

Largest patient-led conference kicks off with a call for a coordinated EU strategy on rare diseases

27 June, Paris – Today, on the first day of the [European Conference on Rare Diseases and Orphan Products \(ECRD\) 2022](#), EU policy makers, academia and civil society have come together to show their support for a new comprehensive and cross-cutting [European policy framework for rare diseases](#). ECRD - an official event of the 2022 EU French Presidency - is taking place online from 27 June to 1 July 2022, gathering over 800 stakeholders from across the community to drive reflections on rare disease policy in Europe through 2030.

The 11th edition of the European Conference on Rare Diseases “Mission Possible” puts a spotlight on the current political opportunities and milestones as well as salient issues we need to address. It aims to leverage stakeholder consensus to bring forward a coordinated European strategy on rare diseases that will help achieve meaningful goals for people with rare diseases and society at large.

Opening the Conference, **Avril Daly, Vice-President of EURORDIS-Rare Diseases Europe**, appraised the high added value Europe can have in “protecting and ensuring the health of its citizens, including the 30 million Europeans living with a rare disease.” She further emphasised the importance of collaborative effort “to ensure the needs of our community are not overlooked but well understood, clear and are acted on” and visibility so that rare diseases “remain a public health priority.” With the Rare 2030 recommendations as a basis, she called for “a new framework for policy action and better coordination, one that is consensus driven and urgent.”

“The European Union needs a comprehensive policy framework to connect all policies and initiatives affecting people living with a rare disease at the European and national level.”

– **Frédérique Ries, Member of the European Parliament (MEP)**

The opening plenary session saw a particular focus on the European Parliament’s solidarity and commitment to move forward with a coordinated strategy on rare diseases to address persistent inequalities in accessing health care across Europe and make concrete and tangible improvements in the area of rare diseases by 2030.

In his speech, **MEP Stelios Kympouropoulos**, gave concrete examples of where the lack of oversight hampers the inclusion of rare diseases in EU policy: “the interconnectedness among the European Regulations is essential. The revision of the OMP regulation cannot be successful without foreseeing for social inclusion. It is not enough for a medicine to be produced, and approved, but it should then be accessible and affordable. The necessary social services should be guaranteed even after having taken the medicine.”

Noting the disparities in rare disease care across different European countries and the lack of treatments for rare diseases, **Stella Kyriakides, European Commissioner for Health and Food Safety** stressed that ‘there is work to do here’. She further highlighted the European Commission’s ‘main focus’ being on the implementation of different EU initiatives and legislation, such as the Rare Disease Partnership, ERNs and review of the Orphan Medicinal Products Regulation.

This message has been echoed and further amplified by representatives from current and upcoming EU Council Presidencies, including **Anne-Sophie Lapointe, Rare Diseases Mission Leader, French Ministry of Solidarity and Health**, who stressed that we need to “be vigilant”, as “the pace of change is uneven across the European continent and, without a general framework at the European level, we risk going backwards, especially in this time of health crisis.”

Representing Sweden, **Thomas Lindén from the National Board of Health and Welfare**, once again, confirmed Sweden’s commitment to “continuing to build a Europe that protects health”, as it has been pledged by France and the

Czech Republic in the Trio programme. He continued by saying that “the issue of rare diseases is an important issue for us, both on the EU and national level”, highlighting the importance of EU cooperation as proven by the European Reference Networks.

The largest patient-led policy event, ECRD is taking place online until 1 July 2022. During the five days of the Conference, policy makers, researchers, academia, and civil society will debate on a range of issues facing the rare disease community: from ensuring healthy lives and promoting well-being for all people living with a rare disease, through reducing inequality, to building resilient infrastructure and fostering rare disease innovation.

Co-organised by [Orphanet](#) and supported by the 2022 French Presidency of the Council of the European Union, ECRD 2022 demonstrates considerable attention to rare diseases as a priority for Europe. The last day of the Conference will also mark the first day of the Czech Presidency of the Council of the European Union, which is expected to continue efforts towards a coordinated EU strategy on rare diseases.

EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 1000 rare disease patient organisations from 74 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. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information, visit [eurordis.org](#).

Press contact

Stanislav Ostapenko
Communications Senior Manager
EURORDIS-Rare Diseases Europe
stanislav.ostapenko@eurordis.org
+33 1 56 53 52 61