UNIQUE ANNUAL REPORT

2024-2025

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.

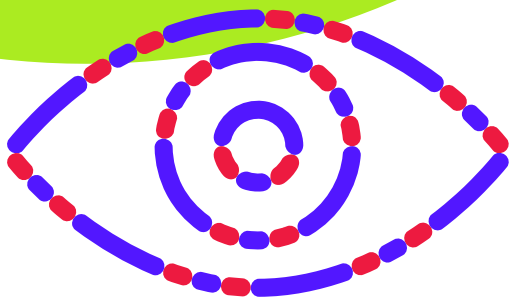
This coming year and into the future, we will continue to work hard to make sure the voices of those living with rare gene and chromosome conditions are heard. Much of our work involves advocating on behalf of our members and this year we have presented at over 40 conferences and meetings, staff members 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)

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

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

"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 mosaicsim
- 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
- RHOBTB2 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 developmental 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.

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 condtions, 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."

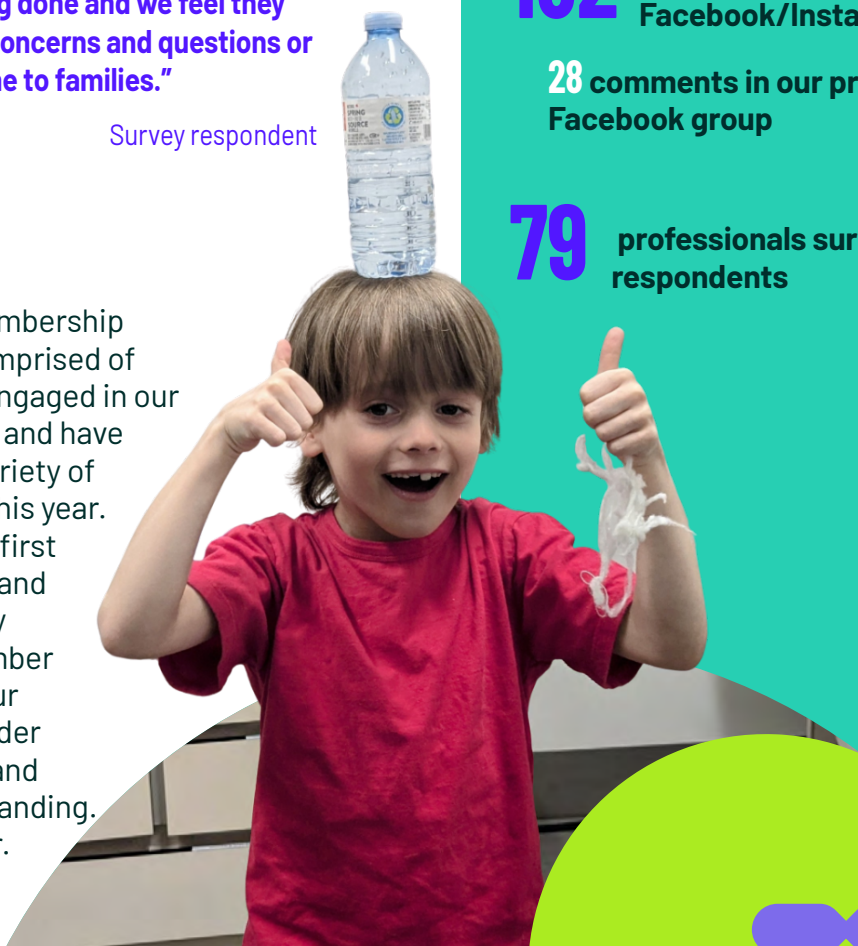
Survey respondent

"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:					
Family support services	4	46,731	-	**46,731**	31,205
Information and awareness	5	13,550	11,298	**24,848**	20,263
Investments		-	7,575	**7,575**	5,331
Total income		70,024	397,168	**467,192**	396,667
Expenditure on:					
Raising funds		-	68,393	**68,393**	54,922
Charitable activities:					
Family support services		24,367	127,715	**152,082**	155,628
Information and awareness		7,020	174,705	**181,725**	159,092
Total expenditure	7	31,387	370,813	**402,200**	369,642
Transfer between funds		(1,614)	1,614	**-**	-
Net income and net movement in funds		37,023	27,969	**64,992**	27,025
Reconciliation of funds:					
Total funds brought forward		37,842	299,960	**337,802**	310,777
Total funds carried forward		74,865	327,929	**402,794**	337,802

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)

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.

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

Items of equipment are capitalised where the purchase price exceeds £500.

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.

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			
Family support services	31,205	-	31,205
Information and awareness	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			
Family support services	29,521	126,107	155,628
Information and awareness	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

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**
	9,743	378,295	**388,038**

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
	25,779	314,089	339,868

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
	46,731	-	**46,731**	31,205

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**
	13,550	11,298	**24,848**

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
	6,125	14,138	20,263

6. Government grants

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

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).

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

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)	**2,350**	2,200

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	**29,083**	13,861
	284,485	272,816

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

10. Taxation

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

11. Tangible fixed assets

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

12. Investments

	2025 £	2024 £
At 31 March 2024 and 31 March 2025	**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. The trustees are satisfied that the print is carried at an appropriate value at 31 March 2025.

13. Stock

	2025 £	2024 £
Merchandise	**8,288**	2,877

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

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					
Designated funds:					
Listening Ear Fund	40,000	-	-	-	**40,000**
Total designated funds	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.

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.

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	16,390	63,109	(41,657)	37,842
Unrestricted funds				
Designated funds:				
Listening Ear Fund	40,000	-	-	40,000
Total designated funds	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

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

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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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Year end: 31st March 2025
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