



2022-2025 STRATEGY

Introduction

Genetic Disorders UK became Gene People in June 2021. This was not just a change of name. It marked a renewed commitment to reaching out to individuals and families living with unmet needs arising from a rare genetic condition, directly through our unique genetic counsellor-led helpline and by the provision of information and support, and indirectly by building the capacity of the organisations supporting those with identified rare genetic conditions who belong to our Partnership Network. Part of our strength comes from working for those with many conditions, being able to see shared experiences and reflecting those to decision-makers.

We will achieve our ambitions through collaboration with others where appropriate. We will be robust in our advocacy and not hesitate to speak truth to power when necessary.

This document sets out our strategy for the next three years. We invite you to join with us and help to bring these ambitions to fruition, and in so doing improve the lives of those living with rare genetic conditions, their families and all those who care for them.

Our History

This strategy marks Gene People's first anniversary. While we have many years of working as Genetic Disorders UK, the past year has seen a refreshed focus on our core objectives. It is the ideal time to launch our new three-year strategy.

Gene People is building on the foundations already laid. We have started to improve our unique genetic counsellor-led helpline and reviewed our web resources. The Gene People Partnership Network of condition-specific support groups is expanding, and the benefits of the free membership are broadening. We have significantly increased our advocacy through responses to national consultations.

We know that we can make a difference. We will do this by working collaboratively and by avoiding duplicating what others are already doing. There is much that needs to be done. Join us in this exciting new part of our journey.

Together, we are Gene People.

Our strategy on a page

Our Vision

Our vision is that anyone affected by a genetic condition receives the support and information they need at the time they need it and in a form they can use.

Our Values

- Inclusive
- Collaborative
- Relevant
- Transparent
- Recognisable
- Trustworthy

Strategic Pillar 1 Support and Information

Aims

- Expand services
- Increase awareness
- Demonstrate service and quality

Strategic Pillar 2 Strengthening condition-specific support groups

Aims

- Develop offer
- Expand range of members
- Explore condition-specific groups to the public, industry and regulators

Strategic Pillar 3 Advocacy and Collaboration

Aims

- Consultations response
- Strengthen networks
- Strategic partnerships and projects

Enabler 1: Income Generation

- Expand community and individual giving fundraising
- Initiate Legacy and in memory giving
- Develop digital fundraising
- Strengthen Trusts relationships
- Develop corporate opportunities
- Explore new opportunities for generating our own income

Enabler 2: Infrastructure

- Refresh IT and focus on efficiency
- Refresh website to be more user-friendly
- Continue to improve communications with our Partnership Network, supporters and partners

Our Vision

Gene People exists to improve the lives of those affected by genetic conditions. Our vision is that anyone affected by a genetic condition receives the support and information they need at the time they need it and in a form they can use.

We work towards this by focusing on three pillars:

- Pillar 1: Support and Information
- Pillar 2: Strengthening condition-specific support groups and organisations
- Pillar 3: Advocacy and Collaboration.

Our Values

- **Inclusive:** We will ensure that our services represent the breadth of the genetic conditions community and are accessible to all.
- **Transparent:** We are clear about what we do, why we do it and how, sharing when we make mistakes and what we have learnt from them.
- **Collaborative:** We work in partnership with others, building strong relationships with a range of partners to achieve the best for our community.
- **Recognisable:** We have a distinct place in the genetic conditions field and will ensure that we do not duplicate effort, maintaining our own area of expertise.
- **Relevant:** We will keep ahead of the curve in this fast-moving field to make sure all we do is relevant to everyone affected by genetic conditions.
- **Trustworthy:** We will prove we are trustworthy by being transparent, inclusive and collaborative to a community that can sometimes feel let down.

Our People

Gene People is led and governed by a Board of Trustees who are all volunteers. They bring a wide range of expertise and skills to the charity, including lived experience of genetic conditions. They set the strategic direction for Gene People, manage risks, and ensure Gene People is well-governed.

The Gene People team is small and ambitious for our community. The start of the strategy sees a team of three in place: the CEO, one Genetic Counsellor and the Trusts and Individual Giving Manager. The team will gradually increase over the course of the strategy.

Our Strategy

The strategy was formulated with input from our Partnership Network Advisory Panel, our Trustees and our staff team. We are grateful for everyone's input.

Pillar 1: Support and Information

Our Goal

We know that high quality, trustworthy support and information can be hard to find by those with genetic conditions and those who work with them. Our goal is to provide support and information in a range of ways that are accessible to as many people as possible, including health care professionals. We run a unique genetic counsellor-led helpline for anyone in the UK affected by any rare genetic condition, and publish web resources.

Our Aims

We will achieve our goal through the following aims:

1. Expand the range of our information services
2. Increase awareness of our services in all parts of the genetic conditions' community
3. Seek ways of demonstrating that our services are meeting the need expressed by our users and are of high quality.

How we will do this

- Refresh web resources so they are up-to-date
- Publish refreshed Directory of Condition-specific support groups and organisations
- Explore creating accessible and relevant information for younger audiences paying attention to how they get their information
- Develop and implement a UK-wide marketing strategy
- Launch the Helpline translation service to the public
- Explore health care professionals' needs as genetics is embedded in the wider NHS
- Explore and work towards relevant external accreditation standards and awards
- Recognise and increase the diversity of our service users and ensure our materials are accessible to and appropriate for a wide range of people

Pillar 2: Strengthening condition-specific support groups and organisations

Our Goal

Condition-specific groups and organisations come in all shapes and sizes. All are experts in their own conditions. All are vital to those with genetic conditions and their families. Our goal is to strengthen them and build their resilience so they can support their communities.

Our Aims

We will achieve our goal through the following aims:

1. Continue to develop the services we offer to the members of the Gene People Partnership Network
2. Expand the range of organisations who are members of the Gene People Partnership Network
3. Explore ways to explain condition-specific support groups and organisations to the public, industry and regulators.

How we will do this

- Marketing campaign to non-members of the Partnership Network
- Develop new services identified by the Partnership Network and the Partnership Network Advisory Panel
- Hold regular webinars on a range of topics for the Network
- Hold the Leadership Symposium
- Develop materials about condition-specific support groups for all audiences
- Explore ways to celebrate and raise awareness of the work of condition-specific support groups
- Support individual organisations with specific projects and campaigns
- Partner with organisations supporting those under-represented in health care

Pillar 3: Advocacy and Collaboration

Our Goal

We seek to amplify the voices of those who find it hard to be heard, both as individuals and organisations. We work collaboratively as we believe that this makes us stronger. Our goal is to increase our advocacy and deepen our collaborations.

Our Aims

We will achieve our goal through the following aims:

1. Respond to consultations on national policy initiatives
2. Maintain and strengthen Gene People's networks
3. Participate in strategic partnerships and projects.

How we will do this

- Launch the Gene People Partnership Network Advisory Panel
- Strengthen our advocacy for individuals in collaboration with conditions specific groups and NHS
- Launch the Gene People Corporate Connection and develop its programme of work
- Continue participating in key partnerships such as ARDEnt, Breaking Down Barriers, and the Pharma Insight Group
- Submit responses to consultations with input from our Partnership Network where possible
- Contribute to wider strategic partnerships e.g. SHCA and Disabled Children's Partnership
- Represent our community at conferences and events and share those opportunities with our Partnership Network
- Contribute to the success of Rare Disease Day

Enablers

We will not be able to achieve our ambitions without a strong foundation. For the coming three years there are two key enablers that require attention.

Enabler 1: Income generation

Funding is the fuel that keep Gene People working. We are enormously grateful to everyone – individuals, trusts, corporate supporters – who support our work. Our aim is to have sustainable, diversified income sources.

We will

- Expand our community and individual fundraising programme
- Initiate legacy and in memory giving
- Develop digital fundraising opportunities
- Strengthen our relationships with trusts
- Offer corporate supporters a range of opportunities to support our work
- Explore opportunities for earning our own income.

Enabler 2: Infrastructure

To be effective, efficient and compliant, Gene People needs strong infrastructure. Our aim is to have reliable and efficient systems and devices, and strong and user-friendly communications.

We will

- Refresh our IT hard- and soft-ware with a focus on efficiency
- Refresh our website to be more user-friendly and to comply with best practice for accessibility
- Continue to improve our communications with our Partnership Network, supporters, and partners.

How you can get involved

There is so much that can be achieved for those affected by genetic conditions and Gene People cannot do it on our own. If you would like to support our work, join our Partnership Network of condition-specific support groups, or our Corporate Connection initiative, please get in touch by emailing hello@genepeople.org.uk or calling 0800 987 8987.

Together, we are Gene People.

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Nightingale House, 46-48 East Street, Epsom, Surrey KT17 1HQ

www.genepeople.org.uk