

**Statement to support people with Rare Diseases and Complex Conditions
affected by the war in Ukraine**

Monday March 14th 2022

As the Ukrainian war continues, we, the Coordinators of the 24 European Reference Networks (ERNs), solemnly and urgently want to raise awareness to all national and European public health decision making bodies about the absolute necessity to consider that **at least 6% of the Ukrainian population**, including those currently migrating, are affected by a rare disease. Currently, about **120 000 Ukrainian rare disease patients have already** arrived amongst the 2.5 million refugees in the EU on Friday 11 March 2022.

Our 24 ERNs, founded and funded by the European Commission, are **specialized in the diagnosis and treatment of almost all rare/very rare illnesses** and complex conditions in 24 medical specialties (for example: rare adult and paediatric cancers, rare immune or endocrine diseases, rare epilepsies, rare liver diseases, rare kidney diseases, rare heart diseases, rare neurological diseases etc...).

ERNs are virtual networks comprised of more than **1500 highly specialized medical teams** located in **300 Hospitals in 25 EU countries and Norway**, including in the EU countries neighbouring Ukraine (Poland, Romania, Slovakia and Hungary). Therefore, we expect that healthcare providers in these countries especially will see increasing numbers of patients, including those with rare diseases and complex conditions.

There are more than 7000 rare diseases and 75% of them affect children. Many rare diseases begin in early childhood, most are **chronic and often life-threatening conditions**. Most require **highly specialized care and treatments** that are often complex and may need **orphan drugs, which are costly**. Thus, quality care for patients with rare diseases and complex conditions must be provided by healthcare providers with the required high levels of clinical expertise and resources. All healthcare providers which are full members of the ERNs have been assessed independently as having the necessary high levels of expertise.

The influx of Ukrainian rare disease patients fleeing the war will impact on the triage processes, mainly of the healthcare providers in the neighbouring countries. Some patients with life threatening or clinically extremely urgent rare diseases and complex conditions may need to be quickly and safely transferred to healthcare providers capable of providing this highly specialised healthcare. The ERNs can provide information on where this care (including day care, highly specialised surgery, cancer treatments etc.) can be accessed for each rare disease or complex condition, as some of this highly specialised healthcare is not available in all EU Member States.

To provide optimal care for Ukrainian patients with rare diseases and complex conditions reaching the EU or who need to be transferred between EU healthcare providers, the 24 ERN Coordinators wish to urgently bring to the attention of public health authorities at national and European level the following points:

- The ERNs have launched a **new website (accessible in most EU languages, in Ukrainian and Russian)** with **contact points for each ERN** by speciality as well as their list of members in Ukraine Border countries and beyond. A central ERN contact point is also available. We will actively disseminate information about this website through all available communications channels.



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Rare Diseases Doctors

www.erncare4ua.eu

- The ERNs will support all national and EU public health authorities, the European Commission (including EWRS), WHO, NGOs and any other organisation and healthcare professional, if information is needed for triage or transfer of rare disease patients, by providing lists of healthcare providers which can provide the expert care for specific rare disease patients and providing diagnostic and therapeutic advice if no information is available or if a complex situation occurs. All 24 ERNs can be contacted by the website and there is a central contact point if needed.
- The ERNs will function as an EU medical HUB for rare diseases to support any Healthcare professional in need of diagnostic, treatment options or any other medical matter concerning a specific patient (by contacting the individual ERN or central ERN contact point). ERNs can organise free, virtual and secure panel discussions between our experts and healthcare professionals in Ukraine, for example if needed or any other EU Member State, to provide advice on diagnostic and treatment alternatives, including highly specialised surgery, advise on drug prescription plan and how to safely change prescriptions, particularly in cases where a given treatment is not available in the host country.
- Each ERN, in collaboration with their respective medical scientific societies, can provide support to liaise with pharmaceutical companies to inform them about specific shortages of drugs, and to encourage their involvement as humanitarian partners for a faster supply of medications needed for the treatment of rare diseases and complex conditions, facilitating access to some rare and/or expensive treatments.
- The 24 ERN contact points can connect with Patient Organisations and EURORDIS for information on national patient associations willing to support families and patients from Ukraine.


The 24 ERN Coordinators wish to underline their support, in particular, for our fellow healthcare professionals working under horrendous conditions in Ukraine. We stand with them and want them to know that they are not alone and they can contact us via our ERN websites.

We, the 24 ERN Coordinators, hereby give our full commitment to help all stakeholders, especially doctors and their rare disease patients in this unprecedented situation and, together in solidarity, we must ensure that no rare disease patient is left behind.



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