The AGNC Community Connection Pledge

The Association of Genetic Nurses and Counsellors (AGNC) recognises the unique and essential role of genetic, rare and undiagnosed condition support organisations in supporting patients, families, and communities. Since its founding in 1980, the AGNC has worked closely with support organisations of all sizes to improve the care and experiences of people affected by genetic conditions.

(We recognise that some genetic, rare and undiagnosed condition support organisations are not charities, but use this term for brevity. We intend to be inclusive to all not-for-profit organisations supporting people living with genetic, rare and undiagnosed conditions.)

Charities have been instrumental in shaping the landscape of healthcare and genetics in Britain. Long before the widespread availability of specialist services, they provided vital support, information, and advocacy for families navigating rare and often misunderstood conditions. Their tireless campaigning for recognition, research funding, and equitable access to care has driven the establishment of genetic services within the NHS and influenced national policy.

Charities were also key allies in the development of the genetic counselling profession itself, helping to highlight the need for specialist roles and supporting the growth of the AGNC from its earliest days. Together, we have co-hosted events, developed patient information materials, collaborated on research, and ensured that the voices of people affected by genetic conditions are heard in education, service design, and policy. These partnerships have been, and continue to be, central to the AGNC's mission.

As we look to the future, we pledge to continue and strengthen this collaboration — bringing professional expertise and lived experience side by side to support, empower, and advocate for all those affected by genetic conditions.

Our Pledge

Collaborate openly

- *As individual genetic counsellors:* Build respectful, honest relationships with charity representatives in daily practice; seek opportunities to connect our patients with charity support services.
- *As AGNC:*
    - Participate in existing forums and establish regular forums for dialogue with charities, including opportunities to co-develop resources and policy responses.

    - Publish FAQs on how genetic counsellors and prospective genetic counsellors can help charities in a way that benefits both.

Listen and learn

- *As individual genetic counsellors:* Invite and listen carefully to patient and family stories; integrate their perspectives into counselling practice.
- *As AGNC:*
    - Develop mechanisms (e.g., advisory panels, joint workshops) and use existing consultative opportunities to ensure lived experience informs AGNC priorities, education, and guidelines and to ensure that the voices of charities shape not only our organisational direction but also the statements we make in national policy.
    - Using our charity working group to liaise directly with charities and gather feedback around our work.

Share knowledge

- *As individual genetic counsellors:* Provide accurate, evidence-based information to our patients and signpost to reliable charity resources.
- *As AGNC:*
    - Distribute existing and create new engaging resources around genetic inheritance, genetic counselling and family planning options on a dedicated space on our website able to be downloaded and used by registered charities.
    - Offer registration places to genetic charities for our AGNC conference.
    - Facilitate the interested and dedicated genetic counsellors to speak at charity events/conferences around the country.

Promote equity

- *As individual genetic counsellors:* Challenge inequities in access to care and advocate for people affected by genetic conditions who face barriers.
- *As AGNC:*
    - Work with charities to influence policy and commissioning decisions, ensuring equitable access to genetic services nationwide.

- Create opportunities for genetic counsellors to engage with smaller or under-resourced charities and extend support to communities whose needs are not yet met by existing groups, ensuring equitable representation in our work.

Our Shared Commitment

By signing this pledge, the **Association of Genetic Nurses and Counsellors (AGNC)** and **genetic counsellors** affirm our commitment to collaboration between professionals, people affected by genetic conditions, and the charities that support them — ensuring that lived experience continues to shape the future of genetic healthcare across the UK.

We pledge to act with openness, compassion, and integrity — working side by side to create a more connected, equitable, and informed genetic community.

Support organisations and charities are invited to **endorse** this pledge, recognising and supporting our commitment to partnership and shared purpose.

Signed on behalf of the Association of Genetic Nurses and Counsellors (AGNC):
Name: _____
Signature: _____
Date: _____

Endorsed on behalf of support organisations
Name: _____
Organisation _____
Signature: _____
Date: _____

Signed on 13th November 2025, London

Individual supporters and endorsers

We, the undersigned, add our names in support of this shared pledge, affirming our personal commitment to collaboration, compassion, and advocacy within the genetic community.

Name	Role / Affiliation	Signature