

Company no. 05460413
Charity no. 1110661

Rare Chromosome Disorder Support Group

Report and Unaudited Financial Statements

31 March 2024

Rare Chromosome Disorder Support Group

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For the year ended 31 March 2024

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Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2024

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	Trustee
Isobel Hindle	Trustee
Edna Knight, MBE	Founder, Life President, Trustee
Gillian Manvell	Trustee until 10 October 2023
Dr Shwetha Ramachandrappa	Trustee
Sophie Sainty	Chair
Benjamin Stern	Trustee
James Toop	Trustee until 24 January 2024
Fiona de Zoete	Trustee

Chief executive officer Dr Sarah Wynn

Company secretary Craig Mitchell

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 2024

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 2024

Welcome from the Chair of Trustees

Thank you for taking the time to read Unique's annual report and accounts for 2023-24.

The start of the period 2023-24 was challenging for our charity. After ending the previous financial year with a large deficit, we had to take some very difficult decisions, in particular around staffing. After an exhaustive review and consultation process, we had to take the tough decision to reduce our staffing level, hand-in-hand with a strategic plan to return to growth, through cost controls and investment in fundraising capacity to increase our income. We are pleased to have ended this financial year in a much stronger position, and that we face the future with renewed optimism and confidence.

We are very proud of the way in which our staff team responded to a difficult situation, working incredibly diligently and with great professionalism. They played a full part in streamlining our work processes to ensure that we can continue to meet the needs of an ever-growing number of families with the same levels of excellence in service provision. Over 2,300 new families came to us for help about a family member's diagnosis and we reached the milestone of 30,000 individual members living with one of these rare gene or chromosome conditions. No mean feat for a small charity!

Particular highlights this year have been our in-person events. In a first for Unique, we were honoured to be invited by the Royal Society of Medicine (RSM) in London to hold a prestigious "Medicine and Me" event for our families. Medicine and Me is a philanthropic programme of events for patients funded and run by the RSM in conjunction with selected patient organisations. It was a great success, with talks from experts in the field and a parents' panel, along with the opportunity for parents to meet others. The recording is available at <https://www.youtube.com/watch?v=8Bz7-jOsUSs>

We have also run three more of our ever-popular family days, in Nottingham, Birmingham and Newcastle, thanks to funding from the Pears Foundation. These weekend events are designed to enable Unique families to meet others who understand the challenges of living with a rare disorder and to learn more about genetics while their children have fun in an inclusive, non-judgmental environment. It was so nice to see so many of our families and we have events planned in Manchester and Glasgow in the coming year.

In June, our 'Rarechromoday' awareness campaign was greatly enhanced by Unique being featured on the BBC's prime time television drama programme '*There She Goes*' starring David Tennant and Jessica Hynes. Written by Unique member parents Shaun Pye and Sarah Crawford, the storyline greatly resonated with many of our families. It was a huge boost to our awareness raising and many new families found and joined us as a result.

As Unique enters its 40th year since being established by our Life President Edna Knight, we are hugely proud of our achievements as a charity but mindful that there is still much to do. Awareness among many medical and other professionals and the wider public about rare chromosome and gene conditions remains too low and so we are thrilled to have begun a two-year pro bono partnership with Havas Life Medicom, a specialist medical communications agency, to develop our awareness-raising efforts.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024

This year and into the future, we will continue to work hard to make sure the voices of those living with rare gene and chromosome conditions are heard. During the year, staff gave 32 presentations to a wide variety of professional audiences and working together with a group of other charities, we are continuing to push for the benefits of the Down Syndrome Act 2022 to apply to those with other genetic conditions too. In a climate in which services for Unique families are patchy at best, it is now more important than ever that the needs of our families are recognised and protected, and we will do all we can to ensure that happens.

Finally, and on behalf of the board of Trustees, I would like to take this opportunity to thank our members Gillian Manvell and James Toop who stepped down from their Trustee roles this year. James, an IT expert and Unique dad, has helped enormously with the scoping and specification process for our planned database upgrade and continues to volunteer his time on this project, despite no longer being a Trustee. Gill served as a Trustee of Unique for over 20 years, during which time she helped establish Unique as a formal charity and company limited by guarantee and led the board as Chair of Trustees during a particularly challenging period, including the 2008 global financial crisis. She selflessly gave lots of time to the charity and made a huge contribution to Unique's development, for which we all owe her a debt of gratitude. We send Gill, James and their families our grateful thanks and very best wishes.

I would also like to thank all our members, supporters and volunteers who give so generously of their time, money and creativity in organising an amazing range of fundraising activities, and to our members who by joining and sharing their medical and developmental data and life experiences, do so much to help others. Last but not least, thank you to our dedicated staff who support us all by connecting us, answering our questions, writing the guides that help us to better meet the needs of all of us and our families who are affected by rare gene and chromosome conditions.

Sophie Sainty, Chair of Trustees



Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024

Our Aims and Objectives

At Unique, we aim to inform, support and alleviate the isolation of anyone born with a rare chromosome or gene disorder (RCD), their families and carers and to raise public awareness. RCDs are lifelong genetic conditions, present at birth, though often not inherited from a parent. They involve parts of one or more of a person's chromosomes having material missing, duplicated or rearranged, or having a tiny change to one or more of their genes. This means the instructions for growing and developing as expected aren't the same for them.

Life-limiting, occasionally life-threatening, causing medical issues and a wide range of learning and physical disabilities, there is currently no cure for any of these conditions. Many of those living with them are totally reliant on their parents and carers throughout their lives. Others are affected relatively mildly, diagnosed only when they try to have their own children and face issues like problems conceiving and multiple miscarriages.

We aim to help by:

- Providing specialist information and support to anyone living with RCDs, their families and the professionals working with and caring for them;
- Working to relieve the isolation of those affected and their families;
- Increasing our knowledge and understanding of all these rare conditions; and
- Acting as an umbrella organisation for all RCDs.

Advances in diagnostic technology mean the diagnosis/detection of rare chromosome and gene disorders has increased greatly. Although individually rare, collectively they affect at least 1 in 150 people and we support families who have children with hundreds of different RCDs.

Some RCDs are incredibly rare, with just a handful of reported cases worldwide, so remain poorly understood. Parents liken receiving a diagnosis for their child to a "sledgehammer blow". With complex terminology and uncertain outcomes, they can be left with lots of unanswered questions, adding to their confusion, distress and sense of desperate isolation.



Rare chromosome & gene conditions can affect anyone, regardless of their background

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024

Our Activities

To meet our aims as a charity, there are three main strands of our work: Support, Information and Networking. Our activities under each strand are summarised below.

Support

When they reach out to Unique, the first point of contact for families is our **'Listening Ear' telephone and email helpline**. Often in shock, having received a distressing diagnosis, families need an informed, understanding, sympathetic response. Our highly qualified and experienced team explain the diagnosis, answer many of their questions, go through complex genetics terminology and offer a shoulder to cry on. Many families tell us how, having felt bereft and with a great many unanswered questions, speaking to someone who understands is such a huge relief. It is the first stage in coming to terms with their child's diagnosis.

Our team provide other tailored help, e.g. in the form of letters of support to assist families in educational or funding tribunals, helping them obtain the care they need. Increasingly, families are receiving an in-utero diagnosis of a RCD so need more specialised help. One of our team has a background as a midwife and other staff have a PhD in Genetics and a Masters in Genetic and Genomic Counselling so are well placed to answer these questions. A number of our staff and trustees are parent-carers of children and adults with RCDs and staff also have lived experience of special educational needs and we draw on this to support and understand families, helping them to feel less isolated as well as informed. Our CEO has personal experience of having a balanced translocation in her family and other staff members are parenting children with SEND.

Information

Reliable, easy to understand information about their family member's condition is key for anyone affected by a rare chromosome or gene disorder. Through our **Information Project**, we produce condition-specific information guides to RCDs, a unique resource of their type drawing on published medical literature, research studies and most importantly, data provided by our member families. In addition to explaining the what the condition is, the health issues, learning and physical disabilities it is known to cause, the guides cover relevant areas such as impact on communication, learning and behaviour. All our guides are independently verified prior to publication by clinical or academic experts who volunteer their time.

Lots of issues affecting those with RCDs 'cut across' different conditions, so we also publish more generic 'practical guides' for families, covering a diverse range of topics. These include what to expect at a genetics appointment, what happens after receiving a diagnosis, communication, hearing loss, sleep issues and sourcing travel insurance.

To address the issue of a general lack of understanding about RCDs, we work closely with researchers to design projects which are of real patient benefit and often signpost families to relevant research projects. We then disseminate results and share learning with families to help them better care for their children.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024

Networking

A crucial part of our service is **family matching**, linking families who have a family member with the same or similar RCD and/or symptoms. With no clear care pathway as found with other, more well-known conditions, it can be tricky for families to know what to expect. Being able to email, speak to and get to know another family can be life changing. We also run a private, moderated Facebook group for our members, on which they can chat, ask questions, discuss issues, celebrate achievements with others who understand and meet other families virtually and in complete confidence.

Our **family days** and other events bring families together, helping establish informal support networks that otherwise wouldn't exist. With such rare conditions, it can be hard to meet other families, but nobody quite understands the challenges like someone who is living them too!

Additionally, **networking with professionals** is hugely important in helping ensure families can find us and get the help they need. We work closely with medics, counsellors, therapists and other professionals and have close working relationships with many genetics professionals, who often signpost families to us, demonstrating how much they value our services. Our team often give presentations, workshops and attend events, all helping to raise awareness of our work and RCDs generally. This is vital to helping ensure the needs of our families are met.

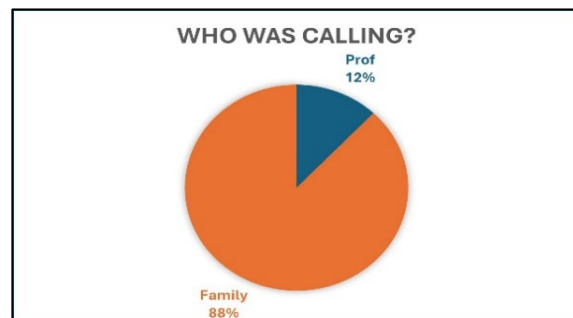
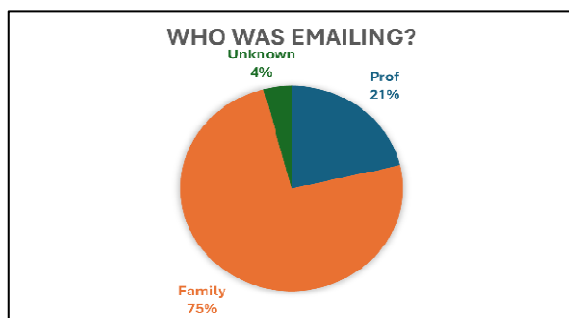
Our Performance and Achievements During 2023-2024

In delivering the services we have detailed above, our key achievements this year include:

Supporting an ever-growing number of families in need of our help

This year, our 'Listening Ear' team:

- Helped **2,322 new families**, an increase of 171 (8%) on the previous year;
- Passed the milestone of having helped and supported **30,000 individuals** with RCDs;
- Responded to **more than 850 emails** from patients, parents, grandparents, siblings, professionals and others who had queries and needed help and information;
- Answered **over 250 helpline calls**, many from distressed parents who had just received their child's diagnosis; and
- Passed another significant milestone of having helped individuals with a change to more than **700 different single genes**.



Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024



A social media post from January 2024, showing hundreds of different single genes our members have changes in, drew over 500 comments from families happy to see their child's condition represented.

This year, 3% of calls and emails were seeking prenatal support and/or information, after a diagnosis during pregnancy. This is already increasing and will continue to do so. We have a staff member with a background as a midwife and we can offer an understanding, sympathetic response and explain the diagnosis and its potential effects in a non-judgmental and non-prescriptive way, offering neutral guidance.

Providing reliable, accessible information

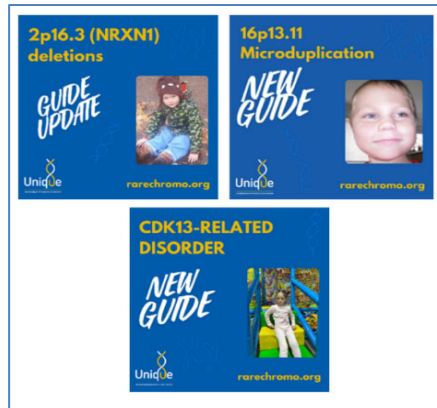
Our two Scientific Communications Officers continued to produce new and updated information to benefit thousands of families now and well into the future. Highlights this year included:

- The launch of our second 'Jargon Buster' animation, explaining genetic tests, was launched. See <https://rarechromo.org/what-is-dna-sequencing/>;
- 4 brand new information guides to specific rare chromosome and single gene conditions;
- Substantial updates to a further 4 of our existing information guides;
- A further **30 of our information guides translated into other languages**, benefitting those for whom English is not their first language – taking the total over 500 translations;
- Producing **6 brand new 'My Chromosome Story' guides** for children with genetic conditions and their siblings, taking the total to 22;
- 3 brand new 'generic guides' for parents and carers being published, including our guides to hearing loss and how to interpret genetic test results;
- A further 3 of these guides being **substantially updated**; and
- 985 members were contacted as part of our rolling data update programme. Up to date and longitudinal data from families is crucial to the information and other services we can provide.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024



Some of the new and updated information guides produced during the year

Networking with families and professionals and raising awareness

Receiving a diagnosis of a RCD for your child can be incredibly isolating so by bringing them together we aim to help families overcome these feelings on loneliness. We raise awareness through our social media campaigns but also by engaging with policy makers, researchers and professionals at all levels. Highlights during 2023-24 have included:

- A special episode of 'There She Goes', written by a Unique member family, airing on BBC TV the day before our awareness day in June, mentioning Unique and our work extensively. June and July became our busiest months, with many new families finding us;
- Linking many hundreds of new and existing member families via our **family matching service**, bringing together those living with similar RCDs and/or symptoms;
- Running **three more family day events, in Nottingham, Birmingham and Newcastle** attended by well over 350 family members and professionals;
- Being awarded a prestigious "Medicine and Me" event at the Royal Society of Medicine in London, attended by over 100 Unique family members to learn more about RCDs and related topics;
- Welcoming over **1,100 new family members to our private/closed, moderated Facebook group** where they can meet and get to know others in the same boat;
- **15 families giving presentations at school/work** for our awareness day;
- Our team giving **32 presentations to a wide variety of audiences**, raising the profile of RCDs and Unique's work;
- Involvement in numerous research projects, including large national projects such as the Generation Study; and
- Unique staff sit on a number of high-level boards including Manchester Rare Conditions Centre and NIH Manchester Biomedical Research Centre.

Giving presentations & training sessions to a variety of audiences:

Some of the highlights this year included:

- Our CEO, Dr. Sarah Wynn presented at Wales Gene Park Virtual Public Genomics Café;
- Sarah was also invited to take part in the R14 rapid sequencing 2-day workshop in Exeter;
- Francesca Wicks, one of our Information Officers was awarded the Laura Kerzin-Storarr prize and so was given the opportunity to present at the Association of Genetic Nurses and Counsellors (AGNC) annual meeting;

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024

- Anita Davis, another one of our Information Officers, ran a workshop for NHS East Genomics: Prenatal exome sequencing R21 meeting;
- Anita also ran a stand with Charlotte Wilmshurst, another of our Information Officers, for students at the Royal Holloway University Rare Disease Day event;
- Francesca delivered f2f training session to teachers at Strathmore School;
- Our Scientific Communications Officer, Dr Claire Andersen, was invited to give a presentation to medical students at Brighton Medical School; and
- Our COO, Craig Mitchell, presented to two separate groups of medical students at UCH medical school about Unique and what it's like for families living with a genetic disorder.



Unique staff members Francesca & Anita raising an awareness at an event at Royal Holloway, University of London

Our awareness-raising efforts also included Claire being interviewed on the Word on Health podcast about living with RCDs and the need for co-ordination of care. Sarah recorded an episode of the G Word Podcast with Shaun Pye and Sarah Crawford, (Unique members and writers of 'There She Goes'). Our team also attended the Genomics England Research Summit, the rapid sequencing service commemoration with Amanda Pritchard (NHS CEO) and Professor Dame Sue Hill (NHS England Chief Scientific Officer).

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 this specific field, throughout this report we have detailed the ways in which we help beneficiaries, providing specialist information as well as softer support.

For the wider public benefit, we continue to ensure there is representation of the public and patient voice by sitting on NHS boards including the NHS Clinical Reference Group for Genomics, the NHS People and Communities Forum and the multi-disciplinary Joint Committee on Genomics in Medicine. 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. Unique staff reflect the views of our community by inputting into England's Rare Disease Action plan, working with the Department of Health and Social Care (DHSC) to help develop the guidance underpinning the Down Syndrome Act and sitting on numerous research project advisory boards. Our staff have also inputted into UK service delivery for example by providing expert advice in the development of the Association of Clinical Genomic Science updated Variant Interpretation Guidelines.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024

Infrastructure

Throughout the year, Trustees and staff continued to ensure Unique's infrastructure is fit for purpose. We maintain a small office hub, with most staff dividing their time between working from the office and working from home. Data security is paramount, with sensitive medical information stored, accessed and processed by staff according to our data protection policies, with which all staff are expected to familiarise themselves. All data are processed in accordance with the Data Protection Act/the General Data Protection Regulations (GDPR). We contract an expert IT company to provide secure systems including off-site solutions, allowing staff to work securely on a hybrid basis.

Volunteers & Pro Bono Support

We are very grateful to the large number of volunteers who helped during the year. These include hundreds of genetics specialists who give their time freely to review our condition specific information guides prior to publication. To ensure accuracy, it is our policy that none of our information is published until this independent verification has taken place.

After an introduction by Passion Partnership, we are delighted to have entered a two-year pro bono partnership with Havas Life Medicom, a specialist medical communications agency. Their team have worked with great passion and enthusiasm, assisting with our marketing and social media content on Rare Disease Day in February and undertaking a review and consultation process, with an exciting refresh and rebranding of the charity planned for the coming year.

Creative marketing professional Roberta Elliott has been hugely helpful, creating a variety of assets for use in our social media and other marketing, particularly in relation to our annual awareness day campaign. Roberta donates her time, as does Unique member Simon Jackson, a business analyst who specialises in databases who is helping us with the planning and spec for our planned database upgrade – an extremely significant project for us.

Financial Review 2023-24

Income

After a very challenging year in 2022-23, which we ended with a large deficit, we undertook a thorough review and consultation process. Trustees took some difficult decisions which unfortunately ended with two staff being made redundant at the beginning of this financial year. With robust plans in place, we have continued to control costs closely whilst at the same time working hard to increase our income. We end this year in a much stronger financial position and are able to look forward with renewed optimism and confidence. We are touched and deeply grateful to all those members, supporters and friends who have fundraised for us, often while caring for disabled children, made donations or encouraged their colleagues to help us become Charity of the Year at their workplace. We couldn't exist without you.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024



We are touched and hugely grateful to all those who get out there and fundraise for us

Our total income for the year is £396,667, which is not only an increase of just over 37%, it also represents our best ever year. Unrestricted income from donations and fundraising from members and supporters, corporates, trusts and foundations totalled £333,558. This is particularly important as it affords the flexibility to direct expenditure to where Trustees feel it can be of most benefit to those who need us. It also avoids a reliance on restricted funds for specific projects, which can be for a relatively short term and have strict constraints. From charitable trusts and foundations, we received unrestricted funding of £64,000 and restricted income of £52,230. This was for costs associated with our planned database upgrade, regional family support across the UK, in-person family events and published information guides.

Expenditure

Total expenditure for the year was £369,642, a reduction of just under 4%, although this did include costs of approximately £13,900 in respect of redundancy payments. We continued to budget prudently but strengthened our infrastructure and capacity to serve those who need us. Trustees and senior staff met regularly during the year (in person and via Zoom), monitoring financial performance to take action as necessary. Our robust financial management procedures mean that moving forward we can continue to invest in staff, resources and infrastructure to ensure longer-term sustainability in the face of ever-increasing demand.

Level of reserves

The Trustees have decided to adopt a policy, reviewed annually, of holding a minimum reserve equivalent to four months' average operating costs for the previous year. For this year, this equates to not less than £121,000. Having ensured expenditure remained tightly under control, reserves at the end of the year are at £337,802, of which unrestricted reserves stand at £299,960. Reserves protect our current and future beneficiaries, safeguarding key services to ensure the charity's future sustainability. Over the coming year, we expect our planned database project to come to fruition, meaning levels of reserves will reduce significantly. Trustees have again this year decided to designate £40,000 this year to protect our Listening Ear Telephone and Email helpline service, our crucial first port of call for families in distress.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024

Future plans

Our key aim in the coming year is the design, development and launch of our new database, which is so crucial to everything we do. With the voluntary assistance of James Toop, a data scientist, 'Unique Dad' and formerly a Trustee of Unique and Simon Jackson, also a 'Unique Dad' who is a database analyst, key staff and Trustees have undertaken lots of work to scope out and begin planning this work. This is a mission critical project for Unique as the database, containing data, provided by our families about more than 30,000 individuals with RCDs, is the bedrock of all the services we provide and will bring significant benefits to service users. We aim to have a full spec in place mid-way through this year, with the database build to begin in late 2024/early 2025.

Trustees and senior staff will also carry out a full strategic review of all Unique's work, including our services, fundraising, branding and marketing. We have engaged a consultant with specific experience in the rare disease space to assist with this and she is beginning with a comprehensive survey of our beneficiaries, including many professionals who have used our services. The views, experiences and needs of our families will be vital in informing our thinking moving forward and alongside the survey, we are establishing Unique's first Membership Engagement Committee, to act as a sounding board and steering group for our future strategy.

Structure, Governance and Management

Unique is an incorporated charity and company limited by guarantee, governed by a Memorandum and Articles of Association. The charity currently has seven Trustees with diverse backgrounds including law, business, finance, accounting, education and medicine. New Trustees are recruited by advertising as widely as possible, including via our own networks and we operate a fair, transparent and equal opportunity policy for recruitment of Trustees and staff.

Governance and management structures of the charity are regularly reviewed to ensure optimal use of resources. Trustees meet three times per year and also correspond regularly via email and other digital means, taking a proactive approach to any fluctuations in income and refining strategy accordingly.

The Trustees delegate day-to-day management of the charity's activities to Dr. Sarah Wynn, Chief Executive Officer (CEO), together with Craig Mitchell, Chief Operating Officer (COO), who is also Company Secretary. Unique currently employs eight staff, including the CEO, three of whom are full-time and five part-time. Trustees are currently undertaking a skills audit of the board of trustees, with the aim of identifying any skills gaps prior to recruiting new trustees to replace the two trustees who resigned during the year.

Registered members of the company limited by guarantee and others with an interest in Unique were invited to attend the eighteenth Annual General Meeting which was held in October 2023 and are kept informed by the Company Secretary.

Corporate and social responsibility and sustainability

Our policy is to welcome and help all members of our communities who may be affected by a RCD and their families and carers, irrespective of their background in terms of race, religion, sexuality, marital status or culture. We continue 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 now ask families to provide details about their ethnicity should they wish to do so, when they join us, and will use this information to ensure our services are accessible to all sections of the community.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024

Unique is an equal opportunity employer and take our responsibilities for the welfare of our staff extremely seriously. We contract an external HR provider to ensure our terms and conditions of employment, policies and recruitment processes are fair and transparent. Our CEO, Sarah fosters a strong team ethic, encouraging staff to attend regular meetings both virtual and in-person. Staff are encouraged to act to minimise any environmental impacts of our work and we have greatly reduced the number of printed materials we produce, in favour of communicating digitally with families wherever possible.

Management of risk

Unique's Risk Register is reviewed annually and details the major risks to which the charity could be exposed. A disaster recovery plan is in place, with appropriate contingency plans as operating conditions and/or performance change. The charity's financial and other performance measures are reviewed at each board meeting and at other times as necessary.

Compliance and training

Given the importance to our work of personal and sensitive medical data, staff and trustees are aware of the requirements of data protection law and have received training in this area. All Trustees and staff undergo regular DBS checks and we engage Carecheck to carry these out. Staff performance is kept under ongoing review and all staff have an annual appraisal covering the key responsibilities of their role and how they relate to Unique's charitable aims. Any knowledge/skills gaps or training are identified and appropriate training sourced.

Given that we often receive research proposals from professionals, academics and others who request that we share them with member families, we have an Internal Research and Ethics Committee to appraise them and give approval before sharing.

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.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2024

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.

Independent examiners

Godfrey Wilson Limited were re-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 15 October 2024 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 2024, which are set out on pages 17 to 32.

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.

William Guy Blake

Date: 15 October 2024

William Guy Blake ACA

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 2024

	Note	Restricted £	Unrestricted £	2024 Total £	2023 Total £
Income from:					
Donations and legacies	3	25,779	314,089	339,868	233,252
Charitable activities:					
<i>Family support services</i>	4	31,205	-	31,205	23,327
<i>Information and awareness</i>	5	6,125	14,138	20,263	30,279
Investments		-	5,331	5,331	2,285
Total income		<u>63,109</u>	<u>333,558</u>	<u>396,667</u>	<u>289,143</u>
Expenditure on:					
Raising funds		-	54,922	54,922	48,376
Charitable activities:					
<i>Family support services</i>		29,521	126,107	155,628	184,010
<i>Information and awareness</i>		12,136	146,956	159,092	150,177
Total expenditure	7	<u>41,657</u>	<u>327,985</u>	<u>369,642</u>	<u>382,563</u>
Net income / (expenditure)		21,452	5,573	27,025	(93,420)
Net gains on investment	12	-	-	-	3,300
Net movement in funds	8	21,452	5,573	27,025	(90,120)
Reconciliation of funds:					
Total funds brought forward		<u>16,390</u>	<u>294,387</u>	<u>310,777</u>	<u>400,897</u>
Total funds carried forward		<u><u>37,842</u></u>	<u><u>299,960</u></u>	<u><u>337,802</u></u>	<u><u>310,777</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 2024

	Note	£	2024 £	2023 £
Fixed assets				
Tangible fixed assets	11		2,115	2,802
Investments	12		4,000	4,000
			6,115	6,802
Current assets				
Stock	13	2,877		2,794
Debtors	14	19,156		11,769
Cash at bank and in hand		323,663		307,847
		345,696		322,410
Creditors: amounts due within 1 year	15	14,009		18,435
Net current assets			331,687	303,975
Net assets	16		337,802	310,777
Funds	17			
Restricted income funds			37,842	16,390
Unrestricted funds:				
Designated funds			40,000	40,000
General funds			259,960	254,387
Total charity funds			337,802	310,777

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 2024

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 15 October 2024 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 2024

1. Accounting policies

a) General information and basis of preparation

Rare Chromosome Disorder Support Group is a charitable company limited by guarantee registered in England and Wales. The registered office address is F4, The Stables, Station Road West, Oxted, Surrey, England, RH8 9EE.

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 2024

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:

	2024	2023
Raising funds	9.0%	9.0%
Family support services	52.0%	51.0%
Information and awareness	39.0%	40.0%

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 2024

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 2024

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 £	2023 Total £
Income from:			
Donations and legacies	4,225	229,027	233,252
Charitable activities			
<i>Family support services</i>	23,327	-	23,327
<i>Information and awareness</i>	15,527	14,752	30,279
Investments	-	2,285	2,285
Total income	43,079	246,064	289,143
Expenditure on:			
Raising funds	-	48,376	48,376
Charitable activities			
<i>Family support services</i>	16,681	167,329	184,010
<i>Information and awareness</i>	30,628	119,549	150,177
Total expenditure	47,309	335,254	382,563
Net expenditure	(4,230)	(89,190)	(93,420)
Net gains on investment	-	3,300	3,300
Net movement in funds	(4,230)	(85,890)	(90,120)

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2024

3. Donations and legacies

	Restricted £	Unrestricted £	2024 Total £
Grants more than £5,000:			
Bothwell Charitable Trust	-	5,000	5,000
D & J Hunter Charitable Trust	-	21,000	21,000
Openwork Foundation	15,000	-	15,000
Postcode Society Trust	-	25,000	25,000
Grants £5,000 or less	-	13,000	13,000
Donations from fundraising activities	4,294	148,153	152,447
General donations	6,485	43,961	50,446
Gift aid	-	24,764	24,764
Overseas donations	-	14,760	14,760
Corporate donations	-	10,230	10,230
Gifts in kind	-	5,225	5,225
Legacies	-	1,000	1,000
Give As You Earn (GAYE)	-	1,462	1,462
Pyramids	-	534	534
	<u>25,779</u>	<u>314,089</u>	<u>339,868</u>

Prior year comparative

	Restricted £	Unrestricted £	2023 Total £
Grants more than £5,000:			
D & J Hunter Charitable Trust	-	10,000	10,000
Grants £5,000 or less	-	11,500	11,500
Donations from fundraising activities	-	121,153	121,153
General donations	4,225	34,707	38,932
Corporate donations	-	17,108	17,108
Gift aid	-	21,510	21,510
Overseas donations	-	10,920	10,920
Give As You Earn (GAYE)	-	1,697	1,697
Pyramids	-	432	432
	<u>4,225</u>	<u>229,027</u>	<u>233,252</u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2024

4. Charitable activities: family support services

	Restricted £	Unrestricted £	2024 Total £	2023 Total £
Grants more than £5,000:				
Pears Foundation	8,500	-	8,500	8,500
Awards for All	16,330	-	16,330	-
Grants £5,000 or less	6,375	-	6,375	14,827
	<u>31,205</u>	<u>-</u>	<u>31,205</u>	<u>23,327</u>

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

5. Charitable activities: information and awareness

	Restricted £	Unrestricted £	2024 Total £
Grants £5,000 or less	6,125	-	6,125
Christmas card and merchandise sales	-	12,716	12,716
Conference fees	-	1,422	1,422
	<u>6,125</u>	<u>14,138</u>	<u>20,263</u>

Prior year comparative

	Restricted £	Unrestricted £	2023 Total £
Grants £5,000 or less	15,527	-	15,527
Christmas card and merchandise sales	-	10,424	10,424
Conference fees	-	4,328	4,328
	<u>15,527</u>	<u>14,752</u>	<u>30,279</u>

6. Government grants

No government grants were received during the current or prior year.

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2024

7. Total expenditure

	Raising funds £	Family support £	Information and awareness £	Support and governance £	2024 Total £
Independent examination and accountancy	-	-	-	2,640	2,640
Computer expenses	670	3,972	3,488	-	8,130
Depreciation	126	729	546	-	1,401
Event costs	-	9,640	-	-	9,640
Insurance	-	-	-	2,388	2,388
Office costs and rent	2,268	12,680	8,788	312	24,048
Postage and distribution	126	955	8,385	-	9,466
Printing and design	-	1,932	-	-	1,932
Professional fees	-	-	-	1,878	1,878
Project costs	-	5,225	5,000	-	10,225
Staff costs (note 9)	32,716	91,942	107,528	40,630	272,816
Stationery	71	500	414	-	985
Subscriptions, licences and charges	14,598	510	5,313	13	20,434
Training and other staff costs	18	56	327	30	431
Travel and subsistence	9	1,038	273	115	1,435
Website and database development	-	1,486	307	-	1,793
Sub-total	50,602	130,665	140,369	48,006	369,642
Allocation of support and governance costs	4,320	24,963	18,723	(48,006)	-
Total expenditure	54,922	155,628	159,092	-	369,642

Governance costs were £5,028 (2023: £4,420).

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2024

7. Total expenditure (continued)

Prior year comparative

	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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2024

8. Net movement in funds

This is stated after charging:

	2024 £	2023 £
Depreciation	1,401	1,851
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses	Nil	Nil
Independent examiners' remuneration (excl. VAT)	2,200	2,100

No trustees were reimbursed for expenses in the current or prior period.

9. Staff costs and numbers

Staff costs were as follows:

	2024 £	2023 £
Salaries and wages	232,748	263,937
Social security costs	16,968	20,372
Pension contributions	9,239	10,137
Redundancy payments	13,861	-
	272,816	294,446

No employee earned more than £60,000 during the year (2023: 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 £117,172 (2023: £114,857).

During the year, redundancy payments totalling £13,861 were paid to two employees (2023: nil). No amounts were outstanding at year end.

	2024 No.	2023 No.
Average staff head count	9	10
Average full time equivalent	6	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 2024

11. Tangible fixed assets

	Computer equipment £
Cost	
At 1 April 2023	15,400
Additions	714
Disposals	(1,770)
At 31 March 2024	14,344
Depreciation	
At 1 April 2023	12,598
Charge for the year	1,401
On disposals	(1,770)
At 31 March 2024	12,229
Net book value	
At 31 March 2024	2,115
At 31 March 2023	2,802

12. Investments

	2024 £	2023 £
At 1 April 2023	4,000	700
Gain on revaluation	-	3,300
At 31 March 2024	4,000	4,000

A Tracey Emin print was donated in 2005. The trustees have no immediate plans to sell the print and consequently it has been reported as a fixed asset investment in the accounts. It was revalued during the prior 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 2024.

13. Stock

	2024 £	2023 £
Merchandise	2,877	2,794

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2024

14. Debtors

	2024 £	2023 £
Trade debtors	167	290
Prepayments	7,007	7,243
Accrued income	11,982	4,236
	<u>19,156</u>	<u>11,769</u>

15. Creditors : amounts due within 1 year

	2024 £	2023 £
Trade creditors	-	274
Accruals	5,645	8,353
Other taxation and social security	4,123	5,482
Pension creditor	4,241	4,326
	<u>14,009</u>	<u>18,435</u>

16. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	Total funds £
Tangible fixed assets	-	-	2,115	2,115
Investments	-	-	4,000	4,000
Net current assets	37,842	40,000	253,845	331,687
Net assets at 31 March 2024	<u>37,842</u>	<u>40,000</u>	<u>259,960</u>	<u>337,802</u>

Prior year comparative

	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>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2024

17. Movements in funds

	At 1 April 2023 £	Income £	Expenditure £	Gain on investments £	At 31 March 2024 £
Restricted funds					
Family support services	9,945	31,205	(29,521)	-	11,629
Information and awareness	6,445	6,125	(12,136)	-	434
Database project	-	25,779	-	-	25,779
Total restricted funds	16,390	63,109	(41,657)	-	37,842
Unrestricted funds					
<i>Designated funds:</i>					
Listening Ear Fund	40,000	-	-	-	40,000
<i>Total designated funds</i>	40,000	-	-	-	40,000
General funds	254,387	333,558	(327,985)	-	259,960
Total unrestricted funds	294,387	333,558	(327,985)	-	299,960
Total funds	310,777	396,667	(369,642)	-	337,802

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.

Database project

The Unique database contains all the precious information that our members have given us about their family's rare chromosome or gene disorder and how they have been affected. It enables us to write the existing 300 chromosome disorder guides that have helped so many and to match new members with families with similar conditions. Our existing database is no longer fit for purpose. It's not capable of managing complicated genetic data, is slow and not easy to use. We need a new database that will be tailored to our needs. It will provide our members with real-time access to see their information, and enable them to provide regular updates on medical concerns, milestones and achievements, as well as the day-to-day realities of their experience of living with a rare chromosome or gene disorder. We are in the process of choosing a database provider and scoping the project but implementation and ongoing support will be very costly (current estimate £50k). In addition to our ongoing fundraising campaign via Just Giving which has raised just over £14k including Gift Aid, we have also been applying to various Charitable organisations for funding for this large project.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2024

17. Movements in funds (continued)

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.

Prior period comparative

	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	<u>20,620</u>	<u>43,079</u>	<u>(47,309)</u>	<u>-</u>	<u>16,390</u>
Unrestricted funds					
<i>Designated funds:</i>					
Listening Ear Fund	40,000	-	-	-	40,000
<i>Total designated funds</i>	<u>40,000</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>40,000</u>
General funds	340,277	246,064	(335,254)	3,300	254,387
Total unrestricted funds	<u>380,277</u>	<u>246,064</u>	<u>(335,254)</u>	<u>3,300</u>	<u>294,387</u>
Total funds	<u>400,897</u>	<u>289,143</u>	<u>(382,563)</u>	<u>3,300</u>	<u>310,777</u>

18. Related party transactions

During the year, the charity received donations from trustees, and related charitable trusts of the trustees, totalling £1,563 (2023: £3,419). No amounts were outstanding at year end.