

What do our patient's say?

"Being a Patient Representative is very rewarding, in being able to "pay it forward" as a thank-you for the help we as a family, received in the very early months of diagnosis.

To be able to input into how support for Inherited Cardiac Conditions is developed within the NHS and across Scotland, its interesting to see and hear how the medical world changes with hope for the future.

You can give as much or as little time as you have to support NICCS, and everyone on the Patient Engagement Group is very welcoming. Come say hi, I've met new life friends."

Sarah, NICCS Patient Representative

The Network for Inherited Cardiac Conditions Scotland Information for patients



This leaflet has been prepared by NHS National Services Scotland (NSS) on behalf of the Network for Inherited Cardiac Conditions Scotland (NICCS). Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. NICCS is a collaboration of stakeholders involved in care of inherited cardiac conditions who are supported by an NSS Programme Team to drive improvement across the care pathway.

Contact us:

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Get Involved:

Scan the QR code or visit:
<https://forms.office.com/r/7cyyAC2D2C>

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What are inherited cardiac conditions?

Inherited cardiac conditions (ICC) are disorders that run in families and that affect the heart muscle or heart rhythm. These conditions affect people of all ages.

You may be diagnosed with an ICC after seeing a cardiologist or because someone else in your family has been diagnosed. Sometimes the diagnosis comes after a sudden death.

What is the Network for Inherited Cardiac Conditions (NICCS)?

We are a nationally managed clinical network. The network includes doctors, nurses, counsellors and patient representatives. Our goal is to make sure that people affected by inherited cardiac conditions get high-quality care, in good time.

What do we do?

The network supports patients and families affected by these conditions, such as:

- Having dedicated clinics across Scotland for people who have or at risk of having an ICC.
- Developing pathways and guidelines to support the care of people with ICCs in Scotland
- Providing training and information to healthcare professionals and the public, to raise their awareness of, and improve their knowledge about, these conditions.

Involving the public

We work closely with people and families with these conditions to find out what matters most to them and to see what more we can do.

One of the ways we do this is meeting with our patient group which includes people with inherited cardiac conditions, family members and heart charities. This group helps us to plan information events, develop patient information and patient surveys.

How do I find out more?

You can find out more about the Network and what we do on our website www.niccs.scot.nhs.uk or you can email nss.niccs@nhs.scot

How do I get involved?

You can get involved in our work in different ways, such as:

- Coming along to network meetings
- Commenting on the information we develop
- Telling us about the care that you get
- Suggesting how we can better support you
- Joining our mailing list to find out what we are doing

You can tell us how you want to get involved and what support you would find helpful by scanning the QR code below or visiting: <https://forms.office.com/r/7cyyAC2D2C>

