

Office for Rare Conditions, Glasgow

Support & Information Bulletin for Parents of Children with Rare and Undiagnosed Conditions

Getting Started

Caring for a child with a rare or undiagnosed condition can feel overwhelming.

The Office for Rare Conditions (OfRC) Glasgow is here to support you.

We provide information, help connect families to services, and promote awareness of rare conditions across health and social care.

Where to begin:

- Speak to your GP or paediatrician if you have concerns.
 - Ask for referrals to specialist clinics or genetics services.
 - [Contact us](#) at OfRC for signposting and support.
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Health & Care Support

- **Specialist Clinics:** Many rare conditions are managed through hospital-based specialist teams. We can help you find the right service.
 - **Genetic Services:** NHS Scotland provides [genetic counselling and testing](#) where appropriate.
 - **Transition to Adult Care:** Planning for your child's future is vital. Ask your care team about transition support.
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Educational Support

- Children with rare and undiagnosed conditions may have additional support needs in school.
 - If your child needs extra help at school, speak to the school or local council about support options. This might include a Co-ordinated Support Plan (CSP) or other types of help. You can also contact Enquire for advice: www.enquire.org.uk
 - Communicate regularly with your child's school and consider sharing medical summaries or letters from professionals.
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Support & Peer Networks

Connecting with others can make a big difference:

- [SWAN UK](#) – for families of children without a diagnosis

- [Genetic Alliance UK and Rare Disease UK](#) – national advocacy and support
 - [OfRC Support Group](#) – meet other families locally and online
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Mental Health & Wellbeing

Looking after your own wellbeing is just as important as caring for your child:

- [Parentline Scotland](#) – emotional and practical support
 - [CAMHS](#) – speak to your GP about referral if your child is struggling emotionally
 - [Local Carer Centres](#) – offer counselling, respite and peer support
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Financial & Practical Help

You may be entitled to financial support:

- [Child Disability Payment](#)
 - [Carer's Allowance](#)
 - Help with travel costs for hospital appointments - [Healthcare Travel Costs Scheme](#)
 - Grants for equipment or respite from charities like [Family Fund](#) or [Turn2us](#)
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Useful Tools and Links

- Office for Rare Conditions Glasgow: www.officeforrareconditions.org
 - OfRC Patient Group – Join the private Facebook page
<https://www.facebook.com/groups/officeforrareconditionspag>
 - Rare Disease UK: <https://www.raredisease.org.uk/>
 - Contact: <https://contact.org.uk/>
 - [Personal care summary](#) for healthcare appointments
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News and Updates

- [New resources](#) for families of rare & undiagnosed children available on our website
 - Join us for our next **Family Support Day** – [add me to your mailing list for events](#)
 - [Sign up for our newsletter](#) for regular updates
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You are not alone. Reach out, connect, and let us help you navigate this journey.

Contact: info@officeforrareconditions.org

Website: www.officeforrareconditions.org