

## PRESS RELEASE

# Commissioner Andriukaitis Opens Event on How Patients Influence Rare Disease Policy Making

**24 February 2015, Brussels** – EU Commissioner for Health & Food Safety Vytenis Andriukaitis heads an exciting agenda of speakers at this year's EURORDIS Policy Event, which takes place today in Brussels. The event, which is being held to mark the 8<sup>th</sup> Rare Disease Day, sees people living with a rare disease discuss the 'rare but real' game-changing influence they have had on policy with relevant decision makers.

Commissioner Andriukaitis, who gives the opening remarks at today's event, commented "I believe European action can make a difference in improving the lives of people with rare diseases; people who struggle to find the rare expertise to diagnose and treat their disease. I am committed to working with EURORDIS and all stakeholders to maximise our work towards delivering European solutions to address rare diseases".

Speakers at the event include, among many other esteemed participants, Bojana Miroslavljevic, the mother of a Batten disease patient who influenced change in the prenatal screening law in Serbia, Philip Watt, CEO of Cystic Fibrosis Ireland, a patient group that influenced the reimbursement decision of a cystic fibrosis medicine in Ireland and Philippe De Backer, Belgian Member of the European Parliament.

Yann Le Cam, Chief Executive Officer, EURORDIS, commented, "We are delighted that Commissioner Andriukaitis and our other respected speakers are taking part in this year's event, which highlights the crucial influence rare disease patient organisations have and should have on decisions made in the policy making process. The commitment of patient advocates and policy makers to ensuring the voice of patients is heard in this process drives us forward in our work. This year's Rare Disease Day is bigger than ever and its success is due to the dedication and hard work of patient groups and individuals across the world."

Rare Disease Day 2015 takes place on 28 February. Rare disease patient organisations throughout the world will join together to raise awareness of rare diseases and the millions of people affected by them. Patient organisations in over 80 countries and regions are participating in Rare Disease Day 2015 by holding their own local event, while Bolivia, Estonia and Madagascar are all participating for the first time.

The Rare Disease Day 2015 theme **Living with a Rare Disease** recognises the millions of families, friends and carers whose daily lives are impacted by rare diseases. The 2015 slogan **day-by-day, hand-in-hand** calls for solidarity as together patients, families, carers, patient organisations and healthcare professionals can participate in improving the lives of people living with a rare disease. Learn more at [RareDiseaseDay.org](http://RareDiseaseDay.org).

The 'Rare but Real: Talking Rare Diseases' event is also live streamed on the EURORDIS website ([www.eurordis.org/rareeu2015](http://www.eurordis.org/rareeu2015)) from 10:30 on 24 February, where online viewers can send in questions. Twitter users can also join the discussion using #RareEU2015.

Photos from the event will be available on the [EURORDIS Flickr page](#).

Watch the official Rare Disease Day 2015 video [here](#). A short version of this video for news clips is available on request.

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### **Rare Disease Day**

Rare Disease Day was launched by EURORDIS and its Council of National Alliances in 2008. Held on the last day of February each year, a rare day, it seeks to raise awareness of the impact that rare diseases have on the lives of patients and those who care for them. What began as a European event quickly became international in scope, with participants from more countries joining each year.

Since Rare Disease Day began, thousands of events have been held throughout the world, reaching hundreds of thousands of people. The political momentum resulting from the Day has also served advocacy purposes, contributing to the advancement of EU policies on rare diseases and to the creation of national plans for rare diseases in a number of EU Member States. Visit [RareDiseaseDay.org](http://RareDiseaseDay.org).

### **Rare Diseases**

The European Union considers a disease as rare when it affects fewer 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.

### **EURORDIS**

EURORDIS, the European Organisation for Rare Diseases, is a non-governmental patient-driven alliance of patient organisations representing over 600 rare disease patient organisations in more than 60 countries. EURORDIS represents the voice of an estimated 30 million people living with a rare disease in Europe. Follow [@eurordis](https://www.facebook.com/eurordis) or see the EURORDIS [Facebook page](https://www.facebook.com/eurordis). For more information visit: [www.eurordis.org](http://www.eurordis.org).

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