

Innovative Approaches to Rare Diseases Research, Education and Awareness

[Poster No: 213 Poster theme : 8]

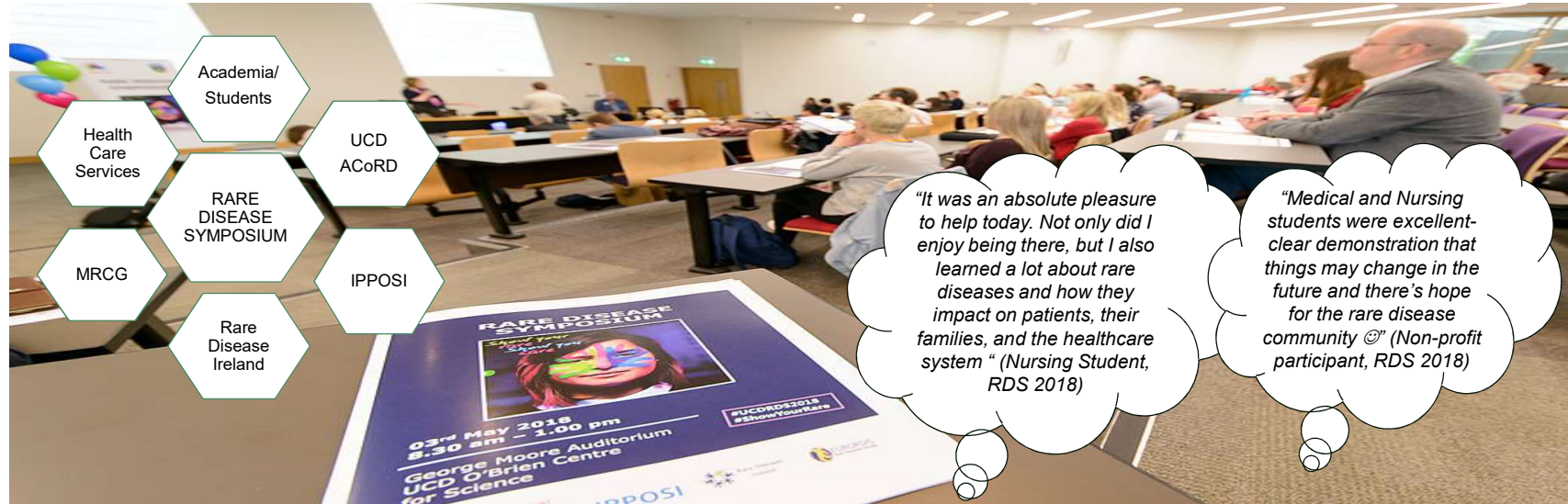
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Background

A rare disease symposium was organised on the 03rd of May 2018 in Dublin, to raise awareness among healthcare professionals, policymakers and the public about rare diseases and its impacts on patients and their families' lives. University College Dublin hosted this open event which was open to the public and guests. This was supported by Rare Disease Ireland, the Medical Research Charities Group (MRCG), the Irish Platform for Patient Organisations (IPPOSI). This symposium was also linked with the Health Research Board Ireland (HRB) funded Patient, and Public Involvement (PPI) Ignite initiative, which seeks to grow PPI competency across all health and social care research in close collaboration with the patient and public partners.

Rare Disease Symposium Collaborators



"It was an absolute pleasure to help today. Not only did I enjoy being there, but I also learned a lot about rare diseases and how they impact on patients, their families, and the healthcare system" (Nursing Student, RDS 2018)

"Medical and Nursing students were excellent- clear demonstration that things may change in the future and there's hope for the rare disease community" (Non-profit participant, RDS 2018)

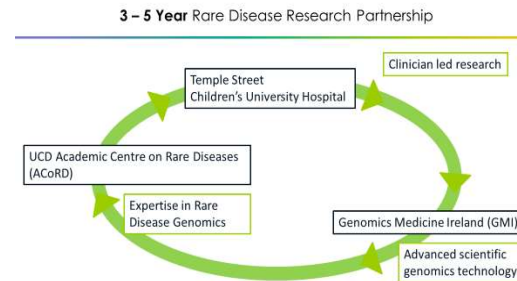
Key Features

- The panel conversations were based on "Innovative Approaches to Rare Diseases" and "Holistic Care in Rare Diseases" involving patients, families, siblings, clinicians, academics and policymakers.
- Rare Disease symposium outcome results are presented in this poster to stimulate further international discussion.

Social Media

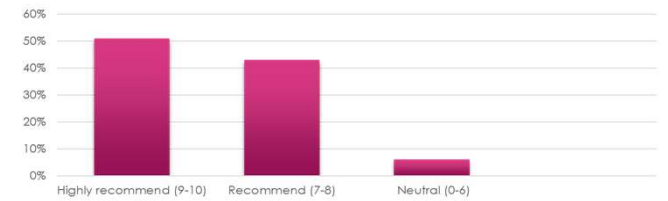


Rare Disease Research



Rare Disease Education

How likely is it that you would recommend symposium to a friend or colleague?



Rare Disease Awareness

Networking



- Research 1**
Parents experience of living with and caring for children with MPS- rare diseases (2010-2016)
- Research 2 (IMPACT Study)**
Measuring the impact of caring for children with rare diseases (Parents /HCPs)(2017-Present)
- Research 3**
Measuring the social needs of families of children with rare diseases (2018-Present)
- Research 4 (SAMPI)**
Giving voice to the children and their families with Rare Diseases (Sand Therapy, Arts, Music, Photo Voice, and Interviews)



Acknowledgement
Should you have any queries or require any further information please do not hesitate to contact us: email: rarediseasesymposium@ucd.ie