Update from Northern Ireland

Dr Fiona Stewart
Northern Ireland is very small with a population of 1.8 million
We are separated from the rest of the UK by a smallish but very expensive stretch of water – the Irish Sea
We have a land border with another EU state
• Established in 2011
• Involves clinicians, patient organisations, industry
• Organised Rare Disease Day 2014
• Involved in disability pride day in Belfast, Rare disease and Research Even, Rare disease event for medical students
Rare Disease and Research

September 25th 2014
6.30pm
Postgraduate Lecture Theatre
Belfast City Hospital

Food and Drinks reception from 6pm

Programme
6.30 – 6.40 Christine Collins
(NIRD and HDANI)
An Introduction to the Rare Disease Plan

6.40 – 7.00 Majella McConville
(Huntington’s Disease Specialist Nurse)
Huntington’s Disease

KEYNOTE SPEAKER
7.00 – 7.30 Charles Sabine
(International Patient Advocate)
Why does research matter?

7.30 – 8.00 Prof. P Morrison MD DSc
(Professor in Genetic Medicine)
Research on a Shoestring

8.00 – 8.15 Dr Amy Jayne McKeight
(Queens University Senior Lecturer)
Rare Disease Research – the nuts and bolts!

8.15 – 8.30 All Speakers
Panel Discussion

Registration: Please register by way of email to events@nirdp.org.uk
Please include any dietary requirements
Rare disease Day 2014

• Cross border meeting
• Attended by both Ministers of Health
• Good attendance
We got a new Minister for Health
• Northern Ireland statement of intent was put out to consultation at an event organised by NIRDP on October 27th
• Attended by MLA’s, health care professionals and patient organisations
• Consultation is for 12 weeks
Consultation Process

• Statement of intent has been circulated to as many health care professional and patient organisations as possible

• ‘Road shows’ with a DHSS person, a clinician and an NIRDP person are being organised throughout Northern Ireland
What are we doing in the meanwhile to deliver services to individuals with rare diseases?
• **Send people** Some highly specialised services are only provided at major centres in other parts of the UK e.g. liver and heart transplantation, major craniofacial surgery etc.

• **Bring people in** For consultations it may make sense to bring specialists from elsewhere to NI to see patients in a specialised clinic.
Examples

• Out reach paediatric hepatology service from Birmingham four times per year

• Metabolic bone marrow transplant specialist from Manchester will come over and talk to families and the local team prior to any particularly challenging transplants

• Multidisciplinary MPS clinic held in Belfast in partnership with the patient organisation and medical colleagues from Manchester
Partnership with patient organisation

• MPS clinic
• Held twice a year
• MPS society fund Dr Simon Jones and sometimes one of the nurses to do a multidisciplinary clinic with the local metabolic/genetics team and all relevant clinicians
• Now in its nineteenth year......
Cross border initiatives

• A great opportunity
• Some issues – different health care system with different funding, major economic crisis
• Political history was not conducive to this but we are in a much better climate for this now
IRELAND-26
AUSTRALIA-23

Successful cross border co-operation can achieve a great deal!