



Parliamentary Advocates for Rare Diseases kick-start action for next five years

Working towards a new EU policy framework for rare diseases

18 February 2020, Brussels – At an MEP Briefing and separate Policy Event held today at the European Parliament, EURORDIS-Rare Diseases Europe is relaunching the **Network of Parliamentary Advocates for Rare Diseases**, made up members of parliament advocating to improve the lives of the 30 million people living with a rare disease in Europe.

The EURORDIS [‘Reframe Rare’ Policy Event](#) is held to mark the occasion of **Rare Disease Day**, the global campaign with events in 100+ countries around the world.

Participants will hear from event co-hosts **MEPs Tanja Fajon, Stelios Kypouropoulos and Frédérique Ries**, as well as **MEPs Kateřina Konečná and Tomislav Sokol**, who will host conversations with patient representatives from across Europe on topics including research and innovation, access to medicines, holistic care and cross-border healthcare and access to specialised care.

With this relaunch of the Network of Parliamentary Advocates for Rare Diseases, this group of MEPs commit to move from a pledge to real action to bring about a new EU policy framework on rare diseases and stronger EU-wide action in health, research, social affairs and other relevant policies.

In June 2019, the European Court of Auditors [recommended](#) to review and reframe the current EU rare disease policy strategy. This recommendation was endorsed by the Council of the EU and the European Commission has accepted to **revise its rare disease strategy by early 2023** where appropriate. The Parliamentary Advocates for Rare Diseases will therefore take action now and over the next five years to advocate for, and put in place, a new EU political framework for rare diseases.

Tanja Fajon, MEP for Slovenia, commented “I am a proud Parliamentary Advocate for Rare Diseases. Through my personal experience, I understand how challenging it can be to get a diagnosis and access appropriate medicines and healthcare. At today’s meetings we are looking forward to how the EU can build a new policy framework that best serves its 30 million citizens affected by a rare disease.”

Yann Le Cam, Chief Executive Officer, EURORDIS, said, “Great progress has been made in the last decade to make rare diseases a public health priority at the EU level and to put in place European and national policies that benefit people living with a rare disease. However, Europe’s challenge to address the needs of 30 million people living with a rare disease is far from won; only 10 years of action cannot do it all. We must build on the achievements of the last decade to build an EU policy framework in the next decade that helps achieve equity for patients and families. We need to build progress that will translate into meaningful health, social and improved well-being for people affected by rare diseases.”

“With the support of the Parliamentary Advocates for Rare Diseases, we call on all stakeholders - from the European institutions and national governments, the NGO community, academic and research institutions, as well as the private sector - to join and move forward the conversation about a renewed EU framework for rare diseases based on the work of the [Rare2030 Foresight Study](#), which was initiated by the European Parliament and funded by the European Commission.”

From pledge to action

In 2019, [nearly 40 MEPs pledged](#) to support a new EU political framework that:

- Enables all people living with a rare disease to receive an accurate diagnosis and appropriate care within one year of coming to medical attention,
- Supports holistic care and social systems that are inclusive of people living with a rare disease, throughout their lives, and
- Seizes opportunities in science and innovation that embody hope for people living with rare diseases and their carers and can change their lives.

The Parliamentary Advocates for Rare Diseases will now advocate for a new EU policy framework that encapsulates these three aspects.

A track record for rare disease policy at the EU level

The EU enables the rare disease community to create the **critical mass** of patients, experts, knowledge, guidelines and resources needed by coordinating and adding value to national efforts. Rare diseases are an area with **high European added value**, where coordinated European action has borne fruit.

Europe has a strong track record of achievements since the first European legislative text concerning rare diseases – the Regulation of 1999 on Orphan Medicinal Products and the subsequent Commission Communication (2008) and Council Recommendation (2009), not to mention the Directive on Patients’ Rights in Cross Border Healthcare (2011) – including national plans for rare diseases, investment in research, development of treatments and the establishment of European Reference Networks.

However, there is still a lot more to do to ensure equitable access to appropriate medicines, health and holistic social care for the 30 million Europeans living with a rare disease. Through the ongoing [Rare 2030 Foresight Study](#) (led by EURORDIS and partners) and the Network of Parliamentary Advocates for Rare Diseases, next steps will be taken to bring into place a much-needed EU policy framework for rare diseases.

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Contact

Eva Bearryman

Senior Communications Manager, EURORDIS-Rare Diseases Europe

eva.bearryman@eurordis.org

About the Network of Parliamentary Advocates for Rare Diseases

The Network of [Parliamentary Advocates for Rare Diseases](#) will help tackle the challenges faced by the 30 million people living with a rare disease in Europe by fostering cross-border EU collaboration. 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, and
- 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.

MEPs interested in becoming a Parliamentary Advocate for Rare Diseases are invited to contact Konstantinos Aligiannis, Public Affairs Director: konstantinos.aligiannis@eurordis.org.

About Rare Disease Day

A patient-led campaign, [Rare Disease Day](#) was launched by EURORDIS and its Council of National Alliances in 2008 and brings together millions of people in solidarity. EURORDIS coordinates the global community in organising Rare Disease Day, which takes place on the last day of February each year to raise awareness of the impact that rare diseases have on over 300 million people around the world. [Multiple events](#) are taking place to mark Rare Disease Day at the European Parliament.

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 800 rare disease patient organisations from 70+ 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.

About Rare Diseases

[Read more about rare diseases.](#)