PRESS RELEASE

Rare Disease Day 2016

29 February

"Join us in making the voice of rare diseases heard"

3 February 2016, Paris – On the 29 February, the rarest day of the year, patients around the world will mark the ninth annual Rare Disease Day.

People living with or affected by a rare disease, patient organisations, politicians, carers, medical professionals, researchers and industry today come together in solidarity to raise awareness of rare diseases. Rare Disease Day is a patient-led campaign and everyone can get involved!

Organisations in over 80 countries and regions are participating in Rare Disease Day 2016 by holding local events. This year also sees organisations in **Andorra**, **Indonesia, Tanzania, Tunisia** and **Uganda** participate for the first time.

Rare Disease Day 2016 theme and slogan

The Rare Disease Day 2016 theme **Patient Voice** recognises the crucial role that patients play in voicing their needs and in instigating change that improves their lives and the lives of their families and carers.

The Rare Disease Day 2016 slogan **Join us in making the voice of rare diseases heard** appeals to a wider audience, those that are not living with or directly affected by a rare disease, to join the rare disease community in making known the impact of rare diseases. Read more on the 2016 theme and slogan.

Rare Disease Day amplifies the voice of rare disease patients so that it is heard all over the world.

The Rare Disease Day 2016 video has been translated into over 30 languages. A short version of this video for news clips is available on request.

The video celebrates the special moments in the lives of people living with a rare disease. Everybody experiences those special moments with their relatives, children, friends and colleagues. These moments can be big or small, every personal moment is as important as another. For people living with or affected by a rare disease, the emotion during these moments can be very strong as they leave behind the challenges they face on a daily basis. The video features Elisa, who is living with Williams syndrome, and her parents Sergio and Catia.

Rare Disease Day offers the opportunity to celebrate everyone's special moments – people all around the world are encouraged to tell their story.

The Rare Disease Day 2016 official poster is also available. The poster features Yuliya, who is living with type 2 spinal muscular atrophy.

Sean Hepburn Ferrer, the eldest son of the late Audrey Hepburn who passed away from rare cancer pseudomyxoma adenocarcinoma, is **Rare Disease Day Ambassador**. He commented, "Rare Disease Day brings together the millions of people affected by a rare disease across the world. The number of people living with a rare disease is staggering, 60 million and counting. This number cannot be ignored."

He added, "Rare Disease Day is the global platform for the rare disease community and raises awareness among the general public and their decision makers, to advance national policies and opens our eyes to the myriad of benefits we will inherit thanks to what we are learning today from the treatment of rare diseases. Let us celebrate Rare Disease Day - all that has been done, all that is being done, and all that will be done for everyone living with a rare disease."

Yann Le Cam, Chief Executive Officer of EURORDIS, the European Organisation for Rare Diseases, said "This Rare Disease Day we are celebrating the Patient Voice. Every person living with a rare disease and their family can tell a story of the journey of resilience they travel in trying to navigate a diagnostic maze and to access care and treatment."

He added, "Rare disease patients around the world work strenuously to ensure their voice is heard and that they bring about the change needed to improve their lives. We are moving from isolation and despair to a critical mass of citizens that bring a strong voice and hope through positive actions. The momentum for Rare Disease Day is truly global and growing."

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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, 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.

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.

EURORDIS

EURORDIS, the European Organisation for Rare Diseases, is a non-governmental patient-driven alliance of patient organisations representing nearly 700 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 or see the EURORDIS Facebook page. For more information visit: www.eurordis.org.

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