

Czech Deputy Health Minister calls for a European Union Action Plan on rare diseases, as Czechia takes over the EU Presidency

1 July, Paris – Closing the European Conference on Rare Diseases and Orphan Products 2022, Czech Deputy Health Minister, **Jakub Dvořáček** gave a strong message to the European institutions and rare disease community, saying that the Czech Republic, which begins today its six-month EU Presidency, will “continue to support enhanced cooperation and coordination between EU Member States and encourage the creation of the European Action Plan on rare diseases”.

Opening the closing plenary session of ECRD, **Mr Dvořáček, Deputy Ministry of Health of the Czech Republic**, stated that, following participation of the French and Swedish who make up the trio of EU Council Presidencies, “it was a real honour to join on the last day of the conference, and at least symbolically, to take over the topic of rare diseases as a crucial agenda”.

“A strong foundation that has been built within the last thirteen years that provides a solid basis for the creation of an overarching action plan in order to bring forward the best of various initiatives,” he said. “The action plan would provide a roadmap for all European countries to work towards the same targets, to reduce inequalities, improve health and increase innovation”.

Speaking of other important EU legislation currently being developed or revised, **Mr Dvořáček** also highlighted the motivation of Czechia to drive good data practices through the European Health Data Space and to improve access to treatments through greater cooperation in joint procurement.

From European to international rare disease developments, **Hans Kluge, Regional Director for Europe, World Health Organisation (WHO)** praised the United Nations Resolution on Addressing the Challenges of Persons Living with Rare Diseases, adopted in December 2021 as “a milestone, recognising that policies to support the over 300 million people globally living with a rare disease are essential to make progress towards the Sustainable Development Goals in the spirit of leaving no one behind.” He stressed that now, “to drive implementation, we need to focus on the ‘how’ through the development of an action plan for health systems and services to meet the needs of persons living with a rare disease.”

“The question is no longer *if* we need a new European Strategy, but *how* and *when*. We have witnessed the strong political momentum insisting that the current strategy is not enough, this is not the time to relinquish our efforts.”

– **Yann Le Cam, Chief Executive Officer at EURORDIS-Rare Diseases Europe**

During the five-day conference, over 800 stakeholders came together online through engaging sessions at the 11th European Conference on Rare Diseases and Orphan Products on how Europe can move forward in putting policy into action for the 30 million people living with a rare disease in Europe. The conference was organised around three collective goals - health and well-being, inequality and innovation - that would make a difference to the 30 million people living with a rare disease in Europe.

Patient organisations and representatives from the current and upcoming EU Council Presidency countries highlighted the expectations of their community from their government. **Prof Milan Macek, Head of the Department of Biology and Medical Genetics, Charles University (Prague)**, stressed the need to revise the current regulatory framework for rare diseases, as “a lot has happened in the last 13 years”, and with technological and regulatory developments of the past years, our policies are no longer fit-for-purpose. His message was echoed by **Anna Arellanesova, President of the Board of Directors, Rare Diseases Czech Republic**, who added that “all in all, we have started a wonderful way towards making a real difference, now we need to keep that momentum.”

The closing session also offered a chance to look to the future generation of rare disease advocates and ask what they expect from Europe. **Adéla Odrihocká, Young Patient Advocate from Czechia**, stressed the urgency of European action on rare diseases, by saying that “as rare disease patients and young citizens we have been told our whole life to wait. We don't have this time. We need hope for our future. We need to take action now, to ensure better management of symptoms and guarantee a better quality of life.” As a rare cancer patient herself, Oriana de Sousa also highlighted the EU's added value for people with rare diseases: “We cannot work individually. No country has the means nor knowledge to carry all rare diseases. We need a European strategy. We need it so that we are not left behind, but understood and supported.”

While ECRD draws to an end, the drive of the community for European action on rare diseases is far from over. The Czech Presidency will see a series of conferences on rare diseases, including a two-day conference in October on the creation of an action plan.

About the European Conference on Rare Diseases & Orphan Products

The ECRD is recognised globally as the largest, patient-led rare disease event. Leading, inspiring and engaging all stakeholders to take action, the Conference is an unrivalled opportunity to network and exchange invaluable knowledge with all stakeholders in the rare disease community - patient representatives, policy makers, researchers, clinicians, industry representatives, payers and regulators. ECRD 2022 takes place exclusively online 27 June-1 July. For more information visit: www.rare-diseases.eu/.

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