Office for
Rare
Conditions
Glasgow

Office for Rare Conditions Summer Newsletter 2025

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

We are most grateful for our continued funding this year by Glasgow Children's Hospital Charity.

As we move into the summer months, we want to take a moment to thank everyone who supports and engages with the Office for Rare Conditions community in Glasgow and across Scotland. Whether you are a patient, a family member, a healthcare professional or a partner organisation - your voices, insights and commitment continue to shape our work.

- **Rare Disease Day 2025**
- **Rare Conditions Patient Navigator**
- **Navigating Rare: Support, Services, and More**
- **Coming Up**
- **Farewell to Liz Dougan, Project Manager OfRC**
- **Contact Us**

*1 - **Rare Disease Day 2025***

Observed annually on the last day of February, **Rare Disease Day** raises awareness for patients, families and carers affected by rare conditions.

Raising Awareness on Rare Disease Day

To mark Rare Disease Day 2025, the Office for Rare Conditions hosted an awareness stand in the atrium of the Royal Hospital for Children. Our team was joined by staff, patients, families, and charity partners to highlight the importance of early diagnosis, coordinated care, and support for those living with rare and undiagnosed conditions. The stand featured information resources, interactive materials, and creative activities that encouraged conversations and helped raise awareness among the hospital community. We're grateful to everyone who stopped by to show their support and learn more about the rare condition journey.


I SUPPORT
#RAREDISEASEDAY
#ORCGLASGOW
Office for Rare Conditions Glasgow
RAREDISEASEDAY.ORG
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FEBRUARY
NESS AND GENERATING CHANGE FOR THE
3.5 MILLION PEOPLE
IN THE UK
LIVING WITH A RARE CONDITION


RARE DISEASE DAY
RARE DISEASE DAY
Rare Disease Day
25
Office for Rare Conditions Glasgow
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ARE DISEASES
#RAREDISEASEDAY
GENETIC ALLIANCE UK
RARE DISEASE UK
BRILLIANT

72% GENETIC
70% OF GENETIC RARE DISEASES START IN CHILDHOOD
THINK ZEBRA
RARE DISEASE DAY
Rare Disease Day 2025
Glasgow Children's Hospital Charity
Office for Rare Conditions Glasgow


CANCERS IS RARE
Individually Rare, Together Strong
Office for Rare Conditions
5% OF THE WORLD POPULATION IS AFFECTED BY A RARE DISEASE
FEB 28 2025
72% OF RARE DISEASES ARE GENETIC
THERE ARE 6,000+ IDENTIFIED RARE DISEASES
THE WORLD'S 3RD LARGEST COUNTRY
NHS


RARE DISEASE DAY
Rare Disease Day 2025
Glasgow Children's Hospital Charity
Office for Rare Conditions Glasgow
Office for Rare Conditions Glasgow
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#RAREDISEASEDAY
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Or email us at:
www.officeforrareconditions.org
info@officeforrareconditions.org
@ORCGlasgow
Our Supporters
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NHS Greater Glasgow and Clyde
contact
Office for Rare Conditions


Office for
Rare
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Glasgow


RARE DISEASE DAY
Rare Disease Day 2025
Glasgow Children's Hospital Charity
Office for Rare Conditions Glasgow
FEB 28 2025
DIAGNOSIS,
OPPORTUNITIES.
#ORCGLASGOW
#RAREDISEASEDAY
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RARE DISEASE


RARE DISEASE DAY
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FEB 28 2025
72% OF RARE DISEASES ARE GENETIC
70% OF GENETIC RARE DISEASES START IN CHILDHOOD
HEAR HOOFBEATS?
WHO WHAT WHERE
Patient Information Leaflet

Did You Know? Rare Condition Statistics at a Glance

- There are over ***7,000 known rare conditions***, and new ones are discovered every day.
- A condition is considered rare in the UK if it affects ***fewer than 1 in 2,000 people***.
- Collectively, rare conditions affect ***1 in 17 people*** - that's approximately ***350,000 people in Scotland***.
- ***80% of rare conditions have a genetic cause***, and more than ***50% affect children***.
- Diagnosis can take time: the average person with a rare condition waits ***more than 4 years*** for a definitive diagnosis.
- Most rare conditions are ***chronic, complex and affect multiple systems***, requiring co ordinated care across specialties.

These figure highlight why celebrating **Rare Disease Day** - and the work happening throughout the year - is so important.

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*A massive **Thank You** to everyone who took part in supporting **Rare Disease Day 2025!***

Patients, Families/Carers, Health Care Professionals, Contact, the Hyperoxaluria Foundation, TSSS UK and the OfRC Patient Advisory Group.

*and to **Glasgow Children's Hospital Charity** for their continuous help and support. We couldn't have done it without them!*

Rare Disease Day 2025 Reception at Holyrood Palace

Championing Rare Conditions at the Scottish Parliament On 18th March 2025, Genetic Alliance UK hosted this key event at the Scottish Parliament in Edinburgh, bringing together patients, families, clinicians, and policymakers to explore progress and set priorities for those living with rare and undiagnosed conditions in Scotland.

The Office for Rare Conditions was represented by our Clinical Lead, Dr Martina Rodie, and Arlene Smyth, Chair of our Patient Advisory Group. They engaged in valuable discussions about the ongoing challenges faced by individuals affected by rare conditions, as well as those involved in their care and support.

To mark Rare Disease Day 2025, Genetic Alliance UK also launched their new anthology: a powerful collection of creative works that bring to life the experiences of individuals with genetic, rare and undiagnosed conditions.

[More than you can imagine: an anthology of rare experiences.]()

Celebrating Success: Patient Navigator Pilot

The **Patient Navigator** role was developed by the Office for Rare Conditions Glasgow to provide personalised, practical support to individuals and families affected by rare, low prevalence, and undiagnosed conditions across Glasgow and the West of Scotland.

Launched in **January 2023**, the pilot was generously funded by **Glasgow Children's Hospital Charity**. Despite the clear need and positive impact, the role concluded in **January 2025** after NHS funding could not be secured to sustain it.

What Did the Patient Navigator Do?

The role aimed to bridge gaps between patients, healthcare professionals, and services — offering a more joined-up, compassionate approach to care. Key responsibilities included:

- Providing tailored information and guidance to patients and families
- Supporting communication between patients, clinicians, and care teams
- Helping individuals access the right services within and beyond the NHS
- Advocating for a smoother, more coordinated care journey

This pilot also helped us better understand common challenges in navigating complex care pathways and demonstrated the benefits of dedicated support in improving the overall patient experience.

Recognition & Impact

The Patient Navigator role received national recognition:

- **Finalist in the Scottish Health Awards 2023** – Tackling Health Inequalities category
- **Featured in Rare Revolution Magazine** – February 2024 edition
- **Poster presentation at the 12th European Conference on Rare Disease 2024**

We are proud of what was achieved during the pilot. The learning from this initiative continues to inform future planning and highlights the vital importance of integrated, person-centred support for those with rare and undiagnosed conditions.

While the role has ended, we remain hopeful that sustainable funding will one day allow this critical support to return.

For more information or a copy of the pilot report, please contact the Office for Rare Conditions.

Navigating Rare: Support, Services, and More

NHS Inform and Rare Conditions in Scotland

NHS Inform is Scotland's national health information service, run by NHS 24. It provides trusted health and care information to the public, including support for people living with rare, low prevalence, and undiagnosed conditions.

What NHS Inform Offers:

- **Dedicated Rare Conditions Hub**
- The Rare Conditions section provides information and guidance for individuals and families affected by rare conditions in Scotland.
- **Signposting to Trusted Resources** NHS Inform links to specialist resources including:
- Genetic Alliance UK
- SWAN UK (Syndromes Without a Name)
- Orphanet – a comprehensive international database of rare diseases
- **Information on Services in Scotland** includes details about:
- Genetic clinics and testing
- Mental health support
- Accessing NHS care and referrals

NHS Inform plays a key role in improving awareness and making it easier for people with rare and undiagnosed conditions to access the information and services they need in Scotland.

Congenital Conditions and Rare Diseases Registration and Information Service for Scotland (CARDRISS)

Understanding the background of Scotland's national register for rare and undiagnosed conditions

Why was CARDRISS set up?

CARDRISS (the Scottish Register for Rare and Undiagnosed Conditions) was created to help improve care for people living with rare conditions in Scotland.

Until recently, Scotland didn't have a national register for rare conditions. This meant it was hard to understand how many people were affected, where they lived, or what care they needed. That made planning support and services more difficult.

CARDRISS helps by:

- Recording information about people diagnosed with rare conditions (with consent where required)
- Identifying patterns to improve diagnosis, care, and services
- Supporting planning, research, and policy development
- Making sure Scotland's data is part of wider UK and international efforts to improve outcomes for people with rare conditions.

CARDRISS is not a screening programme or a diagnostic service. It is a population health resource that aims to **support better care** and **give rare conditions greater visibility** in the healthcare system.

National and UK policies helped shape the need for CARDRISS:

- UK Strategy for Rare Diseases (2013)
- **It's Not Rare to Have a Rare Disease** (2014) – Scotland's own plan
- **Final progress report** (2021)
- UK Rare Diseases Framework (2021)
- Scotland's Rare Disease Action Plan (2022)
- **Scotland's response to the UK strategy**

CARDRISS is part of Scotland's response – helping to improve understanding, care, and support for people with rare and undiagnosed conditions.

FindZebra: Smarter Searching for Rare and Undiagnosed Conditions

FindZebra

Rare Disease Search

Looking for answers can be overwhelming when a condition is rare or hard to diagnose.

FindZebra is a free, easy-to-use search engine designed for rare and undiagnosed conditions. It helps healthcare professionals—and the families they support—by offering trusted, symptom-based search results from expert medical sources like Orphanet and OMIM.

Whether you're exploring possibilities or supporting someone still waiting for answers, FindZebra can help guide the search.

Visit FindZebra

Scottish Strategic Network for Genomic Medicine

Scottish Genomic Test Directory for Rare and Inherited Disease

The **Scottish Genomic Test Directory for Rare and Inherited Disease** contains a list of all services currently available in Scotland. You can view or download the most up to date version of this test directory below.

Genomic Test Directory

Be Part of Research

What is Be Part of Research? https://bepartofresearch.nihr.ac.uk/

Be Part of Research is a UK-wide service that helps people understand what research is and what it might mean to take part. It also shows what research is currently happening across the UK.

You can create a free account or search for trials and studies into health conditions you're interested in, at locations near you.

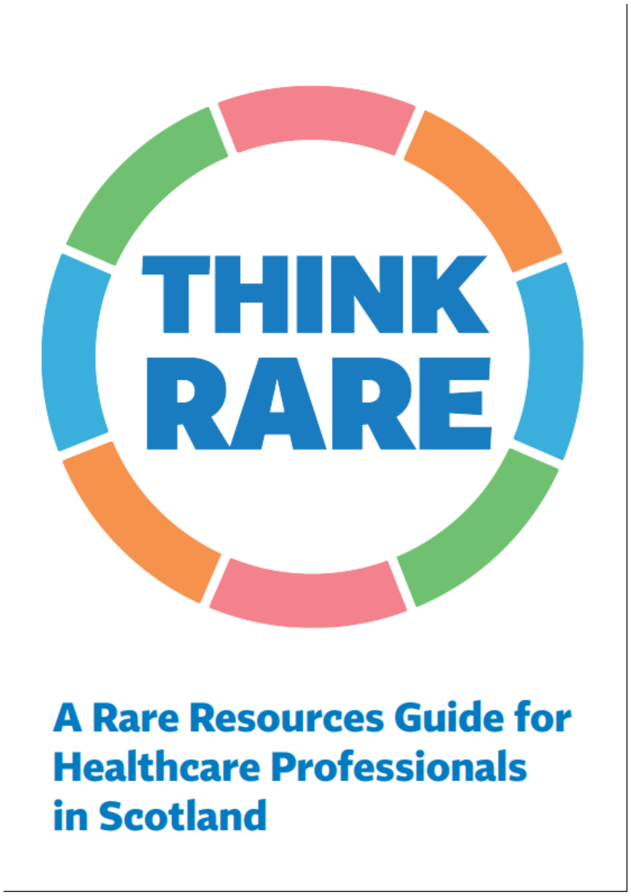
Be Part of Research is run by the National Institute for Health and Care Research (NIHR), in collaboration with the NHS and devolved administrations in Scotland, Wales and Northern Ireland.

The mission of the NIHR is to improve the health and wealth of the nation through research.

Be Part of Research is funded by the UK government, through the Department of Health and Social Care (DHSC).

Rare Resources for Health Care Professionals

Genetic Alliance Rare Resources Guide for Healthcare Professionals



THINK RARE

A Rare Resources Guide for Healthcare Professionals in Scotland

A practical, easy-to-use guide from Genetic Alliance designed to support healthcare professionals in understanding and navigating rare conditions. It includes reliable information, tips for patient communication, and links to specialist organisations to help improve care and support for individuals with rare and undiagnosed conditions.

OfRC Glasgow Webinar Series: Insights into Rare Conditions

Office for
Rare
Conditions
Glasgow

Our ***Office for Rare Conditions webinar series*** offers a wide range of short, accessible talks on individual rare and undiagnosed conditions. Presented by experts, these webinars aim to raise awareness, share clinical insights, and support education for healthcare professionals, patients, families, and anyone with an interest in rare conditions.

The full collection is freely available to view on our website, and we continue to add new talks regularly. Watch the series here

Medics 4 Rare Diseases (M4RD): Shaping a New Mindset in Medical Training

M4RD is changing how future doctors think about rare conditions. While no one can know all 7,000+ rare conditions, doctors *can* recognise that rare is common and understand the challenges patients face.

M4RD provides training to improve diagnosis and the patient-doctor relationship.

👉 Learn more at the M4RD website.

Working in Partnership

ENGAGEMENT

Meeting Patients, Families & Carers

The Office for Rare Conditions continues to partner with many 3rd sector organisations, bringing information on available resources directly to patients and families through our information stands within the hospital and at community events.

Contact regularly joins our stand in the Royal Hospital for Children to reach out to patients and families, providing invaluable support and information.

If you know of an organization that could benefit patients and families and would be a great addition to our stand, please let us know.

2 - Family Information Stand

Raising Awareness

To help raise awareness and enhance understanding of rare conditions, the OfRC collaborates with patient support organisations on their designated awareness days. We provide information on the condition and its management, linking with clinical services whenever possible.

Are you aware of an upcoming awareness day for a rare condition? The OfRC is here to help you raise awareness and support. Get in touch with us for more information.

e-mail info@officeforrareconditions.org

Information & Signposting - patients and families

Patient and Family Resources

At the **Office for Rare Conditions,** we're always on the lookout for helpful resources to support individuals and families living with rare and undiagnosed conditions. From practical guides and specialist support services to patient stories and awareness campaigns, we regularly share what we find on our **website** and **Facebook page**. You can explore a selection of trusted resources on our dedicated page: **External Resources for Patients and Families,** which brings together information from a range of local and UK organisations.

Whether you're looking for information, connection, or reassurance, we hope these resources can offer a bit of support when it's most needed.

Office for Rare Conditions Glasgow

Information & Resources Bulletin

Summer 2025

KIDS – Kids Independently Developing Skills

KIDS is a user-friendly digital resource created by NHS Greater Glasgow and Clyde to support children and young people in living healthy, independent lives.

It offers quick access to trusted advice, strategies, and self-help tools from a wide range of children's health professionals – including occupational therapists, physios, dietitians, speech and language therapists, and more.

Explore KIDS website https://www.nhsggc.org.uk/KIDS

Follow them on Facebook
https://www.facebook.com/nhsggckids/

Glasgow Helps.org

Glasgow Helps is a free online directory designed to make it easier for people in Glasgow to find **support, services, and activities** that can improve their lives. Whether you're looking for social groups, mental health support, financial advice, or help with a health condition, you'll find a wide range of options here. The services listed are mostly run by charities, voluntary groups, and community organisations – some local, some national. Glasgow Helps aims to connect people with the right support at the right time and make it easier for organisations to work together.

the Yard

The Yard is a Scottish charity providing adventure play services for children and young people with disabilities. With centres already in Edinburgh, Dundee, and Kirkcaldy, we're excited to share that Glasgow will soon have its own centre in Linn Park (summer 2025).

The Yard offers a safe, supportive, and fun environment where families can play together, build friendships, and enjoy creative indoor and outdoor activities.

Families can become members to access weekend play sessions, family days, and holiday events, all designed to support social inclusion and build confidence through play.

To find out more, including how to refer a family or join as a member, visit www.theyardscotland.org.uk.

Disability Sport GLASGOW

Disability Sport Glasgow provides a wide range of Disability Sport opportunities and sessions. Make sure to check their Clubs & Activities and Events Calendar pages for more information.

To keep everyone updated on new resources, helpful organizations, and the latest guidance, the OfRC publishes regular bulletins on its website.

Take a look here.

We would be thrilled to feature your recommended resources in our quarterly bulletin. Please send them to info@officeforrareconditions.org.

Have you explored our patient and parent-inspired resources on our website: www.officeforrareconditions.org?

Alternatively, click this link.

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Social Media: @ORCGlasgow

Office for Rare Conditions Glasgow

CARE SUMMARY

ESSENTIAL INFORMATION

Full Name :
CHI :
Contact person :
Diagnosis :
Comment:

SAFETY ALERT/ALLERGY

Comment:

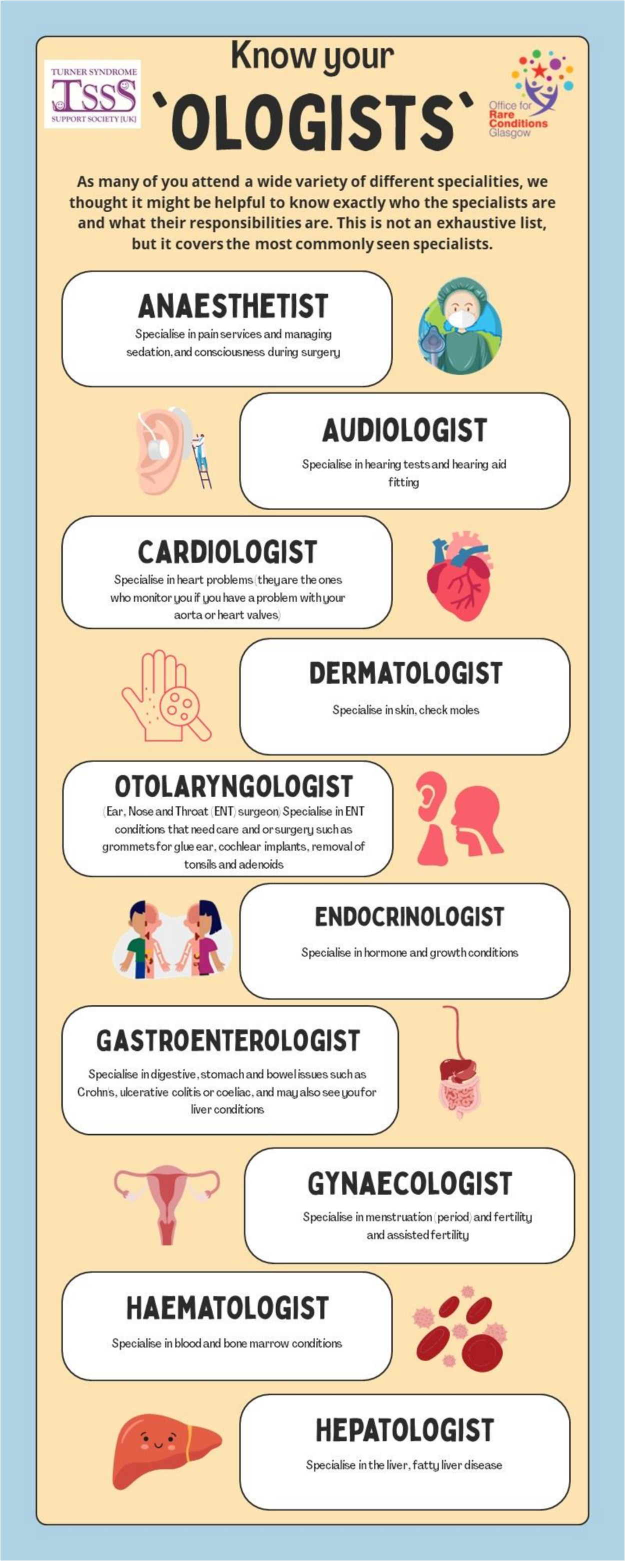
IMPORTANT INFORMATION ABOUT ME

Comment:

MEDICATIONS AND MEDICAL DEVICES

Medication names :
Direction-Dose and Duration:
Any Additional Instructions:

3 - *Patient Passport/Care Summary*



TURNER SYNDROME TSSS SUPPORT SOCIETY [UK]

Office for Rare Conditions Glasgow

Know your `OLOGISTS`

As many of you attend a wide variety of different specialities, we thought it might be helpful to know exactly who the specialists are and what their responsibilities are. This is not an exhaustive list, but it covers the most commonly seen specialists.

ANAESTHETIST

Specialise in pain services and managing sedation, and consciousness during surgery

AUDIOLOGIST

Specialise in hearing tests and hearing aid fitting

CARDIOLOGIST

Specialise in heart problems (they are the ones who monitor you if you have a problem with your aorta or heart valves)

DERMATOLOGIST

Specialise in skin, check moles

OTOLARYNGOLOGIST

(Ear, Nose and Throat (ENT) surgeon) Specialise in ENT conditions that need care and or surgery such as grommets for glue ear, cochlear implants, removal of tonsils and adenoids

ENDOCRINOLOGIST

Specialise in hormone and growth conditions

GASTROENTEROLOGIST

Specialise in digestive, stomach and bowel issues such as Crohns, ulcerative colitis or coeliac, and may also see you for liver conditions

GYNAECOLOGIST

Specialise in menstruation (period) and fertility and assisted fertility

HAEMATOLOGIST

Specialise in blood and bone marrow conditions

HEPATOLOGIST

Specialise in the liver, fatty liver disease

4 - Know Your Ologists

Glasgow Children's Hospital Charity

NHS Greater Glasgow and Clyde

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?

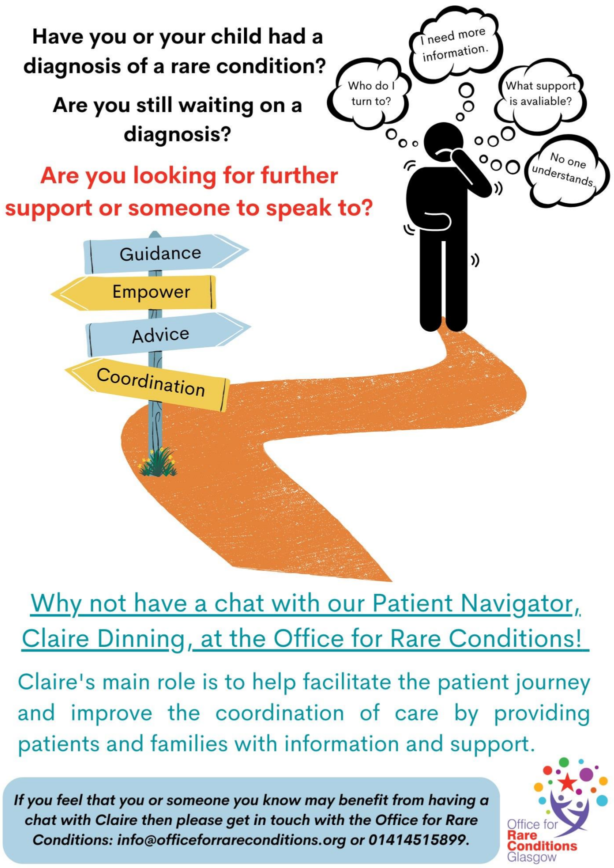
Read our welcome letter to the Office for Rare Conditions

'A Warm Hug'

by scanning the QR code

Office for Rare Conditions Glasgow

Office for Rare Conditions
Phone: 0141 451 5899
Email: info@officeforrareconditions.org
Social media: (FB/Instagram/Twitter): @ORCGlasgow



Have you or your child had a diagnosis of a rare condition?

Are you still waiting on a diagnosis?

Are you looking for further support or someone to speak to?

Why not have a chat with our Patient Navigator, Claire Dinning, at the Office for Rare Conditions!

Claire's main role is to help facilitate the patient journey and improve the coordination of care by providing patients and families with information and support.

If you feel that you or someone you know may benefit from having a chat with Claire then please get in touch with the Office for Rare Conditions: info@officeforrareconditions.org or 01414515899.

6 - ***Information on the Patient Navigator***

Brilliant Support from Contact Scotland!

Contact in Scotland offers a fantastic range of resources and support for families with children who have additional needs. This summer, they've put together a list of fun activities and events that will accommodate children with additional support needs or disabilities AND help families connect, unwind, and have fun together.

They've also introduced a new group specifically for teenagers with PDA (Pathological Demand Avoidance), providing a safe and supportive space to share experiences. Find out more and get involved via their Scotland webpage.

By Your Side Scotland friendly and knowledgeable Patient Advisor Lynn Shields has regular monthly stands in RHC, Glasgow and Wishaw General, Lanarkshire. Find out more about By Your Side.

Patient Advisory Group

Our **Patient Advisory Group** (PAG) continues to meet regularly online, led by a dedicated and enthusiastic committee of patients and parents. The group offers a welcoming space for peer support, sharing experiences, and working together to improve life for those affected by rare and undiagnosed conditions. If you're looking to connect with others who understand the challenges of living with a rare condition, we encourage you to join our closed [Facebook group](#) — a safe and supportive community where you can share, learn, and feel less alone.

Office for
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SUPPORT
SHARE
CONNECT
Officeforrareconditions
NETWORK

Patient Reported Experience Measure for Rare & Undiagnosed Conditions

Help us if you can: Do you know someone managing a rare condition that could tell us about their journey. Our **Patient Reported Experience Measure** helps us understand what it is like to live with a rare condition, what kind of support works well or not so well, and what services and support might be helpful. We are keen to identify gaps in the provision of services and areas of good practice.

Complete our PREM survey here

https://link.webropolsurveys.com/Participation/Public/780c6c6f-175d-459f-af8d-d4bf552732ba?displayId=Uni2726868

Coming Up!

Registration is now open for our 9**th Annual Neonatal Study Day**

MANAGEMENT OF RARE CONDITIONS IN THE NEONATE.

This year the day will be completely online and we are delighted that, once again, there will be no charge to attend!

Register now to secure your place

https://link.webropol.com/ep/9thneonatalevent

Book Now for the 9th Annual

Early Management of Rare Conditions in the Neonate

Monday 1st September 2025

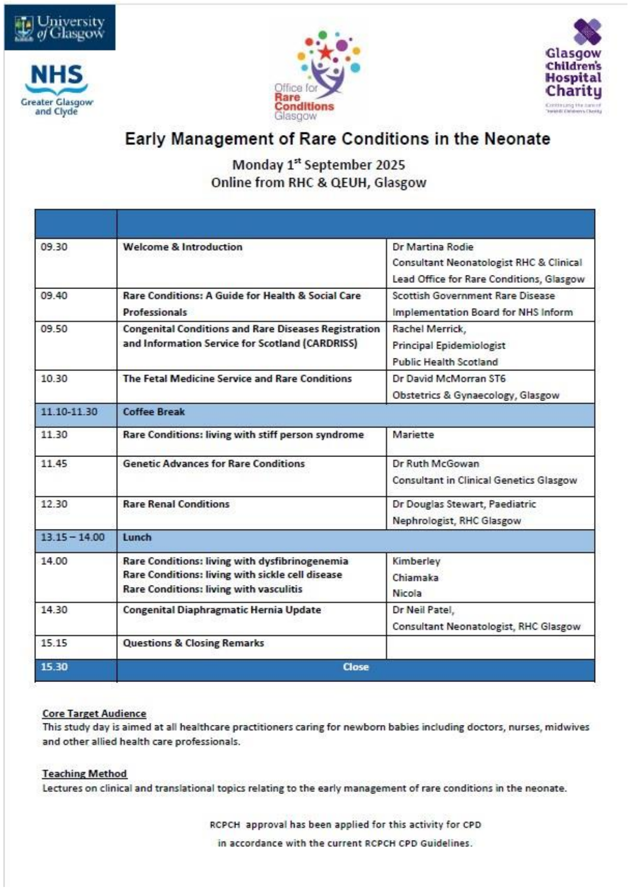
Join us online – no travel required!

Now in its 9th year, this well-established event brings together expert speakers and collaborative learning — all delivered via Zoom.

We are delighted to once again be able to offer this study day FREE to all healthcare professionals!

Register here:

https://link.webropol.com/ep/9thneonatalevent



University of Glasgow

NHS Greater Glasgow and Clyde

Office for Rare Conditions Glasgow

Glasgow Children's Hospital Charity

Early Management of Rare Conditions in the Neonate

Monday 1st September 2025
Online from RHC & QEUH, Glasgow

09.30	**Welcome & Introduction**	Dr Martina Rodie Consultant Neonatologist RHC & Clinical Lead Office for Rare Conditions, Glasgow
09.40	**Rare Conditions: A Guide for Health & Social Care Professionals**	Scottish Government Rare Disease Implementation Board for NHS Inform
09.50	**Congenital Conditions and Rare Diseases Registration and Information Service for Scotland (CARDRISS)**	Rachel Merrick, Principal Epidemiologist Public Health Scotland
10.30	**The Fetal Medicine Service and Rare Conditions**	Dr David McMorran ST6 Obstetrics & Gynaecology, Glasgow
11.10-11.30	**Coffee Break**	
11.30	**Rare Conditions: living with stiff person syndrome**	Mariette
11.45	**Genetic Advances for Rare Conditions**	Dr Ruth McGowan Consultant in Clinical Genetics Glasgow
12.30	**Rare Renal Conditions**	Dr Douglas Stewart, Paediatric Nephrologist, RHC Glasgow
13.15 – 14.00	**Lunch**	
14.00	**Rare Conditions: living with dysfibrinogenemia** **Rare Conditions: living with sickle cell disease** **Rare Conditions: living with vasculitis**	Kimberley Chiamaka Nicola
14.30	**Congenital Diaphragmatic Hernia Update**	Dr Neil Patel, Consultant Neonatologist, RHC Glasgow
15.15	**Questions & Closing Remarks**	
15.30	**Close**	

Core Target Audience
This study day is aimed at all healthcare practitioners caring for newborn babies including doctors, nurses, midwives and other allied health care professionals.

Teaching Method
Lectures on clinical and translational topics relating to the early management of rare conditions in the neonate.

RCPCH approval has been applied for this activity for CPD
in accordance with the current RCPCH CPD Guidelines.

7 - Early Management of Rare Conditions in the Neonate:Programme

A Fond Farewell and Heartfelt Thanks to Liz Dougan

Project Manager, Office for Rare Conditions Glasgow

In September 2025, after nearly nine years at the heart of the Office for Rare Conditions Glasgow, our dedicated Project Manager, Liz Dougan, will be retiring. Liz joined the team in December 2016, just ahead of the official launch of the Office in early 2017. From the very beginning, she has played a pivotal role in shaping its direction and ethos. With professionalism, warmth, and a clear sense of purpose, Liz has helped establish a vibrant network of support, connecting individuals and families living with rare and undiagnosed conditions with the healthcare professionals and services that can best support them. Her initiative and creativity in responding to the needs of patients and families has been a hallmark of her work — whether finding new ways to communicate complex information, developing tailored resources, or building relationships across hospital departments to ensure families feel supported and understood. Among her many achievements, Liz has:

- Organised a wide range of impactful events — including patient information sessions, educational workshops, and family fun days;
- Supported the creation and development of our Patient Advisory Group;
- Provided vital support to the Patient Navigator role;
- Supervised and mentored administrative staff with care and attention;
- Contributed to awareness-raising and educational efforts for healthcare professionals;
- Compiled project reports and created newsletters and notice boards to share valuable information about rare conditions;
- Fostered strong links with charities and patient support organisations, building lasting partnerships and collaborative initiatives.

Through her thoughtful leadership and deep understanding of people's needs, Liz has helped make the Office a recognised centre of connection and compassion. Her ability to bring people together — patients, families, clinicians, and support organisations — has had a lasting impact and will be remembered with gratitude by all who have worked with her.

As Liz prepares for her well-earned retirement, we offer our heartfelt thanks for her years of outstanding service — and our warmest wishes for the adventures that lie ahead.

Follow us on Social Media! @ORC Glasgow

Office for Rare Conditions

Office Block Zone 0.01

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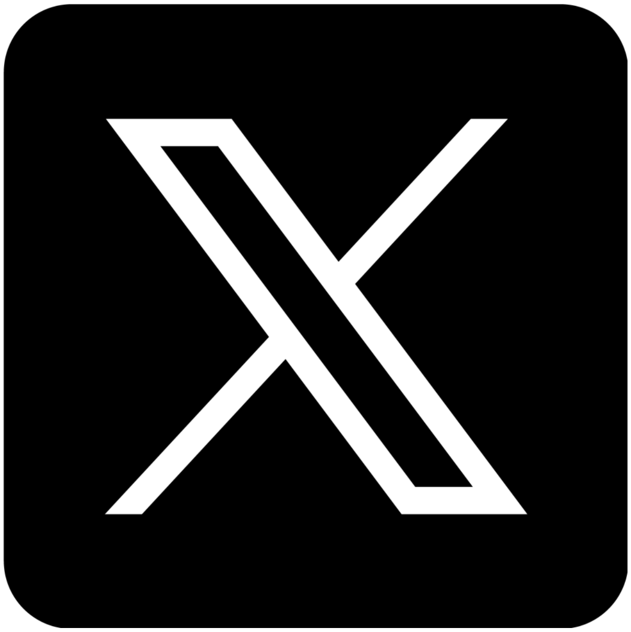
8 - @orcglasgow



9 - @ORCGlasgow

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11 - www.officeforrareconditions.org