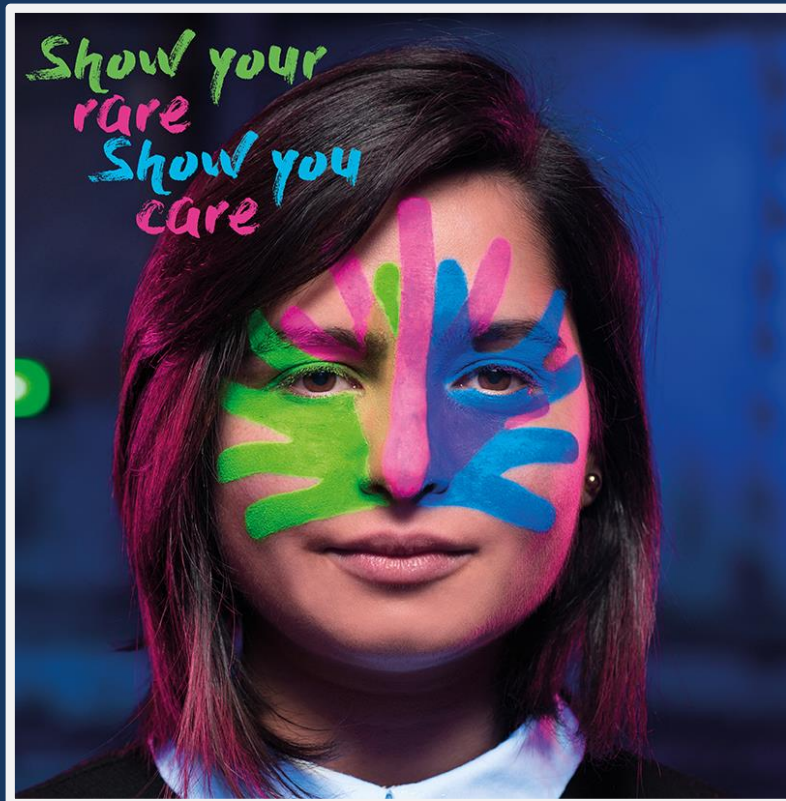


RARE DISEASE SYMPOSIUM



03rd May 2018
8.30 am – 1.00 pm

George Moore Auditorium
UCD O'Brien Centre
for Science

#UCDRDS2018
#ShowYourRare



SCHEDULE:



0830	Registration & Networking	
	Chair: Philip Watt , CEO, Cystic Fibrosis Ireland	
0900-0910	Welcome Address	Prof Orla Feely , UCD Vice President for Research Impact and Innovation
0910-0920	Rare Diseases- Progress at National & European Context	Prof Eileen Tracey , Clinical Lead, National Clinical Programme for Rare Diseases
0920-0930	Rare Diseases: National Plan Review	Simon Harris , Minister for Health (TBC)
0930-0940	UCD Academic Centre on Rare Diseases updates	Dr Sean Ennis , Director UCD Academic Centre on Rare Diseases
0940-1020	<p>Conversation: Innovative Approaches to Rare Diseases</p> <p>Chair: Dr Avril Kennan, CEO, Medical Research Charities Group</p> <p>Participants:</p> <ul style="list-style-type: none"> ▪ Prof Thilo Kroll, Prof of Health Systems Management, HRB PPI Ignite Lead for UCD, UCD School of Nursing, Midwifery and Health Systems ▪ Dr Atif Awan, Consultant Pediatric Nephrologist, Temple Street Children's University Hospital ▪ Prof Sally Ann Lynch, Consultant Clinical Genetics, Our Lady's Children's Hospital Crumlin ▪ Mr Nigel Nicholls, Director and Country Manager UK/Ireland for BioMarin Europe Ltd. 	
1020-1050	Coffee Break	
A Cross-Border Perspective on Rare Diseases		
1050-1110	Social Care in Rare Diseases 'INNOVA Care Project'	Raquel Castro , Head of Social Policy EURORDIS
1110-1130	Stronger- Together	Julie Power , Vasculitis Ireland

1130-1210

Conversation: Nothing about us without us- Holistic Care

Chair: **Dr Avril Daly**, Chair Rare Disease Ireland, Vice President EURORDIS- Rare Diseases Europe, CEO, Retina International

Participants:

- **Dr Suja Somanadhan**, Assistant Professor of Children’s Nursing, UCD School of Nursing Midwifery and Health Systems
- **Ms Anne Lawlor**, Parent, Chairperson of the 22q11 Ireland Support Group
- **Mr Gary Woods**, My sibling is my hero, Mucopolysaccharidosis III or Sanfilippo Syndrome
- **Ms Maureen Mason**, Transition Nurse Coordinator, National Rare Diseases Office

Chair: **Dr Paula Byrne** Associate Professor, UCD School of Medicine

1210-1220

Rare Diseases:

Kate Bailey, Medical Student

Student’s Perspectives

John Hutchings, Nursing Student

1220-1240

Rare Diseases and Funding Opportunities

Kay Duggan Walls, Health Research Board of Ireland (HRB), EU Project Officer & National Contact Point for Health, Horizon 2020

1240-1250

Research Support UCD

Dr Anne-Louise Holloway, Research Programme Officer National Programmes, UCD Research & Innovation

1250-1300

Key Learning and Next Steps

Dr Derick Mitchell, CEO IPPOSI

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Unity is our Strength



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