



INTERNATIONAL RARE DISEASE DAY

“PATIENTS AND RESEARCHERS: PARTNERS FOR LIFE!”

28 February marks the third Rare Disease Day.

For this annual event hundreds of patient groups and their partners organise activities to raise awareness on rare diseases and the 30 million people affected by them in Europe.

Rare Disease Day was launched and is coordinated by the European Organisation for Rare Diseases - [EURORDIS](http://www.eurordis.org) (www.eurordis.org), a federation representing more than 400 patient organisations in 42 countries. The campaign involves rare disease national alliances and patient groups in 40 countries, in the EU as well as in the USA, Canada, Argentina, Australia, New Zealand, Japan, China and Taiwan, amongst others.

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. 80% have a genetic origin and the majority affects children. Most rare diseases are serious, chronic and life-threatening. Due to their low prevalence, medical experts are also rare, knowledge is scarce, offer for care is inadequate, research is limited and very few cures exist.

This year's theme focuses on the importance of rare disease research. Research represents hope for the millions of rare disease patients without cure today. In the last decade, scientific and medical progress has opened up new opportunities in the field of rare disease research; rare diseases have in turn made major contributions to research and treatment discoveries for more frequent diseases.

Rare Disease Day 2010 highlights the importance of collaboration between patients and researchers. A survey recently conducted by EURORDIS amongst 300 patient organisations representing over a million individual patients in 29 countries - shows that patients are important catalysers of research.

The results of the survey will be presented at a European Workshop organised by EURORDIS, on March 1ST, 2010, in Brussels. The event, co-organised with [E-RARE](http://www.e-rare.eu) (www.e-rare.eu) in partnership with the European Commission, [Orphanet](http://www.orpha.net) (www.orpha.net) and [EuroPlan](http://www.europlanproject.eu) (www.europlanproject.eu), will make the case for rare disease research to be included in public funding schemes.

In line with this year's theme, patient organisations are invited to nominate a scientist - who has helped advance research into their disease, to the Rare Disease Research Hall of Fame (39 nominations to date). Individual patients can enter the photo and video contests (more than 300 new entries to date) and share their stories on *Facebook* (over 6000 fans to date and more than 50 joining each day).

More information on: www.rarediseaseday.org

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