



RARE DISEASE COUNTRY REPORT: MOLDOVA

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

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THOUGH WELL-ORGANISED AND GENEROUS, LIMITED HEALTHCARE PROVISION MEANS MOLDOVA IS LARGELY A SHORT-TERM PLACE OF TRANSIT FOR UKRAINIANS LIVING WITH A RARE DISEASE

At the time of writing, the [UNHCR](#) estimates that 6.5 million of Ukrainians have fled the war in Ukraine and are residing mostly in the country's neighbouring states. While its own population amounts to only slightly more than 4 million people, the Republic of Moldova is among the 5 main hosts of displaced Ukrainians in absolute figures – the country has accepted more than 400 000 of those fleeing the war. Nearly 3/4 of them have left the country shortly after (towards Ukraine and Romania or westwards) with the remaining 100 000 Ukrainians still residing in Moldova.

As it follows from the cited figures, some 75 % of those entering the country from Ukraine are transiting towards other European countries. This still represents a substantial number of people for a country that has limited resources. The vast majority of displaced Ukrainians who remain in Moldova are coming from the nearest regions to the Ukraine border: [Odesa, Mykolaiv, and Kherson](#).

This unprecedented arrival of displaced persons heavily impacted the state, from its economy and social services to its provision of health care.



Though there are Ukrainian families living with a rare disease in Moldova (especially those from Odesa, Mykolaiv and Kherson who hope to be able to return to Ukraine soon), our current understanding is that the majority of Ukrainians affected by a rare disease have moved on to other locations, as there is limited provision available within Moldova and it is typically not viable for them to remain.

In this sense, **we should support Ukrainians with rare diseases to move from Moldova to countries with more resources to support their complex needs.** Though we always would advocate to support people where they want to be, we recognise that the Moldovan healthcare system has limited capacity when it comes to diagnosis or treating rare diseases. In the short term, therefore, NGOs and governments should make it easier for Ukrainians living with a rare disease to understand where in the EU they can get treatment and support them financially to travel there, perhaps in particular to the geographically close Romania.



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 May 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.

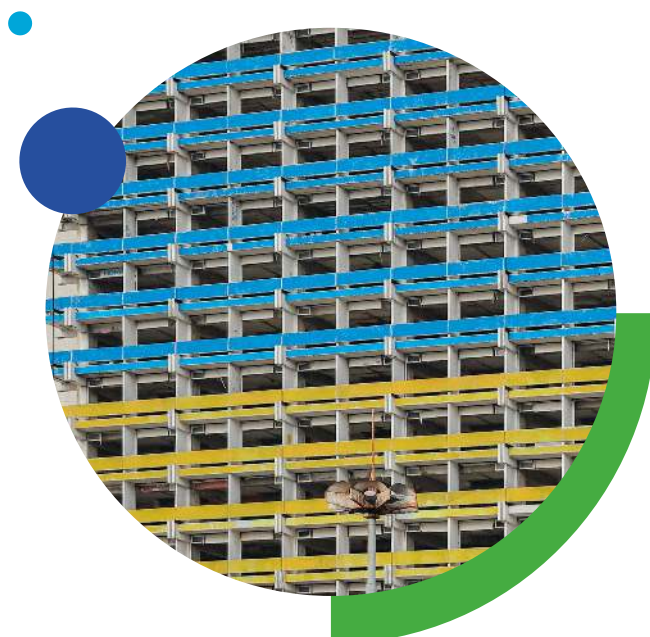
SUPPORT PROVIDED TO UKRAINIANS LIVING WITH A RARE DISEASE IN MOLDOVA



FROM THE FIRST DAYS OF THE MASSIVE DISPLACEMENT OF UKRAINIANS CAUSED BY THE WAR, MOLDOVAN LEADERSHIP HAS ANNOUNCED ITS OPENNESS TO ACCEPT AND SUPPORT AS MANY REFUGEES AS NECESSARY, AND THE SOCIETY AT LARGE HAS SHOWN INCREDIBLE SUPPORT FOR THE DISPLACED POPULATION

In the case of rare diseases, organisations as **Organisation for people with disabilities in Moldova (AOPD)**, **Centre SOS Autism**, **Federation for Rights and Resources for People with Autism Spectrum Disorders in the Republic of Moldova (FEDRA)**, **Children of the Rain Association (Copii Ploii)** provided necessary assistance that included:

- Arranging adapted transportation from the Ukraine-Moldova border to the host country's bigger cities;
- Securing short-term (for cases of transit) or more sustainable housing solutions;
- Covering basic needs (food etc.);
- Providing necessary medication and healthcare services or therapies;
- Hiring personal assistants or carers for people with disabilities;
- Placing rare disease patients within Moldovan rehabilitation institutions;
- Promoting inclusion of people with special needs (including those with rare diseases) within different response programmes.



The country's healthcare facilities are doing their best to help. For example, the Republican Centre for Children Rehabilitation, took care of more than 70 child refugees, at least half of them living with a rare disease, who were referred to them from the border crossing points, as well as by the Ministry of Health of Moldova and through Ukrainian doctors.

It is important to note, that in general Moldovan civil society organisations, healthcare professionals, refugees, international actors and the government have managed to build up their response in a very coordinated and well-structured manner including through having weekly coordination calls. They are also linking with their counterparts in Romania and are well-organised despite the emergency.

This valuable support and collaboration of many individuals and organisations has proven to be essential in addressing the needs of displaced Ukrainians.





Finally, we recognise that both the rare disease community from Ukraine in Moldova and the Moldovans themselves would benefit from significant resources to address the needs of people living with a rare disease.

Despite an unprecedented mobilisation on the part of the Moldova government and its civil society, issues remain, and the families from Ukraine and the organisations in Moldova who support them require more involvement on the part of the international community.

To the extent possible, EURORDIS will support Ukrainians living with a rare disease in Moldova 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](#)



THE HIGHEST PRIORITY OUTSTANDING ISSUES

1)

Insufficient capacity of the Moldovan healthcare system and lack of resources to support rare disease patients with therapeutic services

2)

Adapted housing, public transportation and accessibility for people with limited mobility

3)

Shortages of medication, medical devices and specialised nutrition (for instance, gluten-free food)

4)

Poor ability to diagnose rare diseases

5)

Psychological support for displaced Ukrainians living with a rare disease and their families and carers





We had requests coming from the refugees for therapy. We have a day centre for children with rare disease and autism so they have requested therapies. Unfortunately, we do not have this possibility because we cannot afford it financially

Moldovan patient organisation



The therapies are very expensive, we only have a few specialists. And the training is very expensive, it takes a lot of effort to identify people and time to train people [...] And of course we need funds to cover expenses

Moldovan patient organisation



Parents from the Republic of Molodva have to pay for this [therapy], it is quite costly. And we need money to cover the staff salaries for those who work overtime

Moldovan patient organisation



We had rare genetic diseases which we never encountered before – seen them for the first time with the refugees from Ukraine [...] We do not have specialised therapies for [this condition]

Moldovan public healthcare facility





A large part of the disabled families [...] decided to go to other countries able to provide them with more support. [...] Temporarily placement centres are not physically adapted, we do not have public transport adapted to the needs for patients who suffer from rare diseases and disabilities for them to be able to see a doctor, to access healthcare services

Moldovan patient organisation



There is special equipment for children with rare genetic diseases. In our country such devices are not produced. We may get second-hand devices but at least we should have some devices even so (second-hand)

Moldovan public healthcare facility



The Republic of Moldova does not have consumables to start to diagnose people. And we asked for the price for the consumables, and we try to find the funds [...] This will be the need also for the citizens of the Republic of Moldova

Moldovan patient organisation



We do not have diagnostic capacities regarding the knowledge in the field of rare genetic [diseases] – we have a big gap

Moldovan public healthcare facility



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



EURORDIS-Rare
Diseases Europe



Organisation for people with
disabilities in Moldova (AOPD)



Centre SOS Autism



Federation for Rights and
Resources for People with Autism
Spectrum Disorders in the
Republic of Moldova (FEDRA)



Children of the Rain
Association (Copii Ploii)



NoRo Centre



Romanian National Alliance for
Rare Diseases



Centrul Republican de
Reabilitare pentru Copii
PUN SUFLET ÎN TOT CE FAC

The Republican Centre for
Children Rehabilitation



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