

RARE DISEASE FORUM

WRAPPING DISABILITY SERVICES AROUND RARE DISEASES

Wed 18th Oct 2023, 6.30-8.00 pm - ONLINE MEETING

[REGISTER HERE](#)

Rare Diseases Ireland (RDI) and Northern Ireland Rare Disease Partnership (NIRDP) are pleased to invite you to the upcoming Rare Disease Forum event. This event aims to highlight the gap between disability services and care for people living with rare diseases.

Wrapping Disability Services Around rare Diseases

Disability is an umbrella term covering impairment, activity limitation, and participation restrictions. Many people living with rare diseases also have disabilities and need disability services. However, they often face difficulties getting access to these services – either disability services don't recognise their diagnosis or there is no pathway. This meeting will explore what is being done to bring the rare community under the disability umbrella and what more needs to be done.

Agenda

18.30 Welcome from the meeting chair

Rosaline Callaghan; Person with lived experience of a rare disease, Rare Disease Forum Steering Group member and NIRDP volunteer.

18:35 Setting the scene: living with a rare diseases and disability.

Ciara Micks living with Ehlers Danlos Syndrome

18:45 Rare disease policy and the overlap with disability

Helena Brown, Northern Ireland Department of Health

19:00 Disability advocacy – capturing rare disease needs

Cathy McGrath, Disability Federation of Ireland

19:15 Panel discussion and audience questions

Helena Brown, Northern Ireland Department of Health

Cathy McGrath, Disability Federation of Ireland

Gary Brennan, Prader Willi Syndrome Association Ireland

TBC

19:45 Audience engagement

Vicky McGrath; CEO Rare Diseases Ireland.

19:55 Reflections and meeting close

Who should attend?

The meeting is open to people living with rare diseases, caregivers, patient organisations, as well as key stakeholders, including healthcare professionals, healthcare managers, policymakers, politicians, industry, researchers and anyone with an interest in rare diseases. **Please share the link to register with anyone you think might be interested.** <https://bit.ly/RDForumOct2023>

Other useful information

When you register, you will be sent a Zoom **link to log on to the meeting at 6:30pm on October 18th**. Your microphone will be muted but we encourage people to have their camera on. You will be able to ask questions through the chat box. As it is an evening event, we want to keep it short, so we may not get to all questions. **It's important to note that it won't be possible to answer clinical questions or questions about an individual's care.**



The Rare Disease Forum (RDF) is a collaborative Patient and Public Involvement (PPI) initiative for the 32 counties of Ireland. Its primary aim is to address the pressing health and social care needs of individuals living with rare diseases in Ireland. The RDF Steering Group comprises Rare Diseases Ireland, the Northern Ireland Rare Disease Partnership, Rare Ireland, Health Research Charities Ireland, and the Irish Platform for Patient Organisations, Science and Industry and two contributors with lived experience of rare disease.

The Rare Disease Forum serves as a platform for inclusive discussions, informative events, and meaningful progress in tackling the significant challenges faced by individuals with rare diseases. Meetings are open to people living with rare diseases, caregivers, patient organisations, as well as key stakeholders, including healthcare professionals, researchers, industry representatives, funders, policymakers, politicians, and anyone with an interest in rare diseases. Please note that the events primarily focus on overarching topics, and will not specifically address individual rare diseases and individual needs.