

The Office for Rare Conditions, Glasgow

About 7% of the general population have a rare condition, defined as a condition that affects about 1 in 2000 or less. There are about 8,000 known rare conditions and, in any one year, it is estimated that around 10,000 children with rare conditions attend the Royal Hospital for Children (RHC), Glasgow for high level specialist care. Children and families with rare conditions, as well as the expert health care professionals who look after them, have several common needs and the Office for Rare Conditions has been developed to address these areas.

Funding for the first 2 years of the project has been secured through the Reid-Timoney Charitable Foundation and Glasgow Children's Hospital Charity as well as Kyowa Kirin and Novo Nordisk. The steering committee that will guide the work of the Office will consist of these supporters as well as other key stakeholders.

The project will be led by Professor Faisal Ahmed in Child Health at the University of Glasgow and will be managed by Liz Dougan, previously an occupational therapist with extensive experience of looking after children with rare conditions at RHC. The Office, which was launched in January 2017, is in the process of developing a website and, in the near future, will also provide expertise and support on website development, databases and registries as well as links to international resources for rare conditions

For further information contact:

Liz Dougan, Project Manager, Office for Rare Conditions, Glasgow

University of Glasgow, Royal Hospital for Children

Zone 1, Office Block, RHC & QEUH Campus

1345 Govan Road, Glasgow G51 4TF. Scotland UK.

E-mail: elizabeth.dougan@glasgow.ac.uk

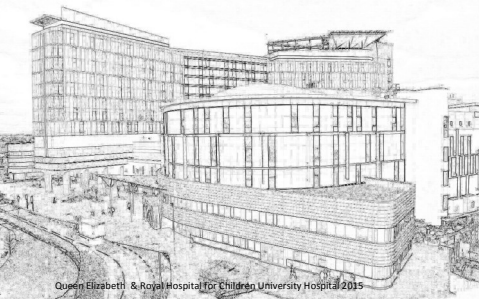
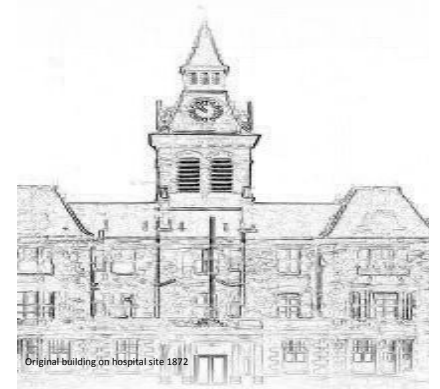
Tel: 0141 451 5844



KYOWA KIRIN



Continuing the care of
Yorkhill Children's Charity



General Objectives:

- ◆ Increase awareness of rare conditions amongst health care staff looking after children who attend RHC, Glasgow
- ◆ Enhance the support that is available to children and their families/carers.
- ◆ Promote standards of clinical care for affected children.
- ◆ Increase the participation of children with rare conditions in multi-centre research.