

Unique
UNDERSTANDING GENES
& CHROMOSOMES

UNIQUE ANNUAL REPORT 2025-2026

and Unaudited Financial Statements

Rare Chromosome Disorder Support Group
trading as Unique
Company no. 05460413
Charity no. 1110661
Year end 31st March 2026

LIVING WAGE EMPLOYER

disability confident COMMITTED

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, (also directors under company law) who served during the year and up to the date of this report were as follows:
Helen Campbell - Interim Chair of Trustees, appointed 16th October 2025
Cecely Hugh - Vice Chair of Trustees, appointed 16th October 2025
Edna Knight, MBE – Trustee, Founder, Life President
James Lucas - Trustee
Dr Shwetha Ramachandrappa - Trustee
Sophie Sainty - Trustee, resigned as Chair of Trustees 16th October 2025
Benjamin Stern - Trustee
Fiona Catherine Fulton de Zoete - Trustee

Staff

Chief Executive Officer: Dr Sarah Wynn
Finance and Operations Manager: Louise Jeffree
Scientific Communications Manager: Dr Anna Pelling
Scientific Communications Manager: Dr Claire Andersen
Helpline, Family Support and Scientific Communications Officer: Niamh Marshall
Helpline and Family Support Officer: Anita Davis
Helpline and Family Support Officer: Emily Fee
Helpline and Family Support Officer: Francesca Wicks
Engagement and Communications Officer: Matthew Hamer
Administration Officer: Gemma Mitchell
Administrative Assistant: Emma St John
Company secretary: Louise Jeffree

Patrons

Baroness Pauline Neville-Jones, UK
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

David Howard Ltd, Chartered Accountants, 5 The Square, Bagshot, GU19 5AX

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

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.

"As you navigate the world of rare chromosome and gene disorders, we want you to know that you are not alone.

At Unique, we understand genes and chromosomes.

That's why we offer accurate and accessible medical information to support research and diagnosis in this field. Unique is an open, supportive community for people who are looking to learn, share lived experiences and connect with others.

We work with anyone whose life has been touched by rare chromosome or gene disorders. Whether you're someone living with a condition, a caregiver, a carer, an educator, a social worker, a doctor or a scientist – whoever you are, Unique is here for you!



By working with one another and sharing our stories, we know we can find more ways to support and celebrate people living truly unique lives.

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



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.



Our Strategy for 2026 – 2030

During the course of the year, we have been working on our new five-year Strategy for 2026-2030. This significant piece of work has involved many stakeholders and is based around performance against four strategic aims which are:

1. Increase recognition

and visibility of rare chromosome and gene disorders so all people and families feel seen, supported, and fully included in wider conversations about disability and rare genetic conditions.

2. Influence policy

and drive system change to secure fair and proportionate recognition of rare chromosome and gene disorders.

3. Improve our membership

and services to reflect the needs and diversity of the rare chromosome and gene disorders community.

4. Invest in our organisation

so we remain robust and able to deliver our strategic aims.

The finalised strategy will be communicated early in the next financial year.

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. For a full list of involvement please see Appendix.

LETTER FROM CHAIR

Welcome to Unique's annual report and accounts for the year ended 31 March 2026 and on behalf of all the Trustees I thank you for your interest in our work.

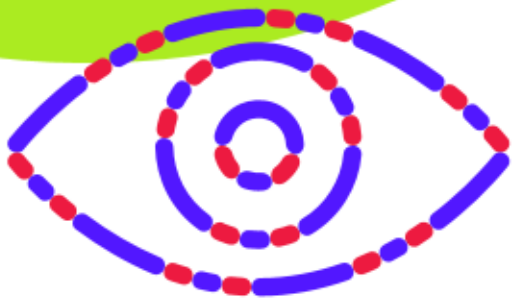
In October 2025 I was appointed interim Chair and we hope to appoint a new Chair in the next financial year. I previously served as Chair between 2015 and 2022, and it is a massive privilege to be asked to serve again. Unique currently has 35,000 members across 135 countries, a 25% increase since I was last in this role 4 years ago and a 250% increase since I joined the Board 12 years ago. Unique was at that point in 2014 celebrating its 30th anniversary, having been started as a group of 4 families, the Trisomy 9 support group, by our Life President and Trustee Edna Knight MBE in 1984. Every year we seem to note record numbers of new families reaching out for help and information, and every year our staff outperform expectations in the level of service they provide. We are rightly proud of our team, led by Dr Sarah Wynn, and we see that appreciation from both member families in the form of fundraising and from professionals in the requests for presentations and the Boards on which our staff sit.

In 2025/26 we have been working on our next 5-year strategy (2026~30). One of our strategic aims is to improve our member services, and a key pillar of that will be the relaunch of our local contact programme for which we have successfully secured 3 years of National Lottery Funding. We also have adopted a goal of influencing policy decisions, using our status as a widely respected voice for the rare chromosome and gene disorder community to make a wider societal impact on your behalf.

Helen Campbell
Interim chair of Trustees



ACHIEVEMENTS AND PERFORMANCE - Unique at a glance



"Thank you also for all the information and resources you sent us. Finding Unique has already given our family hope because it reminds us that we are not alone"

Unique member

Membership

33,911 total members in our registry

1,753 new members registered in 2025/26

135 countries represented in our membership

52 new professional members

11 parents in our Membership Engagement Committee

5 Parents in our US Membership Group

Engagement

122k active users on the website

1m 11s per active user spend on the website

4 WhatsApp groups created with over 100 members

5 family events attended by almost 200 families

6 webinars hosted with over 780 participants

457k views across our website pages

COMMUNITY FUND

Success with our National Lottery Reaching Communities Application to reinvigorate our community contacts program around the country.

Helpline

1,065 people supported via our helpline

268 helpline calls taken

797 emails to the helpline

Resources

324 condition-specific information guides

109k+ visits to disorder guides webpage

55 presentations and talks given

20 advisory groups or strategy boards participated in (see Appendix 1)

4 important peer-reviewed published papers co-authored

We have also presented at numerous conferences including: European Society for Human Genetics in Berlin (May 2025), RareSummit25 (November 2025), NHS Genomics Summit (December 2025), Festival of Genomics (February 2026).

Highlight

We held our first Unique Conference since 2014 in Birmingham in March 2026.

INFORM

"The guide looks amazing. It's so good to finally have something published like this for other families. Thank you"

Unique member

Providing accessible, accurate and easy-to-understand information is one of Unique's core services. We have a continuously expanding library of disorder-specific guides covering chromosome and gene conditions, as well as guides on other related genetic topics. We are also currently developing our 'My Gene/Chromosome Story' booklets for children and Easy Read guides for adults with a learning disability. In addition, we offer a range of practical guides designed to provide support and information for everyday living.

"The guide is absolutely fantastic!!! It's so informative and getting a view from an older child and adult is amazing that also has [our child's] condition it gives our family hope! Thank you all again for all the work you and your team have done for creating this guide for many families like ours. I just wish it was available years ago when [our child] got diagnosed"

Unique member



This year we published:

10 new condition specific guides

56 translations

34 'My Chromosome/Gene Story' booklets

1 practical guide

1 Easy Read guide

Total publications:

324 condition specific guides

233 on chromosome disorders

91 on single gene disorders

61 'My chromosome' story guides

13 Easy Read condition specific guides

638 translated guides

23 languages

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

Collaborations

Our guides are developed in partnership with professionals and people with lived experience. This year, we have continued to work on two pilot projects.

Collaboration with Manchester Uni & Shorthills AI

In 2024, we established a collaboration with the Manchester Rare Conditions Centre, North West GMSA and Shorthills AI (India), to leverage AI Large Language Models (LLMs) to generate Unique information guides. The main aim was to reduce the time required for expert clinicians to help produce new and updated guides.

In the first year, the project resulted in the successful creation and testing of a generative AI-based model for drafting Unique guides. In 2025, a project was advertised to recruit expert clinicians to lead the development of five to ten new Unique information guides using this model. This project has required extensive input (many 100s of hours!) from our Scientific Communications Team, but we are delighted to say that a greater than planned 11 new Unique guides are now in the final stages of development, with the first guide to TUBB3 syndrome scheduled for publishing on the Unique website in June 2026. Following this successful pilot project, the collaboration is scheduled to continue for another two years.

Collaboration with the Julia Garnham Centre (JGC)

In 2024, we first established an exciting collaboration with the JGC, an equal partnership between the Sheffield Children's Hospital and the University of Sheffield, aimed at increasing the number of new and updated chromosome disorder and single gene disorder (SGD) Unique guides.

In the past year, our scientific communications team have worked extensively with both clinical staff and BSc, MSc and PhD students from Sheffield to establish a successful guide production pipeline. This has resulted in seven new SGD guides, which are due to be published in June 2026. The project will be presented at the annual European Society of Human Genetics (ESHG) conference in Gothenburg in June 2026. Following a successful pilot, the collaboration is scheduled to continue.

Julia Garnham Centre

University of Sheffield

Sheffield Children's NHS Foundation Trust

Manchester Rare Conditions Centre

Shorthills

NHS North West Genomic Medicine Service Alliance



"Thank you!! This looks wonderful. It is so incredibly informative and lovely. Thank you for all of your work on putting this together!! What a gift this will be for our community! We truly appreciate your hard work on making this such a comprehensive guide"

Unique member

OUR NEW GUIDES

Single gene disorder guides

- POGZ White-Sutton syndrome
- TAOK1-related neurodevelopmental disorder
- KBG syndrome in adulthood
- ATP11A - HLD24
- CAPRIN1-related NDD
- CHAMP1-related NDDs
- Perrault syndrome
- RAC1-associated neurodevelopmental disorders
- SON (ZTTK)
- KMT2E-NDD

My Chromosome/Gene Story booklets (MCS)

- CAPRIN1-related NDD
- CHAMP1-related NDD
- Idic(15)
- KMT2E-NDD
- POGZ White-Sutton syndrome
- RAC1-associated neurodevelopmental disorders
- SON (ZTTK)
- TAOK1-related neurodevelopmental disorder
- 1p36 microdeletions
- 1q21.1 microdeletions
- 2p15p16.1 microdeletions
- 2q13 microduplications
- 2q23.1 deletions
- 2q32 microdeletions
- 3p25 deletions
- 3p26 deletions
- 3q13 deletions
- 5q14.3 microdeletion syndrome
- 7q21.11 microdeletions
- 8p12 deletions
- 8p23 duplication syndrome
- 8p23 deletions
- 14q11.2 deletions
- 14q12 deletions
- 14q13 deletions
- 15q14 deletions
- 15q24 deletions
- 15q25 deletions
- 19p13.13 microdeletions
- 19p13.2 deletions
- 20q13.33 microdeletions
- 22q11.2 deletion syndrome
- 22q11.2 distal deletions
- 22q13 deletions

Easy Reads

- RAC1-associated neurodevelopmental disorders

Translations

Arabic
- Deletions and microdeletions MCS
- Duplications and microduplications MCS
- Single Gene Disorder MCS
- TAOK1-related NDD MCS

Bengali
- 22q11.2 deletion syndrome VCFS

Chinese (simplified):
- ReNU syndrome
- TAOK1-related NDD MCS

Chinese (traditional):
- ReNU syndrome

French
- Balanced translocations MCS
- CAPRIN1-related ID MCS
- Cat Eye syndrome MCS
- CDK13-related disorder MCS
- Deletions and microdeletions MCS
- DYRK1A syndrome MCS
- HIST1H1E syndrome MCS
- Idic(15) MCS
- Malan syndrome MCS
- ReNU syndrome MCS
- Single gene disorders MCS
- TAOK1-related NDD MCS
- 2q23.1 microdeletion syndrome
- 4q deletions between 4q11 and 4q22
- 6q25 deletions
- 16p13.11 microduplications MCS
- 49XXXXY syndrome MCS

Georgian
- DDX3X syndrome
- Wiedemann-Steiner syndrome (WSS) KMT2A
- 1q4 deletions
- 5q14 duplications
- 5q35 duplications

German
- ReNU syndrome
- ReNU syndrome MCS

Portuguese
- ReNU syndrome

Spanish
- Balanced translocations MCS
- CHAMP1-related NDD MCS
- DYRK1A MCS
- POGZ White-Sutton syndrome
- Deletions and microdeletions MCS
- Duplications and microduplications MCS
- Single Gene Disorders MCS
- TRAF7-related NDD
- TAOK1-related NDD MCS

Russian
- After diagnosis what next overseas edition
- Autosomal dominant single gene disorders FTNW
- Autosomal recessive single gene disorders FTNW
- CDK13-related disorder
- CIMDAG syndrome (VSP4A variants)
- Deletions and microdeletions MCS
- Duplications and microduplications MCS
- FISH
- HNRNPH2-NDD
- Inversions
- ReNU syndrome MCS
- sSMCs
- Variable expressivity reduced penetrance
- Wiedemann-Steiner syndrome MCS

Webinars

During the year we hosted **6** webinars with over **780** people attending.

- Introducing the Behaviour Checklist with Hayley Crawford
- What is Makaton and how can it aid communication?
- Supporting Pica and Polydipsia
- ReNU syndrome webinar in Spanish
- Feeding and eating difficulties in children with rare genetic conditions
- Introduction to blended diet for tube feeding

We have plans for lots more webinars next year, including some as part of the Adult Carers Project.

"Really informative and engaging. I am glad I took the time to watch the recording"

Attendee of the Behaviour Checklist webinar

"I appreciated the follow up email with the link to the recording and the download, and the Q&A"

Attendee of the Behaviour Checklist webinar



Collaborations



Havas Life London (HLL) pro bono partnership: Communique awards

Our pro-bono relationship with Havas Life London (HLL) came to an end in October 2025. We are so grateful for their expertise over the last two years. With their help, we have introduced a new logo and branding, produced a Unique song and celebrated our 40-year anniversary with a fabulous launch video and new online and printed Little Red Book, helping our wonderful community celebrate its Unique-ness. We thank everyone on the team for their hard work, and are delighted to report that they were nominated for two Communique awards thanks to their work with Unique, Excellence in pro bono working, for which they were 'Highly Commended' and Charitable campaign of the year. Sarah attended the awards ceremony with them at the Grosvenor House Hotel in July 2025. The team also received another prize for their Unique efforts: Excellence in Corporate Social Responsibility at the PMEA and our new logo launch video has also been entered into the Brand Film Awards.

New collaborations

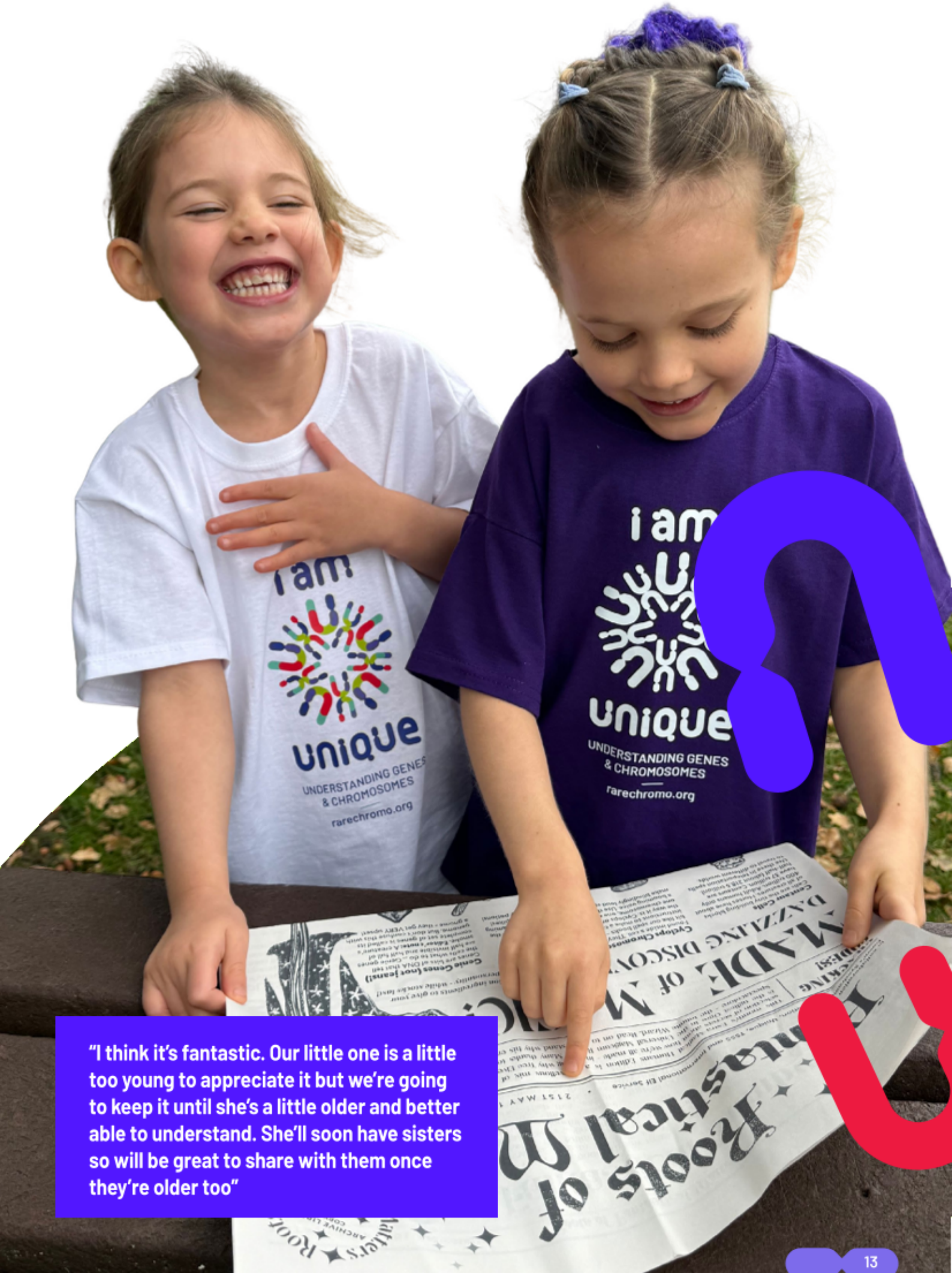
- Collaboration with the DECIPHER team to ensure that direct links to our single gene guides will be put on their platform going forward.
- We have collaborated with Genetic Alliance UK to make a video about the benefits of data sharing.
- Rare Disease Research UK platform for Nucleic Acid Therapies (UPNAT) collaboration: Unique (Claire) presented the PPIE aspect of this project at the annual UPNAT Symposium in November. This provoked significant interest and a webinar is planned to inform families and other support groups about the initiative and promote input to the planned guide.
- McGill Rare collaboration: A new collaboration has been established with a student group at McGill University. Many My Chromosome / Gene Story booklets and translations have been published, many more are in progress and booklet animations/ voice overs are planned, as is expanding the collaboration to include EasyReads.
- Magical Newspaper collaboration: The Down's Syndrome Association, Unique, Turner Syndrome Support Society (UK), and International Elf Service joined forces to create the Roots of Fantastical Matters: Extra Magical Humans edition newspaper. This beautifully illustrated, interactive newspaper used the wonder of the Magical Realm to spark important conversations with children about genetics and disability, not through deficit or superhero tropes, but with curiosity, creativity and respect. Funded by the Down's Syndrome Association, we were given 200 copies which we posted out to families for free. It was enormously popular, reflected in the quotes from members to the right, and all copies were posted out within a matter of days.

"We've framed it ready to put up in my son's room, once he's home from hospital"

Member who received our Magical Newspaper

"I gave this to the head of SEND at my university. We have many teacher training courses (including SEND focused) and will be using this newspaper for education of trainee teachers to learn about chromosome disorders and how to educate children with it"

Member who received our Magical Newspaper



"I think it's fantastic. Our little one is a little too young to appreciate it but we're going to keep it until she's a little older and better able to understand. She'll soon have sisters so will be great to share with them once they're older too"

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 and continue to work with the Department of Health and Social Care (DHSC) to inform the Down Syndrome Act guidance.

Unique has been asked to collaborate with the Rare Disease Research UK (RDRUK) platform for Nucleic Acid Therapies (UPNAT) to help produce an information guide to Nucleic Acid Therapies as part of the RDRUK project. A webinar and guide will be published in the upcoming year.

We continue to work on the Genomics AI Network (GAIN) project which will shape how Artificial Intelligence should be used in Genomic Medicine.

As well as networking with organisations and professionals designing and delivering care for Unique members, we have continued to network our members with each other to provide peer to peer support and relieve the isolation that accompanies rare chromosome or gene disorders. Over 2025/26 we have found family matches for more than 95% of our new members. Our active private Facebook group for Unique members continues to be a lifeline of support and information for the 11,887 members.

"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

Research study involvement

We have advised, supported and shared numerous research projects. Open research projects are shared via our social media channels, our bi-annual magazine and on our website.

Academic papers

The team was involved in the production of 4 peer reviewed academic papers.

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 condition 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

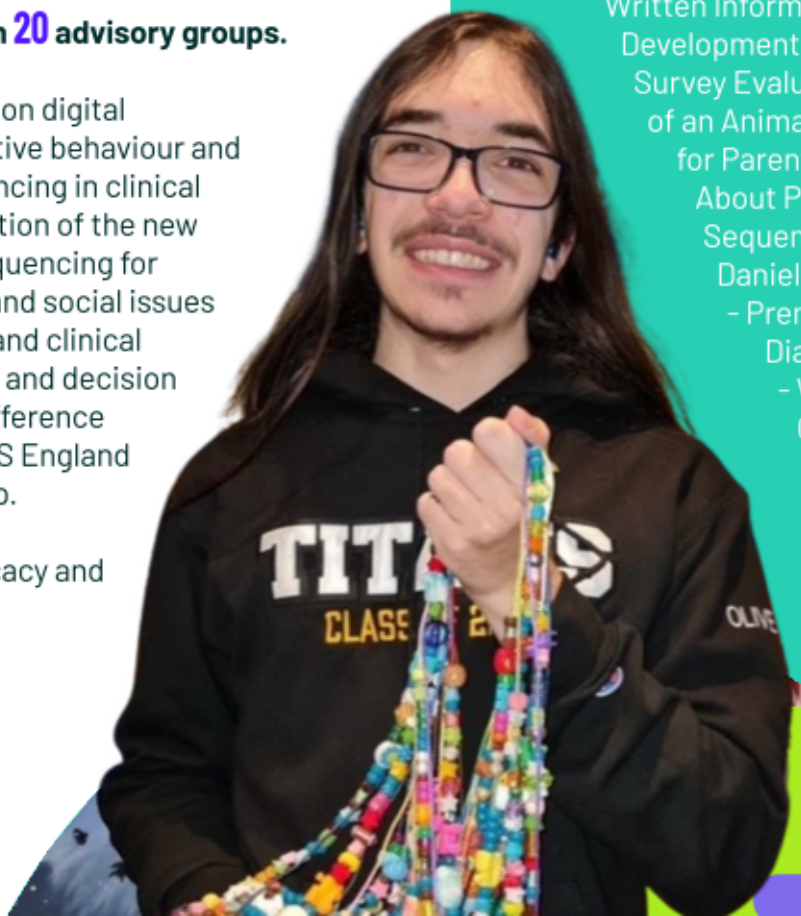
The Unique team sit on more than 20 advisory groups.

These 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 NHS England Genomics Clinical Reference Group.

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

Academic papers we have been involved in:

- Optimising rapid prenatal exome sequencing in the NHS genomic medicine service: the EXPRESS Synopsis | NIHR Journals Library
- JMIR Pediatrics and Parenting - Parental Use of Social Media and the Internet in the Context of Their Child's Genetic Neurodevelopmental Disorder: Mixed Methods Study Nested in the GenROC Cohort Study
- Identifying the Impacts, Obstacles and Information Barriers for Parents of Children Living With Genetic Neurodevelopmental Disorders: A Qualitative Study - Low - 2025 - Health Expectations - Wiley Online Library
- 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 - Daniel - 2026 - Prenatal Diagnosis - Wiley Online Library



SUPPORT

The Unique Team



Unique now supports over 35,000 members in over 135 countries. With our membership growing, we have also grown the Unique team during 2025-26. We welcomed Matt Hamer, our new Engagement and Communications Officer in April 2025 since when we have made huge strides in our social media and newsletter communications, increasing awareness of Unique and the services we provide both within our membership and externally. We also want to acknowledge and thank Alfie Portman-Carroll, who supported our communications before Matt joined, and continued to assist with tasks up until August 2025. Matt also looks after our wonderful fundraisers, helping to increase the much-needed unrestricted funding that we rely on.



We also welcomed two new members to our helpline team in September 2025, Emily Fee and Niamh Marshall. Emily is in the final year of her Genetic and Genomic Counselling MSc degree at Cardiff University and Niamh recently qualified as a genetic counsellor via the NHS Scientific Training Programme (STP). As well as being on the helpline team, Niamh is also assisting our Scientific Communications team in writing new Easy Read guides. Both Niamh and Emily are fabulous additions to the helpline team, further strengthening the offering of support to our members.

Finally, we have added some operational assistance to the team with the addition of Emma St John, also in September 2025. Emma is a Unique member, and mum to Ophelia who is 5 years old and has a complex chromosome disorder involving chromosome 10, and will be assisting the Operations team with the online shop, administration and the organisation of events. She is using her lived experience to great effect with updates to our merchandise offerings already!



We also added recent Cardiff University graduate Grace Hummerston to the team for a 6-week internship. Grace assisted the helpline team over the 2025 summer holidays and was a fantastic help covering staff leave over the holiday period. We will likely continue to offer a summer internship in the years to come given it worked so well this year. Thank you, Grace!

We had to say a sad farewell to Charlotte Wilmshurst in August 2025. Charlotte joined us as maternity leave cover and seamlessly fitted into the helpline team, being a huge asset and a joy to work with. Thank you Charlotte, for all your hard work in the year you were with us.

The Unique team has been very busy over the last year with lots of new initiatives taking shape which will enable us to continue supporting our increasing membership. We are also now an accredited Living Wage employer as well as a Disability Confident employer, ensuring our staff team are fully supported during their career with Unique.

Membership Engagement Committee progress

Our Membership Engagement Committee was set up in 2024/25 and now includes 11 active members from around the world who meet once each quarter with our CEO and the team to share ideas and opinions on current initiatives for which we need their advice. They meet quarterly and are a sounding board for all the work we are doing as well as future planning. This year they have provided lived experience input on topics such as fundraising ideas for US members, the National Lottery funded parent/carers of adults project, webinar suggestions, awareness day ideas and provided feedback on our new strategy.

Our grateful thanks to the Committee for volunteering their valuable time to assist us and shape our future strategy.



RARE CHROMOSOME AND GENE DISORDER AWARENESS DAY

Rare Chromo Day is the focal point of the Unique community bringing together families from around the world to celebrate the achievements of their affected family members. Highlights from the awareness day on 19th June 2025 included:

Little Red Book

We released our digital Little Red Book on our awareness day, followed by the print version available from February 2026 in time for Rare Disease Day. Our partnership with Havas Life London enabled us to develop and publish our digital update of the Little Red Book. This brought together over 100 stories of people and families affected by rare chromosome disorders, describing the joys and sometimes challenges of rare diagnoses. The book is wonderful and has been very enthusiastically received (some quotes from readers and contributors are shared to the right).

Our Little Red Book has been getting a lot of love amongst the community and has been shared across the world. It has also sparked other members of the community to get involved and share their stories which we have shared on our social media pages. There was no stopping our community on social media, where members were helping to spread the word around the world, sharing our posts, writing their own and raising awareness for the work we do here at Unique.



"HOW SUCCESSFUL THAT HAS BEEN!! I have sent it far and wide, as I'm sure everybody else has. How wonderful to be able to read snippets of other family's journeys. Their trials and tribulations, and the adversity, strength and love that shines through, like a beacon of hope for those still struggling. It was such a marvellous idea to resurrect the 'Little Red Book' again, how such a simple process of writing down your feelings can help just a little bit. I am not ashamed to say I cried when I saw our beautiful daughter Laura's face staring back at me from the 'Unique Adult' pages! Tears of pure pride and love"

"Awesome book! I'm grateful for Unique. Thank you for sending me this magical book"

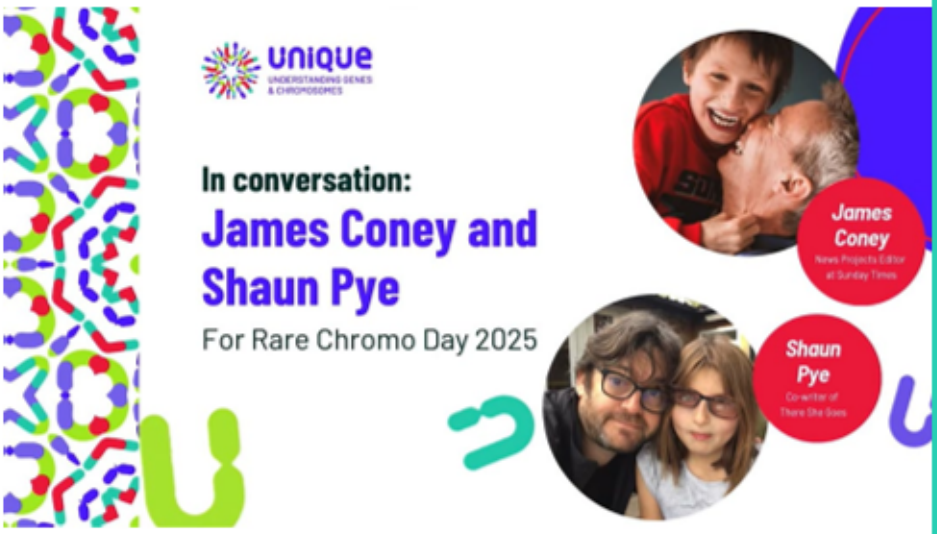
"As well as Rare Chromo Day, it was also the day my 16 year old should of left mainstream high school, but she had to leave mainstream high school three years earlier due to her needs not being met by school. It was a day I was dreading all the first and last days of school photographs all over Facebook. Shirt signings and prom dresses. Instead of feeling sad, I felt happy, proud, and totally in love with my girl and her Daddy. I shared this book all over social media. Thank you"

Survey report published

As well as the Little Red Book, on Rare Chromo Day we published Unique Experiences: Living with a Rare Chromosome or Gene Disorder, the report from our extensive consultation last year exploring the experiences of families and individuals affected by rare chromosome and gene disorders. The findings reveal a complex picture of resilience, grief, stress, strength and struggle but provide an evidence base for which we can more effectively advocate on behalf of people and families affected by rare chromosome and gene disorders. This report has been extremely well received by families and professionals. Take a look at some of the lovely responses we received in the column to the right.

Other highlights:

- 'In conversation with James Coney and Shaun Pye', a webinar that was attended by over 100 members and has since had over 400 additional views on our YouTube.
- Our private Facebook Café had 190 posts from our members throughout the day, those posted gained 565 comments and 4,358 reactions, showing just how supportive our community is with one another.
- On Facebook we had 56,972 views and gained 65 followers. On Instagram we had 79,706 views, reached 10,966 accounts and gained 196 followers.
- Our Little Red Book reel on Instagram received over 12,000 views, 64% of which were non-followers, helping us to reach an audience outside our usual membership.
- Our community was sharing all about the awareness day non-stop and we loved reading posts and seeing all the ways our community got involved. Including this creative poem we were tagged in by Serene Dunlop on Facebook.
- 2,000 people visited our website on the day.
- Our song, Touch the Sky, continues to get plays and views. On YouTube it received an additional 2,883 views since April.



"It's really encouraging to see Unique's commitments for the next five years, thanks for setting out the goals so clearly"
Unique member

"This report hits the spot. Very well and professionally put together and really represents the key points from parents' point of view. I hope there's a way of sharing it to maximise the audience - and to raise awareness's by including readers who do not necessarily have close family affected by rare disorders"
Unique member

"Thank you for sharing the survey report. Taking part in a survey and then being sent the report is, sadly, so rare. I've taken part in tens of surveys by local health and social care organisations and never had any feedback"
Unique member



You can stil watch and listen to the event on our YouTube channel here.

Cri du Chat Support Group

The Cri du Chat Support Group (CDCSG) was sadly wound up in the summer of 2025 with their membership redirected to Unique. We have committed to keeping their website and Facebook group running for the next two years and the group's remaining funds were transferred to Unique and ring fenced for a Unique Cri du Chat guide which is currently in production. Many of their members have joined us and we will continue to nurture and support their community. Unique CEO, Dr Sarah Wynn, welcomed the group to Unique:

"While we are enormously sad to see the standalone CDCSG charity come to an end, we want to reassure any CdC family that there is a home for you here with us at Unique. We are delighted to welcome all of you into our worldwide community of people impacted by rare chromosome and gene disorders (of which CdC is one). We know that navigating life with a child with a rare condition can be a unique and sometimes isolating experience, so Unique is here to provide a sense of community and to help families connect with others. We can't wait to get to know you all, hear your stories and to continue the amazing work of CDCSG in supporting all those affected by CdC."

Parent/Carers of Adults Project

This National Lottery Awards for All funded 2-year project began with setting up a working group of six parent/carers who had their first planning meeting in May 2025. The committee was involved in suggesting suitable presentations for our March 2026 conference where we ensured there was a presentation aimed at this group throughout the day, options for webinars for them, and setting up a WhatsApp Group to use for ongoing support. Upcoming plans include webinars on available welfare benefits and ensuring best quality healthcare for adults with rare chromosome or genetic conditions as well as setting up an adult parents/carers virtual drop-in session on a quarterly basis.



Unique's new registry project

We have been in desperate need of a new membership database for many years, our old Access database being no longer supported by Microsoft and therefore not fit for purpose. Having campaigned for funds over the last couple of years, we have now begun the process of developing our new Membership Registry which will provide us with the tools to support our members into the future. We have partnered with Dendrite Clinical Systems who are a global leader in designing clinical databases and registry systems and have begun working with them on the detailed design process. This is due to be launched in the coming year.

Events for families

This year was a busy year for events around the country. Thanks to a grant from Awards for All – Wales, we held two events in Cardiff. In April we brought together 150 adults and children who enjoyed entertainment from a magician and face painter as well as being able to meet with local geneticists and NHS lab staff for advice. We then held a Meet and Learn day in September for parents/carers to learn more about issues common across many conditions including speech and communication, sleep, mental health in people with intellectual disability, toileting and continence and behaviour that challenges. Both events were well received and a great opportunity for our families to learn and build a supportive network.











In July and December 2025, we also held events at Head2Head Sensory Theatre near Oxted, Surrey. July's performance of 'Thumb Size Grim' and their Panto 'Jack and the Beanstem' were a lot of fun and families appreciated the opportunity to gather together in a safe space where their children could join in the fun without any worry.

Finally, we held our first Unique Conference in over ten years in March 2026, in Birmingham. Funded in the main by a grant from Jeans for Genes, over 100 families and countless genetics professionals came together to create an amazing day for all with presentations, exhibitions, lab experiments laid on by the staff from the West Midlands Genomics Lab, children's entertainment and special needs creche, 1:1 meetings with geneticists, education specialists and a continence expert and an evening meal social to round off the day. It was a wonderful opportunity to showcase Unique's work and create opportunities for members to form new bonds and learn how best to advocate for their children. The feedback from the day was excellent and we were able to record the presentations and distribute them amongst our members unable to attend on the day.

"We found the conference so informative. It was obviously emotional at times, which is to be expected but overall, we found it really cathartic sharing stories with people and just knowing we're not so alone with everything"

Conference attendee



"Congratulations everyone ! The conference was brilliant, the atmosphere was just so lovely and we really enjoyed it. The talks we went to were also very interesting and informative; I came away with very helpful information and a sense that we are part of an amazing family. Thank you so much to everyone who was part of organising it and being part of it! Best wishes everyone, you are all amazing!"

Member conference attendee

"The whole event was so positive for everyone who attended, and it does make a huge difference to be able to talk to other families in the same position, and realise that you're not on your own... that you create connections and support for everyone. You should be SO proud of what you achieved - thank you, just for being there."

Member conference attendee





"It was a privilege for us to be part of your day and to meet so many wonderful families. We are in our happy place dealing with families face to face rather than through our laptops, so it was a welcome change for us. We would be very happy to work with you and offer support in any way you think could be helpful. Please do reach out if we can be of assistance"

Professional conference attendee

Future events:

- A Kent Family Day is being planned for June 2026 in Ashford. Our thanks to The Lawson Trust and The Diana Edgson Wright Charitable Trust for funding this event
- A Northern Ireland Family Day is planned for Autumn 2026, funded by the National Lottery Northern Ireland
- We will be going back to the Head2Head Sensory Theatre, Oxted, in December 2026 for another panto
- We hope to have many smaller events being run by member volunteers around the country as part of our National Lottery Reaching Communities funding, details below

Success with our National Lottery Reaching Communities application

For many years we have been wanting to re-invigorate our local contacts programme whereby our members volunteer their skills to help support other families in their local community. We applied to the National Lottery Reaching Communities Fund with a proposed three-year project asking for funding to recruit a new 'Community Contacts Coordinator' who will support volunteers and members in co-designing a local real-world and virtual network of families. The postholder will help empower our volunteers on the ground to plan and run events across the country to reduce their isolation, share their lived experience and use their accumulated collective knowledge to overcome the many barriers and inequalities they face. In January 2026 we were delighted to hear that our application had been successful! The project began with a recruitment process at the start of March 2026. Once the postholder is in place, it will be full steam ahead with recruitment of volunteers from our membership and hopefully a frenzy of activity on the events front. We are looking forward to getting going! Our thanks to everyone at the National Lottery for their confidence in our project.

COMMUNITY FUND



HELP TO MAKE IT POSSIBLE

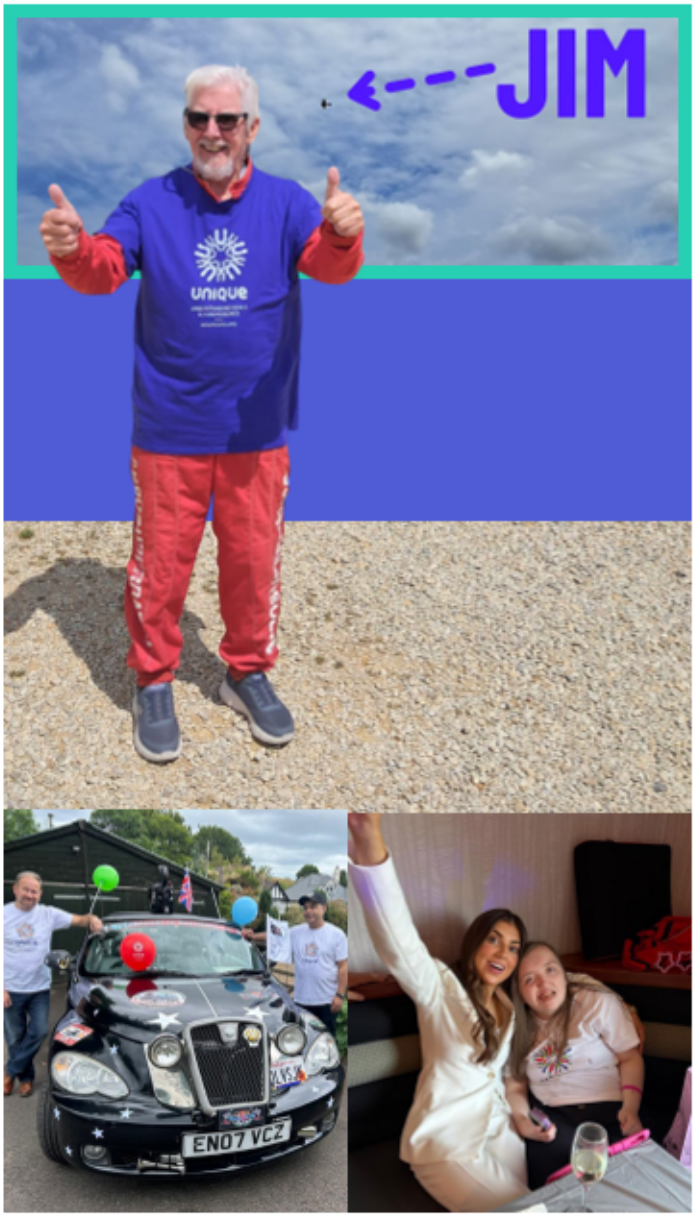
As always, our membership and their family and friends have continued to support us with their fundraising efforts throughout 2025-2026. Unique receives no government funding meaning we are reliant on the unrestricted funds raised by our amazing supporters in order to provide the services we offer. Our thanks to all those who have thrown themselves into marathons, tough mudders, inflatable courses, wacky car races, corporate events, bake sales and school fundraisers. Your efforts are much appreciated. We don't have the space here to mention everyone but here are a few examples of the fundraisers our supporters have done for us over the year:

116
amazing individual fundraisers

£141,221
raised by our fundraisers

2025/26 notable fundraisers

- Our five Paris Marathon runners raised £4.3k
- Our seven London Marathon runners raised £26k
- Member Geoff Bailey and his colleagues completed an amazing bike ride from London to Paris over a long weekend in June raising over £30k
- US based member Tara Barcia and her son's 'Dylan's 6p Dream Team' put on a wonderful fundraiser for the second year in a row, raising over £15k for Unique!
- Our 12 Great North Run runners raised £6.8k
- Jim Crosbie went on a wing walk for his 80th birthday and raised £1,590 (pictured right)
- Unique member and teacher Mitchell Horne ran two miles every day throughout June with the entire school joining him on their sports day for the final run. They raised £2,055 for Unique
- Charity of the Year for two years, London Business Interruption Association held 2 black tie dinners and a golf fundraiser for Unique during the 25/26 financial year, raising over £13k
- Sukee and Andy went on a Wacky Rally to Barcelona raising £2,323 (bottom left)
- Eric Lovatt's Supernova Walk raised £1.4k
- Karis Haining held a fundraiser as part of the Miss Glasgow competition raising £5.3k (bottom right)



Funders

In 2025/26 we received over £127k in grants from Charitable Trusts and Foundations. £30k of these grants were unrestricted while the rest were restricted to fund specific projects/events such as family days, our Birmingham conference, our information guides and the start of our Community Contacts project. We thank all our funders for their ongoing support of our work.

Website, marketing and awareness raising

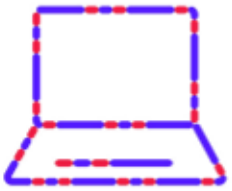
We're continuing to monitor monthly statistics, a few highlights from the 2025/26 financial year were:

Social media



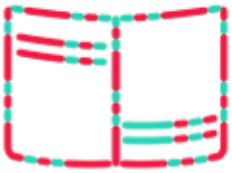
- **We reached 10k followers on Instagram, with 997 new followers this year**
- **On Facebook we gained 1.7 million views and recieved 2.3k followers**
- **Our National Non-Speaking Day post reached 39k accounts, the best performing post**

Website



- **Our website gained 457k page views with an average of 1.9 pages viewed per user**
- **Our Little Red Book page was viewed 5,656 times**
- **Our Disorder Guides page had 109k+ visits by 38k active users, the most viewed page on the website**

Newsletters and emails



- **We sent 527,232 member and support emails**
- **Our open rate for emails in this period was 46%**
- **Our newsletters gained 6,794 clicks**
- **Our most clicked items were our August 2025 magazine (725) and our Little Red Book (656)**

VOLUNTEERS AND PRO BONO SUPPORT

Unique wouldn't be able to support as many families as we do without the large number of volunteers who help us! These include hundreds of genetics specialists who give their time freely to write and/or review our condition specific information guides prior to publication. The list of volunteers this year is long!

- Havas Life London - Our grateful thanks for a very fruitful 2-year relationship which ended October 2025
- McGill Rare Collaboration – Thanks also to Bertille Hurel and her team for their work on guide translations, My Chromosome / Gene Story books for children and Easy Reads
- March 2026 Birmingham Conference Volunteers
  - a. Alzbeta Namesa, Alesha Butt, Emily Andersen, Sneha Banka and Ruby Allen
  - b. Videography - Matthew Robinson and assistant, Daniel Berrens
  - c. Photography - Marc and Isaac Lewell
  - d. The Lab staff from the West Midlands Genetics Lab: Katie Krygier, Zoe Borman, Mohammed Zaman, Rumina Begum, Jessie Desai, Shaima Mohammed and Daria Leszczynska
  - e. Clinical Geneticists Dr Karen Low, Prof. Sid Banka, Dr Derek Lim, Dr Lizzie Wall, Prof. Emma Baple, Dr Shwetha Ramachandrappa, Dr Neeta Lakhani and Genetic Counsellor Eleanor Nicholson.
  - f. Presenters Rosie Ashworth, Sibs, Philip Warford, Hayley Crawford, Prof. Angela Hassiotis and Dr Stephanie Yin
  - g. Education Specialists from AMA Ltd - Vickie Kottler and Michaela Eggleston
  - h. ERIC - Brenda Cheer

Thank you everyone!





- Keele University students - Emily Bradbury and Jevan Hundal who updated our welcome pack for new members and Jeremiah Uworuya who is producing a video showcasing the work of our helpline team
- Alesha Butt – for updating the West Midlands Resource list and preparing communications alongside our Engagement and Communications Officer
- Freya Sutcliffe, Isabelle Potts, Honna Roasoul, Alice Lo, Sameya Bakarow, Harriet Green, Flora Dyson, Aimee Oldacre and Elizabeth Claridge – all helped with survey analysis
- Anwar Nijm and Marwa Galal – helped with Arabic guide translations
- Marisa Pindoria, Abigail Owen, Natalie Winterbotham, Greta Fiore Melki, Selina Parveen and Daisy Taylor - for their assistance with Little Red Book summaries for social media posts
- Unique member Simon Jackson - helping us with the planning and spec for our planned database upgrade – an extremely significant project for us
- Unique member James Toop, an IT specialist and former Unique Trustee - assisting us with our database upgrade

Ruby Allen, a first-year PhD student at the University of Manchester studying RAC1-associated neurodevelopmental disorders, spent three months at Unique helping the Guide Team write and update guides, including the newly published guide on RAC1-associated neurodevelopmental disorders and updating our template guides. Her contribution was so valuable that we awarded her Unique's first Volunteer of the Year prize!



FINANCIAL REVIEW

Income

Income for the 2025/26 financial year came to £457,833, a drop of only 2% from the previous year in what was a much more difficult economic climate for small charities. Income from fundraising was down 20% on the 24/25 financial year showing the impact the cost of living has had on the number of fundraisers and donations to them, but an increased programme of grant applications including our successful bid for National Lottery funding for our community contacts project mitigated the reduction in that income stream. This does mean however that our unrestricted income, which we depend on to fund our core costs, amounted to a reduced figure of £359,548 (£397,168 24/25). £30,000 of this unrestricted income came from charitable trusts and foundations who also granted £95,708 in restricted funding for projects including in-person events in Kent and Northern Ireland as well as our March 2026 conference and funding for our new Community Contacts Project.

Expenditure

Expenditure for the year came to £445,846 which is an increase of 11% on the previous year, caused by our additional salary and overhead costs as well as our Birmingham conference, all of which was funded by restricted grants. Trustees and senior staff keep a close eye on our financial performance throughout the year, meeting regularly to assess the results against our annual budget. Our robust financial management procedures mean that we can continue to invest in staff resources and infrastructure to ensure long term sustainability in the face of ever-increasing demand.

Reserves

Our Reserves Policy for 2025/26 was to hold a minimum reserve equivalent to six months' average operating costs for the previous year. Trustees have also designated £40,000 each year towards the continuation of our helpline service. This means our reserves for the 2025/26 financial year need to equate to at least £224,875. Unrestricted reserves at the end of the year came to £311,610 with restricted funding carried forward to 2026/27 of £103,171. Whilst our reserves at the end of the year are high, Trustees are mindful of the need to update our reserves policy to include designating funds towards two large projects we are embarking on in 26/27, our new Membership Registry and the National Lottery Community Contacts projects. The reserves policy will be updated at our April 2026 Board meeting.

Future plans

We are continuing to work closely with Dendrite Clinical Systems Ltd on designing our new Membership Registry, ensuring the data we hold is secure and fit for purpose. This new registry will launch in the upcoming year.

We are also excited to get started with our Community Contacts project, hiring a new member of staff who will work towards ensuring our membership feel less isolated and more supported.

Finally, we are planning on piloting an appointment system on our helpline where members can book themselves in at a time convenient to them for support and assistance.

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. Sophie Sainty resigned as chair at the AGM in October 2025 and Helen Campbell was appointed as an Interim Chair. The intention is to recruit a new chair externally in the upcoming year. Cecely Hugh was appointed as Vice Chair at the same meeting.

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, Finance and Operations Manager, who is also Company Secretary.

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

Staff and Trustees are aware of the requirements of data protection law and have received training in this area to ensure that the sensitive medical and personal information of our members is protected. All Trustees and staff undergo regular DBS checks. Staff performance is kept under regular 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. The helpline team have supervision with Dr Stephanie Yin from Rareminds every two months.

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 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

Trustees decided that we should look to move to new independent examiners for the 2025/26 financial year in order to get a fresh look at our accounts as a safeguard against over-familiarity. They subsequently appointed David Howard Accountancy Limited as independent examiners to the charitable company at the AGM in October 2025. Trustees thank Godfrey Wilson Limited, for their invaluable support and advice over many years.

Approved by the trustees on 16 October 2026 and signed on their behalf by Helen Campbell - Trustee (Chair)



Helen Campbell
Chair of Trustees

APPENDIX

Presentations and talks

- St George's Hospital Genomics Day conference
- AGNC annual conference in Birmingham about Unique experiences from our survey
- University of Oxford - Public and Community Engagement 'Making It Personal' Theatre Engagement project
- Genetic Counselling Conference, Arizona
- Talk delivered as part of an Oxford meeting: The Discovery of ReNU Syndrome - cpm
- Presented to a team of social care workers, members of local authority, SENCO team and member family foster carers about genetic disorders, specifically 15q13.3 deletion and discuss our guide in detail to help support affected teenager
- Royal College of Paediatricians webinar (Genomics in Paediatrics) on Unique's work, guides, family support and awareness raising with paediatricians
- East Genomics paediatricians
- Taught on the in-person Ethics course for genetic counsellor trainees, Wales
- Genomics England Healthcare Tribe Away Day – presentation of the patient experience of rare condition diagnoses
- Scientiic Advisory Board (SAB) for the NIHR Manchester Biomedical Research Centre (BRC)
- ESHG Genetics Sounds podcast: The diary of a journal editor: voices, values and the vocabulary of science. Invited to be part of a panel discussing the importance of language
- ID consultants on their study day – presentation about Unique services
- Paradigm project research retreat, Cambridge
- Panel on Newborn Screening at the Curating the Clinical Genome meeting, Cambridge
- Chairing the DECIPHER Scientific Advisory Board meeting
- "Unique and ReNU" Presentation at the inaugral ReNU syndrome in NYC
- Clinical Genetics Department, GOSH
- Introduction to RSM: A practical guide to whole genome sequencing and its real world complexities
- The Genomics and Adults with ID conference, London
- Paediatricians Alder Hey Hospital
- RCPCH Genomics working group: Unique's work and case studies of how paediatricians have helped Unique families
- Amegreen Children's services: Talk to staff including therapists and therapeutic practitioners at a children's home regarding supporting 10-year-old put into their care with rare genetic disorders
- Warwickshire Specialist Teaching Services
- Progress Education Trust (PET) event: Rare Disease Genomic Testing: How Do We Make Access Equitable and Timely?
- UK Platform for Nucleic Acid Therapies (UPNAT) Symposium. London. Presentation of our collaboration with the node on a guide to the use of nucleic acid therapies
- Rare Summit 2025. Workshop on rare condition naming with Nicky Whiffin (scientist) and Dr Jon Roberts (genetic counsellor)
- The Unique Network. Presentation to MSc Genomic Medicine Students, Imperial College, London
- Public Genomics Cafe in Wrexham. Talk to North Wales families about Unique. Organised by Genetic Alliance UK
- Oxford Global Multiomics conference. Excel centre. Two panels
- Paediatric Genomics in 2025 – How to get the right test, at the right time, for the right child
- NHS Genomics Healthcare Summit. Panel discussing the new Clinical Genetics Service Spec
- Unique - supporting children with rare disorders and additional resources. Primary school, Swansea training event
- Presentation to Paediatricians. GOSH
- BSGM seminar: NHSE Clinical Genomics Service transformation programme update.

Presentations and talks (continued)

- Unique presentation at UoS MSc counselling module
- Genomic medicine clinical AI interest group webinar, delivered in collaboration with the Alan Turing Institute
- Teaching Brighton and Sussex Medical School's MDM160 Developmental Paediatrics
- Spotlight event 'genomics and the newborn'
- Genomics Leaders Breakfast, Excel, London
- Panel event at Festival of Genomics, London: Lived Experience of Medical Nomenclature
- Unique - supporting children with rare disorders and additional resources – presentation to children's residential home
- "Rare Diseases" presentation to Ashford and St Peter's Hospitals NHS Foundation Trust
- Midwifery genomics training course: Unique: the patient lived experience of rare chromosome and gene disorders
- Presentation to Specialist Teachers
- Presentation to Scientist Training Programme Genomic Counsellor Trainees
- Scotland GA-UK RDD reception
- Lunchtime presentation to St Peter's Hospital
- CPD Seminars - The patient perspective on Genomics testing and challenges
- Poster presentation: Information for All: Connecting People and Families Affected by Rare Conditions Across Languages
- BSGM lunch and learn: CGS transformation
- Presentation to UCL MS year 2 Genetics module - patient voice session
- Unique awareness raising presentation to specialist school and teachers
- Unique awareness raising presentation to specialist school and teachers in Wales
- Preconception Precision Health: Integrating Genomics for Optimised Maternal Outcomes

Unique Board positions

Strategy/Advisory Boards

- PPV rep on the NHSE Genomics Clinical Reference Group (CRG)
- DECIPHER Data Access Policy Group
- DDD Data Access Policy Group
- RDUK's Patient Empowerment Group (PEG)
- NHS GMS People and Communities Forum
- England Rare Diseases Action Plans Patient Advisory Group (PAG)
- Manchester Rare Conditions Centre Advisory Board
- Joint Committee on Genomics in Medicine
- Scientific Advisory Board, NIHR Manchester Biomedical Research Centre (BRC)
- External Strategic Advisory Board for the NIHR Exeter Biomedical Research Centre (BRC)
- Eurordis JARDIN Undiagnosed Multistakeholder Task Force
- Clinical Genomics Service Specification Working Group
- Medicines, (MHRA) newly formed Rare Disease Consortium
- Advancing Research Global Consortium Formation Steering Committee
- OpalMedica Advisory Board
- MRC CoRE in Therapeutic Genomics Strategic Advisory Board
- Shaping a future framework steering group (developing the new Rare Disease action plan)
- Mainstreaming GCs group
- Midwifery in Genetics and Genomics (MIGG)

Unique research project advisory board/partnerships:

- Genomics England Conditions Framework working group (Newborn Genomes Programme)
- Chromosome 6 Project. Prof. Conny Ravenswaaij-Arts (Netherlands)
- Evaluating rapid genomic sequencing for critically ill children. Dr Melissa Hill (UCL)
- Genomics England's Generation Study Evaluation Advisory Group (led by Dr Celine Lewis, UCL)
- Co-production in rare genetic disorders: digital interventions for childhood disruptive behaviour and anxiety. Dr Jeanne Wolstencroft, ICH
- Rare Disease Node: Ethical, legal and social issues (ELSI) in rare conditions research and clinical practice. Angus Claire (Cardiff) Ramona Moldovan (Manchester), Anneke Lucassen (Oxford)
- Rare Disease Node: Epigenomics of Rare Diseases Node. Siddharth Banka (Manchester).
- Rare Disease Network of Excellence: Rare and Inherited Disease
- Research supervision. 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. (with Prof Marianne van der Bree, Cardiff University)
- European Network on ethics in Psychiatric Genetics (ENEPG)
- Advisory Group: Prenatal screening and therapies (Led by Dr Melissa Hill, UCL)
- Advisory Group: Equity in Genomics (Led by Hannah McInnes-Dean, ARC)
- Advisory Board: Genomics AI Network (GAIN) project
- Networking Support Scheme in the European Joint Programme on Rare Diseases (Netherlands): Evaluated applications and consensus meetings
- PREGCARE project (University of Oxford, UK): Unique liaison
- PGT-M surveys (GA-UK): Unique liaison
- ENRICH study: In collaboration with UCL (Claire is on the advisory board)
- GENROC study (Karen Low, Bristol)
- University of Manchester/Shorthills AI project to assess the ability of AI to help generate patient information guides

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

Company registration number 05460413 (England and Wales)

Charity registration number 1110661 (England and Wales)

RARE CHROMOSOME DISORDER SUPPORT GROUP

ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2026

RARE CHROMOSOME DISORDER SUPPORT GROUP

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Helen Elizabeth Campbell James Edward Lucas Cecely Hugh Shwetha Ramachandrappa Ben Stern Fiona Catherine Fulton DE Zoete Edna Margaret Knight MBE Sophie Priscilla Sainty	
Country of incorporation	United Kingdom (England and Wales)	05460413
Charity registration	England and Wales	1110661
Registered office	Unique The Stables Station Road West Oxted Surrey United Kingdom RH8 9EE	
Independent examiner	Siobhan Glenister, FCA 5 The Square Bagshot Surrey United Kingdom GU19 5AX	

RARE CHROMOSOME DISORDER SUPPORT GROUP

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Balance sheet	3 - 4
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RARE CHROMOSOME DISORDER SUPPORT GROUP

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF RARE CHROMOSOME DISORDER SUPPORT GROUP

I report to the trustees on my examination of the financial statements of Rare Chromosome Disorder Support Group (the charity) for the year ended 31 March 2026.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law), you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006.

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

Independent examiner's statement

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

I have completed my examination. I confirm that no 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 charity as required by section 386 of the Companies Act 2006.

2 the financial statements do not accord with those records; or

3 the financial statements do not comply with the accounting requirements of section 396 of the Companies Act 2006 other than any requirement that the financial statements give a true and fair view, which is not a matter considered as part of an independent examination; or

4 the financial statements 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 financial statements 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 financial statements to be reached.



Siobhan Glenister, FCA
5 The Square
Bagshot
Surrey
GU19 5AX
United Kingdom
Date: 16 / 10 / 2026

RARE CHROMOSOME DISORDER SUPPORT GROUP

STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)

FOR THE YEAR ENDED 31 MARCH 2026

	Notes	Unrestricted funds 2026 £	Restricted funds 2026 £	Total 2026 £	Total 2025 £
Income from:					
Donations and legacies	**3**	331,723	2,577	334,300	388,038
Charitable activities	**4**	20,966	95,708	116,674	71,579
Investments	**5**	6,859	-	6,859	7,575
Total income		359,548	98,285	457,833	467,192
Expenditure on:					
Charitable activities					
Raising funds	**6**	54,879	-	54,879	68,393
Information and awareness	**6**	190,386	14,857	205,243	181,725
Family support	**6**	130,602	55,122	185,724	152,082
Total charitable expenditure		375,867	69,979	445,846	402,200
Total expenditure		375,867	69,979	445,846	402,200
Net income/(expenditure)		(16,319)	28,306	11,987	64,992
Net movement in funds		(16,319)	28,306	11,987	64,992
Reconciliation of funds:					
Total funds brought forward		327,929	74,865	402,794	337,802
Fund balances at 31 March 2026		311,610	103,171	414,781	402,794

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

RARE CHROMOSOME DISORDER SUPPORT GROUP

BALANCE SHEET

AS AT 31 MARCH 2026

	Notes	2026		2025	
		£	£	£	£
Fixed assets					
Intangible assets	**11**		18,000		-
Tangible assets	**12**		5,475		2,103
Investments	**13**		4,000		4,000
			27,475		6,103
Current assets					
Stocks	**14**		13,501		8,288
Debtors	**15**		53,783		15,619
Cash at bank and in hand			337,250		389,984
			404,534		413,891
Creditors: amounts falling due within one year	**16**	(17,228)		(17,200)	
Net current assets			387,306		396,691
Total assets less current liabilities			414,781		402,794
The funds of the charity					
Restricted income funds	**17**		103,171		74,865
Unrestricted funds	**18**		311,610		327,929
			414,781		402,794

RARE CHROMOSOME DISORDER SUPPORT GROUP

BALANCE SHEET (CONTINUED)

AS AT 31 MARCH 2026

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2026.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 16 / 10 / 2026



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Helen Elizabeth Campbell

Trustee

1 Accounting policies

Charity information

Rare Chromosome Disorder Support Group is a private company limited by guarantee incorporated in England and Wales. The registered office is Unique, The Stables, Station Road West, Oxted, Surrey, RH8 9EE, United Kingdom.

1.1 Basis of preparation

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)". The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a statement of cash flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

1 Accounting policies **(Continued)**

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

1.5 Expenditure

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

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

1.6 Intangible fixed assets other than goodwill

The Company has capitalised costs of £18,000 in respect of the development of a database. These costs are recognised as an intangible asset where the relevant recognition criteria under FRS 102 are met.

The database remains under development at the reporting date and is not yet available for use. Accordingly, no amortisation has been charged in the current year. Amortisation will commence when the database is complete and available for its intended use, over its estimated useful economic life.

The intangible asset is reviewed for indicators of impairment at the reporting date and, where appropriate, an impairment assessment is undertaken in accordance with FRS 102.

1.7 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Computers	4 years straight line

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.8 Fixed asset investments

Fixed asset investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

1 Accounting policies **(Continued)**

1.9 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.10 Stocks

Stocks are stated at the lower of cost and estimated selling price less costs to complete and sell. Cost comprises direct materials and, where applicable, direct labour costs and those overheads that have been incurred in bringing the stocks to their present location and condition. Items held for distribution at no or nominal consideration are measured the lower of replacement cost and cost.

Net realisable value is the estimated selling price less all estimated costs of completion and costs to be incurred in marketing, selling and distribution.

1.11 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.12 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

1 Accounting policies **(Continued)**

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.13 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated 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 where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Income from donations and legacies

	Unrestricted funds 2026 £	Restricted funds 2026 £	Total 2026 £	Total 2025 £
Donations and gifts	331,723	2,577	334,300	388,038

3 Income from donations and legacies (Continued)

	Unrestricted funds 2026 £	Restricted funds 2026 £	Total 2026 £	Total 2025 £
Donations and gifts				
Grants more than £5,000: Dorothy Hay-Bolton Charitable Trust	-	-	-	9,000
DJ Hunter Charitable Trust	10,000	-	10,000	-
The Hamilton Wallace Trust	10,000	-	10,000	-
Grants £5,000 or less	10,000	-	10,000	16,750
Donations from fundraising activities	156,441	845	157,286	206,866
General donations	57,819	1,732	59,551	50,130
Gift aid	27,302	-	27,302	42,793
Overseas donations	43,331	-	43,331	15,249
Corporate donations	12,856	-	12,856	19,398
Gifts in kind	2,000	-	2,000	5,000
Legacies	-	-	-	20,800
Give As You Earn (GAYE)	1,496	-	1,496	1,520
Pyramids	477	-	477	532
	331,723	2,577	334,300	388,038

4 Income from charitable activities

	Unrestricted funds 2026 £	Restricted funds 2026 £	Total 2026 £	Total 2025 £
Charitable activities: family support services				
Jeans 4 Genes	-	19,923	19,923	-
National Lottery Reaching Communities	-	29,362	29,362	-
Awards for All	-	8,200	8,200	35,181
Grants £5000 or less	-	20,850	20,850	11,550
Charitable activities: information and awareness				
Christmas card and merchandise sales	12,898	-	12,898	8,833
Conference fees	1,500	-	1,500	2,177
Other income	6,568	-	6,568	288
Grants £5000 or less		17,373	17,373	13,550
	20,966	95,708	116,674	71,579

5 Income from investments

	Unrestricted funds 2026 £	Unrestricted funds 2025 £
Interest receivable	6,859	7,575

6 Expenditure on charitable activities

	Raising funds	Information and awareness	Family support	Total	Total
	2026	2026	2026	2026	2025
	£	£	£	£	£
Direct costs					
Staff costs	23,313	135,591	84,908	243,812	236,943
Depreciation and impairment	150	1,005	983	2,138	2,340
Advertising	-	-	-	-	800
Computer expenses	493	3,318	3,247	7,058	8,587
Event costs	-	-	37,017	37,017	13,078
Office costs and rent	1,778	12,851	13,557	28,186	23,589
Postage and distribution	86	10,277	748	11,111	9,869
Printing and design	647	863	159	1,669	3,715
Professional fees	10,284	183	826	11,293	13,729
Project costs	-	175	150	325	5,000
Stationery	89	368	1,127	1,584	809
Subscriptions, licences and charges	12,715	6,200	908	19,823	22,086
Training and other staff costs	115	740	1,199	2,054	489
Travel and subsistence	74	1,261	5,376	6,711	1,893
Website and database development	300	-	1,798	2,098	2,848
Donated Services	-	-	2,000	2,000	-
	50,044	172,832	154,003	376,879	345,775
Share of support and governance costs (see note 7)					
Support	4,608	30,888	30,231	65,727	56,425
Governance	227	1,523	1,490	3,240	-
	54,879	205,243	185,724	445,846	402,200

6 Expenditure on charitable activities (Continued)

Analysis by fund					
Unrestricted funds	54,879	190,386	130,602	375,867	370,813
Restricted funds	-	14,857	55,122	69,979	31,387
	54,879	205,243	185,724	445,846	402,200

7 Support costs allocated to activities

	Support and governance 2026 £	Total 2025 £
Staff costs	60,399	47,542
Insurance	1,933	1,851
Office costs and rent	156	312
Professional fees	1,843	3,126
Subscriptions, licences and charges	34	34
Traning and other staff costs	1,094	625
Travel and subsistence	267	79
Computer expenses	-	36
Governance	3,240	2,820
	68,966	56,425

Governance costs comprise:	2026 £	2025 £
Independent examination fee	3,240	2,820
	3,240	2,820

8 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

9 Employees

The average monthly number of employees during the year was:

	2026 Number	2025 Number
	9	9

Employment costs	2026 £	2025 £
Wages and salaries	304,211	284,485

There were no employees whose annual remuneration was more than £60,000.

Remuneration of key management personnel
The remuneration of key management personnel was as follows:

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 £112,499 (2025: £111,866).

10 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

11 Intangible fixed assets

	Software £
Cost	
At 1 April 2025	-
Additions - internally developed	18,000
At 31 March 2026	18,000
Amortisation and impairment	
At 1 April 2025 and 31 March 2026	-
Carrying amount	
At 31 March 2026	18,000
At 31 March 2025	-

12 Tangible fixed assets

	Computers £
Cost	
At 1 April 2025	12,972
Additions	5,510
Disposals	(4,230)
At 31 March 2026	14,252
Depreciation and impairment	
At 1 April 2025	10,869
Depreciation charged in the year	2,138
Eliminated in respect of disposals	(4,230)
At 31 March 2026	8,777
Carrying amount	
At 31 March 2026	5,475
At 31 March 2025	2,103

13 Investments

	£
Cost or valuation	
At 1 April 2025 & 31 March 2026	4,000
Carrying amount	
At 31 March 2026	4,000
At 31 March 2025	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 2026.

14 Stocks

	2026 £	2025 £
Merchandise	13,501	8,288

15 Debtors

Amounts falling due within one year:	2026 £	2025 £
Trade debtors	2,268	152
Accrued income	44,418	7,192
Prepayments	7,097	8,275
	53,783	15,619

16 Creditors: amounts falling due within one year

	2026 £	2025 £
Other taxation and social security	9,288	6,628
Trade creditors	282	3,500
Accruals and deferred income	7,658	7,072
	17,228	17,200

17 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 April 2025 £	Incoming resources £	Resources expended £	Transfers £	At 31 March 2026 £
Family support services	14,112	79,868	(51,506)	-	42,474
Information and awareness	2,000	18,357	(14,857)	-	5,500
Database project	38,872	60	-	-	38,932
Careers of Adults Outreach Project	19,881	-	(3,616)	-	16,265
	74,865	98,285	(69,979)	-	103,171

Previous year:	At 1 April 2024 £	Incoming resources £	Resources expended £	Transfers £	At 31 March 2025 £
	-	26,850	-	-	26,850
Family support services	11,629	-	(24,367)	-	(12,738)
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
	37,842	70,024	(31,387)	(1,614)	74,865

17 Restricted funds **(Continued)**

Purpose 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 valuable information provided by members about their families' rare chromosome or gene disorders and the impact of these conditions. The database has enabled Unique to produce chromosome disorder guides and to match new members with families experiencing similar conditions.

The existing database is no longer fit for purpose, and Unique has been fundraising to develop a new database with the capacity to support the charity's work for many years to come.

During the 2025/26 financial year, Unique partnered with Dendrite Clinical Systems, a global leader in the design of clinical databases and registry systems, and commenced the detailed design and development of a new registry system. £18,000 was incurred during the year in respect of the New Registry Software Package and has been capitalised as an intangible fixed asset in accordance with the charity's accounting policies. This expenditure was funded from the restricted Database Project fund and, accordingly, an equivalent balance of the restricted fund is represented by the related intangible fixed asset at the year end. The development of the new registry is expected to be completed and launched during the coming year. Once the software is completed and brought into use, the cost of the asset will be amortised over its estimated useful economic life and the related amortisation charge will be recognised as expenditure against the restricted Database Project fund, resulting in a corresponding reduction in the restricted fund balance over time.

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). This project involves setting up a working group with 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 is better understand the needs of this section of our community and develop more long-term support for families throughout their journey, not at the point of diagnosis.

Family Days

The purpose of the Family Days project is to provide families and carers affected by rare genetic and chromosomal conditions with opportunities for peer support, education and access to specialist advice. The project enables families to meet in a safe and inclusive environment, share experiences, build supportive networks and access information from relevant healthcare, genetics and education professionals.

18 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2025	Incoming resources	Resources expended	Transfers	At 31 March 2026
	£	£	£	£	£
Listening Ear Fund	40,000	-	-	-	40,000
General funds	287,929	359,548	(375,867)	-	271,610
	327,929	359,548	(375,867)	-	311,610

Previous year:	At 1 April 2024	Incoming resources	Resources expended	Transfers	At 31 March 2025
	£	£	£	£	£
Listening Ear Fund	40,000	-	-	-	40,000
General funds	259,960	397,168	(370,813)	1,614	287,929
	299,960	397,168	(370,813)	1,614	327,929

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.

19 Analysis of net assets between funds

	Unrestricted funds 2026 £	Restricted funds 2026 £	Total 2026 £
At 31 March 2026:			
Intangible fixed assets	-	18,000	18,000
Tangible assets	5,475	-	5,475
Investments	4,000	-	4,000
Current assets/(liabilities)	302,135	85,171	387,306
	311,610	103,171	414,781

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £
At 31 March 2025:			
Tangible assets	2,103	-	2,103
Investments	4,000	-	4,000
Current assets/(liabilities)	321,826	74,865	396,691
	327,929	74,865	402,794

20 Related party transactions

During the year the charity received donations from trustees, related charitable trusts of the trustees, and key management totalling £12,740 (2025: £6,427). No amounts were outstanding at the year end.

Year end: 31st March 2026
Author: Unique, The Rare Chromosome and Gene Disorder Support Group

Unique
UNDERSTANDING GENES & CHROMOSOMES