

Company no. 05460413
Charity no. 1110661

Rare Chromosome Disorder Support Group

Report and Unaudited Financial Statements

31 March 2023

Rare Chromosome Disorder Support Group

Contents

For the year ended 31 March 2023

	Page
Reference and administrative details	1 - 2
Report of the trustees	3 - 12
Independent examiners' report	13
Statement of financial activities	14
Balance sheet	15 - 16
Notes to the financial statements	17 - 29

Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2023

Company number 05460413

Charity number 1110661

Registered office and operational address F4, 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 until 17 October 2022
Isobel Hindle	Trustee
Edna Knight, MBE	Founder, Life President, Trustee
Gillian Manvell	Trustee
Shwetha Ramachandrappa	Trustee
Sophie Sainty	Chair from 18 October 2022
Benjamin Stern	Trustee
James Toop	Trustee
Fiona de Zoete	Trustee

Chief executive officer Dr Sarah Wynn

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 2023

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

Independent examiners

Godfrey Wilson Limited
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 2023

Welcome to Unique's annual report and accounts for the year ended 31 March 2023 and thank you for your interest in our work.

As a small charity, this is an incredibly challenging time, with a squeeze on our income, accompanied by the steep rises in costs that we are all experiencing. At the same time, we are attempting to serve an ever-increasing number of families in real need of our help and support. Having entrusted the leadership of the charity to Dr. Sarah Wynn as CEO, with Craig Mitchell supporting her as COO, we are hugely proud of the way the team has met these challenges head on and continue to provide families with the same excellence in service provision that has become our hallmark. Between April 2022 and March 2023, we saw a 10% increase in the numbers coming to us, welcoming and helping over 2,150 new families. This takes the total supported to over 28,000 families, representing more than 30,000 affected individuals.

A real highlight this year was running our first in-person event since the pandemic, a family day in Exeter attended by lots of families from across the South West, as well as local professionals. Networking in this way is so important to families who can otherwise find themselves feeling very isolated. One parent told us they had "learnt more in three hours than in the three years since the diagnosis." During the coming year, we are planning three more in-person events for families and professionals and are hugely grateful to the Royal Society of Medicine who are hosting one of these events, planned for October 2023.

Given the bleak wider economic and charity sector forecasts, we prepared a worst-case scenario budget which we kept under constant review during the year to carefully control our expenditure. Our income for the year was disappointing, down by around 5%, following on from the previous already tight year. We made use of some of our reserves to protect Unique's key services but towards the end of the financial year, having reviewed our entire cost base, and given the reduction in income, we took the extremely difficult decision to consider reducing staff headcount. Whilst we are very mindful that as a support organisation our staff are at the centre of all our work, as Trustees we must also ensure the charity's long-term sustainability so we can continue to serve our beneficiaries. Towards the end of the financial year, after taking advice and after appropriate consultation, with a heavy heart we began the redundancy consultation process with staff. We aim to conclude this in April 2023. We have also taken the decision to work with a specialist consultant trust fundraiser to increase our fundraising efforts to specifically target larger grants. We will continue to keep our costs closely under review throughout 2023-24 but we believe that these steps will put us on the path to grow to meet the ever-increasing numbers of families affected by rare chromosome and gene disorders.

A key aim for the next year is to launch our new database. The cornerstone of much of our work, used to inform families and professionals alike about many hundreds of different rare chromosome and gene disorders, this is a crucial piece of work. Much of the groundwork for this has been done, overseen by James Toop, our trustee with responsibility for IT and we are confident it will bring huge gains in terms of efficiency of working and developments to our frontline services. We will also further develop our offering to the growing number of families who come to us having received a diagnosis during pregnancy and naturally have lots of questions. We are also expanding our information resources to include Easy Read guides aimed at our members who have a learning disability or who have difficulty processing information. The Easy Read adapted format uses pictures, simple language and larger font to help older children and adults understand more about their own condition.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

We are confident that the actions we have taken this year and the plans we have in place, together with our strong working relationships with a great many professionals and our dedicated, professional staff team mean that Unique continues to be in a very strong position to weather the current macro-economic challenges and serve all those needing our help and support.

Sophie Sainty, Chair of Trustees

Our Mission, Aims and Objectives

Unique's mission is to inform, support and alleviate the isolation of anyone affected by a rare chromosome or gene disorder and to raise public awareness.

Rare Chromosome and Gene Disorders (RCDs) are lifelong conditions, present at birth (though not usually inherited) which cause often severe learning and physical disabilities and complex medical issues. They involve parts of one of more of a person's chromosomes or single genes being missing, duplicated or rearranged or a change to just one single gene. They are life-limiting and occasionally life-threatening, with many of those affected being reliant on parents and carers for all their needs. Others are affected only mildly, with relatively few symptoms, only finding out they have a condition when trying to conceive or facing distressing issues such as stillbirth or miscarriage.

New technology, e.g. 'Whole Genome Sequencing' which is now part of routine clinical practice, makes it possible to diagnose much smaller changes, e.g. in just one gene. As a result, many more children (and adults) are receiving a diagnosis. At least 1 in 200 babies is born with a rare chromosome or gene disorder, and whilst knowledge and understanding have grown considerably, the rarity of the individual conditions we support means they remain relatively poorly understood. Parents often receive a complex, confusing diagnosis with little information and are left devastated, with a great many unanswered questions.

At Unique we aim to help them understand and begin to come to terms with the diagnosis and how their child is likely to be affected. We – and often we alone – can provide answers to many of their questions and connect them to other families facing similar daily challenges. We do this by:

- Providing specialist information and support to anyone affected by and dealing with RCDs;
- Helping to relieve the isolation of those affected and their families;
- Promoting, participate and facilitate medical and other research; and
- Acting as an umbrella organisation for all RCDs.

As ever-increasing numbers of families come to us desperate for answers, we want them to feel better supported, less isolated and able to face the future with hope, confident that they will be able to care for their disabled child.

Our Activities & Achievements During 2022-23

Our key services can be summarised in three strands: **Family Support, Information, and Networking.**

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

1. Family Support

Our key service to families is **Unique's Listening Ear Telephone and Email helpline**, the first point of contact for distressed parents in need of help. Our experienced Information Officers are able to answer many of their questions, explain complex terminology, take them through what the diagnosis means and outline what the future may hold for their child in terms of the disabilities, health issues and other challenges they will face. At their lowest ebb, families tell us they greatly value being able to talk this through with someone understanding, empathetic and knowledgeable.

Families receive a tailored response, including information about their child's specific condition and a welcome pack of resources and we link them to other families via our **Family Matching Service**. Contact with others who have a family member with a similar condition and/or symptoms is crucial to overcoming feelings of isolation and establishing support networks. Individual conditions can be very rare, so without this families seldom meet another family in the same position. We also facilitate these links through events such as our **Family Days** across the UK, bringing lots of families together with geneticists and other professionals.

Under the Family Support strand of our work, our activities and achievements this year included:

- 2,151 new families joining us, a 10% increase on the previous year;
- our Listening Ear team answering more than 1,100 telephone and email queries from families, expectant parents, professionals and others;
- assisting hundreds of professionals caring for their patients, as the number of professionals who are members of Unique passed 800;
- answering over 1,000 messages received via social media, for the second year running. Over 30% of new families took the opportunity to join our private, closed Facebook 'Café' during the year – a safe, confidential, moderated environment for mutual support; and
- linking thousands of new and existing member families, to make contact, swap tips, resources and guidance and forge support networks and friendships.

2. Provision of Specialist Information

Access to reliable information is crucial in overcoming the initial shock of receiving the diagnosis. One parent likened being told their child has a rare chromosome disorder to a "sledgehammer blow" and this can be compounded when they are also told it is a very rare condition, about which there is little knowledge. There is often no recognised care pathway as with other, better-known conditions.

Our **Unique Information Project** seeks to address this, producing family-friendly and independently medically verified guides to specific conditions. We have now produced over 300 such guides, giving families and professionals reliable, accurate information not otherwise available. They are based on information from Unique member families and also draw on carefully researched data from medical literature. Prior to publication, they are verified by geneticists or paediatricians who are the world expert on the specific condition who volunteer their time. Each one covers the medical issues associated with the condition but also topics such as learning, development and behaviour and families and professionals alike regularly tell us how incredibly valuable they find them.

During the year we also reached the milestone of publishing the 30th of our '**practical guides**'. These sit alongside our condition-specific guides, covering topics of relevance to many families regardless of their child's condition. Topics include communication, sleep, toileting and dental issues and this year we published our guide to Hearing Loss. This will benefit lots of children born with a diverse range of rare chromosome disorders who are affected by hearing loss, from mild to moderate, to full deafness.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

To produce all this tailored information, we collect data from families in our **Unique database**. Each family's entry contains medical information for their child together with behavioural, social, educational and developmental issues affecting them. As well as informing families, this can then be used in anonymised form to assist researchers, geneticists and other professionals.

Our key activities and achievements this year as part of our work to provide specialist information are:

- publishing 8 brand new information guides to specific rare chromosome or gene disorders, including 4 newly-emerging single gene disorders;
- releasing substantial updates to 15 of our existing information guides, with lots of information provided by member families;
- translating 72 more of our information guides into different languages, including 3 new languages (Malay, Vietnamese and Turkish), a huge help for those for whom English is not their first language who would otherwise struggle to understand their child's condition;
- publishing 5 new 'My Chromosome Story' picture books, taking the total to 16. These are simple, easy-to-understand graphical booklets for children, explaining specific disorders;
- publishing 2 more of our 'practical' guides for families, helping them learn and access help about issues that 'cut across' many different conditions; and
- contacting a further 1,612 families to update their data as part of our data update programme.

Our two Scientific Communications Officers (one full-time and one part-time) continue to work incredibly hard to meet demand from families for tangible, reliable resources. Being able to give families these resources is incredibly valuable in helping them come to terms with their diagnosis and we are committed to produce as many information guides as possible over the next year.

Our ongoing **Data Update Programme** also continued apace as we work to ensure we have up to date and relevant data for all our member families. Their data is used to write and publish our information guides, provide tailored responses to families in need of our help, assist with clinical and other research and further our collective knowledge of rare chromosome and gene disorders.

We also facilitate and are involved in **research projects** wherever possible. Two of our team are co-authors on a publication in The Lancet looking at children with intellectual disability with an underlying genetic cause. Other studies we are involved in include GENROC, looking at 500 children with single gene disorders with the aim of improving clinical predictions for them.

3. Networking and Awareness-Raising

Rare chromosome and gene disorders affect at least 1 in 200 babies, with rates of diagnosis rapidly increasing, yet they remain relatively poorly understood. Individually, many of the disorders are incredibly rare so networking to raise awareness is a key aim for us. We have continued to build on our already strong working relationships with geneticists and other relevant professionals, many of whom refer families to us as a first point of contact, demonstrating their trust in us. We also work closely with other charities and policy-makers to raise the profile and awareness of these disorders. Hundreds of professionals have given their time freely and we are extremely grateful to them all, particularly for verifying our information resources which are so important to families.

We network with a large and ever-growing social media audience via Facebook, Instagram and Twitter, a cost-effective way to raise awareness and also fundraise. An integral part of this is our secret, private group for families; a safe, moderated environment for confidential discussions and mutual support.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

As part of our networking and awareness raising activities this year, the Unique team have attended over 25 meetings and conferences and given 29 presentations, including:

- a plenary lecture at The British Society for Genetic Medicine (BSGM) annual conference;
- giving the keynote speech at the launch of the Public Policy Projects (PPP) Rare disease report: A Fairer Future;
- presenting at UK Clinical Genetics Society meeting on our 'My Chromosome Story' project;
- chairing a session on the Newborn Genomes programme at the annual Festival of Genomics;
- delivering a talk as part of a Royal College of Paediatrics and Child Health webinar: Whole genome sequencing: developments and future perspectives;
- chairing the afternoon session at the first ever NHS Genomics Summit;
- being invited to the Rare Disease All Party Parliamentary Group (APPG) on Rare, Genetic and Undiagnosed Conditions meeting launching the Good Diagnosis Report and the Co-ordinating Care Report;
- providing input on our experiences of providing information and support to the rare disease community at the England Rare Diseases Framework Delivery Group;
- producing 'Hands-on' sustainable resources for activities for an event for secondary school students at the Royal Holloway;
- presenting to neonatal paediatricians at St. George's Hospital, with Medics 4 Rare Diseases (M4RD);
- giving a presentation at the launch of Manchester Rare Conditions Centre (MRCC); and
- giving two presentations to classes of medical students as part of University College London's Visitor Sessions on the theme of 'Living with a Genetic Disorder'.

Our staff sit on a variety of high level advisory boards, including the NHS Genomics Clinical Reference Group, Rare Disease UK's Patient Empowerment Group, England Rare Diseases Action Plan's Patient Advisory Group and University of London's ENRICH study. We have close working links with other organisations such as Genetic Alliance UK, Beacon for Rare Diseases, SWAN UK and Gene People. All are undertaken for the benefit of those who need our help.

Social media

For a small charity, social media is a cost-effective way to reach a large and diverse audience. Our public Facebook page has over 41,000 followers, our Twitter feed over 7,500 followers and our Instagram page over 7,000. Whilst we do not pay for advertising, each strand continues to grow rapidly, reflecting our ongoing efforts to raise awareness about our work with regular posts, stories and case studies. We encourage members and supporters to receive our magazine by email rather than by post, as an environmentally-friendly and cheaper option for the charity and our regular email newsletters continue to receive positive open and click-through rates.

With limited resources, we feel it is proportionate to hold a 'Rare Chromo Day' and not a full week as in the past. We selected June 16th as a day on which we aimed to 'celebrate, educate and inform'. Supporters undertook our new 'Unique23' challenge, an inclusive challenge asking supporters to do 23 different activities, regardless of their ability level. We were thrilled to see our member families and their children getting behind it. A number of parents and professionals also gave presentations, wore blue and yellow, held cake sales and coffee mornings or gave out leaflets, all helping to raise awareness. The NHS Genomics unit also ran an awareness campaign creating content for social media including a video clip from Dame Professor Sue Hill, Chief Scientific Officer for England.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

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.

We also continue to ensure that there is representation of the public and patient voice by sitting on a number of NHS boards including the NHS Clinical Reference Group for Genomics, the British Society for Genomic Medicine's Bioethics Committee and the NHS People and Communities Forum. As clinical care is rapidly evolving to include genetic/genomic testing in almost all areas of medicine, it is vital that our beneficiary group continues to be fully represented and heard.

Hybrid Working & Unique's Infrastructure

Unique maintains a small office base in Surrey and staff work a hybrid pattern of office and home working. Regular face to face contact between staff is important but this also promotes a positive work-life balance and mental health, whilst also helping to reduce costs and our carbon footprint. We continue to monitor productivity closely, ensuring beneficiaries continue to receive the excellent service that is our hallmark. We are grateful to our IT providers TQS Ltd. whose continued flexibility and responsiveness enables us to work in this way. They continue to advise staff to ensure operating software and working practices are up to date and secure.

A crucial need is to replace our specialist database, which is now over 20 years old. Much of the groundwork and scoping for this is complete, with a sub-committee including two trustees plus the CEO and COO and we aim for this project to be completed during the coming year. Confidentiality and data security are paramount and all data are processed in accordance with the Data Protection Act 2018 and General Data Protection Regulation (GDPR) and we benefitted greatly from the assistance of a data lawyer who advised us on a pro bono basis in the previous year.

Volunteers

A large number of people helped us voluntarily during the year and we are hugely grateful to each and every one of them. They included:

- A network of more than 150 local volunteer contacts, helping Unique member families in their local area;
- Geneticists and other professionals giving up their time to read through and independently verify our information guides prior to publication;
- At least 50 expert volunteers translating our information guides into a variety of languages;
- Roberta Elliott who gives her time freely and very willingly to help us with designs for our social media and other marketing; and
- Voluntary fundraising undertaken by hundreds of our members and supporters.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

Financial Review 2022-23

Income

This proved to be another challenging year for Unique, with a reduction in income of around 5% to £289,143. As many of our supporters are families caring for disabled children, they really felt the pinch this year with the cost-of-living crisis a significant factor. As a result, we saw a fall in voluntary donations of more than 30%, to just under £95,000. However, we were able to balance this somewhat as fundraising income remained stable and we were able to double our income from grants, to just over £60,000. As always, we are very touched by the numbers of people supporting us many of whom while caring for children with rare chromosome and gene disorders.

Unrestricted income was £246,064 (previous year: £288,305), including unrestricted grants of £21,500. Restricted income from grants plus funds raised by the CEO and COO running the Royal Parks Half Marathon was £43,079, to be spent on Regional Activities, Devon Family Day, Easy Read Guides, East & West Midlands Family Days, Helpline & Information/Awareness. We are fortunate that a high proportion of our income is unrestricted as this gives us the flexibility to direct funds to those aspects of our work which Trustees and senior staff feel will have the greatest impact for beneficiaries.

Expenditure

Total expenditure for the year was £382,563, an increase of around 12% on the previous year. Our relatively healthy reserves during the year meant that we could sustain this, to protect our frontline services which continued to return to more normal levels of demand after the pandemic. Despite therefore ending the year with a deficit of £93,420, protecting our services brought real benefits to families, many of whom were in desperate need of help having received a diagnosis for their child.

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. Based on expenditure for 2022-23, this equates to minimum reserves of approximately £127,000. As it seems likely that the prevailing macro-economic situation, including the ongoing cost of living crisis, will continue into 2023-24, we have again budgeted for a deficit and expect our current free reserves to reduce further during the year. Our reserves policy is reviewed annually and updated as necessary.

The Future

During the process of reviewing our cost base to prepare a budget for 2023-24, in March 2023 we held an extraordinary meeting of the Trustees at which several cost saving proposals were discussed. These included a proposal to reduce our staff headcount which, if agreed, will potentially result in one or more staff being made redundant. We have begun the consultation process, assisted at every step by Primed HR, our retained HR and Employment Law advisers, to ensure fairness and transparency throughout the process. As ever, protecting our key services to those who need us will remain at the heart of all decisions we take, not least because some of the trustees and staff have in the past been beneficiaries themselves, having their own affected children.

This year, in addition to launching the new database described elsewhere in this report, we aim to develop and implement a new social media strategy to capitalise on the strong base that we have in this area. With a large and growing audience, this is crucial to helping people find us and access the information and support they need.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

Structure, Governance and Management

The Trustees delegate the charity's day-to-day management to Dr Sarah Wynn, CEO, supported by Craig Mitchell (COO). At the end of March 2023, Unique employs ten staff, including the CEO, four of whom are full-time and six part-time. Craig Mitchell (COO) is also Company Secretary.

Corporate and Social Responsibility and Sustainability

We welcome and help all members of our communities who may be affected by a RCD, irrespective of their background in terms of race, religion, sexuality, marital status or culture. We are proud to be members of '**Breaking Down Barriers**', a network of organisations working to improve the lives of diverse and marginalised communities, so that they have equal access to health services.

We are an equal opportunity employer and take our responsibilities for the welfare of our staff extremely seriously. As CEO, Sarah Wynn has continued to foster and encourage a strong team ethic, with regular communication and regular staff meetings, both virtual and in-person. Staff are encouraged to take steps where appropriate to minimise any environmental impacts of our work and we continue to reduce the number of printed materials such as magazines we produce, in favour of communicating digitally with families where possible.

Management of Risk

We maintain and regularly review and update Unique's Risk Register, containing the major financial, operational, reputational and other potential risks to the charity. 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 meet formally three times per year, with senior staff present, with the charity's financial position kept under review at each meeting. Monthly management reports are circulated to all trustees and senior staff.

Compliance and Training

We collect a range of sensitive medical and personal data in order to provide our services and are acutely aware of our responsibilities in this area. Our COO has continued to attend workshops provided by organisations such as the Charity Finance Group and ACAS to ensure regulatory compliance. All staff and Trustees undergo DBS checks and we continued to engage Carecheck to carry them out.

We often receive research proposals from professionals, academics and others who request that we share them with member families and we have an Internal Research and Ethics Committee to appraise them. No such proposals are shared without approval from the committee.

Staff performance is kept under ongoing review and all staff also take part in a formal annual appraisal which relates the key responsibilities of their role to Unique's charitable aims. One aim of doing this is to identify any knowledge gaps or training needs in order that appropriate training can be sourced. Appraisals are undertaken 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 met three times during the year and corresponded regularly via email and other digital means, particularly to keep financial performance under review. They receive monthly management reports with a narrative to flag any issues.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

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 Autumn 2022 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.

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 2023

Independent examiners

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

Approved by the trustees on 10 October 2023 and signed on their behalf by

Sophie Sainty- Trustee (Chair)

Independent examiner's report

To the trustees of

Rare Chromosome Disorder Support Group

I report to the trustees on my examination of the accounts of Rare Chromosome Disorder Support Group (the charitable company) for the year ended 31 March 2023, which are set out on pages 14 to 29.

Responsibilities and basis of report

As the trustees of the charitable company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the charitable company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the charitable company's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since the charitable company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- (1) accounting records were not kept in respect of the charitable company as required by section 386 of the 2006 Act; or
- (2) the accounts do not accord with those records; or
- (3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
- (4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and 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.

Date: 10 October 2023

Alison Godfrey FCA
Member of the ICAEW

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 2023

	Note	Restricted £	Unrestricted £	2023 Total £	2022 Total £
Income from:					
Donations and legacies	3	4,225	229,027	233,252	277,844
Charitable activities:					
<i>Family support services</i>	4	23,327	-	23,327	3,250
<i>Information and awareness</i>	5	15,527	14,752	30,279	22,662
Investments		-	2,285	2,285	1,049
Total income		<u>43,079</u>	<u>246,064</u>	<u>289,143</u>	<u>304,805</u>
Expenditure on:					
Raising funds		-	48,376	48,376	39,714
Charitable activities:					
<i>Family support services</i>		16,681	167,329	184,010	180,680
<i>Information and awareness</i>		30,628	119,549	150,177	123,416
Total expenditure	7	<u>47,309</u>	<u>335,254</u>	<u>382,563</u>	<u>343,810</u>
Net income / (expenditure)		(4,230)	(89,190)	(93,420)	(39,005)
Net gains on investment	12	-	3,300	3,300	-
Net movement in funds	8	(4,230)	(85,890)	(90,120)	(39,005)
Reconciliation of funds:					
Total funds brought forward		20,620	380,277	400,897	439,902
Total funds carried forward		<u>16,390</u>	<u>294,387</u>	<u>310,777</u>	<u>400,897</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 2023

	Note	£	2023 £	2022 £
Fixed assets				
Tangible fixed assets	11		2,802	4,653
Investments	12		4,000	700
			6,802	5,353
Current assets				
Stock	13	2,794		1,405
Debtors	14	11,769		16,234
Cash at bank and in hand		307,847		394,606
		322,410		412,245
Creditors: amounts due within 1 year	15	18,435		16,701
Net current assets			303,975	395,544
Net assets	16		310,777	400,897
Funds				
Restricted income funds	17		16,390	20,620
Unrestricted funds:				
Designated funds			40,000	40,000
General funds			254,387	340,277
Total charity funds			310,777	400,897

The directors are satisfied that the company is entitled to exemption from the provisions of the Companies Act 2006 (the Act) relating to the audit of the financial statements for the year by virtue of section 477(2), and that no member or members have requested an audit pursuant to section 476 of the Act.

The directors acknowledge their responsibilities for:

- (i) ensuring that the Company keeps proper accounting records which comply with section 386 of the Act; and
- (ii) preparing financial statements which give a true and fair view of the state of affairs of the Company as at the end of the financial year and of its profit or loss for the financial year in accordance with the requirements of section 393, and which otherwise comply with the requirements of the Act relating to financial statements, so far as applicable to the company.

Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2023

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 10 October 2023 and signed on their behalf by

Sophie Sainty- Trustee (Chair)

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

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 potential impact of the current economic environment in the UK and beyond. 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 2023

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:

	2023	2022
Raising funds	9.0%	7.5%
Family support services	51.0%	58.0%
Information and awareness	40.0%	34.5%

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
--------------------	-----------------------

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 2023

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 2023

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 £	2022 Total £
Income from:			
Donations and legacies	-	277,844	277,844
Charitable activities			
<i>Family support services</i>	3,250	-	3,250
<i>Information and awareness</i>	13,250	9,412	22,662
Investments	-	1,049	1,049
Total income	16,500	288,305	304,805
Expenditure on:			
Raising funds	-	39,714	39,714
Charitable activities			
<i>Family support services</i>	4,301	176,379	180,680
<i>Information and awareness</i>	8,981	114,435	123,416
Total expenditure	13,282	330,528	343,810
Net income / (expenditure) and net movement in funds	3,218	(42,223)	(39,005)

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

3. Donations and legacies

	Restricted £	Unrestricted £	2023 Total £	2022 Total £
Grants more than £5,000:				
Bothwell Charitable Trust	-	-	-	5,000
D & J Hunter Charitable Trust	-	10,000	10,000	-
Grants £5,000 or less	-	11,500	11,500	8,154
Donations from fundraising activities	-	121,153	121,153	122,409
General donations	4,225	34,707	38,932	56,909
Corporate donations	-	17,108	17,108	33,788
Gift aid	-	21,510	21,510	20,710
Overseas donations	-	10,920	10,920	18,966
Gifts in kind	-	-	-	7,124
Legacies	-	-	-	2,000
Give As You Earn (GAYE)	-	1,697	1,697	1,837
Coronavirus Job Retention Scheme	-	-	-	509
Pyramids	-	432	432	438
	<u>4,225</u>	<u>229,027</u>	<u>233,252</u>	<u>277,844</u>

All income from donations in the prior year was unrestricted.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

4. Charitable activities: family support services

	Restricted £	Unrestricted £	2023 Total £	2022 Total £
Grants more than £5,000:				
Pears Foundation	8,500	-	8,500	-
Grants £5,000 or less	<u>14,827</u>	<u>-</u>	<u>14,827</u>	<u>3,250</u>
	<u>23,327</u>	<u>-</u>	<u>23,327</u>	<u>3,250</u>

All income from charitable activities: family support services in the prior year was restricted.

5. Charitable activities: information and awareness

	Restricted £	Unrestricted £	2023 Total £
Grants £5,000 or less	15,527	-	15,527
Christmas card and merchandise sales	-	10,424	10,424
Conference fees	<u>-</u>	<u>4,328</u>	<u>4,328</u>
	<u>15,527</u>	<u>14,752</u>	<u>30,279</u>
Prior year comparative			2022 Total £
	Restricted £	Unrestricted £	
Grants more than £5,000:			
The Openwork Foundation	10,000	-	10,000
Grants £5,000 or less	3,250	-	3,250
Christmas card and merchandise sales	<u>-</u>	<u>9,412</u>	<u>9,412</u>
	<u>13,250</u>	<u>9,412</u>	<u>22,662</u>

6. Government grants

In the prior year the charitable company received government grant income in the year under the Coronavirus Job Retention Scheme. The total value of such grants was £509. There were no unfulfilled conditions or contingencies attaching to these grants.

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

7. Total expenditure

	Raising funds £	Family support £	Information and awareness £	Support and governance £	2023 Total £
Independent examination and accountancy	-	-	-	2,520	2,520
Computer expenses	647	5,134	2,905	-	8,686
Depreciation	167	944	740	-	1,851
Event costs	-	4,838	-	-	4,838
Insurance	-	-	-	2,381	2,381
Office costs and rent	2,139	12,159	8,455	312	23,065
Postage and distribution	270	4,430	6,257	-	10,957
Printing and design	16	3,320	201	-	3,537
Project costs	-	-	10,320	-	10,320
Staff costs (note 9)	29,760	123,856	94,454	46,376	294,446
Stationery	61	540	354	-	955
Subscriptions, licences and charges	10,515	338	4,898	1,117	16,868
Training and other staff costs	4	185	19	90	298
Travel and subsistence	45	506	152	-	703
Website and database development	-	834	304	-	1,138
Sub-total	43,624	157,084	129,059	52,796	382,563
Allocation of support and governance costs	4,752	26,926	21,118	(52,796)	-
Total expenditure	48,376	184,010	150,177	-	382,563

Governance costs were £4,420 (2022: £6,437).

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

7. Total expenditure (continued) Prior year comparative

	Raising funds £	Family support £	Information and awareness £	Support and governance £	2022 Total £
Advertising	-	-	564	-	564
Audit and accountancy	-	-	-	4,140	4,140
Computer expenses	454	5,375	2,090	-	7,919
Depreciation	211	1,630	970	-	2,811
Insurance	-	-	-	2,290	2,290
Office costs and rent	1,498	13,374	7,045	234	22,151
Postage and distribution	252	13,495	1,265	-	15,012
Printing and design	11	6,842	3,795	99	10,747
Project costs	-	6,164	4,680	960	11,804
Staff costs (note 9)	25,724	101,146	79,866	42,481	249,217
Stationery	48	566	418	-	1,032
Subscriptions, licences and charges	7,655	405	4,568	13	12,641
Training and other staff costs	61	635	407	172	1,275
Travel and subsistence	15	317	69	82	483
Website and database development	-	1,458	266	-	1,724
Sub-total	35,929	151,407	106,003	50,471	343,810
Allocation of support and governance costs	3,785	29,273	17,413	(50,471)	-
Total expenditure	39,714	180,680	123,416	-	343,810

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

8. Net movement in funds

This is stated after charging:

	2023	2022
	£	£
Depreciation	1,851	2,811
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses	Nil	8
Auditors' remuneration	Nil	4,140
Independent examiners' remuneration	2,520	Nil

No trustees were reimbursed for expenses in the current year. In the prior year one trustee was reimbursed for travel expenses of £8.

9. Staff costs and numbers

Staff costs were as follows:

	2023	2022
	£	£
Salaries and wages	263,937	223,962
Social security costs	20,372	16,392
Pension contributions	10,137	8,863
	294,446	249,217

No employee earned more than £60,000 during the year (2022: 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 £114,857 (2022: £99,635).

	2023	2022
	No.	No.
Average staff head count	10	10
Average full time equivalent	7	7

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 2023

11. Tangible fixed assets

	Computer equipment £
Cost	
At 1 April 2022 and at 31 March 2023	<u>15,400</u>
Depreciation	
At 1 April 2022	10,747
Charge for the year	<u>1,851</u>
At 31 March 2023	<u>12,598</u>
Net book value	
At 31 March 2023	<u><u>2,802</u></u>
At 31 March 2022	<u><u>4,653</u></u>

12. Investments

	Artwork £
At 1 April 2022	700
Gain on revaluation	<u>3,300</u>
At 31 March 2023	<u><u>4,000</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 was revalued during the year based on the sale of a similar work by the artist. The trustees are satisfied that the print is carried at an appropriate value at 31 March 2023.

13. Stock

	2023 £	2022 £
Merchandise	<u><u>2,794</u></u>	<u><u>1,405</u></u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

14. Debtors

	2023 £	2022 £
Trade debtors	290	-
Prepayments	7,243	9,908
Accrued income	4,236	6,326
	<u>11,769</u>	<u>16,234</u>

15. Creditors : amounts due within 1 year

	2023 £	2022 £
Trade creditors	274	80
Accruals	8,353	8,302
Other taxation and social security	5,482	5,239
Pension creditor	4,326	3,080
	<u>18,435</u>	<u>16,701</u>

16. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	Total funds £
Tangible fixed assets	-	-	2,802	2,802
Investments	-	-	4,000	4,000
Net current assets	16,390	40,000	247,585	303,975
Net assets at 31 March 2023	<u>16,390</u>	<u>40,000</u>	<u>254,387</u>	<u>310,777</u>

Prior year comparative

	Restricted funds £	Designated funds £	General funds £	Total funds £
Tangible fixed assets	-	-	4,653	4,653
Investments	-	-	700	700
Net current assets	20,620	40,000	334,924	395,544
Net assets at 31 March 2022	<u>20,620</u>	<u>40,000</u>	<u>340,277</u>	<u>400,897</u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

17. Movements in funds

	At 1 April 2022 £	Income £	Expenditure £	Gain on investments £	At 31 March 2023 £
Restricted funds					
Family support services	3,299	23,327	(16,681)	-	9,945
Information and awareness	17,321	19,752	(30,628)	-	6,445
Total restricted funds	20,620	43,079	(47,309)	-	16,390
Unrestricted funds					
<i>Designated funds:</i>					
Listening Ear Fund	40,000	-	-	-	40,000
<i>Total designated funds</i>	40,000	-	-	-	40,000
General funds	340,277	246,064	(335,254)	3,300	254,387
Total unrestricted funds	380,277	246,064	(335,254)	3,300	294,387
Total funds	400,897	289,143	(382,563)	3,300	310,777

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 and 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 2023

17. Movements in funds (continued)

Prior period comparative

	At 1 April 2021 £	Income £	Expenditure £	At 31 March 2022 £
Restricted funds				
Family support services	4,350	3,250	(4,301)	3,299
Information and awareness	<u>13,052</u>	<u>13,250</u>	<u>(8,981)</u>	<u>17,321</u>
Total restricted funds	<u>17,402</u>	<u>16,500</u>	<u>(13,282)</u>	<u>20,620</u>
Unrestricted funds				
<i>Designated funds:</i>				
Listening Ear Fund	<u>40,000</u>	-	-	<u>40,000</u>
<i>Total designated funds</i>	<u>40,000</u>	-	-	<u>40,000</u>
General funds	<u>382,500</u>	<u>288,305</u>	<u>(330,528)</u>	<u>340,277</u>
Total unrestricted funds	<u>422,500</u>	<u>288,305</u>	<u>(330,528)</u>	<u>380,277</u>
Total funds	<u><u>439,902</u></u>	<u><u>304,805</u></u>	<u><u>(343,810)</u></u>	<u><u>400,897</u></u>

18. Related party transactions

There were no related party transactions during the current or prior year.

19. Financial instruments held at fair value

	2023 £	2022 £
Financial assets measured at fair value	<u><u>4,000</u></u>	<u><u>700</u></u>

Financial assets measured at fair value comprise investment assets.