

Juggling Care and Daily Life: the Balancing Act of the Rare Diseases Community

Launch of the Parliamentary Advocates for Rare Diseases

Tuesday 17th October

15.30 – 17.30

Room A3F 383 (Altiero Spinelli Building)

European Parliament

Programme

Event moderated by Vivienne Parry OBE, Science Writer and Broadcaster (The Guardian, The Times, BBC), Head of Engagement at Genomics England (100,000 Genomes Project).

Timing	Topic
15.30	Welcome and registration
15.45	<i>Introduction to Rare Diseases - Making the Invisible Visible</i> (Video)
15.50	<i>Why should we act collectively on rare diseases?</i> Françoise Grossetête MEP
16.00	<i>Juggling Care and Daily Life: The Balancing Act of the Rare Diseases Community</i> – Avril Daly, EURORDIS Vice-President, CEO Retina International
16.10	<i>Patient Testimony</i> Lise Murphy, Swedish Marfan Association, ERN mentor, former Co-Chair of the Patient and Consumer Working Party (PCWP) at the EMA
16.20	<i>EU policy for rare diseases: what still needs to be done to improve patients' daily life</i> – Martin Seychell, Deputy Director General DG SANTE, European Commission
16.30	<i>The network of Parliamentary Advocates for Rare Diseases: what it is and what it can do</i> – Yann Le Cam, EURORDIS Chief Executive Officer
16.40	<i>Exchange of views: the EU added value for people living with rare diseases in research, access to health and social provisions</i> Moderated debate with interventions from Marek Plura, MEP and Kateřina Konečná, MEP
17.20 – 17.30	<i>Concluding remarks</i> – Terkel Andersen, EURORDIS President

Why this meeting?

Rare diseases are rare but patients living with rare diseases are many. An estimated 30 million European citizens are affected at some point in their life by one of the 6000 or more rare diseases. Rare diseases can be life-threatening or chronically debilitating diseases with low prevalence and high levels of complexity. Only 5% of rare diseases have a therapy.

Rare disease patients and their families are an extremely vulnerable group of citizens who experience genetic hazard, scarcity of medical knowledge, difficulties in accessing care, isolation from society, often sinking them into economic instability. The small patient populations and expertise, as well as the geographical scattering, deepens inequalities between countries and regions in accessing appropriate medical and social care and treatments.

The specificities of rare diseases single them out as a unique area that benefits highly from action at Community level, for which the most effective strategies are cross-border and EU-wide, with an international perspective. The recently released survey “*Juggling Care and Daily Life: the Balancing Act of the Rare Diseases Community*”, detailing the state of the art of care provisions to people with a rare disease provides a fresh, detailed snapshot of what it means to live with a rare disease, but also places an urgent call on policymakers to take the action.

Rare diseases bring about significant innovation and advances but also raise a number of challenges to policymakers both at the EU and the national level. At stake are fundamental aspects of the EU, including **solidarity**, the **economic sustainability of healthcare systems**, and the **ethical and societal tensions** that are likely to be engendered in this context.

EURORDIS–Rare Diseases Europe thus invites Members of the European Parliament to **join the launch event of the network of Parliamentary Advocates for Rare Diseases to discuss how to concretely work for people living with a rare disease in their constituencies and across Europe** as a whole to make a difference in rare disease patients’ everyday life.

Under the auspices of MEP Françoise Grossetête, EURORDIS – Rare Diseases Europe aims to bring together Members of European and National Parliaments to ensure strong international and local action, shape political input for current and future legislation and integrate rare diseases in all relevant policies at all levels.