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# Parliamentary Advocates for Rare Diseases

A Network of European and national members  
of parliament advocating to improve the lives of  
people living with a rare disease

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September 2017

[#ParliamentAdvocate4Rare](https://twitter.com/ParliamentAdvocate4Rare)

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## About rare diseases and the role of the EU

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 15 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 the 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.

## Why a network of elected advocates?

The network of **Parliamentary Advocates for Rare Diseases will help tackle these challenges by fostering cross-border EU collaboration.** The Network is made up of MEPs and national MPs who have long supported the cause of rare diseases or who have an interest in areas relevant to rare diseases (public health, social affairs, research and innovation). EURORDIS manages the day-to-day secretariat of the Network.



The Network's missions are:

- To explore and discuss specific challenges faced by people living with a rare disease and ensure stronger EU-wide action through targeted support;
- To shape political input for future legislation and programmes, ensuring that rare diseases are made an integral part of EU, national and regional programmes in health, research, social affairs and other relevant policies.

Through the network of **Parliamentary Advocates for Rare Diseases**, EURORDIS-Rare Diseases Europe aims to bring 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.

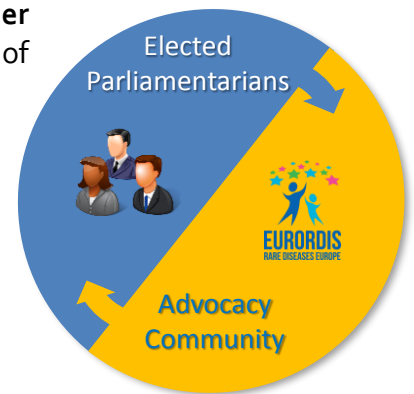
The Network launches at the event '**Juggling Care and Daily Life: the Balancing Act of the Rare Diseases Community**' at the European Parliament, Brussels, on **17 October 2017**.

[Register to attend](#)

# Why join the Parliamentary Advocates for Rare Diseases?

Network members will benefit from opportunities to:

- Participate in **calls to action** in particular areas of policy where efforts by the **European Union could make a significant difference for your constituents living with a rare disease**;
- Learn from other parliamentarians and rare disease policy experts through an **exchange of information on rare disease policies and best practices across borders** in the areas of research, access to treatment, healthcare, social care, among others;
- Connect with **patient representatives in your constituency** and the **national alliance in your country**;
- Participate in events that facilitate **multi-stakeholder dialogue** with other policymakers, as well as representatives of healthcare organisations, the private sector and other members of civil society;
- Become proponent of political action in your respective Parliament, through for example the organisation of **hearings, exchange of views or punctual events** around specific themes, submitting **written / oral questions**.



## About 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.

**Are you interested in joining the Rare Diseases Parliamentary Network? Do you wish to know more?** Please contact the EURORDIS team:



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This paper was produced thanks to funding received under an operating grant from the European Union's Health Programme (2014-2020).



Co-funded by  
the Health Programme  
of the European Union

