WINTER NEWSLETTER 2025

Office for Rare Conditions Newsletter

Who Are We?

The Office for Rare Conditions, based at the Royal Hospital for Children (RHC) and the Queen Elizabeth University Hospital in Glasgow, aims to raise awareness of rare, undiagnosed and low prevalence conditions, enhance the quality of care provided and promote participation in research.

Recent ORC Activity and News

December Events

Tabling in the RHC
The ORC shared a space with CONTACT in the Atrium on November 11th and December 3rd. It was a fantastic opportunity to collaborate and help out families.

Patient Advisory Group (PAG)
On the 4th of December, we hosted the annual wine and cheese Zoom event with our PAG. It was so nice to enjoy a holiday catch up with our members! Gear up for the new year!

Patient Advisory Group Meetings

The Office for Rare Conditions Patient Advisory Group (PAG) meets online every month to two months. Meetings consists of relaxed catch ups, guest speakers and friendly discussions on topics of interest. Above all, the PAG supports an opportunity to chat with others managing life with a rare or undiagnosed condition.

The PAG is open to all patients and parents of children with a rare condition. Why not come along to our next meeting? If you would like to know more please get in touch with us on our website or through our Facebook group @ORCGlasgow!

Upcoming Events

Rare Disease Day 2025
Our annual big event is BACK and we would love to see everyone come celebrate Rare Disease Day 2025! This event will be hosted in the RHC Atrium on February 27th. Details will be released closer to the event, mark your calendars!

Tabling in the RHC
We will be in the Atrium on January 7th from 10am-3pm. If you are in need of signposting services or just want to say hi, swing by the RHC! We'd love to connect with you!

Patient Advisory Group (PAG)
We aim to have our next event in the first two weeks of January. Based on member requests, we hope to bring in speakers and information sessions in 2026. If you or someone you know would be interested in connecting or have a specific interest, please join us. Follow us on socials and be on the lookout for the next event announcement!

@ORCGlasgow

Warm Hug Project

Have you or your child been diagnosed with a rare condition? Are you looking for further support or want to speak to someone who is going through the same experience?
Read our welcome letter to the Office for Rare Conditions 'A Warm Hug' by scanning the QR code.

RARE IS MANY RARE IS STRONG RARE IS PROUD

Services Shoutout!

Need support for the New Year? See the links below to find out more!

Immigration and Government Aid

Citizen's Advice
Need immigration advice, or guidance through disability applications? Citizens Advice is a great organization to look into for virtual or in person help in a variety of societal barriers.

NHS Clear for All
Need translation services? This service through the NHS provides resources to receive transparent, appropriate materials accommodating to people's ability (those with English as a second language, deaf and blind persons, lower literacy levels)

Mental Health Services

Need mental health services tailored to your experience being affected by a rare condition?

Rare Minds is a unique mental health network that specifically works with those in the rare conditions community.

Gene People provides expert and personally tailored information and support for anyone with questions or concerns about a genetic condition including a free, genetic counsellor led helpline.

Patient Reported Experience Measures (PREMs)

PREMS is an opportunity to those in the West of Scotland that have a rare condition or are supporting someone with a rare condition. It is a patient-focused survey tool reporting on different parts of care the rare conditions community receives. Participants always have their information protected and are able to revoke participation at any time.

To see the impact of this survey, review our publication of PREMS results: 'Experience of health care at a reference centre as reported by patients and parents of children with rare conditions', Orphanet J Rare Dis, 16, 65 (2021).

If this applies to you, family and friends, please visit our website or scan the QR Code to share and complete the PREMS. We greatly appreciate all participants!

Recreational Opportunities

Need resources for getting out of the house? It may be winter, but we are still finding ways to play!

The Yard Glasgow consists of an indoor play hall full of toys and activities for all ages with an accessible play park outdoors. During your visit, feel free to take a break while your child participates in building independence through play!

Over the Wall Camp is a residential summer camp in Perthshire that provides an amazing opportunity for kids to socialize and engage in activities both outdoors and indoors. Additionally, they have camp for families and siblings of those affected by a rare condition. If you qualify for the camp and get approved, attending is free!

Research Opportunities

SHARE Registry
This is a new registry out of University of Dundee that already has 300,000+ registered. By joining SHARE, you get contacted when research on a specific rare condition is seeking study participants. They contacted the ORC because the more rare conditions represented means the more research opportunities possible!

Glasgow Children's Hospital Charity Research Fund

We have recently applied for more research funding, so stay tuned for opportunities in the near future!

Follow us on social media!
@ORCGlasgow

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Check out Updates from our Rare Conditions Community!

Brew and Blether Online Sessions

Genetic Alliance UK has created an online space for adults living with rare, genetic and undiagnosed conditions to connect with other people and families living with rare conditions. These friendly, informal sessions will be taking place monthly to help support our rare community. Anyone can share experiences and ask questions with others who really understand what living with rare conditions is like. The next event is February 9th at 12:30 pm. To register, click on the link in the title.

Scottish Parent Academy

The Scottish Parent Network has assembled a course built by parents for parents. This is a great opportunity to connect with other parents facing adversity, the goals you seek to reach and resources of how to obtain them.

The courses are free and available both in-person and online, whatever your preference is! To register, click the title link above.

Talking About Tomorrow

CONTACT, a trusted organization that provides resources for people with a disability and their carers, just released a webpage dedicated to navigating adult life. This includes many aspects following the transition to adulthood including benefits, legal matters such as trusts and wills, rights, civil duties and social opportunities. Check out the link to this resource by clicking ‘Talking About Tomorrow’.

Scottish Assembly of Parents and Carers

The Assembly welcomes all parents and carers of school-aged children, from every background and community to apply to make a difference in Scotland’s education policy. The goal is to build a national voice that highlights the real challenges and successes families experience ensuring these insights reach government and education systems.

Most importantly, we are wishing everyone a safe December full of love, light, and holiday cheer.

Love, the Office for Rare Conditions

Feeling Festive?

The ORC is funded through Glasgow Children’s Hospital Charity. In the spirit of the giving season, please donate if you are willing and able. This is greatly appreciated as it progresses the work we do for the rare condition community and creates a positive impact!

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