

Office for Rare Conditions



What We Do

The Office for Rare Conditions is working to put the patient to the forefront, offering information and support to those affected by conditions that are not common or may not yet even be diagnosed. The Office for Rare Conditions, which is supported by the Glasgow Children's Hospital Charity, the University of Glasgow and Greater Glasgow & Clyde NHS Board works with patients and families affected by rare, low prevalence and undiagnosed conditions and the healthcare professionals who work with them.

We aim to:

Empower

by providing information

by signposting

by raising awareness and understanding of rare conditions

Connect

by liaising and networking with patient support organisations and healthcare professionals

by organising patient & family support meetings and training events

by encouraging participation in rare condition research and clinical trials

Strengthen

by being a strong voice together

by representing patients, families, and clinicians.

Our objectives

- Increase awareness of rare conditions amongst health care staff looking after patients who attend a Glasgow hospital.
- Enhance the support available to adults, children, families and carers.
- Promote standards of clinical care for affected children and adults.
- Increase the participation of people with rare conditions in multi- centre research.

Contact info

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