

## European Conference on Rare Diseases & Orphan Products highlights added value of EU collaboration for patients

### #ECRD2016

**26 May 2016, Edinburgh** – The 8<sup>th</sup> edition of the [European Conference on Rare Diseases & Orphan Products](#) (ECRD) kicks off today in Edinburgh.

Held for the first time in the UK, ECRD 2016 brings together more than 700 participants from over 40 countries including patient representatives, healthcare professionals, researchers, industry, payers, regulators and policy makers.

ECRD 2016 focuses on how cross-border collaboration across the EU and within the UK can help to improve the lives of the 30 million Europeans living with a rare disease. The conference provides a platform to concretely demonstrate the importance of EU-level actions in the field of rare diseases.

The ECRD 2016 theme '[game changers](#)' puts the focus on game-changing policies and initiatives in the areas of research, diagnosis, drug development and authorisation, care provision and social policy. The conference will address current and future issues facing rare disease patients and those who support them so that innovative and sustainable responses can be developed.

**Alastair Kent, Director of Genetic Alliance UK and ECRD 2016 co-chair, commented,** “The ECRD creates an opportunity for change. Patients, family members, academics, doctors, policy makers and industry will come together from across Europe and around the globe to share knowledge and experience, and help build a truly international movement committed to responding to the unmet needs of patients and families wherever they live.”

He added, “Being part of a wider community has made this progress possible in ways that nations acting alone would not have been able to manage. ECRD is a critically important element in this. I am proud to be one of the co-chairs of this event.”

**Yann Le Cam, Chief Executive Officer of EURORDIS, Rare Diseases Europe, commented,** “After more than 20 years of work to increase awareness of rare diseases, developments in research and clinical care are coming together in a pan-European policy framework, as demonstrated by the growing number of rare disease medicines and the creation of European Reference Networks.”

More than ever before can be done for the rare disease community. Constrained healthcare budgets add great pressure but create an opportunity for policy and organisational innovation. Participants at ECRD 2016 will discuss game-changing actions that respond positively to new scientific and care advances, and how collaboration between the different players involved and countries across Europe can ensure the success of these actions.

Key speakers at ECRD 2016 Edinburgh include:

- Maureen Watt MSP, Scottish Minister for Mental Health
- George Freeman MP, Minister for Life Sciences (by video)
- ECRD 2016 co-chairs:
  - Alastair Kent, Director, Genetic Alliance UK
  - Wills Hughes-Wilson, Sobi, Sweden
  - Bruno Sepodes, Chair of the EMA's Committee for Orphan Medicinal Products and Professor, University of Lisbon, Portugal
- Xavier Prats Monné, General Director of the European Commission's Health & Food Safety Unit, DG SANTE, EU
- Key international patient advocates and academics
- Young patient advocates also speaking at ECRD 2016 Edinburgh:
  - Emma Rooney, Gaucher disease patient advocate & storyteller, Canada/ Germany
  - Igor Ban, rare cancer survivor, EURORDIS, Serbia
  - Synne Lerhol, Secretary General, The Norwegian Association for Youth with Disabilities
  - Irina Rotariu, Member of ScotCRN Young Person's Advisory Group, Scotland
  - Eszter Becskeházi, Hungary

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European Conference on Rare Diseases & Orphan Products



### **About ECRD 2016 Edinburgh**

The full conference agenda with speakers listed is [available here](#). For more information on ECRD 2016 Edinburgh visit [www.rare-diseases.eu](http://www.rare-diseases.eu). ECRD is organised by EURORDIS, the European Organisation for Rare Diseases, and co-organised by DIA (see below). Follow the conference on social media with **#ECRD2016**.

### **About EURORDIS**

EURORDIS, the European Organisation for Rare Diseases, is a non-governmental patient-driven alliance of patient organisations representing over 700 rare disease patient organisations in 63 countries. EURORDIS represents the voice of an estimated 30 million people living with a rare disease in Europe. Follow [@eurordis](#), see the [EURORDIS Facebook page](#) or visit: [www.eurordis.org](http://www.eurordis.org).

### **About DIA**

DIA is a neutral non-profit organisation founded to provide the global forum that fosters innovation to raise the level of health and well-being worldwide. DIA is engaged in every facet of the discovery, development, and life-cycle management of pharmaceuticals, medical devices, and related products by involving all stakeholders. Visit [www.diaglobal.org](http://www.diaglobal.org).

### **About rare diseases**

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6000 different rare diseases have been identified to date, affecting over 60 million people in Europe and the USA alone. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.



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