

Company no. 05460413
Charity no. 1110661

**Rare Chromosome Disorder Support
Group
Report and Audited Financial Statements
31 March 2022**

Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2022

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
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 retired 31 August 2021
Dr Sarah Wynn appointed 1 September 2021

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 2022

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 2022

Hello and welcome to Unique's annual report and accounts for the year ended 31 March 2022.

This has been a year of significant change for Unique but one in which we have continued to serve families affected by rare chromosome and gene disorders with the same excellent service that has become our hallmark. In August 2021, Dr Beverly Searle took a well-earned retirement, having served Unique with distinction for over 30 years, first as a volunteer, then as Director of Development and for more than 20 years as Chief Executive Officer. Beverly led the charity through a period of huge change, steering us through our development from an informal support group helping a small number of families, to the significant, growing and award-winning charity we are today, providing a crucial service to many thousands of families. She leaves with our sincere and heartfelt thanks and we wish Beverly and her husband Trevor, who designed and supported our database and volunteered for Unique over many years, a long and happy retirement.

Given the challenging climate that we as a small charity are operating in, we felt that continuity was important. We were therefore delighted when Dr Sarah Wynn accepted our offer to become Unique's Interim CEO from September 2021. We asked her to work with our Chief Operating Officer Craig Mitchell to co-lead the charity and formulate our next 3-5 year operating strategy to steer us through this uncertain period and into the future. Sarah has worked for Unique since 2007 and was able to hit the ground running, bringing fresh energy and enthusiasm that will build on our solid foundations to take Unique forward to the next stage of our development. She and Craig have already begun the significant project to replace our current database, the cornerstone of much of our work, which will be crucial if we are to cope with the ongoing steep increases in demand.

As we all continue our cautious return to normality after the pandemic, we are conscious that we will continue to be buffeted by external, macro-economic factors. Accordingly, we have taken a conservative approach, budgeting to protect our key services by continued investment in the provision of specialist information and softer support. Financially, whilst our income was slightly down this year as Covid support was withdrawn, we were pleased that fundraising activities and voluntary income held up well. We are hugely grateful to everyone who fundraised for us, donated and helped raise awareness. This meant that we were able to increase expenditure to maintain and develop the capacity of our frontline services, so important to families and professionals alike.

Ensuring that these families, struggling to come to terms with their child's diagnosis of a rare chromosome or gene disorder, are able to get the help they so desperately need is, and will remain our top priority. With Covid restrictions now lifted, we are also planning to re-start our face to face events this year and very much hope to meet lots of those families in person, something we have not been able to do for almost three years. Our family events will help them to meet others in the same boat, facing the same day-to-day challenges and establish the sort of informal mutual support networks that can be so valuable.

As the UK's only charity working in this specific field, we now support over 26,000 families who have a child (and increasingly an adult) born with often severe learning and physical disabilities due to a rare chromosome or gene disorder. We expect the growth in demand will increase steeply as genomics becomes a more significant and mainstream strand of healthcare and diagnostic technology continues to develop. As trustees, we are determined that Unique will continue to be the go-to charity for these families and will work with Sarah, Craig and the team to do all in our power to ensure we strengthen and further develop the service we provide to them.

Helen Campbell, Chair of Trustees

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

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.

As technology has advanced rapidly, for example Whole Genome Sequencing (WGS), making it possible to diagnose much smaller genetic changes, many more children (and increasingly adults) are receiving a diagnosis than ever before. The nationally commissioned NHS England's Genomic Medicine Service was launched in 2019 and is underpinned by seven regional genetics laboratories who are implementing the newly formed National Genetic Test Directory for Rare Inherited Disease. The result of this is increased equity of genetic testing but also increased availability to many more people via a variety of different clinical routes, not solely through clinical genetics. Despite this, even in today's world of vast genomics and medical knowledge, these conditions remain relatively poorly understood. Having received an often complex, confusing and upsetting diagnosis, parents can be left reeling, with lots of unanswered questions. This is where we come in, helping them to understand and begin to come to terms with the diagnosis and how their child is likely to be affected, answering many of their questions, offering them support and connecting them to others facing similar daily challenges.

Our key aims are to:

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

Whilst individually these disorders can be very rare, affecting only a handful of people worldwide (and some even unique), collectively they are much more prevalent, in fact more common than even Down's Syndrome and autism combined, affecting at least 1 in 200 live-born babies. As a result, ever-increasing numbers of families are coming to Unique, desperate for answers and in need of the help that quite often only we can provide.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

Our Activities & Achievements During 2021-22

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

1. Family Support

Our key service is Unique's Listening Ear Telephone and Email helpline, the first point of contact for distressed parents in need of help. With an experienced team, bringing a mixture of qualifications and lived experience, we are able to answer many of their questions, explain complex terminology, go through what the diagnosis means and outline what the future may hold for their child. This sort of accessible, sympathetic, tailored response is invaluable when they are often at their lowest ebb.

Working alongside our Listening Ear team, our Family Support Officer provides a welcome pack of resources and is a mine of information on a great variety of topics relevant to families, for example, local sources of support, benefits, accessing grants and much more. We also link families to others in a similar position via our Family Matching Service. Connecting with a family living with a similar disorder and/or symptoms and daily challenges helps establish crucial support networks. The rarity of these conditions means that without this, families would be highly unlikely to meet another family in the same boat. Some are then able to meet in person and attend our events such as our regional Family Days, bringing families together with geneticists and other involved professionals to learn about genomics and establish informal support networks. These events will re-start and continue as government Covid guidelines allow, with the first planned for autumn 2022.

Our activities and achievements in supporting families this year included:

- **welcoming and helping 2,126 new families during the year, a 14% increase.** The number of families approaching us for help has been rapidly increasing as medical and other services have continued to return to normal after the pandemic and is now close to being back to pre-Covid levels.
- **our Listening Ear team answering thousands of emails from new and existing families and took almost 300 inbound telephone calls to the helpline.** Much of this contact is from distressed families who have received a diagnosis for their child and who are in desperate need of help and support.
- **helping hundreds of professionals,** many of whom needed our assistance when counselling and caring for their patients, before referring them on to us as a trusted source of help and support.
- **our Family Support Officer and other members of the team answering more than 1,000 messages via social media** as the different ways in which families prefer to contact us continued to evolve. The team signposted families to the help and support they need, including helping with their emotional wellbeing, assisting them with receiving benefits and linking them to other families.
- **matching thousands of new and existing Unique families with others during the year,** giving them access to others living with similar conditions and/or symptoms for mutual support and to swap tips, resources and guidance.
- **further strengthening our Listening Ear helpline team** by recruiting a new, part-time staff member. Anita King (now Anita Davis) has worked as a midwife for more than 25 years, including in screening and counselling for expectant mothers, so brings crucial skills to complement our existing staff team.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

2. Provision of Specialist Information

When families first approach us for help, they naturally have lots of questions. Imagine being told your child has a '6p25 deletion' or a '1q21.2 microduplication' for example.... you probably wouldn't know where to start (unless you had a Biology degree maybe!). Our Unique Information Project is a key way we try to address this. We have now written over 300 family-friendly information guides to specific rare chromosome and gene disorders, a 'unique' resource of its type. Using data from Unique member families, combined with information from specialist medical literature and research, all our guides are independently verified by specialist professionals in genomics and related fields who volunteer their time. They are not only used by families but also by doctors and other professionals. As well as covering the medical issues known to be associated with the condition, they cover other topics such as learning, development and behaviour, hugely important to those affected and their families. We are constantly contacted by families telling us they would have been lost without this information.

Alongside the disorder-specific guides are our '**practical guides**' to relevant topics like communication, sleep, feeding, toileting, challenging behaviour and what to do once you've received a diagnosis. All are themes that cut across lots of the conditions we support and therefore affect a huge proportion of our member families.

Our **Unique database/patient registry** underpins all this. It contains all the data provided by our member families, including medical information together with behavioural, social, educational and developmental issues. The data is provided anonymously to inform researchers, geneticists and other professionals and by our staff to help and guide families and produce our information resources.

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

- **our Scientific Communications Officers (one full-time and one part-time) writing and publishing 19 brand new information guides to specific RCDs.**
- **substantially updating 21 of our existing information guides.** This is a significant increase, reflecting the hard work and commitment of the team and also the willingness of our member families to provide information about their family member, to be used to help others.
- **translating a further 101 of our information guides into different languages to help those for whom English is not their first language.** This is almost double the number of last year as we continue our commitment to help a diverse audience. RCDs are no respecters of geographical limits or cultural backgrounds and we now have a variety of information translated into 18 different languages, other than English.
- **publishing two more of our 'My Chromosome Story' picture books, taking the total to 11.** These are simple, very accessible booklets, aimed primarily at children, explaining specific disorders in an understandable, straightforward and graphical way.
- **writing and publishing 3 more of our 'practical' guides for families.** One of these which has proved particularly popular is our 'Uniquely Different guide' which aims to help parents to get additional support in relation to birth 'uniqueness' and also help parents struggling with other people's reactions to their child's look/personality/behaviours etc.

The increase in the number and scope of the information guides produced this year reflects a commitment by trustees to continue to support and develop this crucial strand of our work. During the year, one of our existing Scientific Communications Officers moved from working part-time hours to a full-time, permanent position, increasing our capacity to produce more of our vital resources.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

We have now contacted more than 3,000 of our member families as our rolling database update programme continues apace, to ensure we have up to date and relevant data. We hold data provided by thousands of member families and professionals and are aiming to contact them all to ensure they are happy for us to retain their information and if so, to provide us with an update on them/their affected family member. They provide crucial data which we use to write and publish our information guides, provide tailored responses to other families in need of our help, assist with clinical and other research and further our collective knowledge of rare chromosome and gene disorders.

3. Networking and Awareness-Raising

Despite huge advances in diagnostic technology and rapidly rising rates of diagnosis, RCDs remain relatively poorly known about or understood. It remains a key strategic aim for us to continue to forge strong working relationships with geneticists and other relevant professionals to ensure those receiving a diagnosis are then able to access the help they need. Many professionals, recognising the value of our work, now routinely refer families to us as a first point of contact. We also work closely with other organisations such as charities and policy-makers raising the profile of Unique and RCDs generally. We are incredibly grateful to the hundreds of professionals who volunteer their time, for example by reading and verifying our information guides, talking to families or helping us to raise awareness in the specialism or in their local area.

Our Family Support Officer continues to work to support our network of over 150 local volunteer contacts, on hand to help signpost families to local services and resources. We reach and network with a large and ever-growing social media audience via Facebook, Instagram and Twitter, a very cost-effective way to promote our work, fundraise and raise awareness. As part of this, we have several secret, private groups for families, providing supportive, moderated environments for private, confidential discussion and to facilitate mutual support networks.

This year, our activities to raise awareness of Unique, our work and rare chromosome & gene disorders have included:

- Our CEO Dr Sarah Wynn attending a Department of Health and Social Care Rare Diseases Roundtable meeting with Sajid Javid, UK Health Secretary. Unique were one of two patient organisations represented, representing the rare disease community.
- Dr Wynn being a Public and Patient Voice (PPV) representative on the Genomics Clinical Reference Group (CRG) and sitting on the Board of the charity Genetic Alliance UK and COO Craig Mitchell continuing 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' and helping develop a workshop for parents and professionals.
- Giving presentations to various groups, including the Association of Genetic Nurses and Counsellors (AGNC), Cambridge University Hospitals NHS Trust Clinical Genetics Department, Wessex Community Paediatricians and the Being Human Festival.
- Our team representing Unique at various conferences including the British Paediatric Neurology Association conference, the World Congress on Genetic Counselling and Westminster Health Forum's conference on the next steps for genomics in health care.
- Craig Mitchell 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'. Together with Arti Patel, Unique Information Officer, he also gave a workshop presentation with the charity Beacon on how patient groups can improve community engagement.
- Our Scientific Communications Officer, Dr Claire Andersen, taking part in the Disability Terminology Think Tank, with Level Playing Field UK.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

- Francesca Wicks, Unique Information Officer, working with the BINGO project, a research study involving researchers from the MRC Cognition and Brain Sciences Unit (CBU) at the Universities of Cambridge and Oxford.
- Francesca and Craig being elected to the Beacon for Rare Diseases (formerly Findacure) Patient Group Engagement Committee. Unique being members of professional bodies such as the British Society for Genetic Medicine (BSGM) and the Royal Society of Biology (RSB).

We work closely with other organisations, in particular Genetic Alliance UK and were instrumental in setting up a coalition of 10 different patient groups to ensure the collective voice of our families was heard during the passage of the Down Syndrome Bill through parliament. We have close links with other organisations such as Beacon, SWAN UK and Gene People and always seek to work with others for the benefit of those who need our help. We also continued to be an active participant in Rare Disease UK's patient empowerment group meetings, representing Unique families to ensure their perspective and views are heard.

Social networking

We have continued to work hard to grow and develop the different ways we connect with diverse audiences. Our very active presence on social media is reflected in our public Facebook page reaching over 39,000 followers, our Twitter feed over 7,300 followers and our Instagram page having over 5,800 followers. Our regular 'e-news' continues to be well-received and in our efforts to be as environmentally conscious as possible, we continue to encourage families to receive our magazine by email rather than by post – and many more do. All these included items covering the main strands of our work: information, networking and support, benefitting families and professionals alike.

As the effects of the pandemic continued to be felt, we again felt it appropriate and proportionate to hold a 'Rare Chromo Day' rather than our usual Chromosome Disorder Awareness Week. As ever, a great many families, professionals and others engaged with this, awareness raising and fundraising and we are humbled by their support as always. We were particularly grateful for the expert help of the team at **PR Agency Havas Just**, who donated lots of time to prepare a variety of digital content around case studies of Unique member families and secured some excellent media coverage. Hopefully in the next year or two we will be able to return to a full awareness week format.

Covid

As life began returning to normal following the pandemic, the Unique office opened again during the year and staff now work a hybrid pattern of office and home working. This helps us promote a safe working environment, giving staff increased peace of mind as well as helping with their mental health. To facilitate this way of working, we have continued to make good use of solutions such as Zoom and Egress, introduced to our working practices during 2020, to ensure staff can work remotely without adversely affecting the service to families.

Partly as a result of the pandemic, the operating environment remains especially uncertain for small charities like Unique. The spiralling cost of living in the UK means that income is likely to be adversely affected for some time yet. In addition, the London Marathon, a significant income generator for us, has been delayed to October 2022 and there remains some reluctance for people to commit to mass participation fundraising events. As trustees, we therefore continue to budget prudently and control costs carefully. The numbers of families needing our help is now returning to pre-Covid levels so the need to protect and further develop our frontline services remains acute.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

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.

The NHS and clinical care more widely are rapidly evolving to include genetic/genomic testing in almost all areas of medicine including neurology, cardiology and even General Practice. Unique works 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.

Infrastructure

The senior management team, (CEO and COO) have continued to work with trustees to ensure Unique's infrastructure remains fit for purpose and has sufficient capacity. This year we have begun the work, overseen by Trustee James Toop who has a background in IT, to replace our specialist database, which was first developed more than 20 years ago. This is a significant project for the charity but will be crucial in retaining and developing our excellence in service to families. All data is processed in accordance with the Data Protection Act 2018 and General Data Protection Regulation (GDPR) and we benefit greatly from the assistance of a data lawyer who advises us on a *pro bono* basis.

As our office is now only in use for part of each week, we took the decision to move our server to a secure, off-site location. This further reduces risks to data and other security. We also converted our telephone system to VOIP rather than fixed-line, further facilitating hybrid working by making the transfer of calls to remote locations much easier. This represents a cost saving on our communications infrastructure. Staff work closely with TQS Ltd. (our chosen IT company) to ensure security and other software is fully updated and hardware is fully functioning and well-maintained.

Volunteers

As always, we are extremely grateful to the large number of people who continued to help us during a challenging year. These included:

- Charlotte Astill, Data Protection Compliance specialist, advising senior staff on GDPR and kindly sourced data protection training for all staff via Vinci Works.
- Over 150 local volunteer contacts continuing to be on hand to help families in their local area.
- Over 50 geneticists and other professionals, verifying our information guides prior to publication.
- At least 50 expert volunteers translating our information guides into a variety of languages. This year we reached the milestone of 100 of our information guides translated into Russian.
- Trevor Searle, who designed the Unique database and was on hand to help with training and maintenance, alongside our IT provider TQS Ltd. Particularly when we moved the server.
- A number of others assisting in areas such as marketing and promotional activities.
- Voluntary fundraising undertaken by lots of our members and supporters.
- Others such as Joe Butt, a lab-based scientist who has completed a MSc in Genomics and is aiming to work in clinical genetics.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

Financial Review 2021-22

Income

After another challenging year, our total income for the year is £304,805. Whilst this represents a decrease of around 15% on the previous year, partly due to not receiving the government's Covid support via furlough grants, we are heartened that fundraising income increased and voluntary income remained stable. In a difficult economic climate, particularly for small charities, with a continued and understandable reluctance from people to sign up to mass fundraising events, we remain touched and very humbled by the numbers of people who did continue to support us in their own way, many of whom while caring for their disabled children.

Unrestricted income was £288,305 (previous year: £316,811), including unrestricted grants of £13,663 which includes Coronavirus Job Retention Scheme grants. Restricted income from grants was £16,500, to be spent on our Jargon Buster project and regional funding for Wales, Surrey and East Midlands. We are fortunate that such 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

Our total expenditure for the year is £343,810, an increase of 15% on the previous year, due to our day-to-day operations returning to normal, having been curtailed during the previous year and to increasing our service capacity by increasing the working hours of one of our Scientific Communications Officers. Our healthy reserves during the year meant that we were comfortable in doing this as it brought real benefits to families who need us, despite ending the year with a deficit.

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 2021-22, this equates to minimum reserves of approximately £113,000. This policy is reviewed annually by trustees and updated as necessary.

The outlook for 2022-23 is extremely challenging with a number of macro-economic factors likely to adversely affect our income as a small charity. With inflation currently running in double figures, driven by dramatically increasing energy, fuel and food prices, our members and supporters, many of whom have additional costs due to caring for very disabled children, are likely to feel less able to donate and are likely to raise less when they fundraise. This situation is forecast to continue throughout the coming financial year and beyond.

Accordingly, against this very difficult economic situation and a backdrop of rising demand as health services continue to return to normal after the Covid pandemic, we have budgeted for a significant deficit for 2022-23. This will necessitate drawing on our free reserves to protect our core services and continue to help an ever-increasing number of families. We therefore expect our current free reserves will reduce considerably during the course of the 2022-23 financial year. Trustees will keep this situation under review constantly to enable us to take swift, appropriate action as necessary.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

The Future

Trustees have charged our new CEO Sarah Wynn and Craig Mitchell (COO) with drafting our next operating strategy and this began with an away day for trustees and senior staff, kindly chaired (voluntarily) by former Unique trustee Sally Cohen. As always, our beneficiaries will remain at the heart of this. A new database, the foundation of all we do but particularly important to being able to provide information to families and answers to their many questions, will be crucial, as will reinforcing and further developing our services to those who need us. We expect the new strategy will come into operation during late 2022.

Structure, Governance and Management

The trustees delegate day-to-day management of the charity's activities to Dr Sarah Wynn, CEO, supported by Craig Mitchell (COO). Unique currently 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

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. We are 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 take our responsibilities for the welfare of our staff extremely seriously and staff currently work on a 'hybrid' basis, dividing their working time between working from home and the office. As trustees, we believe that this is appropriate to the charity's needs and those of staff. Sarah Wynn has taken steps to foster and encourage a strong team ethic, for example using WhatsApp for real-time communication and introducing more regular staff meetings. Hybrid working also helps to reduce costs and our carbon footprint. 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. This year we were hugely grateful to Charlotte Astill and Vinciworks for allowing us access to a range of online training courses on data protection legislation (e.g. GDPR and the Data Protection Act). All staff took the training courses to ensure that all are aware of the law and their individual responsibilities. 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.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

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.

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 2021 via Zoom (with some members present in-person) 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.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2022

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.

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 18 October 2022 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 2022 which comprise the statement of financial activities, balance sheet, statement of cash flows 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 2022 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) have 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: 20 October 2022

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 2022

	Note	Restricted £	Unrestricted £	2022 Total £	2021 Total £
Income from:					
Donations and legacies	3	-	277,844	277,844	307,687
Charitable activities:					
<i>Family support services</i>	4	3,250	-	3,250	19,186
<i>Information and awareness</i>	5	13,250	9,412	22,662	28,698
Investments		-	1,049	1,049	1,676
Total income		<u>16,500</u>	<u>288,305</u>	<u>304,805</u>	<u>357,247</u>
Expenditure on:					
Raising funds		-	39,714	39,714	30,179
Charitable activities:					
<i>Family support services</i>		4,301	176,379	180,680	165,435
<i>Information and awareness</i>		8,981	114,435	123,416	104,071
Total expenditure	7	<u>13,282</u>	<u>330,528</u>	<u>343,810</u>	<u>299,685</u>
Net income / (expenditure) and net movement in funds	8	3,218	(42,223)	(39,005)	57,562
Reconciliation of funds:					
Total funds brought forward		<u>17,402</u>	<u>422,500</u>	<u>439,902</u>	<u>382,340</u>
Total funds carried forward		<u><u>20,620</u></u>	<u><u>380,277</u></u>	<u><u>400,897</u></u>	<u><u>439,902</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 2022

	Note	£	2022 £	2021 £
Fixed assets				
Tangible fixed assets	11		4,653	1,860
Investments	12		<u>700</u>	<u>700</u>
			5,353	2,560
Current assets				
Stock	13	1,405		1,721
Debtors	14	16,234		19,797
Cash at bank and in hand		<u>394,606</u>		<u>439,284</u>
		412,245		460,802
Creditors: amounts due within 1 year	15	<u>16,701</u>		<u>23,460</u>
Net current assets			<u>395,544</u>	<u>437,342</u>
Net assets	16		<u><u>400,897</u></u>	<u><u>439,902</u></u>
Funds	17			
Restricted income funds			20,620	17,402
Unrestricted funds:				
Designated funds			40,000	40,000
General funds			<u>340,277</u>	<u>382,500</u>
Total charity funds			<u><u>400,897</u></u>	<u><u>439,902</u></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 18 October 2022 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 2022

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 2022

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:

	2022	2021
Raising funds	7.5%	6%
Family support services	58.0%	53%
Information and awareness	34.5%	41%

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 2022

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 2022

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 £	2021 Total £
Income from:			
Donations and legacies	-	307,687	307,687
Charitable activities			
<i>Family support services</i>	19,186	-	19,186
<i>Information and awareness</i>	21,250	7,448	28,698
Investments	-	1,676	1,676
Total income	40,436	316,811	357,247
Expenditure on:			
Raising funds	-	30,179	30,179
Charitable activities			
<i>Family support services</i>	18,135	147,300	165,435
<i>Information and awareness</i>	8,198	95,873	104,071
Total expenditure	26,333	273,352	299,685
Net income and net movement in funds	14,103	43,459	57,562

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2022

3. Donations and legacies

	Restricted £	Unrestricted £	2022 Total £	2021 Total £
Grants more than £5,000:				
Bothwell Charitable Trust	-	5,000	5,000	-
D & J Hunter Charitable Trust	-	-	-	15,000
DM Thomas Foundation for Young People	-	-	-	6,489
Grants £5,000 or less	-	8,154	8,154	14,000
Donations from fundraising activities	-	122,409	122,409	100,311
General donations	-	56,909	56,909	48,964
Corporate donations	-	33,788	33,788	29,753
Gift aid	-	20,710	20,710	17,128
Overseas donations	-	18,966	18,966	14,144
Gifts in kind	-	7,124	7,124	-
Legacies	-	2,000	2,000	22,000
Give As You Earn (GAYE)	-	1,837	1,837	1,663
Coronavirus Job Retention Scheme	-	509	509	38,125
Pyramids	-	438	438	110
	-	277,844	277,844	307,687

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 2022

4. Charitable activities: family support services

	Restricted £	Unrestricted £	2022 Total £	2021 Total £
Grants more than £5,000:				
Awards for All	-	-	-	9,936
Grants £5,000 or less	3,250	-	3,250	9,250
	<u>3,250</u>	<u>-</u>	<u>3,250</u>	<u>19,186</u>

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

5. Charitable activities: information and awareness

	Restricted £	Unrestricted £	2022 Total £
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	-	9,412	9,412
	<u>13,250</u>	<u>9,412</u>	<u>22,662</u>

Prior year comparative

	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	-	7,448	7,448
	<u>21,250</u>	<u>7,448</u>	<u>28,698</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 2022 was £509 (2021: £38,125). There are no unfulfilled conditions or contingencies attaching to these grants in 2021/22.

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2022

7. Total expenditure

	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

Governance costs were £6,437 (2021: £6,956).

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2022

7. Total expenditure (continued)

Prior year comparative

	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	2,584	23,823	18,541	(44,948)	-
Total expenditure	<u>30,179</u>	<u>165,435</u>	<u>104,071</u>	<u>-</u>	<u>299,685</u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2022

8. Net movement in funds

This is stated after charging:

	2022 £	2021 £
Depreciation	2,811	1,410
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses	8	Nil
Auditors' remuneration	<u>4,140</u>	<u>3,900</u>

One trustee was paid £8 for travel expenses (2021: £Nil).

9. Staff costs and numbers

Staff costs were as follows:

	2022 £	2021 £
Salaries and wages	223,962	222,351
Social security costs	16,392	13,595
Pension contributions	<u>8,863</u>	<u>7,774</u>
	<u>249,217</u>	<u>243,720</u>

No employee earned more than £60,000 during the year (2021: 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 £99,635 (2021: £78,577). This increased during the year due to voluntary reductions in pay by key management personnel in the prior year to safeguard the charity in the face of financial uncertainty during the Covid pandemic.

	2022 No.	2021 No.
Average staff head count	10	10
Average full time equivalent	<u>7</u>	<u>7</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 2022

11. Tangible fixed assets

	Computer equipment £
Cost	
At 1 April 2021	18,064
Additions in year	5,604
Disposals in year	<u>(8,268)</u>
At 31 March 2022	<u>15,400</u>
Depreciation	
At 1 April 2021	16,204
Charge for the year	2,811
On disposal	<u>(8,268)</u>
At 31 March 2022	<u>10,747</u>
Net book value	
At 31 March 2022	<u><u>4,653</u></u>
At 31 March 2021	<u><u>1,860</u></u>

12. Investments

	Artwork £
At 31 March 2022	<u><u>700</u></u>
At 31 March 2021	<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 2022.

13. Stock

	2022 £	2021 £
Merchandise	<u><u>1,405</u></u>	<u><u>1,721</u></u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2022

14. Debtors

	2022 £	2021 £
Trade debtors	-	122
Prepayments	9,908	8,798
Accrued income	6,326	10,714
Other debtors	-	163
	16,234	19,797

15. Creditors : amounts due within 1 year

	2022 £	2021 £
Trade creditors	80	-
Accruals	8,302	18,100
Other taxation and social security	5,239	4,359
Pension creditor	3,080	1,001
	16,701	23,460

16. Analysis of net assets between funds

	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	20,620	40,000	340,277	400,897

Prior year comparative

	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	17,402	40,000	382,500	439,902

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2022

17. Movements in funds

	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	13,052	13,250	(8,981)	17,321
Total restricted funds	17,402	16,500	(13,282)	20,620
Unrestricted funds				
<i>Designated funds:</i>				
Listening Ear Fund	40,000	-	-	40,000
<i>Total designated funds</i>	40,000	-	-	40,000
General funds	382,500	288,305	(330,528)	340,277
Total unrestricted funds	422,500	288,305	(330,528)	380,277
Total funds	439,902	304,805	(343,810)	400,897

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 2022

17. Movements in funds (continued)

Prior period comparative

	At 1 April 2020 £	Income £	Expenditure £	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	<u>3,299</u>	<u>40,436</u>	<u>(26,333)</u>	<u>17,402</u>
Unrestricted funds				
<i>Designated funds:</i>				
Listening Ear Fund	<u>40,000</u>	<u>-</u>	<u>-</u>	<u>40,000</u>
<i>Total designated funds</i>	<u>40,000</u>	<u>-</u>	<u>-</u>	<u>40,000</u>
General funds	<u>339,041</u>	<u>316,811</u>	<u>(273,352)</u>	<u>382,500</u>
Total unrestricted funds	<u>379,041</u>	<u>316,811</u>	<u>(273,352)</u>	<u>422,500</u>
Total funds	<u><u>382,340</u></u>	<u><u>357,247</u></u>	<u><u>(299,685)</u></u>	<u><u>439,902</u></u>

18. Related party transactions

There were no related party transactions during the year ended 31 March 2022, or the prior year.

19. Financial instruments held at fair value

	2022 £	2021 £
Financial assets measured at fair value	<u><u>700</u></u>	<u><u>700</u></u>

Financial assets measured at fair value comprise investment assets.