



## European Commission's DG SANTE wins EU Ombudsman Award for EU collaboration on rare diseases

**30 March 2017, Brussels** – The European Commission's Directorate General for Health and Food Safety (DG SANTE) today wins the inaugural overall European Ombudsman's Award for Good Administration for its work in promoting cross-border collaboration to improve the lives of the 30 million people living with a rare disease in Europe. The nomination for this award was made by EURORDIS-Rare Diseases Europe.

- [Read the European Ombudsman's press release announcing all winners](#). The highly competitive award attracted 90 nominated projects from the main EU institutions as well as many agencies and other bodies. Prizes were awarded in 7 categories with the overall Award for Good Administration 2017 going to DG SANTE's "Health programme and chronic diseases".
- [Watch today's awards ceremony](#) as Gerhard Steffes and Enrique Terol from DG SANTE collect the award, alongside Valentina Bottarelli, Public Affairs Director at EURORDIS.



The **European Ombudsman, Emily O'Reilly**, presented the award to DG SANTE and recognised the tireless work of EURORDIS to tackle the challenges created by rare diseases. She commented, "The overall winner exemplifies excellent co-operation at the EU and national level to help citizens, in this case around 30 million people affected by rare diseases in Europe. It is also a clear example of the benefits of the EU when it comes to tackling problems that may affect only a small number of people in individual member states but who benefit collectively from EU collaboration."

**Valentina Bottarelli commented**, "It is an honour to be here today with the DG SANTE team. Over the last 20 years things have changed dramatically for the rare disease community and we wanted to recognise that with this nomination. The work of European institutions such as DG SANTE have made this change possible and as a result rare disease patients have been, and will go on experiencing the EU added value of European collaboration every day."

"Innovative approaches led by the European Commission to work with Member States have made national rare disease plans possible. We are also now seeing the fruits of years of work of the patient community and the EU to launch the new European Reference Networks, a concrete example of

European integration that will change the lives of rare disease patients and their families across Europe”, she concluded.

**Enrique Terol of DG SANTE** has played a key role in the development and launch of the new [European Reference Networks](#). He commented when accepting the award, “We have been working hard with patients, Member States and clinicians for many years. Just one month ago, we were able to launch 24 European Reference Networks. These networks bring together 900 medical teams of 300 hospitals from 26 Member States, all working together for the health of the patients.”

**There has been an unusually high level of engagement with those directly concerned during the development of European policy on rare diseases:** patients, firstly, but also researchers, clinicians and national administrations. The European Commission has supported a process that cascaded down into national health systems.

EU actions on rare diseases include the **2000 EU Regulation on orphan medicinal products** (which led to 1805 orphan designations and 126 orphan drugs on the market today) and the **2008 European Commission Communication on rare diseases**. This Communication paved the way for the **2009 Council Recommendation on rare diseases**, as well as a number of **Joint Actions** on rare disease under the EU Health Programme, and boosted the adoption of **23 national plans for rare disease** in EU countries. It also resulted in the creation of the **Commission Expert Group on Rare Diseases**. The **EU Health Programme** has also provided support to vital projects such as Orphanet, the world online reference for information on rare diseases.

Finally, the landmark [European Reference Networks](#) launched by the Commission earlier this year will ensure that rare disease medical knowledge and expertise travels, rather than the patients. The virtual networks bring together nearly 1,000 healthcare providers across Europe to tackle complex or rare medical conditions that require highly specialised treatment and a concentration of knowledge and resources.

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## EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.

By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information, visit [www.eurordis.org](http://www.eurordis.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.

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