

Joint North South All Ireland Rare Disease Conference 2018:
Patients as prime movers in Rare Disease Research

We are busy finalising the programme for this, the Fourth Joint North South Rare Disease Conference. There are still some details to sort out, but see below for the latest version.

Programme

09.00 – 10.15	REGISTRATION AND COFFEE
10.15 – 10.30	Welcome and Introductions <i>Fiona McLaughlin, Chair NIRDP & Philip Watt, Chair MRCG</i>
10.30 – 10.45	“Nothing about us without us” <i>Les Allamby, Chief Commissioner, NIHRC</i>
10.45 – 11.30	Rare Disease and the Strategies <i>Dr Michael McBride, Chief Medical Officer, DoH (NI)</i> <i>Another Speaker TBC</i>
11.30 – 12.30	Participating in Research <i>Dr Maurice O’Kane, NI Clinical Research Network</i> <i>Dr Claire Lundy, Regional Paediatric Neurodisability Service</i> <i>Another Speaker TBC</i>
12.30 – 13.30	LUNCH
	Poster Competition: “Nothing About Us Without Us”
	Side Event – Northern Ireland Human Rights Commission
13.30 – 14.15	Panel Discussion – BUILDING CAPACITY <i>Chair – Mary Hinds, PHA</i> <i>Panellists to include: Derrick Mitchell, IPPOSI; Gemma McKillen, EUPATI; Julie Power, VIA.</i>
14.15 – 15.15	WHAT DOES SUCCESS LOOK LIKE? 100k Genomes Programme – <i>Dr AJ McKnight</i> The 22 Q Journey: Anne Lawlor, Chairperson 22q11 Ireland Support Group; Dr Tabib Dabir, BHSC; Gillian Cassidy, 22Q Support Group Dr Mary Dallas, PHA 22 Q Video
15.15 – 15.30	COFFEE BREAK
15.30 – 16.15	Panel Discussion – BEYOND THE STRATEGIES: NEXT STEPS <i>Chair – Professor Ian Young</i> <i>Dr Avril Kennan, MRCG</i> <i>Philip Watt, MRCG</i> <i>Anne Lawlor, Chairperson 22q11 Ireland Support Group</i> <i>2 Members TBC</i>
16.15 – 16.30	PRESENTATION OF POSTER COMPETITION PRIZES & NIRDP AWARDS <i>Fiona McLaughlin, Philip Watt & Professor Ian Young</i>
16.30	CLOSE – <i>Philip Watt</i>