data, staff and trustees are aware of the requirements of data protection law and have received training in this area. Our COO has attended workshops provided by organisations such as the Charity Finance Group and ACAS to ensure regulatory compliance. Trustees took the decision that all staff and trustees would undergo a DBS check and we engaged Carecheck to carry out DBS checks.

Unique has an Internal Research and Ethics Committee (comprising the CEO, an Information Officer, a Medical Advisor, a trustee and an adult clinician sibling of a member with a RCD) to appraise research proposals of professionals requesting Unique's approval.

Staff performance is kept under ongoing review, with a formal annual appraisal referencing their key responsibilities in relation to Unique's charitable aims. Training needs are identified and training sourced where appropriate. This year staff appraisals took place via Zoom, with the staff member's line manager and a trustee present.

Governance

Unique is an incorporated charity and company limited by guarantee, governed by a Memorandum and Articles of Association. Governance and management structures of the charity are kept under constant review to ensure optimal use of resources. Trustees correspond regularly via email and other digital means, particularly to keep financial performance under review. During the past year, trustees met monthly via Zoom, enabling us to take a proactive approach to any fluctuations in income and refine our strategy accordingly.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

The charity currently has nine trustees with diverse backgrounds in medicine, the law, business, marketing, finance, accounting, IT, the charity sector and education. New trustees are recruited by advertising as widely as possible and through our own networks and we operate an equal opportunity policy for recruitment of trustees and staff.

Registered members of the company limited by guarantee and others with an interest in Unique were invited to attend the Annual General Meeting which was held in late 2020 via Zoom and are kept informed by the Company Secretary.

Statement of responsibilities of the trustees

The trustees (who are also directors of the charity for the purposes of company law) are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing those 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 judgements and accounting estimates that are reasonable and prudent;
- state whether applicable UK accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Companies Act 2006. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Members of the charity guarantee to contribute an amount not exceeding £10 to the assets of the charity in the event of winding up. The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Auditors

Godfrey Wilson Limited were re-appointed as auditors to the charitable company during the year and have expressed their willingness to continue in that capacity.

Approved by the trustees on 11 October 2021 and signed on their behalf by

Helen Campbell

Helen Campbell - Trustee (Chair)

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

Opinion

We have audited the financial statements of Rare Chromosome Disorder Support Group (the 'charity') for the year ended 31 March 2021 which comprise the statement of financial activities, balance sheet and the related notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 March 2021 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report (incorporating the directors' report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the trustees' report (incorporating the directors' report) has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report. We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us;
- the financial statements are not in agreement with the accounting records and returns;
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not obtained all the information and explanations necessary for the purposes of our audit.

Responsibilities of the trustees

As explained more fully in the trustees' responsibilities statement set out in the trustees' report, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as they determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The procedures we carried out and the extent to which they are capable of detecting irregularities, including fraud, are detailed below:

(1) We obtained an understanding of the legal and regulatory framework that the charity operates in, and assessed the risk of non-compliance with applicable laws and regulations. Throughout the audit, we remained alert to possible indications of non-compliance.

(2) We reviewed the charity's policies and procedures in relation to:

- Identifying, evaluating and complying with laws and regulations, and whether they were aware of any instances of non-compliance;
- Detecting and responding to the risk of fraud, and whether they were aware of any actual, suspected or alleged fraud; and
- Designing and implementing internal controls to mitigate the risk of non-compliance with laws and regulations, including fraud.

(3) We inspected the minutes of trustee meetings.

(4) We enquired about any non-routine communication with regulators and reviewed any reports made to them.

(5) We reviewed the financial statement disclosures and assessed their compliance with applicable laws and regulations.

(6) We performed analytical procedures to identify any unusual or unexpected transactions or balances that may indicate a risk of material fraud or error.

(7) We assessed the risk of fraud through management override of controls and carried out procedures to address this risk. Our procedures included:

- Testing the appropriateness of journal entries;
- Assessing judgements and accounting estimates for potential bias;
- Reviewing related party transactions; and
- Testing transactions that are unusual or outside the normal course of business.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. Irregularities that arise due to fraud can be even harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charity's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charity's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity's members as a body, for our audit work, for this report, or for the opinions we have formed.

Alison Godfrey

Date: 12 October 2021

Alison Godfrey FCA
(Senior Statutory Auditor)

For and on behalf of:

GODFREY WILSON LIMITED

Chartered accountants and statutory auditors

5th Floor Mariner House

62 Prince Street

Bristol

BS1 4QD

Rare Chromosome Disorder Support Group

Statement of financial activities (incorporating an income and expenditure account)

For the year ended 31 March 2021

	Note	Restricted £	Unrestricted £	2021 Total £	2020 Total £
Income from:					
Donations and legacies	3	-	307,687	307,687	303,240
Charitable activities:					
<i>Family support services</i>	4	19,186	-	19,186	7,400
<i>Information and awareness</i>	5	21,250	7,448	28,698	10,751
Investments		-	1,676	1,676	2,451
Total income		<u>40,436</u>	<u>316,811</u>	<u>357,247</u>	<u>323,842</u>
Expenditure on:					
Raising funds		-	30,179	30,179	38,982
Charitable activities:					
<i>Family support services</i>		18,135	147,300	165,435	174,073
<i>Information and awareness</i>		8,198	95,873	104,071	118,372
Total expenditure	7	<u>26,333</u>	<u>273,352</u>	<u>299,685</u>	<u>331,427</u>
Net income / (expenditure) and net movement in funds	8	14,103	43,459	57,562	(7,585)
Reconciliation of funds:					
Total funds brought forward		<u>3,299</u>	<u>379,041</u>	<u>382,340</u>	<u>389,925</u>
Total funds carried forward		<u><u>17,402</u></u>	<u><u>422,500</u></u>	<u><u>439,902</u></u>	<u><u>382,340</u></u>

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 17 to the accounts.

Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2021

	Note	£	2021 £	2020 £
Fixed assets				
Tangible fixed assets	11		1,860	3,270
Investments	12		<u>700</u>	<u>700</u>
			2,560	3,970
Current assets				
Stock	13	1,721		2,608
Debtors	14	19,797		10,195
Cash at bank and in hand		<u>439,284</u>		<u>378,719</u>
		460,802		391,522
Creditors: amounts due within 1 year	15	<u>23,460</u>		<u>13,152</u>
Net current assets			<u>437,342</u>	<u>378,370</u>
Net assets	16		<u>439,902</u>	<u>382,340</u>
Funds	17			
Restricted income funds			17,402	3,299
Unrestricted funds:				
Designated funds			40,000	40,000
General funds			<u>382,500</u>	<u>339,041</u>
Total charity funds			<u>439,902</u>	<u>382,340</u>

The financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

Approved by the trustees on 11 October 2021 and signed on their behalf by

Helen Campbell

Helen Campbell - Trustee (Chair)

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

1. Accounting policies

a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities in 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.

Rare Chromosome Disorder Support Group 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 note(s).

b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern, which the trustees consider appropriate having regard to the current level of unrestricted reserves and having considered the impact of the ongoing Covid pandemic. There are no material uncertainties about the charity's ability to continue as a going concern.

c) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from grants, whether 'capital' or 'revenue', 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.

Income received in advance of provision of an event or contract for services is deferred until criteria for income recognition are met.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

1. Accounting policies (continued)

d) Donated services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity of the item, is probable and the economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), general volunteer time is not recognised.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity 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.

e) Interest receivable

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.

f) Funds accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

g) Expenditure and irrecoverable VAT

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

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

h) Allocation of support and governance costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. These costs have been allocated between activities on the following basis, which is an estimate of staff time spent on each activity:

	2021	2020
Raising funds	6%	8%
Family support services	53%	45%
Information and awareness	41%	47%

i) Tangible fixed assets

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

Computer equipment	4 years straight line
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Items of equipment are capitalised where the purchase price exceeds £500.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

1. Accounting policies (continued)

j) Fixed asset investments

Investments are stated at market value. The statement of financial activities includes any recognised gains or losses on revaluations and disposals during the year.

k) Stock

Stock is included at the lower of cost or net realisable value.

l) Debtors

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

m) Cash at bank and in hand

Cash at bank and cash 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.

n) Creditors

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

o) 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.

p) Foreign currency

Transactions in foreign currencies are translated at rates prevailing at the date of the transaction. Balances denominated in foreign currencies are translated at the rate of exchange prevailing at the year end.

q) Pension costs

The company operates a defined contribution pension scheme for its employees. There are no further liabilities other than that already recognised in the SOFA.

r) Operating leases

Rentals applicable to operating leases where substantially all of the benefits and risks of ownership remain with the lessor are charged against profits on a straight-line basis over the period of the lease.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

1. Accounting policies (continued)

s) Accounting estimates and key judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying values of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

The key sources of estimation uncertainty that have a significant effect on the amounts recognised in the financial statements are depreciation as described in note 1 (i) to the accounts.

2. Prior period comparatives

	Restricted £	Unrestricted £	2020 Total £
Income from:			
Donations and legacies	-	303,240	303,240
Charitable activities			
<i>Family support services</i>	7,400	-	7,400
<i>Information and awareness</i>	3,250	7,501	10,751
Investments	-	2,451	2,451
Total income	10,650	313,192	323,842
Expenditure on:			
Raising funds	-	38,982	38,982
Charitable activities			
<i>Family support services</i>	17,731	156,342	174,073
<i>Information and awareness</i>	3,956	114,416	118,372
Total expenditure	21,687	309,740	331,427
Net income / (expenditure) and net movement in funds	(11,037)	3,452	(7,585)

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

3. Donations and legacies

	Restricted £	Unrestricted £	2021 Total £
Grants more than £5,000:			
D & J Hunter Charitable Trust	-	15,000	15,000
DM Thomas Foundation for Young People	-	6,489	6,489
Grants £5,000 or less	-	14,000	14,000
Coronavirus Job Retention Scheme	-	38,125	38,125
General donations	-	48,964	48,964
Corporate donations	-	29,753	29,753
Overseas donations	-	14,144	14,144
Gift aid	-	17,128	17,128
Give As You Earn (GAYE)	-	1,663	1,663
Pyramids	-	110	110
Donations from fundraising activities	-	100,311	100,311
Legacies	-	22,000	22,000
	<u>-</u>	<u>307,687</u>	<u>307,687</u>

Prior year comparative

	Restricted £	Unrestricted £	2020 Total £
Grants more than £5,000:			
D & J Hunter Charitable Trust	-	10,000	10,000
Grants £5,000 or less	-	23,041	23,041
General donations	-	48,888	48,888
Corporate donations	-	15,731	15,731
Overseas donations	-	11,601	11,601
Gift aid	-	24,785	24,785
Give As You Earn (GAYE)	-	1,418	1,418
Pyramids	-	491	491
Donations from fundraising activities	-	167,285	167,285
	<u>-</u>	<u>303,240</u>	<u>303,240</u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

4. Charitable activities: family support services

	Restricted £	Unrestricted £	2021 Total £
Grants more than £5,000:			
Awards for All	9,936	-	9,936
Grants £5,000 or less	<u>9,250</u>	<u>-</u>	<u>9,250</u>
	<u>19,186</u>	<u>-</u>	<u>19,186</u>

Prior year comparative

	Restricted £	Unrestricted £	2020 Total £
Grants £5,000 or less	<u>7,400</u>	<u>-</u>	<u>7,400</u>

5. Charitable activities: information and awareness

	Restricted £	Unrestricted £	2021 Total £
Grants more than £5,000:			
The Dewan Foundation Ltd	10,000	-	10,000
Grants £5,000 or less	11,250	-	11,250
Christmas card and merchandise sales	<u>-</u>	<u>7,448</u>	<u>7,448</u>
	<u>21,250</u>	<u>7,448</u>	<u>28,698</u>

Prior year comparative

	Restricted £	Unrestricted £	2020 Total £
Grants £5,000 or less	3,250	-	3,250
Christmas card and merchandise sales	-	7,001	7,001
Participation in research	<u>-</u>	<u>500</u>	<u>500</u>
	<u>3,250</u>	<u>7,501</u>	<u>10,751</u>

6. Government grants

The charitable company received government grant income in the year under the Coronavirus Job Retention Scheme. The total value of such grants in the period ending 31 March 2021 was £38,125 (2020: £nil). There are no unfulfilled conditions or contingencies attaching to these grants in 2020/21.

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

7. Total expenditure

	Raising funds £	Family support £	Information and awareness £	Support and governance £	2021 Total £
Audit and accountancy	-	-	-	3,900	3,900
Computer expenses	392	4,953	2,864	-	8,209
Depreciation	81	747	582	-	1,410
Insurance	-	-	-	2,811	2,811
Office costs and rent	850	9,709	6,114	520	17,193
Postage and distribution	190	5,161	1,133	26	6,510
Printing and design	-	4,205	2,611	-	6,816
Staff costs (note 9)	22,825	115,628	67,834	37,433	243,720
Stationery	28	273	201	-	502
Subscriptions, licences and charges	3,214	79	3,806	13	7,112
Training and other staff costs	-	-	-	245	245
Website and database development	15	857	385	-	1,257
Sub-total	27,595	141,612	85,530	44,948	299,685
Allocation of support and governance costs	<u>2,584</u>	<u>23,823</u>	<u>18,541</u>	<u>(44,948)</u>	<u>-</u>
Total expenditure	<u>30,179</u>	<u>165,435</u>	<u>104,071</u>	<u>-</u>	<u>299,685</u>

Governance costs were £6,956 (2020: £6,153).

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

7. Total expenditure (continued) Prior year comparative

	Raising funds £	Family support £	Information and awareness £	Support and governance £	2020 Total £
Audit and accountancy	-	-	-	3,720	3,720
Computer expenses	395	3,345	2,772	26	6,538
Depreciation	136	817	852	9	1,814
Insurance	-	-	-	2,433	2,433
Office costs and rent	1,549	10,745	10,070	267	22,631
Postage and distribution	339	11,939	1,998	108	14,384
Printing and design	229	6,568	3,899	4	10,700
Event costs	-	11,521	235	-	11,756
Staff costs (note 9)	24,569	112,229	74,287	22,475	233,560
Stationery	64	1,150	834	4	2,052
Subscriptions, licences and charges	9,341	122	3,975	60	13,498
Training and other staff costs	4	148	24	347	523
Travel and subsistence	46	1,608	1,236	169	3,059
Website and database development	18	526	4,072	143	4,759
Sub-total	36,690	160,718	104,254	29,765	331,427
Allocation of support and governance costs	2,292	13,355	14,118	(29,765)	-
Total expenditure	38,982	174,073	118,372	-	331,427

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

8. Net movement in funds

This is stated after charging:

	2021	2020
	£	£
Depreciation	1,410	1,814
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses	Nil	Nil
Auditors' remuneration	<u>3,900</u>	<u>3,720</u>

9. Staff costs and numbers

Staff costs were as follows:

	2021	2020
	£	£
Salaries and wages	222,351	210,774
Social security costs	13,595	14,893
Pension contributions	<u>7,774</u>	<u>7,893</u>
	<u>243,720</u>	<u>233,560</u>

No employee earned more than £60,000 during the year (2020: none).

The key management personnel of the charity comprise the trustees, the Chief Executive and the Chief Operating Officer. The total employee benefits comprising gross wages, employer pension contributions and employer NI contributions received by the charity's key management personnel in the period was £78,577 (2020: £93,637). This reduced during the year due to voluntary reductions in pay by key management personnel to safeguard the charity in the face of financial uncertainty during the Covid pandemic.

	2021	2020
	No.	No.
Average staff head count	10.00	10.00
Average full time equivalent	<u>7.00</u>	<u>7.00</u>

10. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

11. Tangible fixed assets

	Computer equipment £
Cost	
At 1 April 2020	18,064
Additions in year	<u>-</u>
At 31 March 2021	<u>18,064</u>
Depreciation	
At 1 April 2020	14,794
Charge for the year	<u>1,410</u>
At 31 March 2021	<u>16,204</u>
Net book value	
At 31 March 2021	<u><u>1,860</u></u>
At 31 March 2020	<u><u>3,270</u></u>

12. Investments

	Artwork £
At 31 March 2021	<u><u>700</u></u>
At 31 March 2020	<u><u>700</u></u>

A Tracey Emin print was donated in 2005. The trustees have no immediate plans to sell the print consequently it has been reported as a fixed asset investment in the accounts. It is valued at the average of two professional valuations which were provided in May 2012. No revaluations were carried out in the year. The trustees are satisfied that the print is carried at an appropriate value at 31 March 2021.

13. Stock

	2021 £	2020 £
Merchandise	<u><u>1,721</u></u>	<u><u>2,608</u></u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

14. Debtors

	2021 £	2020 £
Trade debtors	122	122
Prepayments	8,798	7,636
Accrued income	10,714	2,437
Other debtors	163	-
	<u>19,797</u>	<u>10,195</u>

15. Creditors : amounts due within 1 year

	2021 £	2020 £
Accruals	18,100	7,673
Other taxation and social security	4,359	4,473
Pension creditor	1,001	1,006
	<u>23,460</u>	<u>13,152</u>

16. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	Total funds £
Tangible fixed assets	-	-	1,860	1,860
Investments	-	-	700	700
Net current assets	17,402	40,000	379,940	437,342
Net assets at 31 March 2021	<u>17,402</u>	<u>40,000</u>	<u>382,500</u>	<u>439,902</u>

Prior year comparative

	Restricted funds £	Designated funds £	General funds £	Total funds £
Tangible fixed assets	-	-	3,270	3,270
Investments	-	-	700	700
Net current assets	3,299	40,000	335,071	378,370
Net assets at 31 March 2020	<u>3,299</u>	<u>40,000</u>	<u>339,041</u>	<u>382,340</u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

17. Movements in funds

	At 1 April 2020 £	Income £	Expenditure £	Transfers between funds £	At 31 March 2021 £
Restricted funds					
Family support services	3,299	19,186	(18,135)	-	4,350
Information and awareness	-	21,250	(8,198)	-	13,052
Total restricted funds	3,299	40,436	(26,333)	-	17,402
Unrestricted funds					
<i>Designated funds:</i>					
Listening Ear Fund	40,000	-	-	-	40,000
<i>Total designated funds</i>	40,000	-	-	-	40,000
General funds	339,041	316,811	(273,352)	-	382,500
Total unrestricted funds	379,041	316,811	(273,352)	-	422,500
Total funds	382,340	357,247	(299,685)	-	439,902

Purposes of restricted funds

Family support services

This is funding for our frontline services to families such as our Listening Ear telephone and email helpline and Regional Family Days. It includes grants received during the year from a number of funders, including Awards for All, the Mary Homfray Charitable Trust and the Bothwell Charitable Trust, plus various other trusts and foundations, kindly helping us to support families in regions across the UK as part of our wider service.

Information and awareness

These funds are provided by a number of charitable trusts and foundations, helping us to continue to increase our library of 'practical' information guides for families and supporting our work to provide families with specialist information as part of our wider service.

Purposes of designated funds

Listening Ear Fund

The trustees have designated £40,000 from general funds to the charity's 'Listening Ear' project. This sum is to ensure that the Unique helpline, a frontline service providing expert response to first-time callers from the UK and around the world, would be staffed appropriately for at least part of each UK working day during each year. The fund will be spent if and when general funds are unavailable to cover the cost of running the service.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

17. Movements in funds (continued)

Prior period comparative

	At 1 April 2019 £	Income £	Expenditure £	Transfers between funds £	At 31 March 2020 £
Restricted funds					
Family support services	13,630	7,400	(17,731)	-	3,299
Information and awareness	706	3,250	(3,956)	-	-
Total restricted funds	14,336	10,650	(21,687)		3,299
Unrestricted funds					
<i>Designated funds:</i>					
Listening Ear Fund	40,000	-	-	-	40,000
<i>Total designated funds</i>	40,000	-	-	-	40,000
General funds	335,589	313,192	(309,740)	-	339,041
Total unrestricted funds	375,589	313,192	(309,740)	-	379,041
Total funds	389,925	323,842	(331,427)	-	382,340

18. Related party transactions

There were no related party transactions during the year ended 31 March 2021, or the prior year.

19. Financial instruments held at fair value

	2021 £	2020 £
Financial assets measured at fair value	700	700

Financial assets measured at fair value comprise investment assets.