
RARE DISEASE SYMPOSIUM

02nd March 2018

0830- 1300

University College Dublin (UCD)

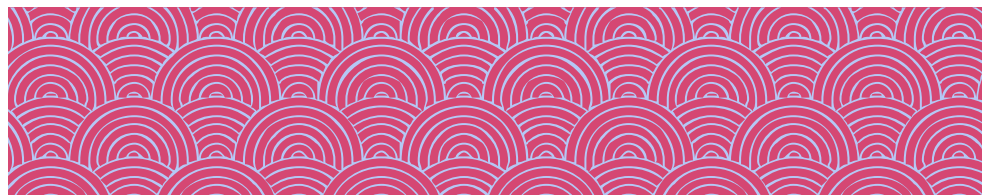
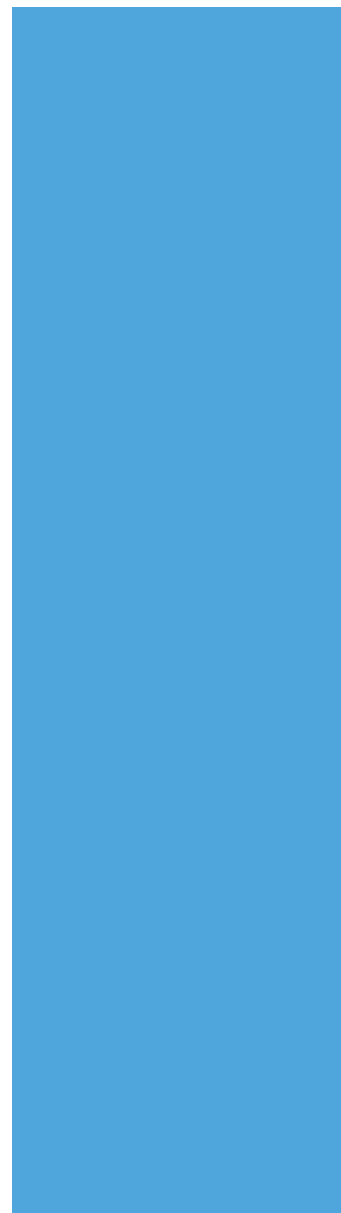
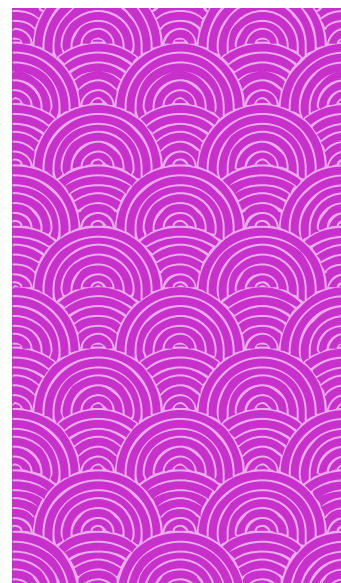
George Moore Auditorium

O'Brien Science Centre

Belfield, Dublin-4, Ireland

www.ucd.ie

UCD O'Brien Centre for Science



0830 am Registration & Networking

Chair: Philip Watt (CEO) Cystic Fibrosis Ireland)

0900 am Welcome Address UCD President Professor Andrew J Deeks (TBC)

0910-0920 am Rare Diseases- Progress at National & European Context Prof Eileen Tracey (National Clinical Lead, Rare Diseases)

0920-0930 am Rare Diseases: National Plan Review (TBC) Simon Harris-Minister of Health

0930-0940 am UCD Academic Centre on Rare Diseases updates Dr Sean Ennis - Director UCD Academic Centre on Rare Diseases

0940-1030 am Conversation: Innovative Approaches to Rare Diseases

Chair: Dr Avril Kennan (CEO, MRCG) (Introduction)

Participants:

- Prof Thilo Kroll (Prof of Health Systems Management, UCD)
- Dr Atif Awan (Consultant Paediatric Nephrologist, TSCUH)
- Prof Sally Ann Lynch (Consultant, OLCHC)
- Mr Fred Doherty (Genzyme)

1030- 1100 am Coffee Break

1100-1120 am Social Care in Rare Diseases 'INNOVA Care Project' (TBC) Raquel Castro -Head of Social Policy EURORDIS

1120 -1130 am Stronger- Together (TBC) Alison Wilson (MPS All Ireland Patient Advocacy Officer)

1130-1210 pm Conversation: Nothing about us without us- Holistic Care

Chair: Dr Avril Daly (CEO, Retina International) (Introduction)

Participants:

- Dr Suja Somanadhan (Asst Prof Children's Nursing, UCD)
- Ms Anne Lawlor (Parent, 22q11 D)
- Ms Meabh Hennelly (Sibling, Cystinosis)
- National Rare Diseases Office Representative

1210-1225pm	Rare Diseases: Student's Perspectives	Nursing Student Medical Student
--------------------	---------------------------------------	------------------------------------

1225- 1235 pm	Rare Diseases and EU Funding	Ms Dipti Pandya, UCD Research
----------------------	------------------------------	-------------------------------

1235-1245 pm Key Learning & Next Steps

Dr Derick Mitchell (CEO, IPPOSI)

Conference location: George Moore Lecture Theatre, O'Brien Centre for Science (East), University College Dublin, Belfield, Dublin 4

Venue: Click [here](#) to view the UCD Campus Map. The O'Brien Centre for Science (East) is numbered 67 on the map. It is a short walk from the main UCD entrance on the N11. The main conference sessions will be held in the George Moore Auditorium on the Ground Floor of the building, on the left-hand side of the main foyer, beside the elevators. Coffee breaks will take place in the Ground Floor Atrium, beside the George Moore Auditorium.

Transport options: UCD is easily accessible by public transport. A useful [online guide to getting to UCD](#) is available to help you plan your journey. A shuttle bus will be available between Sydney Parade DART Station and UCD for a charge of €1 Driving.

Please note the very limited availability of car parking and, if you decide to drive, consider car sharing.

