

The European Reference Networks for rare and complex diseases respond to the Ukrainian crisis

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The abrupt and ferocious Russian military assault on Ukraine at the end of February 2022 coincided with the Rare Diseases Day and the meeting organized by the French presidency of the European Union Council to specifically address the global public health priority of 6% of the worldwide population affected by nearly 7000 rare and complex diseases.¹ Paediatric onset is observed in 70% of rare diseases which are highly heterogeneous covering almost all fields of medicine with often severe outcomes as acute failures or long-life chronic diseases requiring highly specialized expert multidisciplinary teams and complex therapies. Launched in 2017, the 24 European Reference Networks (ERNs)² develop strong links between medical teams from very different disciplines across the EU, facilitating concrete actions for patients suffering from rare and complex diseases. Spontaneously, the coordinators of the 24 ERNs decided to initiate a concerted action to support patients from Ukraine.

In Ukraine, the population of patients with rare diseases is estimated to be about 2 million people. The present humanitarian crisis emphasises the distress of highly vulnerable patients with very immediate or delayed hidden threat when medical care is postponed or stopped due to destroyed healthcare facilities, shortage of therapies or lack of expert medical teams. With more than 6 million Ukrainian refugees and displaced people, this major humanitarian crisis has erupted into unprecedented broad health challenges with a need of urgent responses especially for women and children (but also men) as refugees, and those remaining in Ukraine.^{3,4}

In March 2022, ERNs deployed an almost instant response⁵ to help Ukrainian patients providing direct contact to the 24 coordinating ERN teams connected to more than 1900 European clinical centers based in more than 500 expert health providers. In addition to remote support during the first 3 months, almost 300

cases have been referred to ERN Healthcare Providers, the majority being patients with rare paediatric cancers, blood or developmental diseases.

Specific medical needs were identified:

- Support for medical diagnosis and advice (destroyed or lost patient files, needs to translate medical reports, difficulties of patient families to contact treating physicians, colleagues in Ukraine in need of support; ...)
- Support and advice on treatment issues: access to special diets or drug shortages; switch to equivalent alternative medications; access to specialized surgeries or medical devices
- Support to healthcare professionals in Ukraine and patient associations
- Support in triage and referral of refugees to ad hoc EU medical teams
- Support connections between patients and associations, such as EURORDIS

After the first 4 months, we are now also entering a phase during which patients with chronic rare disorders also risk aggravation, and therefore ERNs are partners of centralized HUB.⁵

As a public health concern, rare diseases must always be systematically considered in major health crisis organisation and settings. Patients need to be recognised as affected by a rare disease, to benefit from ad hoc triage towards specialised centres and/or receive ad hoc remote support via on site medical teams. The ERNs fully support the Ukrainian health professionals involved in rare diseases care and plea for a status to integrate the rebuilding/expanding Ukrainian teams as official affiliated partners to the ERNs with the concept of seamless care on the European territories.

Contributors

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Declaration of interests

NA.

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