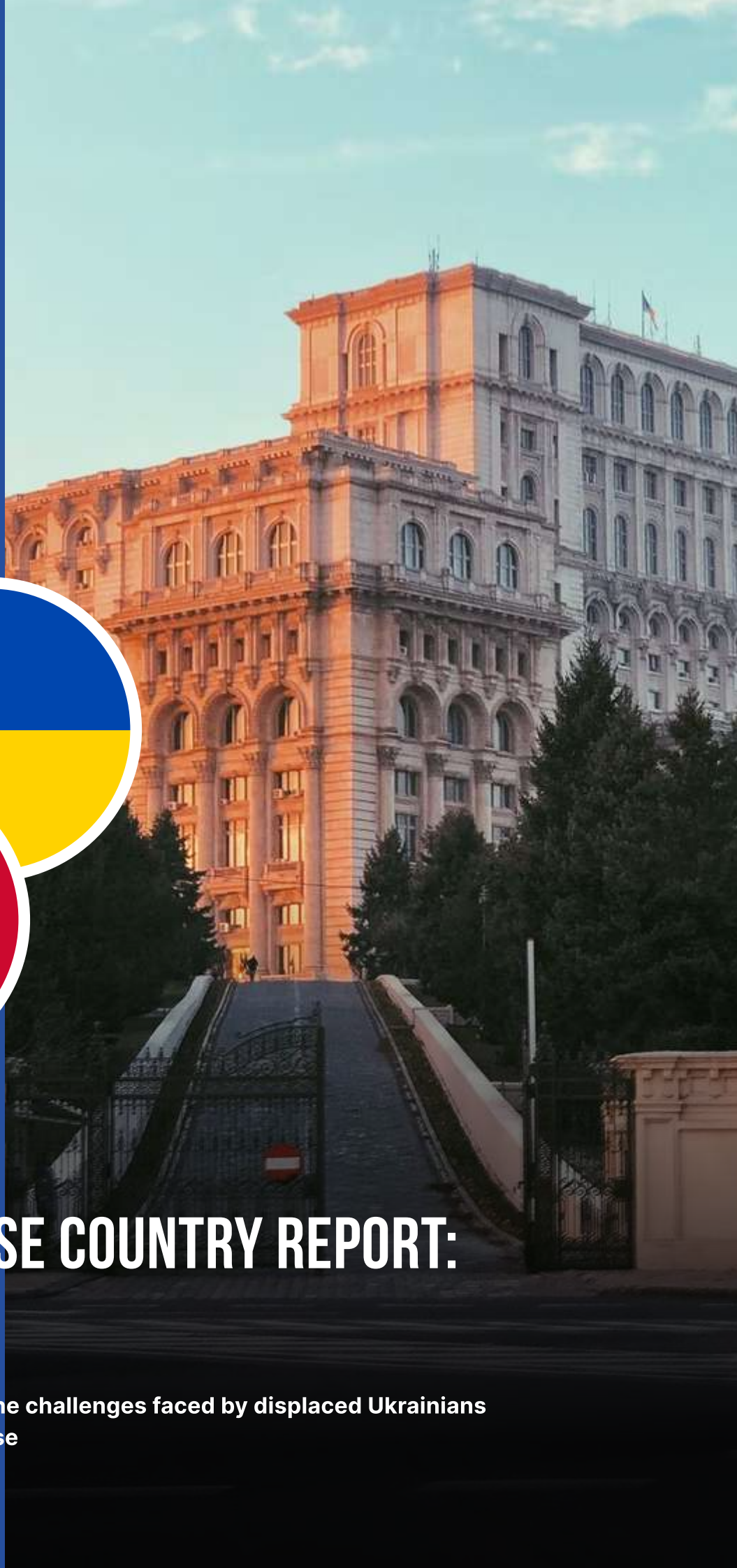




RARE DISEASE COUNTRY REPORT: ROMANIA

A EURORDIS report on the challenges faced by displaced Ukrainians
affected by a rare disease



The ongoing war in Ukraine has pushed more than 6.5 million Ukrainians to flee the country looking for a safer environment. Romania, as one of Ukraine's closest neighbours, hosts one of the largest numbers of displaced Ukrainians, with around 80 000 residing within its territory at the time of writing.

While the general number of Ukrainian refugees in Romania places the country as the second-largest recipient of displaced Ukrainians, the situation is thought to be different when it comes to Ukrainians living with a rare disease (ULWRD).

A general trend suggests that Romania has mostly served as a country of transit and is not considered a temporary or permanent host with only some 10 % of those who have entered the country still residing within its territory. This seems to be even more true for those living with a rare condition.

According to the data shared by Romanian rare disease patient organisations, the total figure of ULWRD who received assistance from these groups constitutes some 20 families, which is an unproportionally small share of the Ukrainian displaced population in Romania. Having said that, there were more families who were supported throughout their short-term stay in Romania and in preparation to move westwards.



While there might be a variety of reasons to explain such a tendency (from language difficulties to the specificities of the local healthcare system), Romania seems more prepared to provide assistance to ULWRD than some of its neighbours, notably Moldova. Given the geographical proximity of the two countries, ULWRD who are now in Moldova need to be supported to move to Romania if they wish to have better access to necessary health care and other types of social services.



The information in this report is derived from a series of meetings with patient organisations in Moldova and Romania. It also includes information shared with EURORDIS by refugees, healthcare professionals and psychologists, all of whom are witnessing different aspects of the humanitarian crisis caused by the ongoing war in Ukraine.

It is important to recognise that this is a rapidly-changing situation. This report was compiled in June 2022, and what is true today may be different in a few weeks' time. EURORDIS will endeavour to review the situation and provide updates as needed.

SUPPORT PROVIDED TO UKRAINIANS LIVING WITH A RARE DISEASE IN ROMANIA



Filip T -
Acondroplasia

AS WITH OTHER EUROPEAN COUNTRIES BORDERING UKRAINE, ROMANIA HAS EXTENDED ITS SOCIAL BENEFITS (INCLUDING ACCESS TO HEALTH CARE) TO UKRAINIANS FLEEING THE WAR TO AN EXTENT NOT SEEN BEFORE. AT THE SAME TIME, IT IS BELIEVED THAT THE PROVIDED ASSISTANCE IS MORE COMMUNITY-BASED RATHER THAN INSTITUTIONAL

In the case of rare diseases, organisations as **the Romanian National Alliance for Rare Diseases, the NoRo Centre, the Romanian Red Cross Society, Haemofilia Association, and the Association for patients with CMT** have provided the following assistance:

- Integrated information on rare diseases into a platform created in Romania for civilians fleeing the war in Ukraine where they can find out more about seeking protection in Romania.
- Joined the Refugee Coordination Forum Health Working Group to coordinate their response and be better informed about other actors' intervention.
- Provided urgent assistance with translations, access to healthcare services, and housing and covered basic needs for those transiting Romania.
- Placed ULWRD within Romania's healthcare system so that they have access to necessary treatments and urgent surgeries.
- Included rare diseases in the Integrated Action Plan of MoH in response to the Ukrainian humanitarian crisis.



Autism, Florian H.

In addition to that, several centres of expertise for rare diseases expressed their availability and readiness to provide clinical services to the displaced Ukrainians—including genetic testing and necessary treatments when available.

Romanian patient organisations have also been very successful at proactively offering their services to the displaced rare disease community. In particular, they have offered their support to Ukrainian and Moldovan rare disease groups with information resources, and working with local partners to coordinate care and support in Romania. They have also organised meetings with local patient organisations to coordinate their crisis response activities and advocated more broadly to integrate ULWRD in the crisis response programmes.

To the extent possible, EURORDIS will support Ukrainians living with a rare disease in Romania in the following areas:

- To support travel costs for Ukrainian families and the staff and volunteers who help them
- To enable access to Ukrainian-speaking therapists
- To provide short-term housing for vulnerable families through [a partnership between EURORDIS and Airbnb.org](#)

Catalin B. – PWS
and Codrin B. –
Acondroplasia



THE HIGHEST PRIORITY OUTSTANDING ISSUES

1)

Accessing health care or social services, housing and other goods and services usually takes time and requires additional assistance on the part of Romanian-speaking family assistants or case managers who understand the local system

3)

Adapted longer-term housing solutions should be put in place for families of ULWRD given the protracted character of the humanitarian crisis in Ukraine

2)

Not all necessary treatments for rare diseases are available for ULWRD as they are not covered by state programmes for Romanian citizens either

4)

Due to the combined effect of the war trauma and psychological vulnerabilities associated with rare diseases, there is a demand for psychosocial support provided by Ukrainian- and Russian-speaking therapists

undiagnosed patients
(Tamara T. and Gabi M.)
and therapist





There are certain treatments that are not accessible to Romanian patients, so we had to intervene and buy some treatments. [...] Lack of medicines is another problem, not everything can be found in Romania

Romanian patient organisation



We recommend treatments, some of them are not covered by the health insurance, so they have to pay, but in the case of the children from Ukraine, we could not do it. We were fortunate to have an organisation that helped us. On this occasion, maybe things that are hidden within our system will come to light. Patients perform many examinations that are not fully covered by the health systems, and they are necessary to diagnose a disease, especially a rare disease

Centre of Expertise for rare diseases



The psychological impact is quite big because the future is uncertain for these patients, for these families, and separating them from their family members has a huge psychological impact

Romanian patient organisation



The integration into medical and welfare service at the national level takes time, more than expected, sometimes these services are quite slow. [...] Therefore, these services have to be optimized

Romanian patient organisation



We need more translators, and we need accurate interpretation, otherwise an interpreter is perceived as a barrier in the relationship with a therapist. And the need for support therapy is quite high

Romanian patient organisation



The most important problem was the language barrier. We were lucky to have a Ukrainian in our team and whenever he was available, he helped us

Centre of Expertise for rare diseases

NON-GOVERNMENTAL ORGANISATIONS, PATIENT GROUPS, AND PUBLIC ENTITIES CONTRIBUTING TO THIS REPORT



EURORDIS-Rare
Diseases Europe



Romanian National Alliance
for Rare Diseases



NoRo Centre



Ministry of Health
of Romania



Romanian Red
Cross Society



PKU Life Romania

Centre of Expertise for
rare eye diseases,
Timisoara

Hospital Obregia,
Centre of Expertise for
rare paediatric
neurological diseases

Centre of Expertise for
congenital anomalies
Oradea



Asociația Neuro Move CMT



Asociației Române de Hemofilie



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