



Rare Disease Day

**Focus on Rare Diseases in Ireland;
What is the National Plan?**

European Public Information Centre,
European Union House, 18 Dawson St, Dublin 2

Wednesday 25th February 2009

9.30am Opening: A Patient's Perspective
Ms Doris Noe, Pompe Patient

Session 1

- 9.45am – 9.50am Welcome
Chair: **Ms Eibhlin Mulroe**, Chief Executive, IPPOSI
- 9.50am – 10.05am Accessing Treatment and the Experience of Rare Disease Patients in the UK
Mr Eric Low, Chief Executive, Myeloma UK
- 10.05am – 10.25am Plan for Rare Diseases in Europe
Ms Christel Nourissier, General Secretary, European Rare Diseases Organisation (EURORDIS)
- 10.25am – 10.40am What can Ireland learn from other EU countries – a patient perspective
Mr Larry Warren, Chief Executive, Alpha1
- 10.40am – 10.55am What can Ireland learn from other EU countries – an industry perspective
Mr Brendan Martin, UK & Ireland Business Unit Director, Genzyme Corporation
- 10.55am – 11.10am Discussion
- 11.10am – 11.25am *Coffee*

Session 2

- 11.25am – 11.30am Chair: **Ms Avril Daly**, Chairperson, GRDO
- 11.30am – 11.45am A Case Study: The Importance of Research into Rare Diseases in Ireland
Dr. Patrick Harrison, University College Cork (UCC)
- 11.45am – 12.00pm A Case Study: Diagnosis is difficult and for many Rare Diseases there is no cure
Dr. Aisling Ryan, Neurology, Cork University Hospital
- 12.00pm – 12.15pm Economics of Orphan Medicines
Mr Paolo Morgese, Market Access Manager, Health Policy & Market Access – Europe, Merck Serono SA, Geneva
- 12.15pm – 12.30pm Department of Health and Children and its role in developing a plan for Rare Diseases
Speaker from the Dept. of Health & Children
- 12.30pm – 12.50pm Discussion
- 12.50pm – 1.00pm Closing Comments
Mr John McCormack, Chairperson, MRCG
- 1.00pm *Lunch*