



Rare Diseases
Ireland

Rare Diseases Ireland Round Table of Companies

(RDI – RTC)
22 Nov 2018

Avril Daly, Chair RDI, VP EURORDIS,
CEO Retina International

Who we are....

- National Alliance of patient organisations, charities and voluntary groups acting as a voice for those affected or at risk of being affected by a genetic, inherited condition
- Board made up of patient groups
- A MSAB, Dr Avril Kennan, Dr David Barton, Prof. Dr. Eileen Treacy

A dynamic environment requires adaptability

Change of name not purpose.....

- Formed in 1988 as IDO – Inherited Disorders Organisation
- Changed name to GIDO – Genetic Inherited Disorders Organisation
- Changed name to GRDO – Genetic and Rare Disorders Organisation
- Changed name to Rare Disease Ireland

Why we formed

- To advocate for the establishment of a national center for medical genetics,- established at Our Lady's Children's Hospital Crumlin in 1994
- acted as a watchdog against the practice of genetic discrimination
- Developed voice in the development of policy to meet the needs of the rare disease community on issues concerning, access to a diagnosis and the appropriate medical and social care

Active in European policy since 1997

- Adoption of the EU Regulation on Orphan Medicinal Products in 1999
- Adoption of the EU Commission Communication on Rare Diseases in 2008
- Adoption of the EU Council Recommendation on European Action for Rare Diseases in 2009
- Adoption of the EU Directive on Patients' Right to Cross-Border Healthcare in 2011
- The promotion and maintenance of rare diseases as an EU Public Health Policy priority and an EU Research Framework Programme priority
- Promotion of National Plans and Strategies on Rare Diseases in EU Member States and beyond, resulting in the publication of the Irish National Plan for Rare Diseases in 2014
- The development of the annual International Rare Disease Day

Road to National Plan 1.0...

- November 2007 - Members of group to devise Rare Disease Day, 2007
- 2010/11 – EuroPlan Conference, Farmleigh multistakeholder event
- Rare Diseases Towards 2013 Taskforce – MRCG, IPPOSI & GRDO (RDI)
- February 2011, formation of steering committee on NP development at DoH
- June 2012, Europlan 2, outcomes of subgroups, surveys and consultation discussed
- December 2013 NP Finalised
- July 2014 NP launched by Minister
- September 2014, Oversight committee at DoH established

Implementation.....

- Recognition of rare disease – Information and research
- Access to diagnosis and care
- Prevention, diagnosis and care
- Development of research strategy
- Empowering, protecting and supporting rare disease patients and carers
- Implementation, monitoring and review of the National Rare Disease Plan

Key Achievements

- 2014 - Establishment of National Clinical Programme for Rare Disease
- 2015 - Establishment of National Office for Rare Disease
- 2018 - Establishment of Rare Disease Technology Review Committee

National Plan 2.0.....

- 2018 Turing attention to National Plan 2.0
- July 2018, approval from Health Minister to support next steps
- Review of what has been implemented to date what needs revision
- Work on implementation of recommendations not yet in place and still valid

STRUCTURED COLLABORATION

Next steps in multistakeholder engagement