



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

We are delighted to announce the **Glasgow Children's Hospital Charity** have renewed the Office for Rare Conditions funding for another year! We are very excited to be able to continue the work of the office and would like to thank everyone for their continued support.



An update from our PAG Chair

The Patient Advisory Group (PAG) have continued to meet regularly throughout the pandemic and it has been heartening to have been able to meet with so many patients and families in this way. On 9th July we hosted an excellent online meeting, our first large meeting on Zoom.

At that meeting we had some very informative talks from **CONTACT UK**, **FAMILY FUND**, and **GENETIC ALLIANCE UK**. We also had the opportunity for members to chat informally with each other, generating a great discussion. We hope to continue in this new format with the group becoming a stronger voice for patients and families affected by rare, low prevalence and undiagnosed conditions.
Kind Regards
Arlene Smyth, Chairperson PAG.



Office for Rare Conditions

September 2020

Glasgow Paediatric Research Day!

This year's Glasgow Paediatric Research Day will be held on **Friday 6th November 2020 via Zoom**. The invited speakers' plenary session entitled, "**A Practical Pragmatic Approach To Research**", will be hosted by Dr Ben Reynolds, Consultant Paediatric Nephrologist (The Royal Hospital for Children, Glasgow) and will feature presentations from Dr Lisa A Robinson (The Hospital for Sick Children, (Sick Kids) Toronto, Canada) and Dr Sally Johnson (Great North Children's Hospital, Newcastle, UK). Click [here](#) to register.

Genetic Alliance UK have set up a [Covid-19 Information Hub](#) to support the UK's genetic, rare and undiagnosed community during the Covid-19 pandemic. The information hub contains Scotland-specific information and is updated regularly with key pieces of information and guidance for Scotland.

Genetic Alliance UK is also hosting a weekly virtual community check-in meeting every Tuesday between 10-11am for any organisations supporting communities affected by genetic or rare conditions. You do not need to be a member organisation of Genetic Alliance UK to attend, [just get in touch here](#) for joining instructions.

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

@ORCGlasgow

Facebook.com/ORCGlasgow

COVID-19 Survey Results

The Office for Rare Conditions conducted a short survey to discover the impact of the COVID-19 pandemic on those with rare, low prevalence and undiagnosed conditions in Glasgow. Here are the key messages we picked out from the survey:

-75% of respondents used online telemedicine services, many for the first time. Overall, online consultations were viewed positively by patients and families with many stating they preferred this format and will happily continue to use it when face-to-face appointments resume.

-69% reported positive experiences of effective and efficient health care support throughout the pandemic from both hospital and local healthcare services, however postponed or cancellation of hospital clinic appointments were cause for concern for 55%.

GCHC Research Fund Call Out

Through funding from Glasgow Children's Hospital Charity, the GCHC Research Fund and the Office for Rare Conditions, invites applications for Project Support Grants (up to £40k) and Small project grants (up to £5k) in research that benefits children's health. Applications that focus on conditions that are rare or have a low prevalence will be particularly welcome. For full details on eligibility and application forms, please visit [GCHC Research Fund website](#).



Our 4th annual neonatal study day held on Zoom!

OFFICE FOR RARE CONDITIONS

Royal Hospital for Children
Zone 0.01 Office Block, 1345 Govan Rd.
G51 4TF, Glasgow, Scotland, UK
Tel: 0141 451 5899
Email: info@officeforrareconditions.org