

RARE CHROMOSOME DISORDER SUPPORT GROUP

England & Wales · Charity number 1110661

Details

Other names	RARE CHROMOSOME DISORDER SUPPORT GROUP, UNIQUE RCD LTD
Status	Registered
Legal form	Charitable company
Company number	05460413
Registered	2005-08-01
Register	View on the Charity Commission register

Contact

Address	F4 The Stables Station Road West Oxted Oxted Surrey RH8 9EE
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Phone	01883330766
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Email	info@rarechromo.org
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Website	www.rarechromo.org
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Activities

Objects: 3.1 TO ASSIST AND RELIEVE SUFFERERS FROM RARE CHROMOSOME DISORDERS3.2 TO EDUCATE THE PUBLIC REGARDING RARE CHROMOSOME DISORDERS3.3 TO RELIEVE THE PARENTS AND CARERS OF PERSONS SUFFERING FROM RARE CHROMOSOME DISORDERS WHO ARE IN CONDITIONS OF NEED HARDSHIP OR DISTRESS

Activities: Unique - The Rare Chromosome Disorder Support Group, is a source of information and support to families and individuals affected by any rare chromosome disorder and to the professionals who work with them.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities, Other Defined Groups

Geography

- **Area of benefit:** NATIONAL AND OVERSEAS
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£467,192	£402,200	-	-
2024-03-31	£396,667	£369,642	-	-
2023-03-31	£289,143	£382,563	-	-
2022-03-31	£304,805	£343,810	-	-
2021-03-31	£357,247	£299,685	-	-

Trustees

Name	Role	Appointed
Helen Elizabeth Campbell	Chair	2014-06-17
Ben Stern		2014-08-14
Cecely Hugh		2024-12-16
EDNA MARGARET KNIGHT MBE		
FIONA CATHERINE FULTON DE ZOETE		2013-05-01
James Edward Lucas		2025-01-14
SOPHIE PRISCILLA SAINTY		
Shwetha Ramachandrappa		2019-10-11

RARE CHROMOSOME DISORDER SUPPORT GROUP

England & Wales - Charity number 1110661

Accounts



unique

UNDERSTANDING GENES
& CHROMOSOMES



UNIQUE

2024-2025

ANNUAL REPORT

Rare Chromosome Disorder Support Group
trading as Unique
Company no. 05460413
Charity no. 1110661
Year end 31st March 2025

Reference and administrative details

Company number: 05460413

Charity number: 1110661

Address

Registered office and operational address:

F4, The Stables Station Road West Oxted Surrey RH8 9EE

Website

rarechromo.org

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, until 3rd September 2024

Cecely Hugh – Trustee, appointed 16th December 2024

Edna Knight, MBE – Trustee, Founder, Life President

James Lucas – Trustee, appointed 14th January 2025

Dr Shwetha Ramachandrappa – Trustee

Sophie Sainty – Chair

Benjamin Stern – Trustee

Fiona Catherine Fulton de Zoete – Trustee

Staff

Chief Executive Officer: Dr Sarah Wynn

Chief Operating Officer: Craig Mitchell (until 31st January 2025)

Information Officer (Family Support): Anita Davis

Information Officer (Family Support): Charlotte Wilmhurst

Information Officer (Family Support): Francesca Wicks

Scientific Communications Officer: Anna Pelling

Scientific Communications Officer: Claire Andersen

Administration Officer: Gemma Mitchell

Finance Officer: Louise Jeffree

Company secretary (until 21st November 2024): Craig Mitchell

Company secretary (from 21st November 2024): Louise Jeffree

Patrons

Baroness Pauline Neville-Jones, UK

Professor Albert Schinzel, Switzerland

Professor Dian Donnai, UK

Professor Jean-Pierre Fryns, Belgium

Professor Judith Hall, Canada

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

**1 in every 150
babies born
has a rare
chromosome
or gene
disorder**

There can be significant variation in the impact of having a rare chromosome or gene disorder. They are lifelong genetic conditions which for some people can cause severe learning and physical disabilities, complex medical issues and may be life limiting and life threatening. Others may be more mildly affected or may not be aware they have a condition until they experience difficulties having a family.

The Rare Chromosome Disorder Support group (known as 'Unique') is the only support group for all rare chromosome and gene disorders. UK based with an international reach, we understand genes and chromosomes, and we work with everyone whose life has been touched by rare chromosome or gene disorders. Whether you're someone living with a condition, a parent or carer, an educator, a social worker, a doctor or a scientist – whoever you are, Unique is here for you!





Mission

Our mission is to inform, support and alleviate the isolation of anyone affected by a rare chromosome or single gene disorder associated with learning disability/developmental delay and to raise public awareness.

Aims and objectives

We aim to act as an international group, supporting, informing and networking with anyone affected by a rare chromosome or single gene disorder and with any interested professionals.

Inform

We aim to provide specialist information relating to many hundreds of different rare chromosome and gene disorders, to inform parents, carers and the professionals working with them.

Network

We aim to facilitate a network of families across the world living with rare chromosome or gene disorders, bringing them together both in person and virtually for invaluable mutual support. By networking with professionals and the wider public we also aim to increase awareness and understanding of what it's like to live with these disorders.

Support

We aim to be there for families and individuals, offering a listening ear, an understanding, sympathetic presence to support them when they need us most, often at or just after receiving a diagnosis of a rare chromosome or single gene disorder.



LETTER FROM CHAIR

Through sharing knowledge and lived experience, Unique helps families and professionals navigate the world of chromosome and gene disorders

This year we celebrated the incredible milestone of Unique turning 40 and, as well as looking back at all that we have achieved, we took it as an opportunity to refresh our image. Working with our members, our staff and trustees and our partnership with Havas Life London, we **launched a brand new logo and branding**. We hope you love it as much as we do! Havas Life London also helped us launch our first ever pop song and video as part of Rare Chromo Day 2024. **Touch the Sky** was co-created with our members using their words, images, and videos to highlight their experiences and emotions throughout their journey, and how it feels to be part of this special community.

As always, our work is informed by and all about our members and the families we serve. Almost 2,000 joined us in the last year to grow our total members to over 32,000 families in over 100 different countries. This year we implemented a long-held plan to set up an advisory board made up of Unique members, whose remit is to guide and advise our plans and strategy. We are also in constant dialogue with our broader membership via the 11,300 members of our Facebook cafe, over 1,000 calls and emails to our helpline and our family day events held this year in Manchester and Glasgow. We also undertook an extensive consultation with our members during this important birthday year. This work will be published in a comprehensive report as part of our Rare Chromo Day 2025 activities but we have taken some of the headline results in order to plan our activities for the upcoming year and beyond:

- 48% of survey respondents felt the focus of Unique's work should be offering opportunities for families to come together locally and nationally. We have secured funding for a Family Conference to be held in Birmingham in March 2026, the talks from which will be recorded to enable our overseas members to benefit too. We will also continue our webinar programme building on the first seven that we put on this year.

- Almost half of survey respondents thought a key focus of Unique's work should be offering more support/information to parents of young people/adults. We have secured funding to run a project targeting parents/carers of young people/adults and outputs from this project will be delivered over the next two years.

This coming 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. Much of our work involves advocating on behalf of our members and this year we have presented at over 40 conferences and meetings, staff members sit on 23 NHS, policy or research project boards and we have also continued to campaign to ensure that all those affected by rare chromosome and gene disorders are not forgotten and their needs are included in policy and service developments.

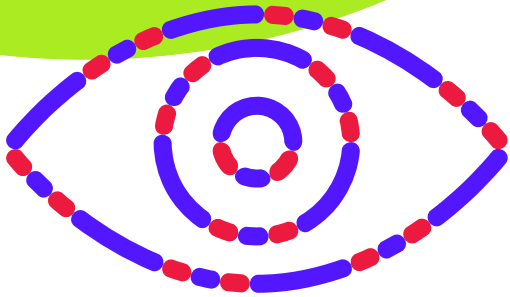
Last but not least, thank you to our dedicated staff who support us all by connecting us, answering our questions, writing the guides that help us to better meet the needs of all of us and our families who are affected by rare gene and chromosome conditions.

We are Unique... and so are you. This is a journey we can make together.

Sophie Sainty
Chair of Trustees



ACHIEVEMENTS AND PERFORMANCE - Unique at a glance



"We love your organisation and want you to know what a light you are to families after diagnosis when no one else knows or understands. Thank you for all you do."

Survey respondent

Membership

32,172 total members in our registry

1,942 new members registered in 2024/25

120 countries represented in our membership

9 parents/carers joined our Membership Engagement Committee from all over the UK and overseas (including 1 from USA, South Africa and New Zealand)

Engagement

1,500 shares, 6,200 likes of our 'I Support #RareChromoDay' graphic

2,500+ responses to our consultation

2 family events attended by over 100 families

7 webinars hosted with over 500 participants

400k views across our website pages

Helpline

1,000+ people supported via our helpline

333 helpline calls taken

801 emails to the helpline

90% found the email helpline helpful

89% found the phone helpline helpful*

960 families were sent matching details

"Unique have been really supportive in a time when we have no understanding or support from professionals at the beginning of our journey. Without Unique it would have been a lot more difficult to understand and navigate around professional jargon and understanding of terminology."

Survey respondent

"It was yet again a super day and so wonderful to see everyone again. We had a great time."

Event attendee

Resources

1270 guides now published

8 new condition specific guides

104K+ views across our condition specific guides

13 academic papers co-authored on

40 presentations and talks given

23 advisory groups participated in

*Unique survey, 2024

INFORM

"I used your website when he was 4 and we were searching for a diagnosis. Because and only because of your website did we figure it out and pointed the doctor in the right directions. We will forever be grateful!"

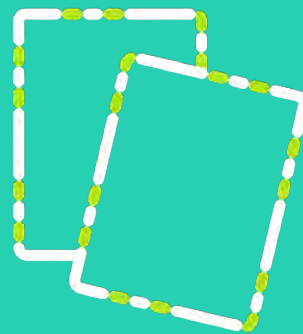
Survey respondent

Being diagnosed with a rare chromosome or gene disorder can be a terrifying time. Families and individuals are desperate for information but there is often very little available, or what is available is targeted at medical professionals and difficult to understand. Providing accessible, accurate and easy to understand information remains therefore one of our core services. All our guides are developed in partnership with professionals and people with lived experience, they are often a lifeline for families.

"Unique's information was helpful and powerful to me. It was my first bit of information and touched my soul that there were others!"

Survey respondent

Survey responses show that 94.5% of respondents find our condition specific guides helpful. 96% of respondents to our professional survey have signposted to the condition specific information guides.



This year we published:

- 8** new condition specific guides
- 47** translations
- 4** guide updates
- 12** minor updates
- 13** additional publications including 'My Chromosome/ Gene Story' booklets and easy reads

Total publications:

- 314** condition specific guides
 - 233** on chromosome disorders
 - 81** on single gene disorders
- 26** 'My chromosome' story guides
- 12** easy read condition specific guides
- 582** translated guides
 - 22** languages

All guides are available to view and download on our website.

OUR NEW GUIDES

New Single Gene Disorder guides

- WSS
- CDK13-related disorder
- BBSOAS
- CIMDAG syndrome
- HIST1H1E Syndrome
- Malan syndrome (NFIX-related disorder)
- RNU4-2 ReNU syndrome
- Urofacial syndrome

Updates

- sSMCs
- USP7-related disorder
- 16p13.11 dups update and new QFN
- 2p16.3 (NRXN1) deletions

My Chromosome/Gene Story booklets

- CDK13-related disorder
- BBSOAS
- WSS
- HIST1H1E syndrome
- Balanced Translocations
- Malan syndrome

EasyReads

- CDK13-related disorder
- BBSOAS
- WSS
- HIST1H1E syndrome
- 2p16.3 (NRXN1) deletions

Others

- 45X/46XY (Minor amendment)
- 17p duplications (Back page update with new charity details)

Minor updates

- Sleep
- Adoption
- Puberty
- Sleep
- Adoption
- Puberty
- Toilet training
- Transition
- Young carers
- Sports Leisure Days Out
- Communication
- Bereavement and Loss

Translations

French

- Chromosome X deletions, duplications and single gene disorders
- X inactivation
- Kleefstra syndrome QFN

Georgian

- CACNA1A-related disorders
- CACNA1C Timothy syndrome Georgian translation
- Trisomy 8 mosaicism
- Trisomy 9 mosaicism
- PACS1-related syndrome
- Ring 22
- STXBP1 disorders
- Wolf-Hirschhorn syndrome (4p16.3 deletions)
- 1q23.3 microdeletions
- Kleefstra syndrome QFN
- 2q37 deletion syndrome
- KIF11 associated disorder
- RHOTB2 syndrome

German

- sSMCs (translation of updated guide)

Italian

- After Diagnosis What Happens Next overseas edition

Russian

- 19p13.3 microdeletions
- 19p13.12 microdeletions
- 8p interstitial deletions including 8p12
- 20q13.33 deletions
- DYRK1A and 21q22.13 deletion syndrome
- 19p13.2 microdeletions
- 9q deletions including 9q33
- 16p11.2 microduplications
- 16p12.2 deletions
- 19p13.3 microdeletions
- 22q11.2 microduplications
- 3q29 deletions and microdeletions
- BBSOAS
- Mosaicism
- DNA sequencing

Spanish

- GATA6 syndrome
- ReNU syndrome
- BBSOAS
- BBSOAS My Gene Story
- BBSOAS Easy Read

Swedish

- Unbalanced translocations
- Triple X
- DNA sequencing
- Planning your next child
- Balanced translocations

Traditional Chinese

- X inactivation
- X chromosome deletions duplications and single gene disorders

Simplified Chinese

- X inactivation
- X chromosome deletions duplications and single gene disorders

Webinars

During the year we hosted **7** webinars with over **500** people attending. Topics have included sleep, speech and language, you and your emotional wellbeing and on the newly discovered RNU4-2/ ReNU syndrome.

Feedback shows participants found these incredibly helpful, for example 90% of attendees at the speech and language webinar said it met or exceeded their expectations and that they would attend another webinar.

- [Living with Rare Chromosome or Gene Disorders: You and Your Emotional Wellbeing, June 2024](#)
- [RNU4-2/ReNU syndrome x3, October 24, November 2024 and January 2025](#)
- [Prof Marianne van den Bree: The Rare Genetic Variant Research Programme at Cardiff University, December 2024](#)
- [Luci Wiggs, Sleep, February 2025](#)
- [Speech and Language webinar with Professor Angela Morgan, September 2024](#)



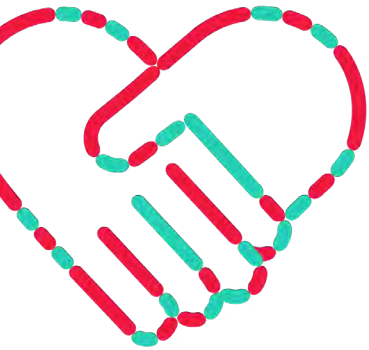
How our activities deliver public benefit

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 in numerous ways. We sit on NHS boards including the NHS Clinical Reference Group for Genomics, the Joint Committee on Genomics in Medicine and the NHS People and Communities Forum. Unique staff also sit on the Scientific Advisory Boards for NIHR Manchester Biomedical Research Centre, DECIPHER and Rare Disease Hong Kong. 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 Diseases Action Plan, working with the Department of Health and Social Care (DHSC) to continue 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 updated specifications for both the NHS Genomic Medicine Service and the NHS Clinical Genetics Service.

New projects to increase and develop information guides

Advances in genetic testing in addition to research into the causes of rare conditions has resulted in more people worldwide being diagnosed with rare chromosome and gene disorders. Unique's mission to provide accessible, family friendly information to all those who desperately need it has struggled to keep apace, given our limited resources. This year we have worked hard to build relationships with the professionals who work with rare genetic condition families and who support our information project, but we have also explored other ways to increase production of these much needed resources.



Collaboration with the Julia Garnham Centre (JGC)

Our collaboration with the JGC (Sheffield Children's Hospital and the University of Sheffield) has continued at a steady pace. Following a Unique presentation at the annual Association of Clinical Genomics Sciences (ACGS), the team from the Julia Garnham Centre made contact to explore the possibility of their interns helping to produce and write Unique information guides. In collaboration we have applied for funding for a pilot project. The grant was successful, and a carefully selected list of conditions have been selected to be considered for guide production and nine students are currently working on these guides.

Collaboration with Manchester University and Shorthills AI

This project, which has also been successful in securing funding for a pilot project aims to design an Artificial Intelligence (AI) tool to aid with the data and literature steps of the information guide production pathway. We have continued to work extensively on our AI systems project with the teams in Manchester and India and attend fortnightly meetings. Scope/depth/accuracy, readability and plagiarism tools are under development and template adherence details have been modified to avoid AI hallucinations. We are now working with 10 clinical geneticists worldwide to trial the model to produce 10 new guides. We hope to apply for further funding to continue this promising and exciting line of work.



Shorthills



NETWORK

Networking is an important part of how we advocate for the rare chromosome and gene disorder community. We actively support, promote and participate in research, training and activities that can improve the lives of our community.

We maintain a number of strategic alliances including being members of Eurordis, Breaking Down Barriers and ERN Ithahca. We are also an active member of Genetic Alliance UK collaborating on a 'SARD' (Seeking A Rare Diagnosis), a suite of information materials aimed at supporting individuals and families seeking a diagnosis for genetic/rare conditions, and on working with the Department of Health and Social care (DHSC) to inform the Down Syndrome Act guidance and writing a follow-up letter to the new Health Minister to reiterate our call for the guidance to adequately cover other genetic conditions which have similar needs.

One member of our helpline team attended Equality and Diversity training with Breaking Down Barriers, including 'Walking on Eggshells' and 'From Challenging Conversations to Comfortable Communication' (May). The team also attended a webinar by Dr Ramy Saad about epigenetics.

Rare Disease Research UK (RDRUK) platform for Nucleic Acid Therapies (UPNAT) collaboration: Unique has been asked to help produce an information guide to Nucleic Acid Therapies as part of the RDRUK project. Initial meetings have been held and a skeleton outline of a guide produced.

Genomics AI Network (GAIN) project: Unique has been asked to sit on the PPIE panel for the GAIN project, which will shape how Artificial Intelligence should be used in Genomic Medicine. We presented at the launch event in November and will attend regular meetings in 2025 and 2026.

We also supported the Royal College of Speech and Language Therapists (RCSLT) Mental Health Bill - Committee Stage Briefing in support of Baroness Whitaker's communication amendments and a parliamentary briefing on cousin marriage prepared by the British Society for Genomic Medicine (BSGM).

Academic papers

The team was involved in the production of 13 academic papers published.

The papers explore topics such as the benefits, harms and costs of genomic newborn screening for rare conditions, promoting timely and equitable access to rare disease genomic testing, evaluations of the NHS Genomic Medicine Service, the experiences of parenting a child with a genetic neurodevelopmental disorder and exploring if animations can improve parents understanding of prenatal sequencing.

Advisory groups

The Unique team sit on 23 advisory groups.

They include groups for research on digital interventions for childhood disruptive behaviour and anxiety, delivering genomic sequencing in clinical practice: a patient-centred evaluation of the new NHS, evaluating rapid genomic sequencing for critically ill children, ethical, legal and social issues (ELSI) in rare conditions research and clinical practice, exploring family planning and decision making for people with a visible difference which can be inherited and the SWAN Pathway specification group.

See appendix for a full list of advocacy and research activities.

SUPPORT

"I could not manage without Unique. Just knowing they are there reduces isolation."

Survey respondent

There are now over
35k members on the
Unique registry
representing over **120**
countries.

"In the beginning I found the family matching service so helpful, it put us in touch with the specific condition group and that helped so much. Since then the [Unique] Facebook café has been great to get and offer advice through"

Survey respondent

Consultation

During 2024/2025 we held an extensive consultation with individuals and families impacted by rare chromosome and gene disorders. Around 70% of survey respondents and all focus group participants were members of Unique. They told us that:

"I'm grateful as Unique was the first place I found practical information on my daughters genetic disorder. The kind most people can manage. Other than this there is just journal articles."

Survey respondent

"Unique are fantastic at supporting parents to make a network and upon early diagnosis unique provide a lot of information to help understand technical terms and terminology."

Survey respondent

"We attended quite a few conferences and they were so helpful in helping us have certain genetic testing done and we feel they are always available to help with any concerns and questions or worries we have had .They are a life line to families."

Survey respondent

Membership committee

A longstanding plan to create a Membership Engagement Committee (MEC) comprised of Unique members who have been engaged in our work, come from all over the world and have children of different ages with a variety of different conditions was realised this year. Two meetings have been held: the first was in May and the MEC evaluated and tested the Unique members survey and the second was held in September where we asked for feedback on our Rare Chromosome and Gene Disorder Awareness Day and also for views and feedback on the new logo and rebranding. We plan to meet 3-4 times per year.

The message from the consultation was clear, Unique members value the community that we provide and would like more opportunities to meet other families in the future – both online and locally.

2,154 people completed survey responses

538 partial responses

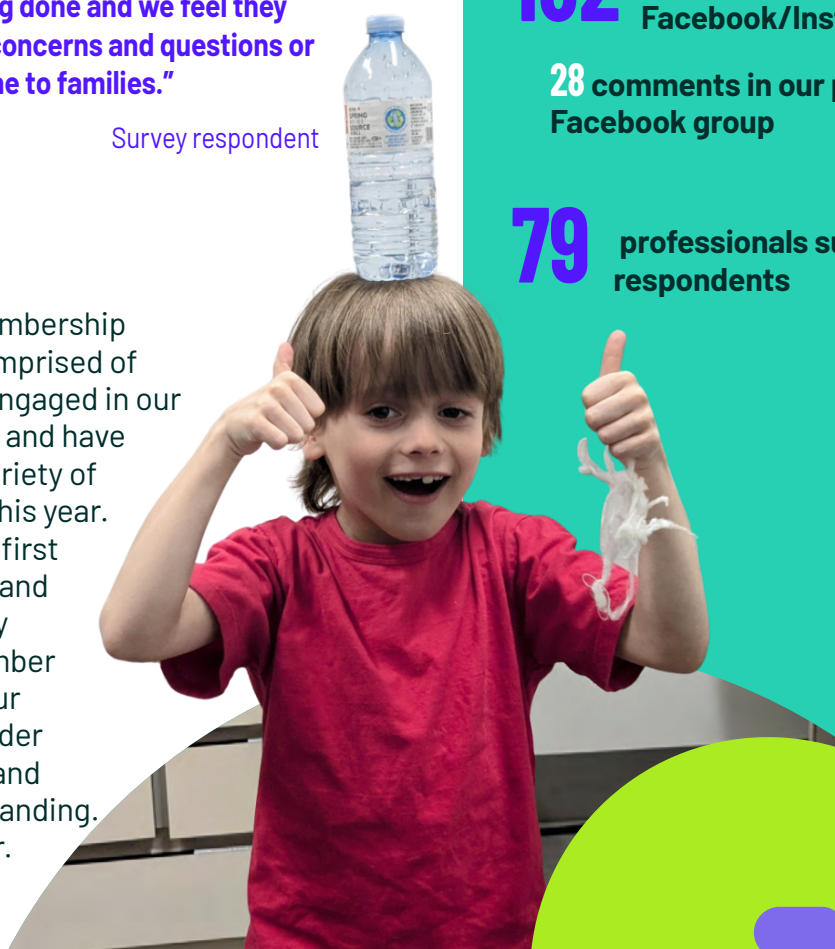
45 focus group participants

53 feedback group participants

182 comments on our public Facebook/Instagram

28 comments in our private Facebook group

79 professionals survey respondents



FAMILY DAYS

GLASGOW



"It was yet again a super day and so wonderful to see everyone again. We had a great time."

Family day attendee



MANCHESTER



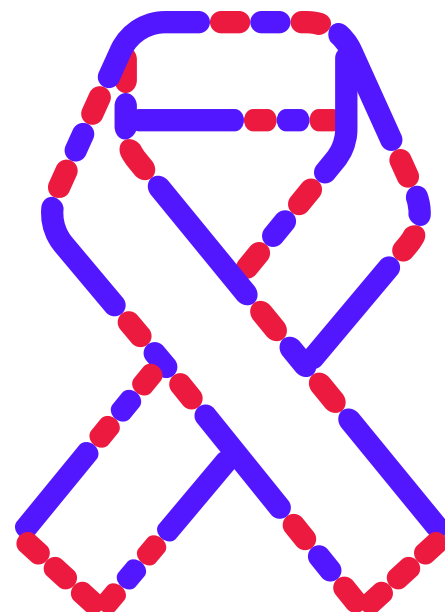
"I loved the opportunity to meet other 'unique' families - we are such a rare bunch! All of my connections since my daughter's diagnosis have been online, so it was really nice to have a chance to connect in person. Thank you for the opportunity!"

Family day attendee



RARE CHROMOSOME AND GENE DISORDER AWARENESS DAY

Also known as Rare Chromo Day, this awareness day is the focal point of the Unique community bringing together families from around the world to celebrate the achievements of their affected family member. This year it took place on 13th June 2024.



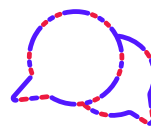
Highlights



The launch of the song 'Touch the Sky' and the accompanying lyrics video, which has to date been viewed almost 3,800 times on our [YouTube channel](#).



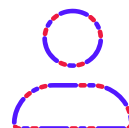
A collaboration with Jean-Christophe Novelli on Instagram, liked more than 2,000 times and his wife Michelle's open and honest interview with Sarah.



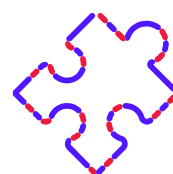
Holding our first live Q&A session via Zoom, which was attended by more than 30 members.



'I Support Rare Chromo Day' graphic being shared 1,500 times, liked 6,200 times and being seen on screen 119,000 times on Facebook and seen 51,000 time on Instagram.



We took over Genomics England's X account to promote our content to their 30,000 followers.



20 people completing our Unique23 challenge, raising over £15,000.



Lots of members and supporters buying merchandise, wearing blue and yellow and holding assemblies, cakes sales etc at school.



HELP TO MAKE IT POSSIBLE

Fundraisers

The 2024/25 financial year was awash with fabulous fundraisers. Our thanks to everyone who threw themselves into cycle challenges, marathon runs, boxing matches, cake sales and our awareness day Unique23 challenge. We receive no government funding so the proceeds from these fundraisers make a huge difference to our work.

67

amazing individual fundraisers

£82k

raised between them

3

companies chose Unique as their Charity of the Year

£58k

raised between them

Our special thanks go to:

- Kat Shaw and over 80 of her colleagues from Accenture who took part in a Who Dares Wins trek through the Peak District over a somewhat chilly weekend in May 2024.
- Catriona Taylor and her colleagues at The Blair Partnership who spent the year raising funds for Unique via so many different events, we lost count and then put them all into a lovely video celebration for their end of year presentation.
- Reece Grundy and his colleagues at Jensten Insurance who also spent the year putting on events and raising funds and awareness of Unique's work.



Funders

During 2024/25, we were the grateful recipients of over £86,000 in grants from Charitable Foundations and Trusts. Many of these were in response to applications made by us but others were from long standing supporters of our work. Some were restricted for use on specific projects while others were unrestricted for assisting with our core costs. We thank them all for their continued support of Unique's aims.

Volunteers and 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 write and/or 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. 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.

A huge thank you to all the genetics specialists who helped to translate our guides



FINANCIAL REVIEW

Income

The 2024/25 financial year was a very successful one, with total income for the year coming to 467,192 an increase of 18% on the previous year, thanks largely to a few corporate fundraisers where we were the chosen Charity of the Year. Unrestricted income from all sources amounted to £397,168. This funding 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. From charitable trusts and foundations, we received unrestricted funding of £24,100 and restricted income of £61,931. This was for costs associated with the planned upgrade of our database, regional family support across the UK including funding for in-person family events in Wales, a Carer of Adults project and published information guides.

Expenditure

Total expenditure for the year was £402,200 an increase of 8.8%, caused by increased costs for hardware as well as the hire of a consultant with specific experience in the rare disease space to conduct a comprehensive survey of our membership and assist with grant applications. Trustees and senior staff met regularly during the year (in person and via Zoom), monitoring financial performance and our budget. 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 recently opted to change our reserves policy to hold a minimum reserve equivalent to six months' average operating costs for the previous year. For this year, this equates to not less than £186,648. Trustees have again decided to designate £40,000 to protect our Listening Ear Telephone and Email helpline service. Reserves at the end of the year are £402,794, of which unrestricted reserves

stand at £327,929. Restricted funding carried forward to 25/26 is £74,865. 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 new registry project to come to fruition, meaning levels of reserves will reduce significantly.

Future Plans

Having conducted a data cleanse of the information currently in our database, we are about to start developing our new registry which will provide Unique with the tools to enhance the service we provide our families for years to come. This has been a longstanding need for Unique, and we are grateful to those who have assisted in the planning stages.

Our recent survey of our membership has highlighted that we need to do more to assist them with the care of their adult family member with an RCGD. In this respect we were successful in applying for a grant from Awards for All England towards a 2-year project which will involve setting up a working group to bring together families of adults with RCGD and co-design new support services to meet their needs. It will include up to 4 regional workshops as well as virtual drop-in-sessions, online information sessions and the setting up of WhatsApp groups. The learning from this project will help us better understand the needs of this section of our community and develop more long-term support for families throughout their journey, not just at the point of diagnosis.

Finally, we have received funding from Jeans for Genes for a Unique Conference being planned for March 2026 in Birmingham. The conference will bring many of our families together to access support and information, develop a network of friends and connections and improve their mental wellbeing.

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 eight 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. Trustees are currently undertaking a skills audit of the board of trustees, with the aim of identifying any skills gaps.

Governance and management structures of the charity are regularly reviewed to ensure optimal use of resources. Trustees meet four 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 Louise Jeffree, Company Secretary. Unique currently employs eight members of staff, including the CEO, three of whom are full time and five part-time.

Registered members of the company limited by guarantee and others with an interest in Unique were invited to attend the nineteenth Annual General Meeting which was held in October 2024 and are kept informed by the Company Secretary.

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

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. 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.

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.

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees (who are also directors of the charity for the purposes of company law) are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice). Company law requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing those financial statements the trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP;
- Make judgements and accounting estimates that are reasonable and prudent;
- State whether applicable UK accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements; and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

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

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

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

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 16 October 2025 and signed on their behalf by



Sophie Sainty
Chair of Trustees

Company no. 05460413
Charity no. 1110661

**Rare Chromosome Disorder Support
Group**

**Report and Unaudited Financial
Statements**

31 March 2025

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 2025, which are set out on pages 23 to 38.

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: 16 October 2025

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 2025

	Note	Restricted £	Unrestricted £	2025 Total £	2024 Total £
Income from:					
Donations and legacies	3	9,743	378,295	388,038	339,868
Charitable activities:					
<i>Family support services</i>	4	46,731	-	46,731	31,205
<i>Information and awareness</i>	5	13,550	11,298	24,848	20,263
Investments		-	7,575	7,575	5,331
Total income		<u>70,024</u>	<u>397,168</u>	<u>467,192</u>	<u>396,667</u>
Expenditure on:					
Raising funds		-	68,393	68,393	54,922
Charitable activities:					
<i>Family support services</i>		24,367	127,715	152,082	155,628
<i>Information and awareness</i>		7,020	174,705	181,725	159,092
Total expenditure	7	<u>31,387</u>	<u>370,813</u>	<u>402,200</u>	<u>369,642</u>
Transfer between funds		<u>(1,614)</u>	<u>1,614</u>	<u>-</u>	<u>-</u>
Net income and net movement in funds		37,023	27,969	64,992	27,025
Reconciliation of funds:					
Total funds brought forward		<u>37,842</u>	<u>299,960</u>	<u>337,802</u>	<u>310,777</u>
Total funds carried forward		<u><u>74,865</u></u>	<u><u>327,929</u></u>	<u><u>402,794</u></u>	<u><u>337,802</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 2025

	Note	£	2025 £	2024 £
Fixed assets				
Tangible fixed assets	11		2,103	2,115
Investments	12		4,000	4,000
			6,103	6,115
Current assets				
Stock	13	8,288		2,877
Debtors	14	15,619		19,156
Cash at bank and in hand		389,984		323,663
		413,891		345,696
Creditors: amounts due within 1 year	15	17,200		14,009
Net current assets			396,691	331,687
Net assets	16		402,794	337,802
Funds	17			
Restricted income funds			74,865	37,842
Unrestricted funds:				
Designated funds			40,000	40,000
General funds			287,929	259,960
Total charity funds			402,794	337,802

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, 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.

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 16 October 2025 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 2025

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.

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.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

1. Accounting policies (continued)

d) Donated services and facilities (continued)

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) Redundancy costs

Where an employee receives a termination benefit the full cost is recognised at the date the employee is notified.

i) 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:

	2025	2024
Raising funds	13.6%	9.0%
Family support services	37.4%	52.0%
Information and awareness	49.0%	39.0%

j) 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 2025

1. Accounting policies (continued)

k) 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.

l) Stock

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

m) 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.

n) 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.

o) 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.

p) 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.

q) 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.

r) 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.

s) 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.

t) 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.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

1. Accounting policies (continued)

t) Accounting estimates and key judgements (continued)

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 (j) to the accounts.

2. Prior period comparatives

	Restricted £	Unrestricted £	2024 Total £
Income from:			
Donations and legacies	25,779	314,089	339,868
Charitable activities			
<i>Family support services</i>	31,205	-	31,205
<i>Information and awareness</i>	6,125	14,138	20,263
Investments	-	5,331	5,331
Total income	63,109	333,558	396,667
Expenditure on:			
Raising funds	-	54,922	54,922
Charitable activities			
<i>Family support services</i>	29,521	126,107	155,628
<i>Information and awareness</i>	12,136	146,956	159,092
Total expenditure	41,657	327,985	369,642
Net income and net movement in funds	21,452	5,573	27,025

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

3. Donations and legacies

	Restricted £	Unrestricted £	2025 Total £
Grants more than £5,000:			
Dorothy Hay-Bolton Charitable Trust	-	9,000	9,000
Grants £5,000 or less	1,650	15,100	16,750
Donations from fundraising activities	8,093	198,773	206,866
General donations	-	50,130	50,130
Gift aid	-	42,793	42,793
Overseas donations	-	15,249	15,249
Corporate donations	-	19,398	19,398
Gifts in kind	-	5,000	5,000
Legacies	-	20,800	20,800
Give As You Earn (GAYE)	-	1,520	1,520
Pyramids	-	532	532
	<u>9,743</u>	<u>378,295</u>	<u>388,038</u>

Prior year comparative

	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>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

4. Charitable activities: family support services

	Restricted £	Unrestricted £	2025 Total £	2024 Total £
Grants more than £5,000:				
Pears Foundation	-	-	-	8,500
Awards for All	35,181	-	35,181	16,330
Grants £5,000 or less	11,550	-	11,550	6,375
	<u>46,731</u>	<u>-</u>	<u>46,731</u>	<u>31,205</u>

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

5. Charitable activities: information and awareness

	Restricted £	Unrestricted £	2025 Total £
Grants £5,000 or less	13,550	-	13,550
Christmas card and merchandise sales	-	8,833	8,833
Conference fees	-	2,177	2,177
Other income	-	288	288
	<u>13,550</u>	<u>11,298</u>	<u>24,848</u>

Prior year comparative

	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>

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 2025

7. Total expenditure

	Raising funds £	Family support £	Information and awareness £	Support and governance £	2025 Total £
Advertising	-	800	-	-	800
Independent examination and accountancy	-	-	-	2,820	2,820
Computer expenses	1,211	2,935	4,441	36	8,623
Depreciation	316	866	1,158	-	2,340
Event costs	-	13,078	-	-	13,078
Insurance	-	-	-	1,851	1,851
Office costs and rent	3,162	9,066	11,361	312	23,901
Postage and distribution	95	1,183	8,591	-	9,869
Printing and design	443	2,474	798	-	3,715
Professional fees	7,463	2,910	3,356	3,126	16,855
Project costs	-	5,000	-	-	5,000
Staff costs (note 9)	32,293	88,517	116,133	47,542	284,485
Stationery	83	298	428	-	809
Subscriptions, licences and charges	15,353	395	6,338	34	22,120
Training and other staff costs	154	130	205	625	1,114
Travel and subsistence	6	1,406	481	79	1,972
Website and database development	124	1,945	779	-	2,848
Sub-total	60,703	131,003	154,069	56,425	402,200
Allocation of support and governance costs	7,690	21,079	27,656	(56,425)	-
Total expenditure	68,393	152,082	181,725	-	402,200

Governance costs were £4,671 (2024: £5,028).

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

7. Total expenditure (continued)

Prior year comparative

	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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

8. Net movement in funds

This is stated after charging:

	2025 £	2024 £
Depreciation	2,340	1,401
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses	Nil	Nil
Independent examiners' remuneration (excl. VAT)	<u>2,350</u>	<u>2,200</u>

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

9. Staff costs and numbers

Staff costs were as follows:

	2025 £	2024 £
Salaries and wages	232,404	232,748
Social security costs	14,388	16,968
Pension contributions	8,610	9,239
Redundancy and termination payments	<u>29,083</u>	<u>13,861</u>
	<u>284,485</u>	<u>272,816</u>

No employees had a base salary above £60,000 in either the current or prior year. During the year, one employee's total earnings, including redundancy / termination payments were between £70,000 and £80,000.

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 £111,866 (2024: £117,172).

During the year, a termination payment totalling £29,083 was paid to an employee (2024: redundancy payments totalling £13,861 were paid to two employees). No amounts were outstanding at year end.

	2025 No.	2024 No.
Average staff head count	<u>9</u>	<u>9</u>
Average full time equivalent	<u>6</u>	<u>6</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 2025

11. Tangible fixed assets

	Computer equipment £
Cost	
At 1 April 2024	14,344
Additions	2,328
Disposals	<u>(3,699)</u>
At 31 March 2025	<u>12,973</u>
Depreciation	
At 1 April 2024	12,229
Charge for the year	2,340
On disposals	<u>(3,699)</u>
At 31 March 2025	<u>10,870</u>
Net book value	
At 31 March 2025	<u>2,103</u>
At 31 March 2024	<u>2,115</u>

12. Investments

	2025 £	2024 £
At 31 March 2024 and 31 March 2025	<u>4,000</u>	<u>4,000</u>

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. The trustees are satisfied that the print is carried at an appropriate value at 31 March 2025.

13. Stock

	2025 £	2024 £
Merchandise	<u>8,288</u>	<u>2,877</u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

14. Debtors

	2025 £	2024 £
Trade debtors	152	167
Prepayments	8,275	7,007
Accrued income	7,192	11,982
	15,619	19,156

15. Creditors : amounts due within 1 year

	2025 £	2024 £
Trade creditors	3,500	-
Accruals	7,072	5,645
Other taxation and social security	2,953	4,123
Pension creditor	3,675	4,241
	17,200	14,009

16. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	Total funds £
Tangible fixed assets	-	-	2,103	2,103
Investments	-	-	4,000	4,000
Net current assets	74,865	40,000	281,826	396,691
Net assets at 31 March 2025	74,865	40,000	287,929	402,794

Prior year comparative

	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	37,842	40,000	259,960	337,802

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

17. Movements in funds

	At 1 April 2024 £	Income £	Expenditure £	Transfers between funds £	At 31 March 2025 £
Restricted funds					
Family support services	11,629	26,850	(24,367)	-	14,112
Information and awareness	434	8,550	(6,984)	-	2,000
Database project	25,779	13,093	-	-	38,872
Hardware grant	-	1,650	(36)	(1,614)	-
Carers of Adults Outreach Project	-	19,881	-	-	19,881
Total restricted funds	37,842	70,024	(31,387)	(1,614)	74,865
Unrestricted funds					
<i>Designated funds:</i>					
Listening Ear Fund	40,000	-	-	-	40,000
<i>Total designated funds</i>	40,000	-	-	-	40,000
General funds	259,960	397,168	(370,813)	1,614	287,929
Total unrestricted funds	299,960	397,168	(370,813)	1,614	327,929
Total funds	337,802	467,192	(402,200)	-	402,794

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 has enabled us to write the existing 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. We have been fundraising for the last couple of years to fund a new database that will have the capability to aid Unique's work for many years to come, and now have sufficient funding to pay for the initial set up costs, data cleansing of the current data and maintenance fee for the first two years. We are in the final stages of planning prior to implementation of the project, so these funds will be spent during the 2025/26 financial year going forward.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

17. Movements in funds (continued)

Purposes of restricted funds (continued)

Hardware grant

These were two restricted grants given specifically to be used for the purchase of laptops for staff. A few of our laptops were too old to cope with the recent Windows 11 upgrade, so these grants were timely, much appreciated and enabled us to purchase two new laptops in 2024/25.

Carers of Adults Outreach Project

This was a grant made in February 2025 by Awards for All - England and is restricted to the use of a two-year project which will support parents of adults with rare chromosome or gene disorders (RCGD). During a recent consultation process, the need for supporting adult carers was identified as a priority. This project involves setting up a working group which will bring together families of adults with RCGD and co-design new support services to meet their needs. It will include up to 4 regional workshops as well as virtual drop-in-sessions, online information sessions and the setting up of WhatsApp groups. The learning from this project will help us better understand the needs of this section of our community and develop more long-term support for families throughout their journey, not just at the point of diagnosis.

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.

Transfers between funds

Transfers between funds reflect the capitalisation of expenditure relating to Hardware Grant items during the year.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2025

17. Movements in funds (continued)

Prior period comparative

	At 1 April 2023 £	Income £	Expenditure £	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	<u>16,390</u>	<u>63,109</u>	<u>(41,657)</u>	<u>37,842</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>254,387</u>	<u>333,558</u>	<u>(327,985)</u>	<u>259,960</u>
Total unrestricted funds	<u>294,387</u>	<u>333,558</u>	<u>(327,985)</u>	<u>299,960</u>
Total funds	<u><u>310,777</u></u>	<u><u>396,667</u></u>	<u><u>(369,642)</u></u>	<u><u>337,802</u></u>

18. Related party transactions

During the year, the charity received donations from trustees, related charitable trusts of the trustees, and key management totalling £6,427 (2024: £1,563). No amounts were outstanding at year end.

APPENDIX

Presentations

- #MedComms webinar to talk about our experience of working with a PR agency on a pro bono basis
- Association for Clinical Genomic Science (ACGS) annual meeting in Birmingham
- ESHG/MRCC Dysmorphology conference
- Adelphi Genetics Forum Annual Conference: The promise and challenges of genomics for patients and families affected by rare conditions
- AGNC lunch and learn: Careers outside of Clinical Genetics centres
- AGNC lunch and learn session: Living with a rare genetic condition: the patient and family perspective
- Brocher Foundation workshop in Geneva: Justice and Genomics. Invited to give the opening talk: The Unique experience: Living with a rare chromosome or gene disorder
- Contact presentation on Unique family days
- Education event for non-genetics HCPs working with people with intellectual disability. Presentation: Patient and family perspective – the impact of a diagnosis of a rare chromosome difference. Also facilitated group discussions
- European Society for Human Genetics (ESHG) in Berlin. Invited panel participant at the 3-day conference involving all those working in genetics in UK, Europe and further afield
- Genomic Ambassador Programme
- Genomic Medicine, Mental Health Services & Equity workshop delivered with Dr Nick Bass, UCL
- [Genomics England podcast recording](#): How has a groundbreaking genomic discovery impacted thousands worldwide?
- Genomics workshop presentation, Home Start, East Lancashire
- Imperial MSc Genomic Medicine students
- Implications of genomics results for the family. Lecture to MSc Genomic Medicine students
- Inaugural RDRUK UPNAT Symposium
- JGC in Sheffield
- Leeds Junior Doctors Genetics Team
- Mainstreaming Genomics module talk (online) – Scientist Training Programme (STP) for Genomic Counselling University of Manchester
- NHS Genomic Healthcare Summit. The hopes and challenges of living with a rare chromosome or gene disorder. Also invited to join a small discussion group with Baroness Merron, Parliamentary Under-Secretary of State, DHSC
- Nottingham Local Government Special Needs Teaching Team
- Panel VUS Interpretation workshop, Festival of Genomics, Excel Centre
- Panel: AGNC ethics workshop, Festival of Genomics, Excel Centre
- Presentation to Belfast clinical genetics dept
- Presentation at the Making Progress with Newborn Screening meeting, Oxford
- [Presentation on Data Access](#) to the Global Alliance for Genomic Health (GA4GH)
- Presentation to Junior Doctors in Leeds
- Presentation to North Thames GMS PPIE group – ‘Unique & GAIN’
- Rare & Inherited Diseases Network of Excellence Event
- Rare disease Research UK: ELSI 2nd annual meeting
- [Rare Early Onset Lower Urinary Tract \(REOLUT\) Disorders Node panel discussion and conference](#)
- Rareminds podcast about PGT
- RD day talk to an audience of clinicians, patients and patient organisations: More than you can imagine: genomics and rare disease
- Scottish Clinical Scientists: Living with a rare genetic condition: the patient and family perspective
- Sweden Rare Disease Conference
- Teaching Brighton & Sussex Medical School MDM160 course
- The Blair Partnership (where we have been selected as their Charity of the Year)
- Westminster Health Forum Next steps for genomics in the UK

Unique memberships

- Breaking Down Barriers
- Eurordis
- ERN Ithahca
- Gene People
- Genetic Alliance UK
- Global Genes
- UK Rare Epilepsies Together (UKRET)
- LeDerR (a service improvement programme for people with a learning disability and autistic people) registered stakeholder

Boards

- DDD Data Access Policy Group
- DECIPHER Data Access Policy Group (DAC)
- England Rare Diseases Action Plans Patient Advisory Group (PAG)
- Eurordis JARDIN Undiagnosed Multistakeholder Task Force
- Joint Committee on Genomics in Medicine
- Manchester Rare Conditions Centre Advisory Board
- NHS GMS People and Communities Forum
- PPV rep on the Genomics Clinical Reference Group (CRG)
- Rareminds Board of Trustees
- Rare Disease UK's Patient Empowerment Group (PEG)
- Scientific Advisory Board, Manchester Biomedical Research Centre (BRC)
- [Adelphi Genetics Forum](#)

Research project advisory board/ partnerships

- Advisory Group: Equity in Genomics (led by Hannah McInnes-Dean, ARC)
- Advisory Group: Prenatal screening and therapies (led by Dr Melissa Hill, UCL)
- BINGO research project
- Chromosome 6 Project (led by Prof. Conny Ravenswaaij-Arts, Netherlands)
- Co-production in rare genetic disorders: digital interventions for childhood disruptive behaviour and anxiety (led by Dr Jeanne Wolstencroft, ICH)
- Delivering genomic sequencing in clinical practice: a patient-centred evaluation of the new NHS
- DHSC: Other genetic conditions working group
- DHSC: DS Act advisory group
- Midwifery in Genetics and Genomics (MIGG)
- Genomics AI Network (GAIN) project
- Genomic Medicine Service (led by Dr Celine Lewis, Institute of Child Health)
- European Network on ethics in Psychiatric Genetics (ENEPG)
- Evaluating rapid genomic sequencing for critically ill children (led by Dr Melissa Hill, UCL)
- Genomics England Conditions Framework working group (Newborn Genomes Programme)
- Genomics England's Generation Study Evaluation Advisory Group (led by Dr Celine Lewis, UCL)
- Mainstreaming GCs group
- Rare Disease Network of Excellence: Rare and Inherited Disease
- Rare Disease Node: Epigenomics of Rare Diseases Node (led by Siddharth Banka, Manchester)

- Rare Disease Node: Ethical, legal and social issues (ELSI) in rare conditions research and clinical practice (led by Angus Claire, Cardiff, Ramona Moldovan, Manchester and Anneke Lucassen, Oxford)
- Research supervision (led by Kerry Montgomery, University of the West of England, Centre for Appearance Research, VCT Foundation. Exploring family planning and decision making for people with a visible difference which can be inherited.
- SWAN Pathway specification group
- SWAN UK/Genetic Alliance UK task and finish group

Research project involvement

- Can artificial intelligence and large language models be employed to create patient information guides for rare conditions. Siddharth Banka (Manchester)
- ENRICH study: In collaboration with UCL
- GENROC study (Karen Low, Bristol)
- Networking Support Scheme in the European Joint Programme on Rare Diseases (Netherlands): Evaluated applications and consensus meetings
- PGT-M surveys (Genetic Alliance UK): Unique liaison
- PREGCARE project (University of Oxford, UK): Unique liaison.
- University of Manchester/Shorthills AI project to assess the ability of AI to help generate patient information guides

Academic and other papers

[ACGS Position Statement on Rare Disease Genomic Testing](#). Submitted to J Med Genetics. Article written by GA4GH: https://www.ga4gh.org/news_item/uncovering-and-overcoming-common-data-sharing-challenges-in-the-rare-disease-landscape/

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Dr Sarah Wynn, Prof Sian Ellard, Prof Emma Baple and Prof Rob Taylor. [Rare disease genomic testing: promoting timely and equitable access](#). Comment in Bionews 11 November 2024. <https://www.progress.org.uk/rare-disease-genomic-testing-promoting-timely-and-equitable-access/>

Ellard, H., Clarke, A., Wynn, S. et al. [Written communication of whole genome sequencing results in the NHS Genomic Medicine Service: a multi-centre service evaluation](#). Eur J Hum Genet (2024). <https://doi.org/10.1038/s41431-024-01636-5>

Karen J. Low, Georgia Treneman-Evans, Sarah L Wynn, GenROC Study Consortium, Jenny Ingram. [“They don’t know how to live with a child with these conditions, they can’t understand...”](#): The lived experiences of parenting a child with a genetic neurodevelopmental disorder. Health Expectations 2025

[Large-scale evaluation of outcomes following a genetic diagnosis in children with severe developmental disorders](#). Accepted by Genetics in Medicine Open

Low KJ, Watford A, Blair P, Nabney I, Powell J, Wynn SL, Foreman J, Firth H, Ingram J. [Improving the care of children with GENetic Rare disease: Observational Cohort study \(GenROC\)-a study protocol](#). BMJ Open. 2024 May 16;14(5):e085237. doi: 10.1136/bmjopen-2024-085237. PMID: 38760043; PMCID: PMC11103197. <https://bmjopen.bmj.com/content/14/5/e085237.long>

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Morgan Daniel 1 2, Hannah McInnes-Dean 1 2 3, Wing Han Wu 1 2, Jane Fisher 3, Caroline Lafarge 4, Kerry Leeson-Beevers 5, Celine Lewis 6, Sophie Peet 7, Dagmar Tapon 8, Sarah L Wynn 9, Lyn S Chitty 1 2, Melissa Hill 1 2, Michelle Peter 1 2. [Can an animation improve parents’ knowledge and how does it compare to written information? Development and survey evaluation of an animation for parents about prenatal sequencing \(BJOG-24-1057\)](#) has been submitted by Morgan Daniel to BJOG: An International Journal of Obstetrics & Gynaecology. <http://doi.org/10.1002/pd.6792>

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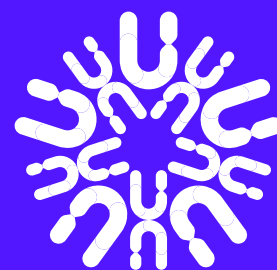
[Press Release for RNU4-2 paper in Nature](#) (Unique are quoted): <https://www.bdi.ox.ac.uk/news/new-discovery-renews-hope-for-thousands-with-neurodevelopment-disorders>





Year end: 31st March 2025

Author: Unique, The Rare Chromosome and
Gene Disorder Support Group



unique

UNDERSTANDING GENES
& CHROMOSOMES

RARE CHROMOSOME DISORDER SUPPORT GROUP

England & Wales - Charity number 1110661

Accounts

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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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.

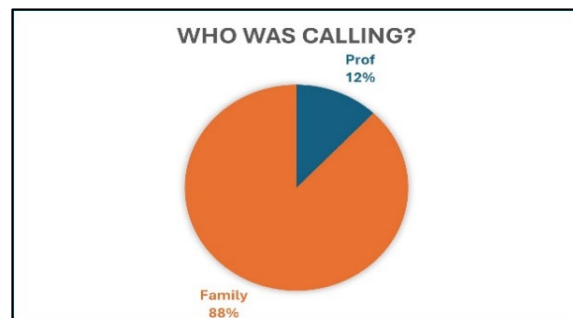
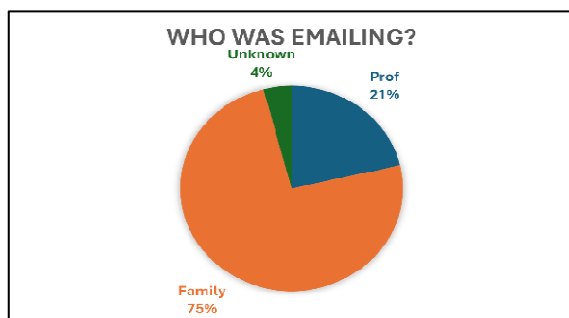
Our Performance and Achievements During 2023-2024

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

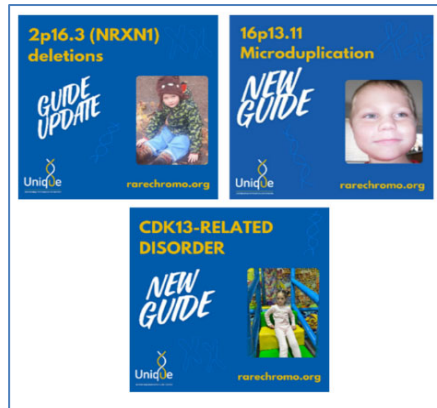
Our two Scientific Communications Officers continued to produce new and updated information to benefit thousands of families now and well into the future. Highlights this year included:

- 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	<u>4,320</u>	<u>24,963</u>	<u>18,723</u>	<u>(48,006)</u>	<u>-</u>
Total expenditure	<u>54,922</u>	<u>155,628</u>	<u>159,092</u>	<u>-</u>	<u>369,642</u>

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
	19,156	11,769

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
	14,009	18,435

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	37,842	40,000	259,960	337,802

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	16,390	40,000	254,387	310,777

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.

RARE CHROMOSOME DISORDER SUPPORT GROUP

England & Wales - Charity number 1110661

Accounts

Company no. 05460413
Charity no. 1110661

Rare Chromosome Disorder Support Group

Report and Unaudited Financial Statements

31 March 2023

Rare Chromosome Disorder Support Group

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For the year ended 31 March 2023

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Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2023

Company number 05460413

Charity number 1110661

Registered office and operational address F4, The Stables
Station Road West
Oxted
Surrey
RH8 9EE

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

Helen Campbell	Chair until 17 October 2022
Isobel Hindle	Trustee
Edna Knight, MBE	Founder, Life President, Trustee
Gillian Manvell	Trustee
Shwetha Ramachandrappa	Trustee
Sophie Sainty	Chair from 18 October 2022
Benjamin Stern	Trustee
James Toop	Trustee
Fiona de Zoete	Trustee

Chief executive officer Dr Sarah Wynn

Company secretary Craig Mitchell MInstF (Dip)

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

Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2023

Bankers

Charities Aid Foundation
Kings Hill
West Malling
Kent
ME19 4TA

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

United Trust Bank
1 Ropemaker Street
London
EC2Y 9AW

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

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

Independent examiners

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

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

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

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

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

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

Sophie Sainty, Chair of Trustees

Our Mission, Aims and Objectives

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

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

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

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

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

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

Our Activities & Achievements During 2022-23

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

1. Family Support

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

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

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

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

2. Provision of Specialist Information

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

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

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

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

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

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

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

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

3. Networking and Awareness-Raising

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

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

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

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

Social media

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

Public Benefit

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

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

Hybrid Working & Unique's Infrastructure

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

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

Volunteers

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

Financial Review 2022-23

Income

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

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

Expenditure

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

Level of Reserves

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

The Future

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

Structure, Governance and Management

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

Corporate and Social Responsibility and Sustainability

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

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

Management of Risk

We maintain and regularly review and update Unique's Risk Register, containing the major financial, operational, reputational and other potential risks to the charity. The CEO and COO take operational responsibility for this, overseen by trustees. A disaster recovery plan is in place, with appropriate contingency plans as operating conditions and/or performance change. The trustees meet formally three times per year, with senior staff present, with the charity's financial position kept under review at each meeting. Monthly management reports are circulated to all trustees and senior staff.

Compliance and Training

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

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

Staff performance is kept under ongoing review and all staff also take part in a formal annual appraisal which relates the key responsibilities of their role to Unique's charitable aims. One aim of doing this is to identify any knowledge gaps or training needs in order that appropriate training can be sourced. Appraisals are undertaken with the staff member's line manager and a trustee present.

Governance

Unique is an incorporated charity and company limited by guarantee, governed by a Memorandum and Articles of Association. Governance and management structures of the charity are kept under constant review to ensure optimal use of resources. Trustees met three times during the year and corresponded regularly via email and other digital means, particularly to keep financial performance under review. They receive monthly management reports with a narrative to flag any issues.

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

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

Registered members of the company limited by guarantee and others with an interest in Unique were invited to attend the Annual General Meeting which was held in Autumn 2022 and are kept informed by the Company Secretary.

Statement of responsibilities of the trustees

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

Company law requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing those financial statements the trustees are required to:

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

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

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2023

Independent examiners

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

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

Sophie Sainty- Trustee (Chair)

Independent examiner's report

To the trustees of

Rare Chromosome Disorder Support Group

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

Responsibilities and basis of report

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

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

Independent examiner's statement

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

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

- (1) accounting records were not kept in respect of the charitable company as required by section 386 of the 2006 Act; or
- (2) the accounts do not accord with those records; or
- (3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
- (4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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

Date: 10 October 2023

Alison Godfrey FCA
Member of the ICAEW

For and on behalf of:

Godfrey Wilson Limited

Chartered accountants and statutory auditors

5th Floor Mariner House

62 Prince Street

Bristol

BS1 4QD

Rare Chromosome Disorder Support Group

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

For the year ended 31 March 2023

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

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

Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2023

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

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

The directors acknowledge their responsibilities for:

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

Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2023

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

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

Sophie Sainty- Trustee (Chair)

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

1. Accounting policies

a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities in preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Rare Chromosome Disorder Support Group meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Going concern basis of accounting

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

c) Income

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

Income from grants, whether 'capital' or 'revenue', is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably.

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

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

1. Accounting policies (continued)

d) Donated services and facilities

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

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

e) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity: this is normally upon notification of the interest paid or payable by the bank.

f) Funds accounting

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

g) Expenditure and irrecoverable VAT

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

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

h) Allocation of support and governance costs

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

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

i) Tangible fixed assets

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

Computer equipment	4 years straight line
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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 2023

1. Accounting policies (continued)

j) Fixed asset investments

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

k) Stock

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

l) Debtors

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

m) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

n) Creditors

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

o) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value.

p) Foreign currency

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

q) Pension costs

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

r) Operating leases

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

1. Accounting policies (continued)

s) Accounting estimates and key judgements

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

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

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

2. Prior period comparatives

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

3. Donations and legacies

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

All income from donations in the prior year was unrestricted.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

4. Charitable activities: family support services

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

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

5. Charitable activities: information and awareness

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

Prior year comparative

	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>

6. Government grants

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

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

7. Total expenditure

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

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

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

7. Total expenditure (continued)

Prior year comparative

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

8. Net movement in funds

This is stated after charging:

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

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

9. Staff costs and numbers

Staff costs were as follows:

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

No employee earned more than £60,000 during the year (2022: none).

The key management personnel of the charity comprise the trustees, the Chief Executive and the Chief Operating Officer. The total employee benefits comprising gross wages, employer pension contributions and employer NI contributions received by the charity's key management personnel in the period was £114,857 (2022: £99,635).

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

10. Taxation

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

11. Tangible fixed assets

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

12. Investments

	Artwork £
At 1 April 2022	700
Gain on revaluation	<u>3,300</u>
At 31 March 2023	<u><u>4,000</u></u>

A Tracey Emin print was donated in 2005. The trustees have no immediate plans to sell the print consequently it has been reported as a fixed asset investment in the accounts. It was revalued during the year based on the sale of a similar work by the artist. The trustees are satisfied that the print is carried at an appropriate value at 31 March 2023.

13. Stock

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

14. Debtors

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

15. Creditors : amounts due within 1 year

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

16. Analysis of net assets between funds

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

Prior year comparative

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

17. Movements in funds

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

Purposes of restricted funds

Family support services

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

Information and awareness

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

Purposes of designated funds

Listening Ear Fund

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2023

17. Movements in funds (continued)

Prior period comparative

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

18. Related party transactions

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

19. Financial instruments held at fair value

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

Financial assets measured at fair value comprise investment assets.

RARE CHROMOSOME DISORDER SUPPORT GROUP

England & Wales - Charity number 1110661

Accounts

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>		<u>8,981</u>	<u>114,435</u>	<u>123,416</u>	<u>104,071</u>
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>40,000</u>
<i>Total designated funds</i>	<u>40,000</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.

RARE CHROMOSOME DISORDER SUPPORT GROUP

England & Wales - Charity number 1110661

Accounts

Company no. 05460413
Charity no. 1110661

**Rare Chromosome Disorder Support
Group
Report and Audited Financial Statements
31 March 2021**

Rare Chromosome Disorder Support Group

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Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2021

Company number 05460413

Charity number 1110661

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

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

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

Chief executive officer Beverly Searle, PhD

Company secretary Craig Mitchell MInstF (Dip)

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

Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2021

Bankers

Charities Aid Foundation
Kings Hill
West Malling
Kent
ME19 4TA

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

United Trust Bank
1 Ropemaker Street
London
EC2Y 9AW

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

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

Auditors

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

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

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

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

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

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

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

Helen Campbell, Chair of trustees

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

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

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

Aims and objectives

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

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

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

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

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

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Our activities - support, information and networking

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

1. Supporting families

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

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

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

2. Specialist information

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

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

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

3. Networking and awareness-raising

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

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

Response to Covid-19

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

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

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

Our achievements during 2020-21

Families in need of more support than ever...

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

During the year, to support families and others we:

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

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

Unique's specialist information – another milestone reached

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

During the year, our team published:

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

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

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Networks built, families helped, awareness raised

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

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

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

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

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

Public benefit

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

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

Infrastructure

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

Volunteers

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Financial review 2020-21

Income

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

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

Expenditure

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

Level of reserves

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

The future

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

Structure, governance and management

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Corporate and social responsibility and sustainability

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

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

Management of risk

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

Compliance and training

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

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

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

Governance

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

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

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

Statement of responsibilities of the trustees

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

Company law requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing those financial statements the trustees are required to:

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

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

In so far as the trustees are aware:

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

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

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

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2021

Auditors

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

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

Helen Campbell

Helen Campbell - Trustee (Chair)

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

Opinion

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

In our opinion, the financial statements:

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

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

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

We have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

Responsibilities of the trustees

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

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

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

Our responsibilities for the audit of the financial statements

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

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

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

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

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

(3) We inspected the minutes of trustee meetings.

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

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

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

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

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

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

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

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

Use of our report

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

Alison Godfrey

Date: 12 October 2021

Alison Godfrey FCA
(Senior Statutory Auditor)

For and on behalf of:

GODFREY WILSON LIMITED

Chartered accountants and statutory auditors

5th Floor Mariner House

62 Prince Street

Bristol

BS1 4QD

Rare Chromosome Disorder Support Group

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

For the year ended 31 March 2021

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

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

Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2021

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

Helen Campbell

Helen Campbell - Trustee (Chair)

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

1. Accounting policies

a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities in preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Rare Chromosome Disorder Support Group meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Going concern basis of accounting

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

c) Income

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

Income from grants, whether 'capital' or 'revenue', is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably.

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

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

1. Accounting policies (continued)

d) Donated services and facilities

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

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

e) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity: this is normally upon notification of the interest paid or payable by the bank.

f) Funds accounting

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

g) Expenditure and irrecoverable VAT

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

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

h) Allocation of support and governance costs

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

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

i) Tangible fixed assets

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

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

1. Accounting policies (continued)

j) Fixed asset investments

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

k) Stock

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

l) Debtors

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

m) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

n) Creditors

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

o) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value.

p) Foreign currency

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

q) Pension costs

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

r) Operating leases

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

1. Accounting policies (continued)

s) Accounting estimates and key judgements

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

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

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

2. Prior period comparatives

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

3. Donations and legacies

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

Prior year comparative

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

4. Charitable activities: family support services

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

Prior year comparative

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

5. Charitable activities: information and awareness

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

Prior year comparative

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

6. Government grants

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

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

7. Total expenditure

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

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

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

7. Total expenditure (continued) Prior year comparative

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

8. Net movement in funds

This is stated after charging:

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

9. Staff costs and numbers

Staff costs were as follows:

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

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

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

	2021 No.	2020 No.
Average staff head count	10.00	10.00
Average full time equivalent	7.00	7.00

10. Taxation

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

11. Tangible fixed assets

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

12. Investments

	Artwork £
At 31 March 2021	700
At 31 March 2020	700

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

13. Stock

	2021 £	2020 £
Merchandise	1,721	2,608

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

14. Debtors

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

15. Creditors : amounts due within 1 year

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

16. Analysis of net assets between funds

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

Prior year comparative

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

17. Movements in funds

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

Purposes of restricted funds

Family support services

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

Information and awareness

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

Purposes of designated funds

Listening Ear Fund

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2021

17. Movements in funds (continued)

Prior period comparative

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

18. Related party transactions

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

19. Financial instruments held at fair value

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

Financial assets measured at fair value comprise investment assets.