



# RARE DISEASE COUNTRY REPORT: POLAND

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

APRIL 2022

Ukrainian children with Cystic Fibrosis  
supported by Ukrainian patient  
organisations





# OVERVIEW

This report provides an overview of the greatest needs facing Ukrainian families living with a rare disease now staying in Poland after being displaced by the war. With a large shared border, and as a preferred destination for many Ukrainian families with ties to the country, Poland is hosting by far the largest number of Ukrainian families at this moment in time.

The information in this report is derived from a series of meetings with patient organisations in Poland and Ukraine. (See the full list on the last page). It also includes information shared with EURORDIS by families moving from Ukraine to Poland as part of our partnership with Airbnb.org. We are working on a structured survey through our [Rare Barometer programme](#) which we hope will give us further insight into the needs of Ukrainian families.

It is important to recognise that this is a rapidly-changing situation. This report was compiled in April 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.



# WHY RARE DISEASES REQUIRE EXTRA FOCUS

The war and its consequences have been traumatic and created disruption for all Ukrainians. When we ask for a different approach to support rare disease patients, we are not trying to say that rare disease patients deserve security more than the general population. We are looking to help others understand that this vulnerable community requires specific actions and support to achieve equitable access to the health and social benefits offered to all people displaced from Ukraine.

There are an estimated 2 million people in Ukraine living with a rare disease. There are >6,000 rare diseases. They are very different conditions, but what unites them is that they are not well understood, are difficult to diagnose, and most often do not have a cure. Those affected by a rare disease typically require frequent and complex care. Many also have disabilities that make movement very difficult. In the context of a war, these families have extreme difficulty leaving their homes without support to access care or retrieve food and supplies needed for survival, even when these are available. To seek safety in another country, many require additional support for transport within Ukraine to the border; once on the other side of the border, they may need adapted accommodation and very quick access to specialised care in a new country (where access to such treatments and care may not be widely understood by first responders and local healthcare professionals).



# AN UNPRECEDENTED MOBILISATION FROM RARE DISEASE COMMUNITY IN POLAND

Polish civil society has generally and rightly been praised for its initial response to the war. Patient groups have responded with exceptional dexterity.

Organisations including [Polish National Forum on the Treatment of Orphan Diseases - ORPHAN](#), [Debra International](#), the [Polish Association For Persons with Intellectual Disability](#), the [Healthcare Education Institute](#), [EB Polska](#) and [Debra Poland](#), [Matio CF](#) and [Fundacja SMA](#) among others have mobilised a network of volunteers to help hundreds of vulnerable families with a great range of activity. Some examples include:

- setting up specialised helplines and translating information resources
- meeting vulnerable families at the border
- registering rare disease patients with specialty medical centres
- buying and transporting essential equipment, such as wheelchairs, that had to be left behind on the journey
- organising transport and emergency accommodation
- supporting their integration into schools equipped to meet their needs, translating medical records
- providing financial support until families can access the benefit system

**Without this support many of these families would simply not have been able to manage.**

**However, issues remain, and the families from Ukraine and the organisations in Poland who support them require significant support to address the needs of the rare disease community.**





# THE HIGHEST PRIORITY OUTSTANDING ISSUES



## MEDIUM-TERM ACCESS TO SECURE AND DISABILITY-ADAPTED HOUSING: THE SINGLE BIGGEST ISSUE FACING UKRAINIAN FAMILIES WITH A RARE DISEASE IN POLAND

The key universal issue raised by every single group remains housing. Most families from Ukraine are now staying with Polish volunteers who have generously opened their doors. However, this is a very short-term solution. The housing is rarely adapted to the needs or disabilities of these families. As the war goes on, organisations tell us that it is less comfortable for both the Ukrainian guests and the Polish hosts to share small spaces together.

Short-term renting options are not easily available nor affordable at the level of assistance being provided. Due to the complexity of rare diseases, these families typically need to live in cities close to the specialty centre for their condition, which limits their choice of where they can stay.

In partnership with Airbnb.org, EURORDIS is trying to support these families by providing short-term housing for free 30-day stays, leveraging the Airbnb network. However, this is only a short-term solution.





*Some [families with rare diseases] are already thinking of returning to Ukraine because of problems with housing.*

**A Ukrainian patient organisation**



*At the moment, we are in a hurry to find housing for our family, we are very worried that we will stay on the street. The lady where we live said that we would have housing quickly. But there is almost no housing. It is very expensive, or you need to pay months in advance. We have no money at all.*

**Applicant for short-term housing under EURORDIS-AIRBNB partnership**



*The problem is to find an independent apartment so that a family with these specific needs can function normally.*

**Polish patient organisation**



*People with wheelchairs are living in homes with strangers and where they cannot sit on the toilet by themselves or even use the bathtub because it's not adapted for their disability.*

**Polish patient organisation**



*It's very difficult to convince people that they have to keep moving [onwards in the EU] but we cannot offer them access to decent accommodation or anything.*

**Polish patient organisation**



*90% of Ukrainians we work with refuse to move to other countries where there is adapted accommodation for them. Sometimes they are hoping that the war will be over soon and they want to be close to home. Or they prefer Poland because they know someone living here from before the war. They can understand some of the language. Now it's estimated that 10% of Polish residents come from Ukraine. They want to stay because they have a community here.*

**Polish patient organisation**



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## UKRAINIAN FAMILIES AFFECTED BY A RARE DISEASE REQUIRE FAMILY ASSISTANTS OR CASE MANAGERS TO FACILITATE THEIR ACCESS TO BASIC SERVICES

Many of the patient organisations consulted are supporting dozens of families, some closer to a hundred. Depending on the diseases represented, many of these families require very complex, specialised, and hands-on support to access basic goods and services. The patient groups are relying on volunteers, many of whom have been mobilised for over a month now. These volunteers are tired and need to return to their normal economic activities.

Case managers or family assistants are required to help vulnerable Ukrainian families access the care they need, navigate the benefits systems, locate and apply for schools that meet their needs, or to move on to other countries in the EU.







*All Ukrainians in Poland have access to healthcare but there are lots of formal things they need to do to get a national ID number... in cities like Gdansk you have to wait at least a month. Therefore, we usually drive these people to smaller towns to get these numbers. They could never do this themselves.*

**Polish patient organisation**



*For children with disabilities they need special documents to get access to special education. It takes time. It's really complicated and you need to contact different institutions.*

**Polish patient organisation**



*It was OK in the beginning that volunteers assisted families. But people need to go back to work. It's OK to support 2 or 3 families. But 10, 20 or 100? We need money to hire family assistants.*

**Polish patient organisation**



*Our government is quite satisfied with what they have done because formally Ukrainian refugees have access to what they need. The problem is no one is supporting them to getting these needs. They have access to healthcare, but many hospitals will not accept them because they have no space. It's great we offered them all these things, but now we need to help them to make use of it.*

**Polish patient organisation**



*Patients and their families need an assistant who will help in organising life in Poland (for example: contact with the refugees centre, help in obtaining social benefits, help with transport to the store, outpatients clinic, hospital - this kind of help is necessary for patients with disabilities who do not have own car. Assistants should help with contact with the Polish medical staff to explain needs of the patients and special medical benefits – due to rarity of [this disease] the medical benefits in Poland are not commonly known even by medical staff.*

**Polish patient organisation**





## UKRAINIAN FAMILIES WITH RARE DISEASES - AND THE POLISH PEOPLE WHO SUPPORT THEM - NEED ACCESS TO PSYCHOLOGICAL SUPPORT

According to a 2017 [EU-funded study as part of the INNOVCare project](#), people or family members with rare diseases are three times more likely to be unhappy or depressed compared to the general population in normal times. In these times of war, where post-traumatic stress disorder (PTSD) is more common, families who already were carrying mental health burdens require additional support to manage.

Most Polish organisations we spoke to referred to the mental health challenges impacting both the families they are supporting as well as the volunteers working with these vulnerable families.



*The psychological status of Ukrainian families has deteriorated. On the first days sometimes you had the impression that they came for holidays. They had a boost of adrenaline and were ready to act. After a few days they become different.*

**Polish patient organisation**



*One mother of a child I was helping would not leave the bed for two days, and we had to find her help. It is not easy to find psychologists speaking Ukrainian. There are some volunteers but they cannot work for weeks or months for free. This is how they make their living and they are often refugees themselves.*

**Polish patient organisation**



*Our volunteers are working day in and day out with people who have experienced trauma. They are absorbing that trauma and need support to process it.*

**Polish patient organisation**



# OTHER SIGNIFICANT ISSUES RELEVANT TO SPECIFIC RARE DISEASE POPULATIONS

## SHORTAGES OF RARE DISEASE MEDICATIONS AND SUPPLIES IN POLAND



*There is a shortage of immunoglobulins in Poland due to the migration. The situation wasn't great even before, but now it's alarming. We estimated that the extra supply of Ig's should be 48 kilograms of immunoglobulins for the next 12 months, just to cover the needs of Ukrainian refugees with immunodeficiencies in Poland. Anyway, there are other indications for Ig's which are not connected to any rare disease (post-covid syndromes (PIMS), neuropathies etc.), so the needs are even higher. And these medicines can't be "taken" from the Ukrainian market as there are different manufacturers in the EU and Ukraine (just a 'national' manufacturer whose products can't and shouldn't be sold in the EU due to safety issue).*

**Polish patient organisation**



*Many supplies required by our patients-bandages and lotions- are also useful to soldiers and individual civilians injured in wartime. These supplies are very hard to come by in Ukraine and there are already shortages in Poland and other countries.*

**International patient organisation**





## LACK OF EQUIPMENT



*We see parents coming with 11-, 12-, 13-year-olds carrying their children because they left their wheelchair behind...We have received wheelchairs from Iceland, and are expecting others from Portugal and Sweden. But even if we have equipment in one city, you still need money to send it from one location to other cities in Poland.*

**Polish patient organisation**



*Can you imagine an adult with a disability travelling from Ukraine without a wheelchair? And then there's someone calling us from the border saying, what do we do with him? We have to take him out of the van but there's nowhere we can put him? So we need to find a shop, take the size, order and pay online to get it delivered to the border. And then we need to find them an accessible hotel near the border...this takes hours and hours.*

**Polish patient organisation**

## SHORTAGE OF HOSPITAL BEDS



*We call hospitals one by one, the patients call hospitals one by one, but they all say they have no more capacity to take adult patients for our condition.*

**Polish patient organisation**



## LOSS OF CONTACT WITH RARE DISEASE PATIENTS REGISTERED IN UKRAINE



*We are working with 60-70 families in Poland, but we know from other sources that as many as 400 families [with our disease] have left Ukraine. We don't know where these families are. Are they in Moldova? Somewhere in Poland but they do not reveal themselves because they are in deep trauma and they try to find their ground? Maybe they are already outside of Poland? Soon we will know more because people with these conditions need medical aid.*

**Polish patient organisation**

## GETTING A DIAGNOSIS WILL BE EVEN MORE DIFFICULT



*For very rare conditions getting a diagnosis is always time-consuming and extremely difficult. With so many services disrupted and with families displaced by the war, we are worried that families will not be able to persist with the diagnostic journey required to successfully get a diagnosis. There will be families from Ukraine in Poland with rare diseases but they will not know how to find out what condition they have or who can help them.*

**Polish patient organisation**



# HOW WILL THIS CRISIS DEVELOP?

Without the benefit of hindsight, we do not now know how this crisis will evolve.

Will the war end soon? If so, maybe the focus will be about supporting some families to move safely back to Ukraine, and how to get lacking medicines and supplies into the country.

Will the horrors of war intensify? If so, we are only facing the tip of the iceberg. And many more desperate families, driven either by desperation or a better understanding of how to access support within the EU, will make the journey westwards. Though countries bordering Ukraine have gained much know-how in the first two months of the war, this 'second wave' would put considerable pressure on infrastructure that is already struggling to cope.

If the status quo drags on, will Ukrainian families begrudgingly accept that Poland cannot meet all of their needs? Will there be a new focus on helping people resettle elsewhere in the EU, and creating more robust and sustainable programmes to ensure families from Ukraine remain both welcomed and supported?





# PRELIMINARY RECOMMENDATIONS FROM EURORDIS

First we **recommend that rare disease patient organisations continue to mobilise** and indeed further mobilise. We can learn from the successes of the organisations that are most active. In the event that this first migration of vulnerable rare disease families is only the tip of the iceberg, we will need to be more prepared and active for the second wave. We can learn from experience, apply for funding that meets our real needs, and continue to monitor trends and developments.

Second, we ask **Polish authorities** to build on their initial generosity by simplifying the processes by which families coming from Ukraine can access needed benefits and social services. This is especially necessary for all vulnerable families with disabilities. We ask that they recognise rare disease families in that category, whether their disability is visible or not.

Third, Poland cannot do this alone. We call on the **European Union to demonstrate unparalleled generosity towards Poland**, in recognition that families from Ukraine want to stay there for the reasons outlined in this report. Already affected by trauma, these families deserve some say in where they live. We need to support Polish social services, healthcare and education systems so that the much-reported generosity of the country is sustained.

Fourth, we believe **local and national aid agencies need to recognise the additional complexities facing rare disease patients** and integrate their needs into their activities in Poland (and indeed in Ukraine). Systems set up to help the greatest number of people as quickly as possible risk leaving the most vulnerable behind.

Finally, we call on **international/federated aid agencies to establish a centralised rare disease bureau** which can co-ordinate, problem-solve and support aid agencies working on the ground to meet the more complex needs required for these patient groups.



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



EURORDIS-Rare  
Diseases Europe



ORPHAN



Rare Diseases  
of Ukraine



DEBRA International



European Reference  
Networks



Boris the Hero  
Foundation



Lupus Poland



Polish Association  
For Persons with  
Intellectual Disability



CF Ukraine



MATIO Polish CF



PHA Ukraine



DEBRA Polska



SAVENTIC Foundation



SMA Foundation  
(Poland)



DEBRA Ukraine



immunoprotect



EB Polska



Federation of Polish  
Patients



Ars Vivendi



Parent Project  
Muscular Dystrophy



Healthcare Education Institute