



To:

Ursula von der Leyen, President of the European Commission
Janez Lenarčič, Commissioner for Crisis Management
Olivér Várhelyi, Commissioner for Neighbourhood and Enlargement
Stella Kyriakides, Commissioner for Food and Health Safety

6th April, 2022

Subject: Call to protect and support the Ukrainian people living with a rare disease

Dear President von der Leyen,
dear Commissioner Lenarčič,
dear Commissioner Várhelyi,
dear Commissioner Kyriakides,

As Members of the European Parliament and on behalf of the Network of Parliamentary Advocates for Rare Diseases, **we wish to bring to your attention the tragic situation of the Ukrainian people living with a rare disease, and call upon you to make sure their specific needs are given due consideration by the Commission's humanitarian and emergency response.**

In Ukraine, an estimated 2 million people live with a rare disease. At the best of times, people living with a rare disease require specific actions and support to achieve equitable access to health and social needs. In times of crisis, relief efforts must also include specific consideration for the needs of this vulnerable population.

Ukrainian patient organisations report that people living with a rare disease in Ukraine are struggling to access critical/life-saving care due to **shortages of medicines and other medical supplies**, and that the health system is not able to cope with the less prominent and vulnerable communities as they are overshadowed by civilian and military casualties. Once again, people living with a rare disease are left behind. Leaving the country is also challenging for those on the most vulnerable end of the spectrum who require **end-to-end support to be transported out of the country**. Families who have managed to flee need **to rapidly access highly specialised care in the host country and extra support to navigate health care systems in Europe**. In Poland, there are already signs that the healthcare system needs extra support to avoid a shortage of medicines and supplies, and overcrowding of specialised care centres.

We welcome the recent Commission's initiatives to support the Ukrainian people in their country and once in the EU, and in particular its efforts to guarantee the access of refugees to healthcare across Europe, as detailed in its Communication on "Welcoming those fleeing war in Ukraine: Readyng Europe to meet the needs" of 23 March.

While we take support of these initiatives, we wish to stress the specific vulnerability and needs of the rare disease community from Ukraine in terms of access to urgent and long-term healthcare and social care.

In particular, we call on the Commission to:

- Organise **fast-track humanitarian corridors to the border**, to help evacuate people living with a rare or chronic disease who often require transport and medical assistance from their home to the border;
- **Set up humanitarian corridors to ensure the rapid export and delivery of life-saving rare and chronic disease medication and medical equipment** to hospitals and medical centres throughout Ukraine. This includes guaranteeing that these treatments and supplies reach rare and chronic diseases patients on the ground, eg. by providing an alternative to private initiatives where drivers cannot be found or shipment insurance is withdrawn due to the situation of war;
- **Invite Ukrainian authorities to make it easier for men** who provide care for people living with a rare or chronic disease to be allowed to leave the country, even when the disability is not easily visible or recognised. This should apply not only to single fathers of young children, but also to fathers of patients older than 18, to husbands, or sons of a parent living with a rare or chronic disease;
- **Intensify its support to bordering countries, such as Poland, to manage the increased patient population** and the associated costs for the health care system, especially ensuring financial assistance to help people living with a rare or chronic disease and the supply of rare and chronic disease medicines to Polish hospitals;
- Look at the best options to help national competent authorities continue to assume their usual responsibilities in spite of the added workload incurred by the reception of refugees, eg to prevent delays in marketing authorisations of new treatments and pharmaceutical innovations;
- Ensure that the **planned triage hubs** at the border in most affected Member States **include rare and chronic diseases specialists** to facilitate potentially difficult diagnosis and identify medical structures for referral;
- **Ensure coordination and support to Member States so they guarantee the immediate access to healthcare services and long-term care in the country of arrival to everyone with a rare or chronic disease fleeing Ukraine**, and facilitate administrative processes for the transfer of medical records and recognition of disabilities; provide guidelines to Member States to ensure that they can assess and

deliver specialised care and social protection to people living with a rare or chronic disease, whose specific needs may not be adequately guaranteed by the application of the Temporary Protection Directive and its implementing Decision; pay particular attention to the situation of refugees involved in clinical studies, whose treatment is interrupted and records may be lost;

- **Ensure that the Commission's solidarity mechanism for intra EU medical transfers includes the relocation, when possible and desired, of people living with rare diseases and their families or carers in the appropriate hospital units across Europe and the transfer of expertise when this relocation is not possible.** This includes liaising coordinating with and supporting the European Reference Networks and their initiative #ERNcare4UA to localise specialised centres and rare disease expertise in Ukraine's border countries and beyond.
- **Create a task force for people from Ukraine living with a rare disease** to coordinate existing and future initiatives in close collaboration with patient organisations and their representatives and the 24 European Reference Networks.

In its humanitarian and emergency response to support the Ukrainian people, the European Commission must do everything it can to leave no one behind and develop a strong, appropriate and coordinated effort to protect the lives, health and rights of the most vulnerable ones.

People living with a rare or chronic disease in and from Ukraine count on our support.

Yours sincerely,

Stelios Kympouropoulos, *Co-Chair*
Brando Benifei, *Co-Chair*
Frédérique Ries, *Co-Chair*
Tilly Metz, *Co-Chair*
Véronique Trillet-Lenoir

On behalf of the Network of Parliamentary Advocates for Rare Diseases