----PRESS RELEASE----

8th edition of Rare Disease Day

“Living with a Rare Disease: Day-by-day, hand-in-hand”

27 February 2015: **28 February 2015 is Rare Disease Day. EURORDIS and the 30 National Alliance rare disease patient organisations from around the world organise the annual awareness campaign to put rare diseases in the spotlight!**

Throughout the world, hundreds of rare disease patient organisations and their partners will join forces to promote awareness for rare diseases and the millions of people affected by them. Thousands of events will take place, bringing together hundreds of thousands of people in solidarity to improve the lives of people living with a rare disease and their families.

2015 marks eight consecutive, successful years of Rare Disease Day. Continuing the momentum, Rare Disease Day 2015 puts **the focus on the daily lives of patients, families and caregivers** who are **Living with a Rare Disease**.

Patient organisations have also become a crucial source of information, experience and resources. This year’s slogan, ***Day-by-day, hand-in-hand***, emphasizes how together we present a united voice to advocate for the treatments, care, resources and services that we all need. Patients, families and organisations are pivotal to the momentum of creating solutions for the daily challenges of living with a rare disease in solidarity with all stakeholders - caregivers, healthcare professionals, specialised social services, researchers, pharmaceutical companies, policy makers, and regulatory bodies.

Internationally, it is essential to send a strong message of solidarity to the countless rare disease patients and families throughout the entire world. Together, we can transform the individual experience of patients and relatives around the world into collective actions, support, advocacy and community building.

To mark Rare Disease Day 2015, EURORDIS hosted a unique face-to-face discussion event, Rare but Real: Talking Rare Diseases, which included contributions from patient representatives who have had a ‘Rare but Real’ game-changing influence on policy.

Vytenis Andriukaitis, EU Commissioner for Health and Food Safety, gave the opening remarks at this year’s event. He 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.”

EURORDIS also disseminated the official Rare Disease Day poster and video (**over 1 million views!**) along with other communications materials for patient organisations around the world to download and use at their events and in their awareness campaigns. The official video was translated in 25 languages, disseminated around the world via Facebook and YouTube.

Rare Disease Day was launched by EURORDIS and its Council of National Alliances in 2008. Held on the **last day of February each year,** it seeks to raise awareness for the impact rare diseases have on the lives of patients and those who care for them. **A truly worldwide movement, thousands of events for Rare Disease Day are held in over 80 countries and regions, on five continents**. First time participants include patient organisations in Bolivia and Estonia.

The political momentum resulting from the Day has also served advocacy purposes, contributing to the advancement of EU policies on rare diseases and the creation of national plans for rare diseases in a number of EU Member States, and now in other countries.

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 is a non-governmental patient-driven alliance of patient organisations representing over 600 rare disease patient organisations in more than 50 countries. We are the voice of 30 million people affected by rare diseases throughout Europe.

Lara Chappell,
Communications Director
EURORDIS
96 rue Didot - 75014 Paris
Tel: +33.(0)1.56.53.52.60
Lara.chappell@eurordis.org

For more information about Rare Disease Day, the events planned in participating countries and communication materials go to: www.rarediseaseday.org.