



Rare diseases are an area of high unmet need, where coordinated action is vital to improve the lives of 30 million of people affected by rare diseases in Europe and 300 million worldwide. 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. A strong track of record of achievements on rare diseases has been established since the first European legislative text in 1999; yet, there is still work to be done.


[Rare Disease Day](#) is an internationally recognised awareness raising campaign, with events taking place in over nearly 100 countries and regions, uniting millions of people living with a rare disease. Working together we have the potential to improve outcomes for patients, their families and our society at large.


Rare Disease Day 2020 at the European Parliament is the initiative to raise awareness about rare diseases and their impact on people`s lives in the EU capital. A series of events will bring together patient organisations, medical professionals, academia and industry, Members of the European Parliament (MEPs) and the European Commission, to discuss the reality of living with rare diseases, the importance of early diagnosis and to highlight achievements, opportunities and challenges that have emerged in the field of rare diseases.

Programme of the day:

-  **An art exhibition by Phil L. Herold (European Parliament, ASP5G)**, a patient living with Spinal Muscular Atrophy (SMA), with the participation of Stella Kyriakides, Commissioner for Health and Food Safety, and a performance by soprano Noémie Desquiotz Sunnen, living with Amyotrophic Lateral Sclerosis. The **exhibition will open at 12.30** and be accompanied by a *standing lunch*. [Register here](#) or contact eu40team@eu40.eu

-  **A high-level recorded media debate at the Voxbox (European Parliament, open space ASP, 3rd floor) from 13.30 to 14.30** on the importance of early diagnosis, new-born screening and EU coordinated actions. Participants will include hosting MEPs, World Health Organisation, patient organisations, medical professionals and industry.

-  **A policy event organised by EURORDIS-Rare Diseases Europe entitled “Reframe Rare” (European Parliament, ASP 5E3) from 15.00 to 17.00.** Through a conversation format (“fireside chats”) around the topics of access to healthcare, holistic care, research, and cross-border healthcare, speakers, including MEPs, patients and other relevant stakeholders, will have the possibility to highlight and discuss challenges and new opportunities for rare diseases in the upcoming years in each of these fields. [Register here](#).

-  **The [Black Pearl Awards ceremony and dinner](#) from 18:30 to 23:00.** This event is organised every year by EURORDIS-Rare Diseases Europe to recognise the outstanding **achievements** and exceptional work of people making a difference for the rare disease community.
Please note that this ceremony will take place at Le Plaza Hotel, Av. Adolphe Max 118-126, 1000 Brussels

Confirmed speakers at the Rare Disease Day 2020:

- European Commissioner for Health and Safety, Stella Kyriakides
- MEP Stelios Kypouropoulos, EPP
- MEP Tanja Fajon, S&D
- MEP Tomislav Sokol, EPP
- MEP Loucas Fourlas, EPP
- MEP Kateřina Konečná, GUE
- Yann Le Cam, Chief Executive Officer, EURORDIS-Rare Diseases Europe
- Mencia De Lemus Belmonte, President SMA Europe
- Johanna Friedl-Naderer, President Biogen
- Prof. Alberto Pereira, Coordinator European Reference Network for Rare Endocrine Conditions (Endo-ERN)
- Claudia Crocione, Managing Director, HHT Europe
- Dr. Daria Julkowska, Coordinator, European Joint Programme on Rare Diseases (EJP)
- Rebecca T. Skarberg, Osteogenesis Imperfecta Federation Europe (OIFE)

Objectives

- Raise awareness about rare diseases, the challenges that people living with rare diseases face every day.
- Provide a forum to explore and discuss specific challenges faced by the rare disease community and ensure stronger EU-wide action in all relevant areas, from early detection and diagnosis through new-born screening to access to therapies and care, research and data management.
- Partner with the Members of the European Parliament and other European and national stakeholders to shape political inputs for future policies and legislation.