

Launch of first network of Parliamentary Advocates for Rare Diseases

#ParliamentAdvocate4Rare

17 October 2017, Brussels – The first network of [Parliamentary Advocates for Rare Diseases](#) launches today at the European Parliament in Brussels.

[EURORDIS-Rare Diseases Europe](#), an alliance of over 700 rare disease patient organisations, is leading the launch of the new network with the aim of bringing together members of the European and national parliaments to ensure strong international and local action, shape political input for current and future legislation and integrate rare diseases into all relevant policies at all levels.

During the launch event '[Juggling Care and Daily Life: The Balancing Act of the Rare Diseases Community](#)' participants will hear about the reality of living with a rare disease.

Event speakers include **MEP Françoise Grossetête**, herself a Parliamentary Advocate for Rare Diseases and patron of the event, **Martin Seychell**, Deputy Director-General DG SANTE of the European Commission, and patient representatives **Terkel Andersen**, President of EURORDIS, **Avril Daly**, Vice-President of EURORDIS and CEO of Retina International, **Lise Murphy**, from the Swedish Marfan Association and **Yann Le Cam**, CEO of EURORDIS-Rare Diseases Europe.



[Infographic](#)

Why a network of Parliamentary Advocates for Rare Diseases?

Rare diseases as a public health issue, and the very notion of rarity, have long justified an approach that goes beyond national borders. Over the last 20 years, efforts to create breakthrough legislation in support of rare diseases and orphan medicines have been driven for the most part by the EU institutions.

The EU Regulation on orphan medicinal products, the Council Recommendation on action in the field of rare diseases and European Reference Networks demonstrate the added value a European approach can bring to improving the lives of the people living with a rare disease in Europe.

However, despite advances over the years, **many major challenges remain today for European citizens living with a rare disease**. These challenges raise important questions as to what more the European Union could do to generate further progress or to eradicate inequalities in research, access to medicines, health and social care between and within Member States.

The network of Parliamentary Advocates for Rare Diseases will help tackle these challenges by fostering cross-border EU collaboration.

To find out more about the Parliamentary Advocates for Rare Diseases contact [Valentina Bottarelli](#), Head of European and International Advocacy at EURORDIS or [read here](#).

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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 <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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