



Office for Rare Conditions

January 2020

The Office for Rare Conditions, based at the Royal Hospital for Children and the Queen Elizabeth University Hospital in Glasgow, aims to raise awareness of rare conditions, enhance the quality of care provided and promote participation in research. It is funded through Glasgow Children's Hospital Charity.

Did you know the **Office for Rare Conditions Patient Friendship Group** was formed to bring together patients, families and carers living with rare conditions, who attend a hospital in Glasgow. You can find out more about the **Office for Rare Conditions Glasgow Friendship Group** through our Facebook page [@ORCGlasgow](https://www.facebook.com/ORCGlasgow)

Family Support and Information Service

Being in hospital can be a worrying time and the **Family Support and Information Service** is there to help. This service is for patients, parents, family members and carers at the Royal Hospital for Children and QEUH in Glasgow.

Find the Family Information and Support Service in the main atriums of both the Royal Hospital for Children and the Queen Elizabeth University Hospital.

Telephone: 0141 452 4012

or visit their website at:

<https://www.nhsggc.org.uk/patients-and-visitors/support-and-information-services/family-support-and-information-service/>



Rare Disease Day 2020



Every year, the last day in February is global Rare Disease Day. Join us to help raise awareness of rare conditions! See our Facebook page for details [@ORCGlasgow](https://www.facebook.com/ORCGlasgow)

Events

Check out details of all upcoming events by [signing up for our newsletter](#) or on our website www.officeforrareconditions.org.

Rare Resources: Scotland is a guide produced by Genetic Alliance UK for families in Scotland who have recently received a diagnosis of a genetic, rare or undiagnosed condition. The Toolkit contains a wide range of general information. For more details contact Genetic Alliance UK contactus@geneticalliance.org.uk

Share Your Views!

Are you a patient with a rare condition? Care for someone who is? Take part in [our survey](#) and help direct priorities in the future work of the Office for Rare Conditions, Glasgow. Find the survey on the Office for Rare Conditions website www.officeforrareconditions.org



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Facebook.com/ORCGlasgow

CARDRISS

November 26th saw the launch of the **Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS)** project to establish a new national congenital anomaly register in Scotland. An anomaly is something that is different from normal or what was expected. This is the first national register in Scotland and will record all babies born with a condition, such as a congenital heart or a limb defect, or a recognised syndrome. Registers such as this can help improve our understanding of many rare conditions. They can also be used in the planning of health services and for helping meet the needs of affected people and their families.

For more information on CARDRISS, visit <https://www.isdscotland.org/Health-Topics/Maternity-and-Births/CARDRISS/>

Information Stand -The Office for Rare Conditions will be in the atrium of the Royal Hospital for Children with Contact and Family Fund on **Jan-29th, Feb-17th, March-23rd**. Come along to chat with us and learn about the range of information and resources that are available.



A snapshot from our Festive Fun Event!

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