UNIQUE

UNDERSTANDING GENES
& CHROMOSOMES

Building a Unique Future

Improving outcomes for rare chromosome and gene disorder families

Strategy 2026 - 2030

Contents

Executive Summary

This strategy details how Unique will work over the next 5 years to meet our commitments in our 2025 report 'Unique Experiences: Living with a Rare Chromosome or Gene Disorder'.

Strategic aim:

Unique will be a strong and visible voice for everyone affected by rare chromosome and gene disorders.

Objectives:

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

1.1 Develop national and international partnerships and collaborations that increase recognition of rare chromosome and gene disorders (RCGDs) and their impact on families.

1.2 Highlight the scale and diversity of the RCGD community so families are visibly and accurately represented.

1.3 Create opportunities for families to share lived experiences to build empathy and understanding.

2. Influence policy & drive system change to secure fair and proportionate recognition of RCGDs.

2.1 Engage parliamentarians, policymakers, and key national bodies and local services to secure equitable attention, investment, and provision for RCGD families.

2.2 Increase the representation of RCGDs in national strategies, research agendas, and service planning.

2.3 Ensure lived experience of RCGDs informs policy discussions and decision-making and is embedded in research and clinical settings.

3. Improve our membership and services to reflect the needs and diversity of the RCGD community.

3.1 Facilitate peer connections and broaden our outreach to under-represented and under-served groups in the RCGD community.

3.2 Expand and develop our information offer to ensure as many families as possible have access to guidance that is relevant and appropriate for them.

3.3 Build our team capacity and ensure our services are shaped by the varied needs across the RCGD community so they are relevant and responsive.

4. Invest in our organisation so we remain robust and able to deliver our strategic aims.

4.1 Invest in our team to increase our capacity and work effectively.

4.2 Ensure strong financial management and reserve use.

4.3 Deliver effective governance through timely meetings, policy reviews and regulatory compliance.

Strategy background

'UNIQUE EXPERIENCES: LIVING WITH A RARE CHROMOSOME OR GENE DISORDER'

Our 2025 report, 'Unique Experiences: Living with a Rare Chromosome or Gene Disorder' shared the findings from our recent consultation exploring the experiences of families and individuals affected by rare chromosome and gene disorders. The survey received 2,154 completed and 538 partial responses, alongside insights gathered through focus and feedback groups, social media discussions and case studies. The findings revealed a complex picture of resilience, grief, stress, strength and struggle.

THE KEY FINDINGS FROM THE REPORT WERE:

1. Lack of awareness and information about rare chromosome and gene disorders creates significant stress.
2. Rare chromosome and gene disorders affect every aspect of daily life.
3. Individuals and families feel isolated.
4. Advocacy is not always valued or a choice.

BASED ON THESE FINDINGS, WE MADE A COMMITMENT THAT OVER THE NEXT FIVE YEARS WE WILL:

Invest in our team to increase our outreach and influencing capacity and develop a strategy to increase the visibility of rare chromosome and gene disorders at a local, national and international level.

Develop new information and advocacy resources to empower our members to educate and raise awareness of rare chromosome and gene disorders in their local areas or countries.

Work with our international partners in the genomics community to embed understanding of lived experience of rare chromosome and gene disorders in research and clinical settings.

Engage with policy makers to ensure rare chromosome and gene disorders are equally represented alongside more well-known conditions such as Down's syndrome and autism spectrum disorders.

Run a targeted education and outreach programme in the UK to increase awareness, diversity, inclusion, understanding and representation of rare chromosome and gene disorders within Unique membership but also throughout health, education and social care. We hope the findings can be employed and rolled out around the world.

Our strategic aims and objectives

This strategy details how we will work to meet the commitments made in our 'Unique Experiences: Living with a Rare Chromosome or Gene Disorder' report . It has been co-designed by our Board of Trustees and staff team looking at what we already do well, where we can improve and what our priority areas for growth over the next 5 years.

AIM: BY 2030 UNIQUE WILL BE A STRONG AND VISIBLE VOICE FOR EVERYONE AFFECTED BY RARE CHROMOSOME AND GENE DISORDERS.

To achieve this, these are our objectives:

1. Increase recognition and visibility of RCGDs so families feel seen, supported, and fully included in wider conversations about disability and genetic conditions.
2. Influence policy and drive system change to secure fair and proportionate recognition of RCGDs.
3. Improve our membership and services to reflect the needs and diversity of the RCGD community.
4. Invest in our organisation so we remain robust and able to deliver our strategic aims.

Our work falls into 3 interrelated pillars which will underpin this strategy:

Inform

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

Information enables connection

Networking & support

We support 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.

Connection through networking and support builds collective voice

Advocacy

We actively support, promote and participate in research, training, and policy activities that can improve the lives of our community.

Collective voice strengthens our advocacy to embed lived experience to improve access to information and services

Objective 1:

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

Despite 1 in 150 babies born in the UK being impacted by a rare chromosome or gene disorder, RCGD families often feel invisible compared to families affected by Autism Spectrum Disorders or Down's syndrome when trying to access support, information and services. They are not represented in broader disability discussions and there is low public, professional and political awareness of the impact RCGDs have on the life chances of affected individuals and their families.

1.1 Develop national and international partnerships and collaborations that increase recognition of RCGDs and their impact on families.

1.2 Highlight the scale and diversity of the RCGD community so families are visibly and accurately represented.

1.3 Create opportunities for families to share lived experiences to build empathy and understanding.

OUR WORK TO MEET THIS OBJECTIVE WILL INCLUDE:

Networking with RCGD condition specific groups, national organisations/alliances, charities, professional bodies.

Education and awareness raising amongst professionals (genetic and non-genetic) through presentations, conferences, workshops and dedicated materials.

Reviewing and refreshing our comms content (website, magazine, videos).

WAYS WE WILL MEASURE OUR IMPACT WILL INCLUDE:

- Tracking public, professional and political references to rare chromosome and gene disorders.
- How many people report improved understanding of RCGDs after hearing our member's lived experiences.
- RCGD families report improvements in professionals understanding of RCGDs.

Objective 2:

Influence policy and drive system change to secure fair and proportionate recognition of RCGDs

RCGDs often encounter barriers to receiving the support and services they are entitled to. At a policy level they are also being excluded and marginalised from legislation, such as the new Down Syndrome Bill that will create inequitable support for the Downs' community despite many individuals with RCGDs having similar symptoms and support needs.

2.2 Engage parliamentarians, policymakers, and key national bodies and local services to secure equitable attention, investment, and provision for RCGD families.

2.3 Increase the representation of RCGDs in national strategies, research agendas, and service planning.

2.4 Ensure lived experience of RCGDs informs policy discussions and decision-making and is embedded in research and clinical settings.

OUR WORK TO MEET THIS OBJECTIVE WILL INCLUDE:

Establishing a role for Unique in the public policy arena (UK specific) and identifying areas where our advocacy is necessary.

Support national and international policy development by providing evidence-based advocacy, including letters of support, informed by the voices and experiences of people with lived experience of RCGDs.

Participating in advisory boards/groups and policy/consultation responses.

Build the capacity of Unique members to become confident and effective advocates for their communities

WAYS WE WILL MEASURE OUR IMPACT WILL INCLUDE:

- Examples of tangible benefit for the RCGD community because of our advocacy activities, including RCGD families participating in the political process.
- Evidence of understanding/awareness of RCGDs appearing in strategies, decisions, or frameworks and/or equitable provision for RCGD people and families.

Objective 3:

Improve our membership and services to reflect the needs and diversity of the RCGD community

We currently have over 32,000 people and families in over 100 countries who we support through our helpline, listening ear and family matching service, information guides and online forum. For many families we are a lifeline as they try to process the trauma of a diagnosis of rare chromosome or gene disorder. From our recent consultation however, we know there is more we can do to ensure that everyone who requires our information and support can do so in a way that is best suited to their needs.

3.1 Facilitate peer connections and broaden our outreach to under-represented and under-served groups in the RCGD community.

3.2 Expand and develop our information offer to ensure as many families as possible have access to guidance that is relevant and appropriate for them.

3.3 Ensure our services are shaped by the varied needs across the RCGD community so they are relevant and responsive.

OUR WORK TO MEET THIS OBJECTIVE WILL INCLUDE:

Work with our Members Engagement Committee to clarify our membership offer for specific cohorts of our membership (including international families, carers of adults, affected individuals and siblings).

Review and refresh our information provision to increase our information outputs across varied topics and formats.

Map and monitor our membership demographics and partner with other organisations specialising in diversity and inclusivity.

WAYS WE WILL MEASURE OUR IMPACT WILL INCLUDE:

- Number of members reporting finding it easy to make contact with other RCGD families.
- Membership and engagement rates from under-represented groups.
- How many time our information is accessed and from where.

Objective 4:

Invest in our organisation so we remain robust and able to deliver our strategic aims

Unique is a small but ambitious Surrey, UK based charity. We have robust financial management procedures, and our 8 Trustees (7 of whom have personal lived experience of RCGDs are very involved in the running of the charity). Our dedicated and committed staff team works closely with the RCGD community, with some members having been actively involved for around 20 years. For our organisational size we already achieve a lot, but we know to achieve even more we must continue to review our ways of working and ensure any growth is sustainable.

4.1 Invest in our team to increase our capacity and work more effectively.

4.2 Ensure strong financial management.

4.3 Deliver effective governance through timely meetings, policy reviews and regulatory compliance.

OUR WORK TO MEET THIS OBJECTIVE WILL INCLUDE:

Commissioning a new database to host our members registry to support delivery of our services and monitoring data for effective fundraising.

Developing our team's expertise through a skill's audit and development plans.

WAYS WE WILL MEASURE OUR IMPACT WILL INCLUDE:

- Monitoring staffing and trustee levels and skills so they remain sufficient to meet organisational demands.
- Annual expenditure remaining in line with income, supported by a diverse mix of income streams to avoid structural deficits.
- Core governance duties are completed on time each year.

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