

Rare Disease Research Conference, 5th November 2026, UCD

Welcome	Prof Rachel Crowley and Prof Cormac McCarthy Co-leads RDCTN	09.00
Session 1	Orphan Medical Devices - Innovation and Regulation	09.10
	- Regulatory Perspective – Dr Donal O'Connor, Health Products Regulatory Authority - Orphan Devices Key Advances – Dr Anneliene Jonker, University of Twente - Industry Perspective – Ms Gwynne Morley, IQVIA & HealthTech Ireland - Panel Discussion	
Trial Spotlight	EB Shield - Dr Fiona Browne, Children's Health Ireland	10.05
PPI Leadership	Shaping & Modelling Best Practice through Partnership - Dr Cassy Dinius, RDCTN	10.15
Networking	Poster Review, Refreshments	10.30
Trial Spotlight	PROSERA - Dr Sarah Cullivan, Mater University Hospital	11.00
Session 2	Innovation, Regulation & Data Systems	11.10
	- Innovative Methodologies - Prof. Dr. Ralf-Dieter Hilgers, RealiseD - Pathways to Rare Disease Therapies - Prof Claire Booth, Great Ormond St Hospital & University College London - Health & Data Systems for Research & Clinical Trials - Prof Catherine Quinlan, Children's Health Ireland - Panel Discussion	
Patient Spotlight	Ms Linda Sheehan, IMPALA 2 Participant in conversation with Prof Bruce Trapnell, Cincinnati Children's Hospital (PI), Mr Brian Robinson, Savara and Prof Peter Doran, UCD Clinical Research Centre.	12.30
Networking	Poster Review, Lunch	13.00
Trial Spotlight	ATMPs - Prof Martina Hennessy, St James's CRC	14.00
Session 3	Efficiency & Effectiveness in Treating Rare Diseases	14.10
	- Introduction: A Patient Perspective – Ms Eva Lally, RDCTN PPI Panel - Overview of Drug Repurposing – Mr Anton Ussi, Eatris & Remedi4All - Case Study: MOI-A Study - Prof Nick Bishop, University of Sheffield - Panel Discussion	
Networking	Poster Review, Refreshments	15.15

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Research spotlight	Poster Lightning Talks	15.45
Session 4	Policy Driven Innovation	16.00
	• European Policy & Partnerships – Dr Daria Julkowska, ERDERA • National Rare Disease Strategy – Prof Atif Awan, National Rare Disease Office • Policy Driven Research Northern Ireland – Prof Amy Jayne McKnight, Queens University Belfast • Panel Discussion	
Awards	Prof Sean Ennis Tribute and Award Presentation	16.45
Meeting Close	Prof Rachel Crowley and Prof Cormac McCarthy Co-leads RDCTN	17.00