



WORKING TOGETHER ON CHALLENGES AND OPPORTUNITIES FOR RARE DISEASES IN UKRAINE

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EURORDIS' main activities in regard to Ukraine

1. Support ULWRD to relocate or leave the country, through information resources, and working with local patient groups and partners
2. Support ULWRDs when arriving as refugees in neighbouring countries and to relocate across EU, through patient networks and partners catalysing new solidarities
3. Inform European, EU-national and Ukrainian authorities of the specific challenges facing ULWRD and advocate for them to address these issues
4. Liaise with Humanitarian organisations to both help solve specific requests for help and to advocate more broadly that they integrate PLWRDs in their response to the crisis

EURORDIS practical resources for ULWRD



RareBnB: EURORDIS & AirBnB partnership

EURORDIS - Rare Diseases Europe has partnered with Airbnb to provide 30 days of free housing abroad for members of the Ukrainian rare disease community who are fleeing the country. This applies to any family affected by a rare disease.

If you know a Ukrainian refugee who is in need of a safe place to stay outside of Ukraine, please make sure to [share this link](#). Feel free to share this information on your website, social media and other relevant channels.



Visit and share our [Ukraine - Rare Disease Resource Centre](#) which collects information about what organisations are doing to help Ukrainians living with a rare disease, and provides information for Ukrainians who are in Ukraine, leaving, or have already located to other European countries. (In English and Ukrainian)



Razem z Ukrainą - a confederation of 12 patient-focused non-profit organisations to meet the critical needs of a minimum of 500 Ukrainian families living with a rare disease who are currently in, coming to, and/or going through Poland.



Very close partnership with **European Reference Networks** to support medical management of families coming from Ukraine + highlight their needs leading to the creation of a **Rare Diseases Hub** in Barcelona

Other parts of our response so far

- Awarded 'emergency **grants**' totaling €29,000 to 7 different rare disease organisations working with Ukrainian families (5 in UA, 1 in Poland, 1 in Romania)
- Fielded a **Rare Barometer survey for Ukrainian families** with a rare disease to better capture their needs with quantitative evidence. (publication due soon)
- Where possible, we **connect patient and humanitarian aid organisations** in Ukraine and neighbouring countries to deliver frontline response to Ukrainians living with a rare disease
- Identify **volunteers** who can be deployed by EURORDIS and our member patient organisations to help individuals navigate care pathways outside of Ukraine (helpline operators, translators, etc)
- **Advocate** on behalf of Ukrainians living with a rare disease through the media, parliamentary networks, and direct outreach to governmental and non-governmental organisations, departments and institutions in Ukraine and in Europe
- Appointed a senior manager to run this programme
- Published reports on [the situation in Poland](#) and [Moldova](#). Next up: a report on Romania and Ukraine
- Organising meetings to share information with patient organisations, with companies, with the EC and MEPs. EURORDIS is part of the Supporting Ukraine network of the European Commission

Razem z Ukrainą

- Confederation of 12 patient-focused non profit organisations
- Name chosen to be understandable in Polish and Ukrainian
- Goal: to meet the critical needs of a minimum of 500 Ukrainian families living with a rare disease who are currently in, coming to, and/or going through Poland.
- Coalition will collaborate to:
 - Provide family assistance to support Ukrainian families to access health care, navigate the social benefit systems, get access to housing and schools, etc.
 - Provide appropriate (adapted) housing for families affected by a rare disease, either through EURORDIS' partnership with Airbnb and/or via directly commissioned housing through coalition members
 - Procure and ship equipment (e.g. wheelchairs, medical supplies) where they are needed
 - Support travel for Ukrainian families and the staff and volunteers who help them
 - Enable provision of psychological support for Ukrainian individuals, children or families, referred by coalition members and facilitated directly by EURORDIS
- Initially existing for 12 month period
- All partners agree to meet every 2-4 weeks (as needed) to compare notes
- To the extent possible, partners will try to support families with a RD outside of their disease group when not represented in the consortium



Razem z Ukrainą partners



Federation
of Polish
Patients



immunOprotect



EDU



FUNDACJA
BOHATERA
BORYSA



- We will allow additional collaborators to join us later as needed

Creating a hub to support Ukrainian families with a RD



- Hosted in Barcelona's Children hospital
- Ukrainian speaking clinicians to help UA families get access to right specialist wherever they are in Europe
- Steering committee includes ERNs, European Commission and EURORDIS
- EURORDIS pushing to expand to include telemedicine, perhaps with UA counterparts where access to normal specialist is lost
- Opportunity to help with mapping centres of expertise (as they were before the war and now)

EURORDIS Rare Barometer Survey



- Fielded across May in Ukrainian
- Nearly 400 validated responses (completed surveys from confirmed rare diseases)

The majority (61%) of the respondents is still living in Ukraine, 25% have left Ukraine and are now living in another country in Europe or in the world, while 13% have moved to another city within Ukraine.

Poland is the country where the highest proportion of those who move are now residing (43%), followed by Germany (13%) and Czech Republic (7%)

Perhaps unsurprisingly, mental health has deteriorated in a context of uncertainty and threat.

Previous research shows people affected by rare diseases are three times more likely to report sadness and depression than the general population. Now these families have a double burden.

83% say they are very often, often, or sometimes depressed or unhappy. With 58% saying they are often or very often unhappy. 76% say they cannot solve their problems. 58% say they feel isolated.

3 in 10 say they would take advantage of online psychological support if available.

Those who are still living in Ukraine (in the same or another city since the war began) express a **widespread feeling of uncertainty: 7 in ten** don't know if they are safe or say that they are *probably* safe where they are. There is a feeling of imminent threat for 26% who do not feel safe and protected where they are. The feeling of uncertainty is still prominent among those who left Ukraine (52%) but the feeling of direct threat only concerns a few (3%).

EURORDIS Rare Barometer Survey



Percentage of respondents who have limited access to medical care/geographical situation

	MEDICAL THERAPIES AT HOME OR AT THE HOSPITAL (INFUSIONS, CHEMOTHERAPY, HORMONAL TREATMENT, ETC.)	APPOINTMENTS WITH THE GP/SPECIALIST WHO PROVIDES CARE FOR THE RARE DISEASE	INFORMATION ON YOUR MEDICAL FOLLOW UP	REHABILITATION THERAPIES (ERGOTHERAPY, SPEECH, PHYSICAL THERAPY, MASSAGE, ETC.)	DIAGNOSIS TESTS (LAB TESTS SUCH AS BLOOD TESTS, BACTERIOLOGI... TESTS, URINALYSIS, MEDICAL IMAGING, CARDIAC AND RESPIRATORY TESTS ETC.)
I am still living in the same place in Ukraine	56%	49%	51%	52%	50%
I had to move to another city within Ukraine	71%	65%	72%	61%	77%
I had to move outside of Ukraine	59%	67%	63%	67%	65%

■ Under-represented elements ■ Over-represented elements

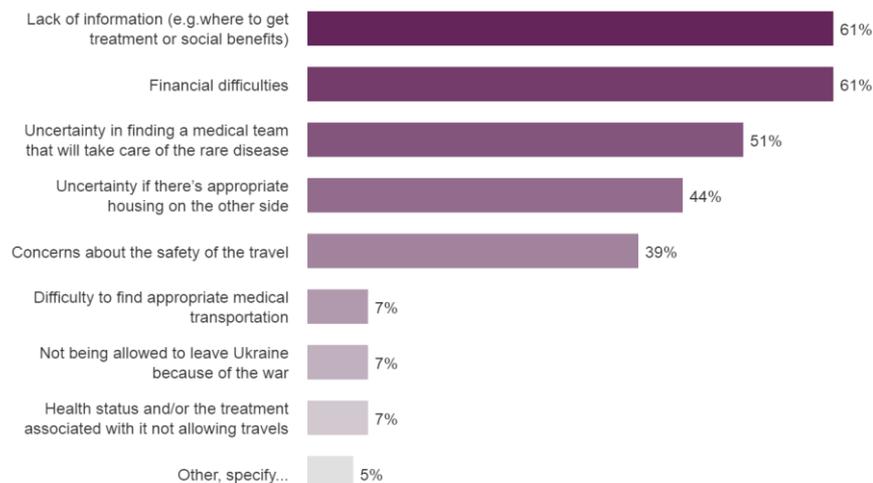
PLEASE CHOOSE THE SENTENCE THAT BEST DESCRIBES YOUR SITUATION. SINCE THE WAR BEGAN...	RENEWAL OR CHANGE OF MEDICATIONS		
	YES SINCE THE WAR BEGAN	YES BUT IT WAS ALREADY THE CASE BEFORE THE WAR	NO
I am still living in the same place in Ukraine	31%	24%	45%
I had to move to another city within Ukraine	50%	10%	40%
I had to move outside of Ukraine	43%	19%	38%
Other, specify...	0%	14%	86%

resented elements

Supporting Rare Disease Families who seek to leave the country

- **2 in ten of those who are still living in Ukraine would seek to leave the country if they could.** The two main obstacles preventing those families from leaving Ukraine is **the lack of information such as where to get treatment or social benefits (quoted by 61% of the respondents)** (EURORDIS and Ukrainian patient orgs can help)
- **financial difficulties (61%).** (Aid agencies can potentially help)
- The other obstacles selected are the **uncertainty in finding a medical team that will take care of the rare disease (51%)** (EURORDIS + ERNs)
- if there is appropriate housing available in other countries (44%), (EURORDIS + AIRBNB)
- difficulty to find appropriate medical transportation ((7%)

What are the main obstacles preventing you or your family from leaving Ukraine? (several answers possible)



ECRD, Ukraine session

Mobilising the Rare Disease Movement for Ukraine: EURORDIS and Our Allies' response to the war in Ukraine

28 June, 11 am – 1 pm

In light of the current humanitarian crisis in Ukraine, the estimated two million Ukrainians living with a rare disease and their families are among the most affected by the conflict, faced with the sizeable challenge of meeting the complex medical needs on their own and falling through the cracks of the humanitarian aid system. In this session, you will hear first-hand from **patient organisations** in Ukraine and Poland who are responding to the crisis on the ground as well as coordinated efforts by EURORDIS, including the **first results of our Rare Barometer survey on Ukraine**, and additional initiatives and provisions put in place by **European Reference Networks** and other humanitarian organisations.

Ukraine visit (1-3 June 2022)



Topics discussed at the meetings with the MoH and with Ukrainian POs:

- Access to humanitarian aid and outstanding needs of ULWRD
- Introduction of the Orphanet in Ukraine; expansion of the NBS and launch of the CoEs
- Advocacy messages targeting industry, aid organisations and decision-makers

Next steps

Publishing **country reports** to highlight the highest priority outstanding needs faced by Ukrainians living with a rare disease in:

- Romania
- Ukraine

To the extent possible, EURORDIS will support Ukrainians living with a rare disease in these countries 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**

Thank you!

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