

FIVE-YEAR STRATEGY

2024-29

Our purpose (why our alliance exists)

is to work together to improve the lives of 3.5 million people in the UK living with lifelong and complex genetic and rare conditions.

Our aim (what we will do)

is to make sure the ambitions in the UK Rare Diseases Framework that matter most to people living with genetic and rare conditions drive action across the four nations.

Our objectives (how we will do it)

- **Influencing national policy and provision where it matters most by:**



Championing timely diagnosis and better coordinated care and treatment for people living with genetic and rare conditions



Ensuring scientific breakthroughs in genomics reach people living with genetic conditions in a timely fashion through research programmes and routine diagnostic and clinical practice



Promoting opportunities to expand newborn and population screening for genetic and rare conditions in line with international best practice



Making sure an understanding of what is most important to people living with genetic and rare conditions shapes research, policy, regulation, practice and the development of new medicines and therapies

- **Making sure our influencing drives action across both policy and practice.**
- **Tracking how people with genetic and rare conditions are affected by this action across the four nations.**

Our critical success factors

(how we are going to get there)



Building a robust, resilient and flourishing alliance in terms of members, income, staff and trustees.



Working collaboratively with key stakeholders such as umbrella groups for genetic and rare conditions, healthcare professional bodies and industry.



Developing an effective influencing strategy to drive action related to the ambitions in the UK Rare Diseases Framework that matter most.



Monitoring and evaluating implementation of the UK Rare Diseases Framework.

Our enablers

(the things that will make it possible)

- Putting our members and the people living with genetic and rare conditions they support at the heart of everything we do: listening to their experience, learning from their expertise, helping members share knowledge with each other, and ensuring our voices are stronger when we work together.
- Professionalising our approach to membership, income generation, corporate services and communications.
- Building on the strengths of our well-regarded policy and research teams.
- Investing in our staff and supporting their training and development.
- Recruiting and retaining trustees with the skills, knowledge and diverse perspectives needed to scrutinise and shape our work.

Our values

(the things we believe are important)

- **People-centred**
- **Collaborative**
- **Independent**
- **Influential**
- **Inclusive**
- **Knowledge-generating**
- **Evidence-led**

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

geneticalliance.org.uk