

Deputy Minister of Health of Ukraine calls for "humanitarian and financial support from pharmaceutical companies and colleagues from EURORDIS" to support Ukrainians with rare diseases in the years to come

28 June, Paris – Opening a dedicated session at the European Conference on Rare Diseases and Orphan Products (ECRD) 2022 on mobilising the rare disease movement for Ukraine, Ukrainian Deputy Health Minister and the Ukrainian National Alliance for Rare Diseases said "we will never forget" the efforts to address immediate needs of Ukrainians with rare diseases but called for greater support to ensure the provision of critical social and healthcare services in the 'challenging' years ahead.

Iryna Mykychak, Ukraine's Deputy Minister of Health, reminded that "as a result of the war, 30% of patients with rare diseases have left Ukraine" to Europe, who need urgent support of EURORDIS, patient organisations, ERNs and industry. It is estimated that 8 million of Ukrainians have fled the war in Ukraine and are residing mostly in the country's neighbouring states, such as Poland, Romania, and Moldova. **Dr Mykychak** continued by expressing her gratitude to Poland and other countries, which take care of Ukrainians. "We are not refugees there", she said. "We are guests there, and we feel that. We appreciate the support of EU countries helping our patients. We will never forget this."

Her message of appreciation was echoed by **Tetiana Kulesha**, Head of **All-Ukrainian Organisation "Orphan Diseases of Ukraine"**, who, however, stressed that other 70 percent remaining in Ukraine, many of whom were forced to leave their homes, are still unable to access medical consultations and life-saving medicines, as their lives are being "put on hold".

Over 20% of people living with a rare disease in Ukraine report that the main obstacles preventing them from leaving the country are lack of information (e.g. on accessing treatments abroad), financial difficulties, and uncertainty in finding a medical team to take care of their rare disease.

Source: Preliminary results of a Rare Barometer survey on Ukraine

Representing the European Reference Networks, Prof **Hélène Dollfus**, accentuated the importance of high-level collaboration with Ukrainian and European professionals as well as the need for structured and well-funded hubs to effectively respond to the challenges of those affected by the war. "We plea for an official partnership with Ukrainian institutions and European Reference Networks (ERNs). It's an important action, to give Ukraine an official link to ERNs."

Ruben Diaz Naderi from the **Rare Disease Virtual Hub** - whose services have been solicited by over 60 Ukrainians living with a rare disease - highlighted the role industry can play to facilitate access to orphan medicines to those in need.

Adrian Goretzki from **Healthcare Education Institute** and **Katarzyna Swieczkowska** from the **Polish Association For Persons with Intellectual Disability** particularly addressed the salient issues faced by Ukrainians residing in Poland, stressing the urgent need for family assistance to support families' access to health care and social and educational systems, appropriate housing, and therapists.

Speaking of accommodating Ukrainian refugees abroad, **Sadie Bynum and Dupe Ajayi** from **Airbnb.org** highlighted the importance of collaboration with EURORDIS, which allows accessing and supporting the most vulnerable populations: "These efforts unlock EURORDIS' network of healthcare providers and patients, to ensure our funding goes to households with legitimate needs and affirmed displacement from the conflict in Ukraine."

Concluding the session, **Anastasiia Saliuk, EURORDIS Senior Project Manager for Ukraine**, highlighted the main four thematic areas where EURORDIS sees its added value: treatments, care and medical consultations, psychological support, and access to basic needs such as food, accommodation, hygiene products and financial means.

One of the most important takeaways from the discussion was the necessity to look at the larger picture and shift the thinking from only addressing the urgent needs and covering gaps to also including mid- and long-term priorities.

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](https://www.facebook.com/eurordis) or see the [EURORDIS Facebook page](https://www.facebook.com/eurordis). For more information, visit eurordis.org.

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