

## Statement

# EURORDIS-Rare Diseases Europe calls on the international community to prepare for a potential crisis and address the challenges of people living with a rare disease in Ukraine

**24 February, Paris** - EURORDIS-Rare Diseases Europe stands in solidarity with the Ukrainian people and would like to extend support to the Ukrainian rare disease community.

There are an estimated 2 million people in Ukraine who live with rare diseases. Of them, children require the most support and effective treatment. As a community that is less mobile and often more dependent on regular care, the wartime destruction of vital infrastructure, such as hospitals and care centres, threatens the lives of this vulnerable population. As the situation escalates rapidly, we need to avoid a potential humanitarian crisis and ensure that people living with a rare disease, whose conditions are often debilitating or need frequent medical attention, are not left behind.

The impact of the invasion threatens to bring more challenges for a community already facing difficulties since the deterioration of the political environment in 2014 when the conflict erupted. Ukrainian Department of Health figures show that 80% of patients with rare diseases in Ukraine lose their lives before the age of 5 due to a lack of systematic diagnosis and qualified treatment. This is higher than the estimated 50% in France, for example. As the military invasion continues to disrupt essential health services, major efforts are required to restore and strengthen health services, including access to medicines and medical equipment.

With this statement, we wish to commend the commitment and determination and express our support to the staff and volunteers of the Association of Patients with Pulmonary Hypertension, the Charitable Foundation "Children with Spinal Muscular Atrophy", the LCCF "Sister Dalila" Pulmonary Hypertension Ukrainian Rare Disease Association, the NGO "Rare Diseases of Ukraine", the Ukrainian Association Crystal People, the Ukrainian Association of Help for Patients with CF, the Ukrainian National Charitable Fund Zaporuka, the Ukrainian Union Of Patients' Organisations, and the Ukrainian Parent Project "Mio-Life", who, notwithstanding the challenges facing the rare disease community in Ukraine, have not ceased for a moment their work to support and assist the rare disease patient community and mobilise policy advocacy and legislation at the national level.

Associations in Ukraine have participated in Rare Disease Day since 2008, using the occasion to launch publicity campaigns in major cities and hold conferences to progress Ukraine's National Plan on rare diseases. Only last year, landmark monuments in major Ukrainian cities, such as Kyiv, Dnipro, Odesa, and Kharkiv, were lit in Rare Disease Day colours to raise awareness for people with rare diseases, and multiple events took place online to express our community's views on living with rare diseases and what can be done to advance the rare disease cause.

**Today, we are calling on the European Union, the United Nations, WHO Europe and other UN agencies, humanitarian organisations and the international community at large to protect the most vulnerable, who are caught in the conflict, unable to flee and without access to humanitarian aid. The current situation should not undermine the reality that the needs of people living with a rare disease are real, huge and unmet.**

**EURORDIS will facilitate a coordinated effort with European Rare Disease Federations and will support patient organisations in Ukraine as best we can to understand the challenges they are facing and to help**

policy makers and the international community understand the challenges people living with a rare disease face on the ground.

## EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 984 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](http://eurordis.org).

## Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date, affecting an estimated 30 million people in Europe and 300 million worldwide. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

## Press contact

Stanislav Ostapenko  
Communications Manager  
EURORDIS-Rare Diseases Europe  
[stanislav.ostapenko@eurordis.org](mailto:stanislav.ostapenko@eurordis.org)  
+33 1 56 53 52 61