

Our Scottish membership already includes people with...

Rare chromosome disorders

Syndromes without a name

Mosaic Turner's Syndrome

Fragile X Syndrome

Alpha-1 Anti-Trypsin Deficiency

Neurofibromatosis

Osteogenesis Imperfecta

Laurence Moon Bardet Biedl
Syndrome

.....but do we represent you?



Winner



healthier
scotland
SCOTTISH GOVERNMENT

Questions for GIG / your doctor

You may find it useful to write down any questions or issues you have here as a reminder.

Answers

Registered Charity no: 1114195
Company Registration no: 05772999



Genetic Interest Group
Scotland



Your genes, your experience

Working to benefit all people
affected by genetic
disorders

The Genetic Interest Group

GIG (the Genetic Interest Group) is a network of 140 patient groups and medical charities that support children, families and individuals affected by genetic conditions.

One of our roles is to inform the Scottish Government about what patients and families really need from the NHS.

What do we do?

- ☀️ Protect patient rights by influencing the Scottish Government
- ☀️ Raise awareness of genetic conditions
- ☀️ Campaign for better health services

What do we want?

A health service that is timely, fair and accessible to all.

Why involve patients?

GIG would like to support people affected by genetic conditions to get involved in the development of their NHS. The Scottish Government's "Patient Focus, Public Involvement" policy states that patients should have a say in how health services are regulated, designed and delivered. GIG is here to make this a reality!

How can you get involved?

The Virtual Patient Panel

This panel is made up of patients with genetic conditions, their families and carers. If you're on the virtual panel then we will:

- ☀️ Invite you to meetings where you can discuss ways we can improve the health service with the NHS
- ☀️ Present your opinions if it's not convenient for you to give them in person
- ☀️ Include your views in other projects that GIG is working on
- ☀️ Help MSPs to hear and understand your concerns

To be part of the Virtual Patient Panel all you need to do is contact **Claire**.



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What will I be asked to do?

You can be involved as much or as little as you want. We will **support** you to raise issues that are important to you with people who can make a difference. This includes:

- ☀️ patient representative training.
- ☀️ Giving you clear information about what is required for each activity
- ☀️ Help with travel & care expenses
- ☀️ Phone and email support

What's in it for me?

- ☀️ Updates about developments in policy and research that might affect you
- ☀️ The opportunity to act as a patient representative, to give your opinions and raise awareness of your condition/s
- ☀️ Information about events and meetings
- ☀️ You can join our **new** online forum

Access to the Online Forum

Our forum is open to all families affected by genetic conditions and aims build an online community in Scotland. Log on at:
www.gig.org.uk/forum