

BECOME A PARLIAMENTARY ADVOCATE FOR RARE DISEASES



1 IN 2000 PEOPLE

A disease is defined as rare in Europe when it affects less than 1 in 2000. One rare disease may affect only a handful of patients in the EU, and another touch as many as 245,000

30 MILLION

30 million people live with a rare disease in Europe

6000

There are more than 6000 rare diseases in Europe

6%

Only 6% of rare diseases have a treatment

70%

70% of rare diseases affect children

5 YEARS

Patients need to wait an average of 5 years for a diagnosis

84%

84% of people living with a rare disease in Europe experienced disruptions to their care during COVID-19

30 MILLION PEOPLE LIVE WITH A RARE DISEASE IN EUROPE

Most rare diseases are chronic, progressive, degenerative, debilitating, life-threatening and have a huge impact on daily life. People living with a rare disease are a vulnerable and neglected population, a situation that worsens in times of crisis: the COVID-19 pandemic has shown the impact this can have with 84% of people living with a rare disease in Europe experiencing disruptions to their care.

Despite major scientific advances and efforts at EU and national levels, people living with a rare disease continue to face unmet needs and inequities in accessing a diagnosis, treatments and care and too often suffer from marginalisation and isolation.

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Rare is not rare if you see how many we are. No one deserves to walk this road alone

— Aleksandra, the Netherlands, as part of the #30millionreasons campaign

WHY A NETWORK OF PARLIAMENTARY ADVOCATES FOR RARE DISEASES?

The rarity of the diseases and the scarcity of knowledge makes cross-border coordination crucial. Rare diseases do not work in silos. For the best possible treatment, research experts and care professionals across Europe need to collaborate and exchange information and expertise.

Over the past two decades, the European and national parliaments have been instrumental in securing major achievements for people living with a rare disease, including on accessing orphan medicinal products and fostering cross-border expertise with the European Reference Networks. The European Parliament also initiated the Rare 2030 Foresight Study that proposed far-reaching recommendations for the next decade of rare disease policies.

“Because the EU has the science, the healthcare and the industry to help patients suffering from rare diseases. Political will and incentives can turn science into treatments

— Boris, France, as part of the #30millionreasons campaign

OBJECTIVES OF THE NETWORK



Ensure rare diseases are high on European and national agendas, including in health, research, social affairs and other relevant policies



Drive the adoption of person-centred legislations, policies and budgets to make a tangible difference to the lives of people with rare diseases



Hold the European Commission and national governments accountable for their commitments to leave no one with a rare disease behind

WHY JOIN THE NETWORK?

By joining the network, MEPs and MPs will:

1. Receive evidence-based information and expertise on the needs of their constituents living with a rare disease to contribute to legislative and policy files
2. Connect with patient representatives in their constituency through EURORDIS' network of 1000+ national patient organisations
3. Share information and best practices with an active group of colleagues committed to making a difference for people living with a rare disease
4. Become a rare disease champion and mobilise decision-makers to achieve key policy changes improving the lives of people with a rare disease.

The network of Parliamentary Advocates for Rare Diseases is a dynamic all-party group of Members of the European Parliament and national parliamentarians who advocate for the rights of people living with a rare disease. The secretariat of the network is provided by EURORDIS-Rare Diseases Europe, a unique, non-profit alliance of 1000 rare disease patient organisations from 74 countries.