RARE DISEASE RESEARCH UK

NEWSLETTER

A forum to illuminate the latest advancements within the rare disease research community.

Rare Disease Research UK (RDR UK) is a £14 million platform to advance research into rare diseases, jointly funded by MRC and NIHR. The platform is made of 11 research nodes, led by various universities across the country, involved in both disease-area-specific and cross-cutting research, and a coordinating hub - hosted by Newcastle University, Newcastle upon Tyne Hospitals NHS Foundation Trust and Genetic Alliance UK, to connect the nodes and provide a well signposted route into the platform for external collaborators, including patients, researchers, industry and international partners.

We're thrilled to share the sixth edition of our quarterly newsletters, packed with insights, activities and updates from across the RDR UK Platform that we're eager to share with you.

With each edition, we aim to illuminate the latest advancements within the rare disease community, share compelling stories, and foster collaboration among researchers, industries, and patients.

NEWS

Congratulations to Professor Francesco Muntoni!

Professor Francesco Muntoni, Chair of Paediatric Neurology at UCL and member of the UPNAT node, has been awarded the 2026 Novo Nordisk Prize for his groundbreaking research bringing new hope to children with Duchenne muscular dystrophy. Find out more...

ExPRESS Node

The ExPRESS node continues to make strong progress, with a total of 78 participants recruited to date, including ~30 since October 2025. They are collecting a wide range of samples, including DNA, plasma, serum, skin biopsies, and CSF, to support our research into parkinsonism & related syndromes. The study is now active across more than 20 sites throughout England, Scotland, and Wales, reflecting excellent national collaboration. They are also looking forward to engaging with the public at their information stall at the UCLH Research Open Day in July 2026.

RDR UK at the LifeArc Translational Science Summit

Prof Dave Jones, Hub Lead for the Rare Disease Research UK Platform, takes to the stage to share the Platform's vision and progress in advancing rare disease research across the UK.

Vicki Hedley, Hub Co-Lead, and Anna Halstead, Senior Project Manager, along with Dr Amber Hart, Project Manager of Accelaration of Rare Disease Trials centre, attending the LifeArc Summit and connecting with partners and collaborators from across the rare disease community.

3rd RDR UK Annual Conference

The 3rd annual Rare Disease Research UK conference was held on 16 April, 2026 at The Birmingham Conference and Events Centre, Birmingham. The day brought together 109 researchers, clinicians, patients, carers, policy makers and industry representatives, with an additional cohort of 42 joining us live. The theme of the conference was ‘The Power of Collaboration’ and every session reinforced that meaningful progress in rare disease research requires everyone working together and not in parallel.

NEWS

Early Career Rare Disease Researcher Award

Early Career Rare Disease Research Award - celebrating the outstanding work of early career researchers from across the RDR UK nodes.

Congratulations!!🎉

Winner: Katarina Gunter
First runner-up: Karen Low
Second runner-up Riona Fumi

The standard of work this year was a real testament to the talent and dedication of early career researchers in the rare disease space.

NEWS

Early Career Researcher Award in PPIE

Early Career Rare Disease Researcher Award in PPIE - celebrating outstanding early career researchers who are advancing meaningful patient and public involvement and engagement in rare disease research!

Congratulations!!🎉

Winners: Laura Cristescu and Chris McQuade
Runners up: Aimee Walker and Linda Fred

Highly commended teams: Eleanor Williams and Helen Bedford-Gay, Laura Kirton and Andrew Westwood, Sergio Julius and Ella Mercer!

GET INVOLVED

RDR UK Hub Team at the CamRARE Fest

The Rare Disease Research UK REOLUT team is excited to be running a series of discussion sessions over the coming months with families affected by rare lower urinary tract conditions.

There will be dedicated sessions for parents and carers (of a child of any age), as well as sessions specifically for 11–18 year olds. Each session will be chaired by engagement specialists from our charity partners, ERIC, The Children's Bowel & Bladder Charity and Vocal, ensuring conversations are inclusive, accessible, and truly reflective of families' lived experiences.

Together, the discussion sessions will focus on:

🔎 Improving understanding of patient and family experiences across the care pathway

🧠 Identifying and prioritising the research questions that matter most to families

🌱 Strengthening partnerships with families and growing their engagement and involvement across our research

If you meet the criteria below, please take a look at the flyer for more information and register!

✔️ Has lived experience of rare lower urinary tract conditions

✔️ Feels comfortable sharing their views in small group discussions with other families

✔️ May have an interest in research

BOOK YOUR CALENDAR

3rd REOLUT Conference

9 July 2026

📍 *Room G15, Wolfson Centre, UCL Institute of Child Health, 43 Mecklenburgh Square, London, WC1N 2AJ*

The REOLUT node is delighted to announce the 3rd REOLUT Conference, which will be held as an in-person event. This event promises to be a dynamic platform for collaboration, bringing together leading researchers, clinicians, and patient groups to explore key topics relating to Lower Urinary Tract Disorders in rare conditions. Find out more and register here.

2nd ELSI Conference

19 November 2026

📍 *Glamorgan Building, Cardiff CF10 3NS*

The ELSI Node is pleased to invite researchers, healthcare professionals, policymakers and patient support groups to share experiences, cases, and insights on the Ethical, Legal, and Social Issues (ELSI) surrounding rare conditions at the 2nd ELSI Conference, hosted at Cardiff University UK. Find out more and register here.

Reach out to us at hub@rd-research.org.uk if you are interested in getting involved in our PPIE activities.

If this newsletter has been forwarded to you, and you'd like to register to receive it directly, please subscribe to our mailing list below.

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