1 YEAR OF COOPERATION

REPORT ON HUMANITARIAN AID FOR UKRAINIAN RARE DISEASE PATIENTS

Report prepared by:

Healthcare Education Institute
The Foundation

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Photos:

The following photos were used in the report:

- p. 29 and 31 – photo taken during "The World for Ukraine Summit" in Rzeszów, **Polish Rescue Organization / https://www.facebook.com/photo?fbid=232623945756079**,
- p. 45 – photos taken during "The EURORDIS Black Pearl 2023" in Brussels, **EURORDIS – Rare Diseases Europe.**

All other photos are from the collection of the Healthcare Education Institute.

Contents

Since the day the war broke out, we have been supporting patients with rare diseases who are fleeing the horrors of war. We help them both in Ukraine and after reaching Poland.

The war that began in Ukraine is an unprecedented event in recent history. A war in which there are no rules and in which civilian objects, homes, kindergartens, and hospitals are bombed and shelled. A war in which the victims are innocent Ukrainians civilians: mothers, children, and the sick.

A war that has already forced **almost 5 million people to flee the country**. Among them are also patients with rare diseases. And even more patients with rare diseases remain in Ukraine, uncertain of whether they will be able to escape and whether anyone will support them in their evacuations and secure their treatments.

Since the beginning of the war, we have been doing our best to prevent Ukrainian patients with rare diseases from feeling abandoned and left to deal with their difficulties alone. We support them in many ways: we help them to flee the war, we provide treatment in Poland and other European countries, we offer legal assistance and provide information, and finally, we provide on-site support for Ukrainian patients and the medical community.

Now it turns from an ad hoc project, forced by the situation, into a well-thought-out support system with a dedicated team responsible for specific actions.

Letter from the Vice-President

It was a year that none of us expected. A year that was a test of solidarity, unity and humanity.

On the 24th of February everything changed completely – not only for Ukraine, but for all of us. Immediately we decided that we need to help Ukrainian refugees with rare diseases. We couldn't let them feel lost and abandoned. We had to learn quickly how to effectively manage such a crisis and I believe we succeeded.

The numbers speak for themselves. Although our resources were rather limited, over the past year we managed to help nearly 90 families of patients with rare diseases from Ukraine. We sent 24 humanitarian transports to Ukraine with medicines, medical equipment and other necessities, with a total value of nearly USD 60,000.

But more important than numbers are the people and their stories. Each saved patient is a great joy and satisfaction. Each safe family is a motivation for further action. Each story sinks deeply into your memory and keeps us going. Because Ukrainian patients still need our help and our solidarity.

All of this, all our activities would not be possible without the support of others. At this point, I would like to especially thank our donors – corporate and individual ones – and sponsors of our projects. I would like to express my gratitude to all entities that supported us in our work, especially to EURORDIS. I would also like to thank the Polish doctors who have provided invaluable care to all Ukrainian patients with rare diseases.

But it's not over yet. The war continues. Our work continues. And it will – for as long as necessary.

Bernadeta Prandzioch-Goretzki

BERNADETA PRANDZIOCH-GORETZKI
Vice-President of the Foundation

What are rare diseases?

A disease is rare when it affects less than 1 in 2,000 citizens in given country. But so far, over 6,000 different rare diseases have been identified, which in total affect 3.5 – 6% of the population worldwide.

That is why rare are not that rare; **in Ukraine, there are approximately 1.5 – 2.5 million people with rare diseases.** Some of them suffer from more common and well-known rare diseases such as haemophilia or primary immunodeficiencies, while others from diseases that affect only few persons in all of Ukraine.

80% of rare diseases are of genetic origin and are often **chronic and life-threatening**.

Around
1.5–2 mln
RD patients
live in Ukraine

RD affect
<1:2000
people

There is over

6000

different RD

80% of RD
are genetics

How do we support rare disease patients from Ukraine?

Our work is currently based on four main areas of activity:

1. Helping patients fleeing the war in Ukraine

We provide patients with support at every stage of their journey to Poland or transit to other European countries, including faster transport across the border, organizing accommodation, and access to treatment.

2. On-site support for Ukrainian patients and the medical community

We organize the transportation of medicines and medical equipment to hospitals treating patients with rare diseases in Ukraine and we also finance the purchase of medicines on the spot.

3. Information and legal support for patients

We prepare dedicated websites with information for RD patients, legal opinions, printed materials, translations of medical records, and provide support in legal matters related to staying in the EU.

4. Raising awareness about the situation of RD patients from Ukraine

We speak at industry conferences and stakeholder meetings, give interviews, and take part in podcasts to draw attention to the needs of RD patients in Ukraine and encourage others to act.

Helping patients fleeing the war in Ukraine

- We provide patients with support at **every stage** of their journey to Poland or other European countries.
- We organize humanitarian corridors to ensure faster border crossings for patients in serious conditio.
- We take care of **short-term accommodation** for the patient's family.
- We provide access to treatment in Poland (we cover all procedures and hospitalizations and **arrange the first visit to a specialist in a given field**).
- We stay in **touch** with patients and monitor their situation. If necessary, we help in arranging further doctors' appointments.
- We offer patients and their family members **free psychological care** in Ukrainian.
- In the case of transit to other European countries, we provide contact to a patient organization in each country **as well as to a medical clinic treating a given disease.**

This is Yehor, an 11 yo
XLA patient receiving
immunoglobulins
at a Polish hospital

So far, we have managed to help over 90 families of patients with rare diseases from Ukraine.

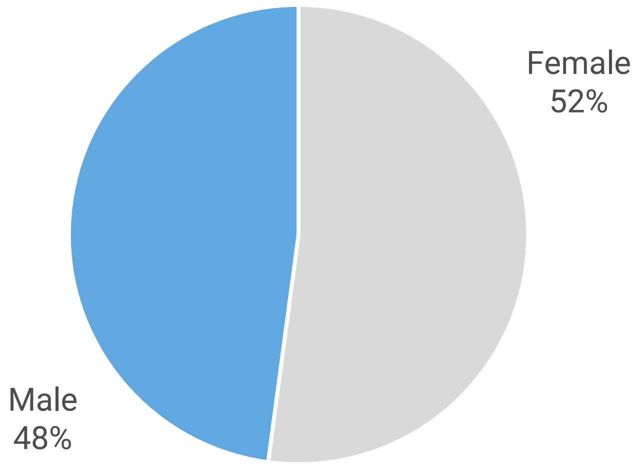
Helping patients fleeing the war in Ukraine

So far, we have helped **over 90 families of patients with rare diseases**, including primary immunodeficiencies, epidermolysis bullosa, or rare cases such as KIF1A.

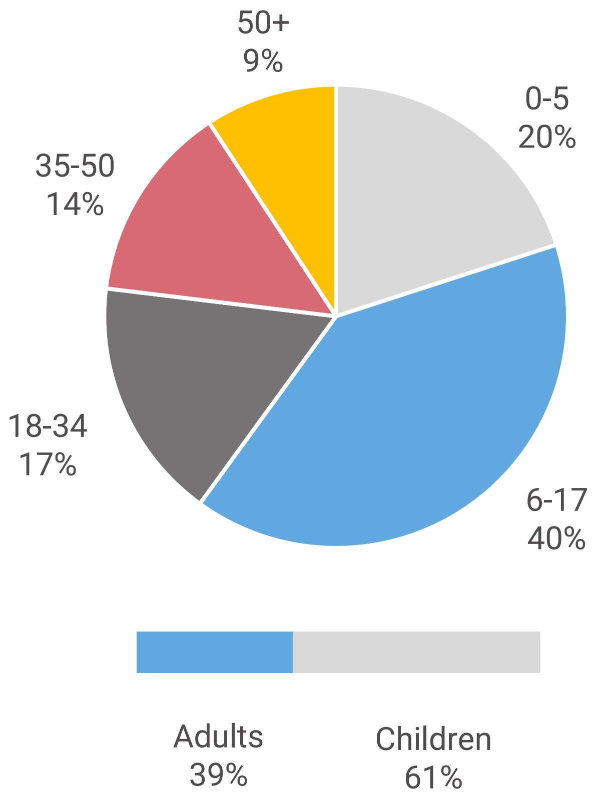
In the cases of patients in serious condition, we make sure **to create a fast track for them** so that they do not have to wait in long lines at the border. In the first days of the war, the long lines required even several days of waiting, so it was crucial to speed up the process for RD patients.

Most of the patients we have helped are children, but almost 40% of them are adults, most often with **very serious forms of their diseases** and requiring advanced treatment outside Ukraine, including transplantations.

Rare disease patients we have helped



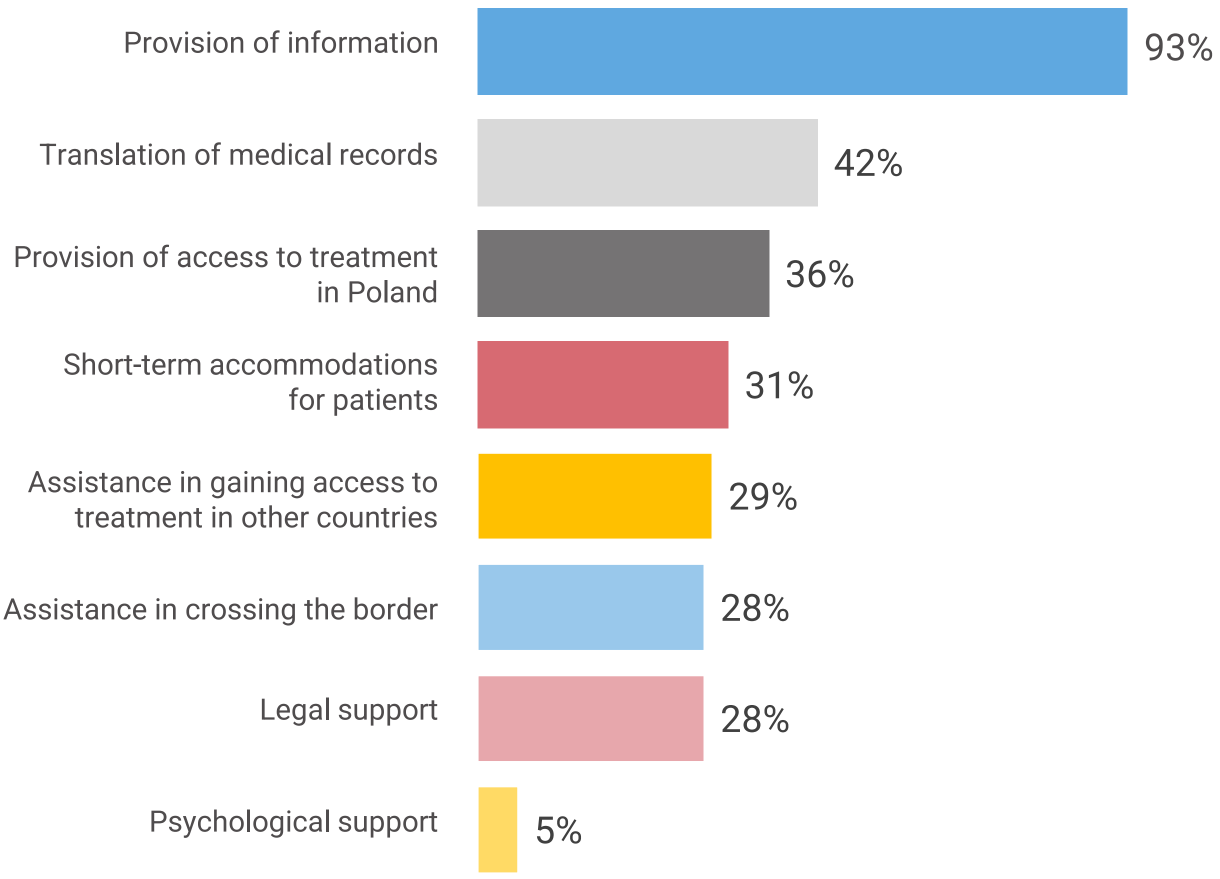
Gender



Age of the patients

Helping patients fleeing the war in Ukraine

The most important form of our help is, of course, **providing patients with access to appropriate treatment** – both in Poland and in other European countries. This concerned **three quarters of the patients we helped** (36% are treated in Poland, and 29% obtained access to treatment abroad). To make this possible, in many cases it first required assistance in **crossing the border quickly** (28%), **arranging short-term accommodation** (31%) and **translating medical records** (42%). However, this certainly does not exhaust the scope of our assistance – **we provided information support to almost all patients at various stages of their stay in Poland.** In many cases, it was also highly specialized assistance in the form of **legal advice** or preparation of letters or documents for the relevant offices in Poland (28%).



Helping patients fleeing the war in Ukraine

Patients whom we've helped cross the border and receive treatment in Poland have often suffered from very rare diseases. Some of them, like LAD-I, only occur in 1 in 500,000 cases. KIF1A-related disorder is even rarer: there are only 150 diagnosed patients worldwide. All of them **require a very specialized approach**. That is why our activities are always focused on **providing adequate medical care** in a specialized medical center **as soon as possible**.

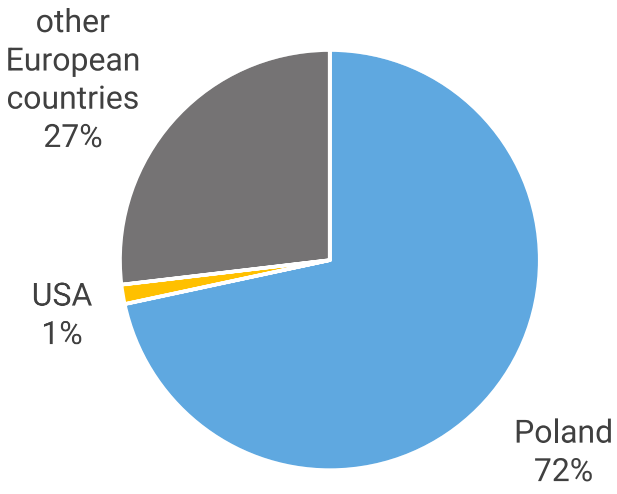
List of rare diseases in Ukrainian patients whom we have helped	
Acromegaly	Juvenile rheumatoid arthritis (JIA)
Autoimmune lymphoproliferative syndrome (ALPS)	Kabuki syndrome
Chondroma	KIF1A-Related Disorder
Combined immunodeficiency due to DOCK8 deficiency	Leukocyte adhesion deficiency type-1 (LAD-I)
Combined immunodeficiency due to LRBA deficiency	Myasthenia gravis (MG)
Common variable immunodeficiency (CVID)	Nijmegen breakage syndrome (NBS)
DiGeorge syndrome	Noonan syndrome (NS)
Epidermolysis Bullosa (EB)	Phenylketonuria (PKU)
Fasioscalpulohumeral muscular dystrophy 1 (FSHD)	Pulmonary Hypertension (PH)
Glut1 deficiency syndrome (Glut1DS)	Severe combined immunodeficiency (SCID)
Hepatopulmonary syndrome (HPS)	Spinal muscular atrophy (SMA)
Hyper IgD Syndrome (HIDS)	SYNGAP1
Hyper IgE Syndrome (HIES)	Wilson's disease
Hypo-IgM Syndrome	X-linked agammaglobulinemia (XLA)

Helping patients fleeing the war in Ukraine

When Poland was the target country, we first provided patients with the necessary support in finding accommodation and completing the necessary formalities (**obtaining refugee status** and a PESEL number). Then, we provided them with **appropriate medical care**: we made appointments with specialist physicians or provided hospitalization in medical centers if their health conditions required it.

Map of hospitals in Poland where RD patients we helped are being treated

Patients who stay in Poland vs. patients for whom we have provided care in other countries



In the cases of patients who decided to travel farther to other countries, we provided contact with patient organizations operating in a given country, obtained information on which medical center they should go to, or contacted doctors directly.

In some cases, patients first stayed in Poland where they received appropriate treatment, and only later decided to travel farther to another country.

Every patient has a unique story (1)

Meet Emilia (Емілія)!

Emilia and her family come from a small village near Lviv, close to the Polish border. She's got an older brother, Markian. She was born in 2021 with a very rare genetic disease called severe combined immunodeficiency (SCID, "the Bubble Boy disease"). This is a very serious type of primary immunodeficiency that most often requires a bone marrow transplant (BMT) in the early months of life.

After being diagnosed with SCID, Emilia was also waiting for BMT, but in the first days of war, the hospital in Kyiv where the procedure was to be performed was bombed. Moreover, the warfare made it impossible to get to Kyiv.

Everyone was frantically looking for another solution. On the third day of the war, we received a call from Emilia's parents. They got our number from doctors from Lviv. It was the very beginning of the war - there were no solutions, procedures, humanitarian corridors, etc. But we knew we had to act.

Thanks to our efforts, after a couple of days, Emilia came to Poland together with her whole family. She was taken care of by doctors in the pediatric department of a university hospital in Bydgoszcz. From the very beginning, she was given exceptional care there. After some necessary tests, they began preparing the transplant procedure for her.

Emilia underwent a successful transplant a couple months ago. Since then, her immune system has started working properly. She feels fine and is recovering surrounded by family in Bydgoszcz.

On-site support for Ukrainian patients and the medical community

So far, we have organized 24 shipments of medicines, medical equipment, and other necessities

- We are in constant contact with hospitals treating patients with rare diseases in Ukraine and we determine their needs for medicines and medical equipment.
- In response to needs, we organize the transportation of medicines and medical equipment to specific hospitals.
- Many of these shipments contain specialized products or equipment needed to treat specific rare diseases, e.g. primary immunodeficiencies, spina bifida, or cystic fibrosis.
- If the situation requires it, we finance the purchase of medicines on the spot.
- We also deliver power stations for RD patients that allow life-saving devices to work even during power outages.

The total value of medicines and medical equipment that we shipped to Ukraine or bought on site so far is over $59,000.

On-site support for Ukrainian patients and the medical community

On-site support for Ukrainian patients and the medical community

In order to adjust our activities to the current needs of patients and the medical community in Ukraine, we are in touch with doctors from many medical centers treating patients with rare diseases across the country, from Lviv to Poltava and from Kyiv to Odesa. When it comes to OTC drugs, medical equipment, and personal protective equipment, we organize the purchase and transportation on our own.

We pass on the requests for specialized medicines to entities that are authorized to transport them abroad, such as the Polish government, the Polish Medical Mission, or the Red Cross, **or we finance the purchases of specialized medicines on the spot**.

Map of hospitals in Ukraine for which we have purchased medicines or medical equipment

Power stations for RD patients in need

One of the biggest challenges faced by patients with rare diseases who remain in Ukraine is uninterrupted access to electricity. Power outages, caused by Russian shelling and regular damage to critical infrastructure, mean not only the lack of heating or the ability to cook a meal.

For many patients, a power outage means that devices that save their lives or help them function better simply don't work. **Devices like oxygen concentrators, respirators or aspirators need to be powered continuously.**

That is why one of the key things we deliver to Ukraine is power stations that allow life-saving devices to work even during power outages. Thanks to them, RD patients can feel safer and more independent from external factors.

"Pumps for Ukraine" project

Our assistance to patients staying in Ukraine includes not only emergency action, such as the purchase of medicines, but also more long-term projects, such as our **"Pumps for Ukraine"** project.

Currently, there is a lack of infusion pumps in Ukraine, but thanks to the support of our donors, patients with primary immunodeficiencies from Ukraine receive infusion pumps and medical equipment that allow them to administer immunoglobulins at home. The infusion pumps are also used in hospital departments.

So far, infusion pumps and medical equipment have been delivered to hospitals in Lviv, Ternopil, Kiyv, Vinnitsa, Ivano-Frankivsk, Chernivtsi and Odesa. Physicians from these hospitals participated in a special online training sessions on the operation of these pumps so that they could also train their patients.

Map of hospitals in Ukraine for which we have delivered infusion pumps and medical equipment necessary for infusions

"Pumps for Ukraine" project

Immunoglobulins for Ukrainian patients with primary immunodeficiencies

Our foundation provided immunoglobulins to the Children's Clinical Hospital in Poltava to secure the needs of Ukrainian patients with primary immunodeficiencies.

Due to legal regulations, not all medicines can be transported across the border and delivered to hospitals in Ukraine, even as part of humanitarian aid. But it doesn't stop us.

Thanks to cooperation with the Ukrainian producer of plasma-derived medicines, we were able to purchase immunoglobulins needed for the treatment of patients with primary immunodeficiencies. The medicines were delivered directly to the hospital by the manufacturer. Buying medicines on the spot is also an opportunity to support the Ukrainian economy, which is struggling due to the effects of the ongoing war.

> *"In such difficult days for our country, there are people who will come to our aid.* ***Infinitely grateful to Adrian Goretzki, Bernadeta Prandzioch for the help provided in the form of expensive medicines for children with immune system disorders."***

”Poltava Regional Children's Clinical Hospital
of the Poltava Regional Council”, 05.07.2022

Every patient has a unique story (2)

Say hello to Masha (Маша)!

Masha is a 2-year-old girl from a small village in the Zaporizhzhya region. She’s got an older brother, Vanya. She has **a genetic syndrome, Nijmegen syndrome, which is manifested in immunodeficiency, a very high risk of tumors and microcephaly.**

From the moment of birth, she was very small, which drew the attention of doctors, but they couldn’t establish a diagnosis for quite some time. The final diagnosis was made after the war broke out.

Until February 24, the life of her whole family was normal. Her mom worked at a school, her dad worked as a welder, and her brother was in kindergarten. She was under the care of her grandparents.

Her mom told us: “When the war started, everything changed. **I woke up in the morning because I heard something flying over the house,** but since Melitopol is not far from us, I thought it was just a plane flying to the airfield. My mother lives in Melitopol. I saw a message from her at five in the morning "call me" and then I immediately realized that it was something wrong. I called her and she was crying: “Anya, the war has started“.

Masha’s parents went into the backyard and at the same moment they spotted four rockets overhead, so close that they could see all the details. **They packed and decided to leave their village. Three days later, Russian soldiers entered the village**.

In the new place, they went to the bomb shelter during every air raid; whenever it was, day, night, at any hour. But after some time, Masha began to run a fever. The family thought that it may be because of

Every patient has a unique story (2)

the conditions in the bomb shelter. So, they stopped going to the shelter, tried to stay in safer areas in the apartment during the air raids and she recovered. And after 2-3 months they decided to go to the hospital again in order to somehow track her developments.

An immunologist at the Zaporizhzhia Regional Children's Hospital advised them to go to Lviv, to the Western Ukrainian Specialized Children's Medical Center, where physicians helped them to learn about the disease. But it still wasn't enough, and the conditions were uncertain, as they still lived in Zaporizhzhia region, close to the frontline. **So, they decided to leave Ukraine and go to Poland.**

“My mother lives in Melitopol. I saw a message from her at five in the morning "call me" and then I immediately realized that it was something wrong.“

With our help, Masha was admitted to a hospital in Wroclaw, had a full examination in the immunology department and consultations with a cardiologist.

For now, Masha feels good and she's under the care of the immunologists. But – as per their advice – she cannot go to the kindergarten yet because of her immunodeficiency. She lacks this connection with peers, but it's for her own good. She has started to get sick a little more often now than before. A common cold can last for 2-3 weeks, so it is a little more difficult for her to get over these common infections than other children.

The whole family is waiting for the Ukrainian victory and the liberation of their territory, as they want to return home to Masha's grandparents and relatives who stayed behind. But, first and foremost, they want to make sure that Masha has the best possible care in Poland.

Information and legal support for patients

- We run websites with information for RD patients:

  www.ridkisnikhvoroby.pl

  www.imunodefitsyt.pl

- We prepare legal opinions regarding access to therapy for Ukrainian patients with chronic diseases and staying in Poland.
- We create educational materials such as information brochures and roadmaps for patients from Ukraine.
- We organize translations of medical documents from Ukrainian to Polish or English.
- We support patients in legal matters related to their stay in Poland (obtaining a PESEL number, refugee status, etc.) or obtaining social benefits.
- We contact the appropriate offices in Poland to receive necessary information and answer questions from patient.

Інформація для пацієнтів з імунодефіцитом в Польщі

Ви знайдете інформацію пр

A guide for patients from Ukraine about the healthcare system in Poland

We have 6 translators on 2 continents who translate patients' medical records to ensure they receive appropriate medical care.

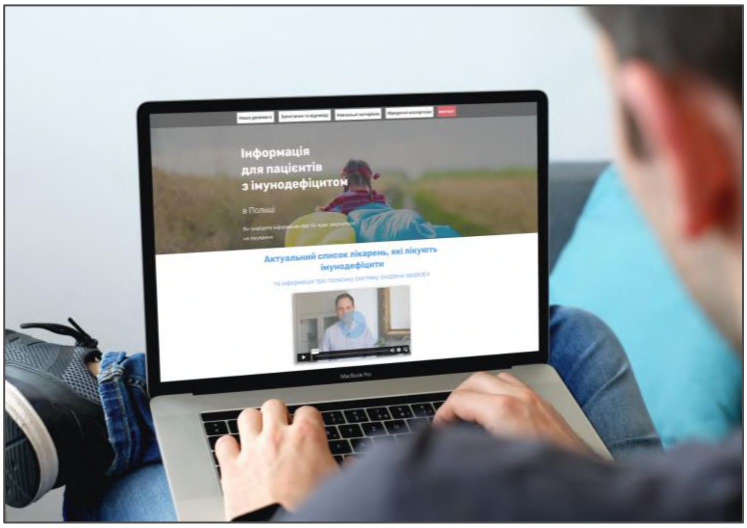
Information and legal support for patients

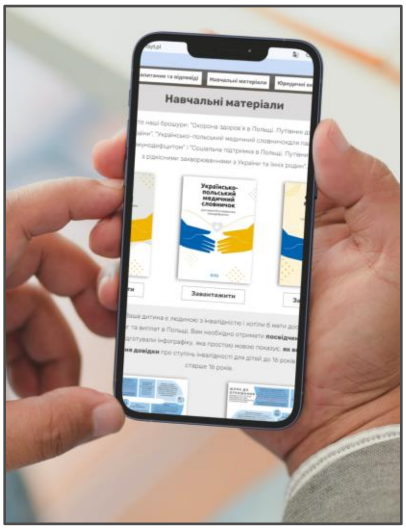
1. Websites with information for RD patients

In the first weeks of the war, we prepared two websites: one for patients with rare diseases and the other for patients with primary immunodeficiencies. On the websites you can find:

- Contact details for hospitals treating primary immunodeficiencies
- Contact details for Polish verified rare disease patient organizations
- **A frequently updated comprehensive FAQ section with answers to almost 50 questions** regarding access to therapy for Ukrainian patients with chronic diseases in Poland, social assistance, and work and education in Poland
- **Legal opinions in Polish and Ukrainian** indicating that Ukrainian refugees have access to free-of-charge medical care in almost all cases, including therapies for rare diseases.

You can visit our websites
by clicking on the pictures!





Educational materials

2. Brochures

We prepared three printed brochures for patients which are available free of charge at hospital wards where rare disease patients from Ukraine are treated.

- **The first one** presents the healthcare system in Poland from the perspective of RD patients
- **The second** is a Ukrainian-Polish medical dictionary for patients with primary immunodeficiencies. It contains over a hundred of the most important medical terms related to PID and often used in a doctor's office or medical records
- **The latest** brochure is about the social benefits available in Poland for RD patients or caregivers of RD patients who, as a result of the war caused by Russia, were forced to flee from Ukraine to Poland.

Click on the covers to download brochures

Educational materials

3. Video guides

We have created **a series of video guides in Ukrainian** for rare disease patients and their families staying in Poland. We chose the topics of the videos based on the most frequent questions asked by Ukrainian patients and their families, as well as the problems they encountered while navigating the Polish health and social systems. Thanks to this, **the films are the answer to real problems and challenges**.

3 videos are already available on our YouTube channel:

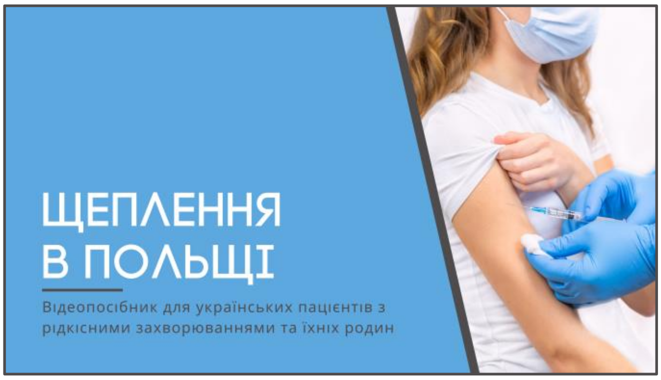
www.youtube.com/@eduinstituteorg

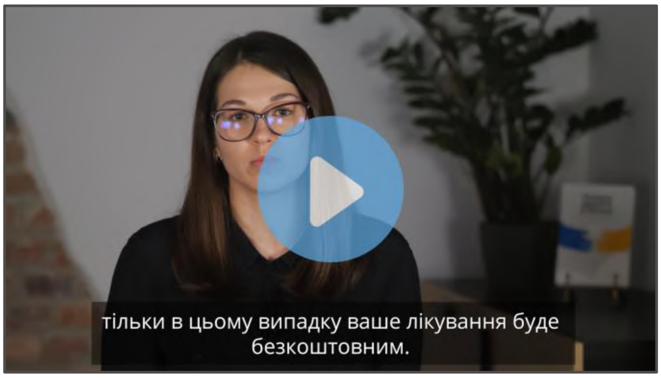
The first video was devoted to the health care system in Poland.

The second film deals with issues related to vaccination in Poland – immunization schedule for babies and children, vaccinations against COVID-19 and influenza available to all.

In the third video, we discuss the treatment of primary immunodeficiencies in Poland.

Two more videos, in which we focus on the social benefits in Poland available for patients with rare diseases and their caregivers, and we discuss the path to obtaining a disability certificate in Poland, will be published in the coming weeks.




тільки в цьому випадку ваше лікування буде безкоштовним.

Click on the picture to check our YouTube channel and watch video guides!

Educational materials

4. Infographics

Since Ukrainian disability certificates are not recognized in Poland and patients have to undergo the procedure in Poland, we have prepared roadmaps, which describes in a simple way how to obtain a certificate of disability in Poland for children up to 16 years and for adult patients over 16 years.

ШЛЯХ ДО ОТРИМАННЯ ДОВІДКИ ПРО СТУПІНЬ ІНВАЛІДНОСТІ ДЛЯ УКРАЇНСЬКИХ ДІТЕЙ МОЛОДШИХ 16 РОКІВ

Довідка про ступінь інвалідності є офіційним підтвердженням того, що Ваша дитина має інвалідність. На її підставі ви можете претендувати на різні пільги, надбавки та виплати в Польщі. Польща не визнає українські довідки про інвалідність. **Для отримання польського посвідчення необхідно пройти процедуру в Польщі.**

Насамперед перевірте, чи відповідає Ваша дитина **ВСІМ** умовам для оформлення інвалідності.

Знайдіть установу з розгляду інвалідності «Zespół do Spraw Orzekania o Niepełnosprawności», яка відповідає **місту вашого постійного проживання на даний момент.**

Отримай в офісі установи або завантаж на веб-сайті наступні документи:
1. заява про отримання довідки про інвалідність,
2. медична довідка.

УВАГА! Кожна установа може мати інший шаблон заяви та довідки.

Заяву заповніть особисто.

Попросіть лікаря, який лікує Вашу дитину або бажано **спеціаліста з його хвороби**, заповнити медичну довідку. Довідка дійсна протягом 30 днів з дати її заповнення.

Підготуйте документи, що підтверджують стан здоров'я Вашої дитини:
1. **медична документація**, наприклад, виписні епікризи після стаціонарного лікування, документація амбулаторного лікування, результати додаткових обстежень, консультацій спеціалістів,
2. **інші документи**, які можуть вплинути на визначення ступеня інвалідності, наприклад, психолого-педагогічні висновки, думка класного керівника.

Якщо вищевказані документи подані українською мовою, до заяви необхідно додати їх переклад, виконаний присяжним перекладачем.

Подати заяву, довідку та документи до установи з розгляду інвалідності **«Zespół do Spraw Orzekania o Niepełnosprawności».**

Після цього очікуйте листа з повідомленням про дату засідання комісії.

Приходьте разом з дитиною на зустріч (ваша присутність обов'язкова!), під час якої дитину оглянуть, команда оцінить стан її здоров'я та визначить чи може вона самостійно виконувати діяльність, яка відповідає її віку.

Ви отримаєте своє свідоцтво поштою протягом 14 днів після слухання. **Платити за довідку не потрібно.**

EDU Healthcare Education Institute The Foundation

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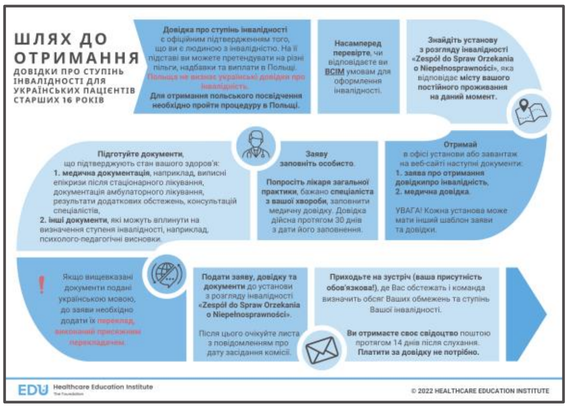

ШЛЯХ ДО ОТРИМАННЯ ДОВІДКИ ПРО СТУПІНЬ ІНВАЛІДНОСТІ ДЛЯ УКРАЇНСЬКИХ ПАЦІЄНТІВ СТАРШИХ 16 РОКІВ

Довідка про ступінь інвалідності є офіційним підтвердженням того, що ви є людиною з інвалідністю. На її підставі ви можете претендувати на різні пільги, надбавки та виплати в Польщі. Польща не визнає українські довідки про інвалідність. **Для отримання польського посвідчення необхідно пройти процедуру в Польщі.**

Насамперед перевірте, чи відповідаєте ви **ВСІМ** умовам для оформлення інвалідності.

Знайдіть установу з розгляду інвалідності «Zespół do Spraw Orzekania o Niepełnosprawności», яка відповідає **місту вашого постійного проживання на даний момент.**

Отримай в офісі установи або завантаж на веб-сайті наступні документи:
1. заява про отримання довідкипро інвалідність,
2. медична довідка.

УВАГА! Кожна установа може мати інший шаблон заяви та довідки.

Заяву заповніть особисто.

Попросіть лікаря загальної практики, бажано **спеціаліста з вашої хвороби**, заповнити медичну довідку. Довідка дійсна протягом 30 днів з дати його заповнення.

Підготуйте документи, що підтверджують стан вашого здоров'я:
1. **медична документація**, наприклад, виписні епікризи після стаціонарного лікування, документація амбулаторного лікування, результати додаткових обстежень, консультацій спеціалістів,
2. **інші документи**, які можуть вплинути на визначення ступеня інвалідності, наприклад, психолого-педагогічні висновки.

Якщо вищевказані документи подані українською мовою, до заяви необхідно додати їх переклад, виконаний присяжним перекладачем.

Подати заяву, довідку та документи до установи з розгляду інвалідності **«Zespół do Spraw Orzekania o Niepełnosprawności».**

Після цього очікуйте листа з повідомленням про дату засідання комісії.

Приходьте на зустріч (ваша присутність обов'язкова!), де Вас обстежать і команда визначить обсяг Ваших обмежень та ступінь Вашої інвалідності.

Ви отримаєте своє свідоцтво поштою протягом 14 днів після слухання. **Платити за довідку не потрібно.**

EDU Healthcare Education Institute The Foundation

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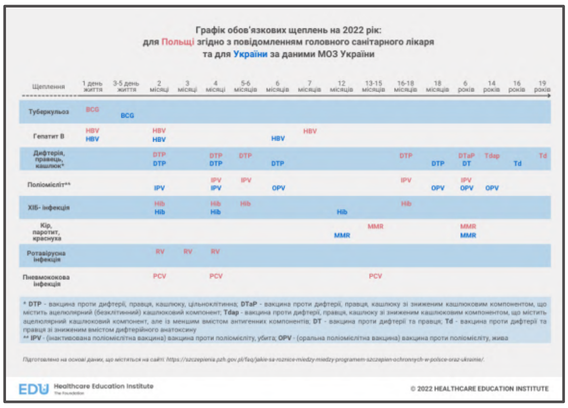
Click on the infographics
to download them

We have also created an infographic showing **a comparison of the vaccination schedule for 2023 in Poland and Ukraine.** This infographic helps Ukrainian parents understand what the vaccination calendar in Poland looks like, to what extent it differs from the Ukrainian one and what vaccinations they should supplement in the near future. All mandatory vaccinations in Poland are free for underage patients from Ukraine.

The vaccination schedule
for 2023 in Poland and Ukraine
can be downloaded here



Графік обов'язкових щеплень на 2022 рік:
для Польщі згідно з повідомленням головного санітарного лікаря
та для України за даними МОЗ України

Щеплення	1 день життя	3-5 день життя	2 місяці	3 місяці	4 місяці	5-6 місяців	6 місяців	7 місяців	12 місяців	13-15 місяців	16-18 місяців	18 місяців	6 років	14 років	16 років	19 років
Туберкульоз	BCG	BCG														
Гепатит B	HBV HBV		HBV HBV				HBV	HBV								
Дифтерія, правець, кашлюк*			DTP DTP		DTP DTP	DTP	DTP				DTP	DTP	DTaP DT	Tdap	Td	Td
Поліомієліт**			IPV		IPV IPV	IPV	OPV				IPV	OPV	IPV OPV	OPV		
ХІБ- інфекція			Hib Hib		Hib Hib	Hib			Hib		Hib					
Кір, паротит, краснуха									MMR	MMR			MMR MMR			
Ротавірусна інфекція			RV	RV	RV											
Пневмококова інфекція			PCV		PCV					PCV						

* **DTP** - вакцина проти дифтерії, правця, кашлюку, цільноклітинна; **DTaP** - вакцина проти дифтерії, правця, кашлюку зі зниженим кашлюковим компонентом, що містить ацелюлярний (безклітинний) кашлюковий компонент; **Tdap** - вакцина проти дифтерії, правця, кашлюку зі зниженим кашлюковим компонентом, що містить ацелюлярний кашлюковий компонент, але із меншим вмістом антигенних компонентів; **DT** - вакцина проти дифтерії та правця; **Td** - вакцина проти дифтерії та правця зі зниженим вмістом дифтерійного анатоксину
** **IPV** - (інактивована поліомієлітна вакцина) вакцина проти поліомієліту, убита; **OPV** - (оральна поліомієлітна вакцина) вакцина проти поліомієліту, жива

Підготовлено на основі даних, що містяться на сайті: https://szczepienia.pzh.gov.pl/faq/jakie-sa-roznice-miedzy-miedzy-programem-szczepien-ochronnych-w-polsce-oraz-ukrainie/.

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Every patient has a unique story (3)

Say hello to Nastya (Настя)!

She's only seven. She's from Donbas, from Lysychansk in the Luhansk region. She's got an autoimmune disease; in fact, a couple of different diseases: a severe form of overlap syndrome, autoimmune hepatitis, ulcerative colitis and fibrillating cholangitis.

When she was nearly two, she ran a very high temperature and was admitted to the regional hospital. But they couldn't provide a proper diagnosis there. Antibiotics didn't help, so the doctors decided to send her to Kyiv, to the Okhmatdyt hospital, where she was diagnosed and started treatment.

Before the war, the family's entire life revolved around Nastya's disease. She had a very strict diet, she had to have meals regularly, she took her medications at certain times and every three months she had to go to the hospital in Kyiv.

On February 24, the family remembers very clearly that they were woken b explosions, turned on the TV and the news was just horrible - there were bombings all over the country. They began to bring the most important things down to the basement: documents, medical records, and warm clothes.

And so, their basement life began. Between the airstrikes, Nastya's mom would go back up to the house, try to cook something, but when the explosions started, she had to quickly turn off the gas and go back downstairs. Every trip to the store was a challenge. The stores opened less and less often, and people had to stand in line for hours.

Nastya should've had her normal diet, but it was impossible to keep. She was getting worse - she had lost a lot of weight and had become very pale. Moreover, the medicine was running out. That's when the family decided to leave. But leaving Lysychansk was more difficult than they had anticipated.

Every patient has a unique story (3)

They were shot at constantly. **The trip was terrible. They were crying, shouting, praying and fighting to stay alive.** Finally, they managed to reach Kramatorsk and went to Lviv by train. And volunteers put them on the bus to Poland.

All their possessions consisted of some valuables, a doll, a backpack full of medicines and another backpack with food. That's all they had taken with them. That's how they had left.

Nastya’s family was brought to the refugee camp in Przybysławice. They were warmly welcomed there. But Nastya was sick. She had stopped eating, had lost even more weight, and her test results were very bad. Nastya’s mom started writing posts on the Internet, calling all the hotlines she could find, asking around for help and that's how she got in touch with our foundation. With a little help from us, Nastya got to the right specialists.

She’s now under professional care and taking immunosuppressive therapy. She can’t go to school but is homeschooled instead.

"It’s very difficult when you had everything, when you lived in your country and then everything changes - you lose everything, you become nobody."

They plan to learn the language first, so as to learn more about the country that welcomed them. **Everything that they had in Lysychansk has been destroyed, so they have nothing to return to.** That’s why they decided to stay in Poland. “It’s very difficult when you had everything, when you lived in your country and then everything changes - you lose everything, you become nobody”, Nastya’s mom said. But they’re determined to start their life once again here, in Poland.

Raising awareness about the situation of RD patients from Ukraine

Adrian Goretzki with members of Orphan Diseases of Ukraine and EURORDIS at the Black Pearl Awards ceremony

- We **participate in numerous meetings and conferences** where we discuss the needs and challenges of Ukrainian patients with rare diseases in order to raise awareness in society about their difficult situation.
- We **cooperate closely with other patient organizations** to work out the best solutions for patients.
- We **conduct surveys** among patients to better understand their situation and adapt our humanitarian activities to their needs.
- We started **the project "Brave RARE Ukraine"** aimed at raising awareness of the needs of rare disease families from Ukraine who have been affected by the Russian aggression. We record the videos with stories of Ukrainian patients and their families.

We appeared at 11 events, during which we publicized the situation of RD patients from Ukraine.

Raising awareness about the situation of RD patients from Ukraine

We appear in front of an international audience to raise awareness about the situation of RD patients from Ukraine

- We participated in the meeting of the network of Parliamentary Advocates for Rare Disease of European Parliament (23.03.2022)
- At the invitation of GlobalGenes, we participated in the *RareCast* podcast hosted by Daniel Levine (May 2022)
- We took part in an online conference for Ukrainian physicians called "Рідкісні захворювання у дітей” (Children with Rare Diseases) (10.06.2022)
- We have prepared a video presentation for participants of the BIO International Convention (San Diego, June 2022)
- We spoke at the 11th European Conference on Rare Diseases (28.06.2022)
- We spoke about Ukraine during the Plasma Protein Forum (Washington, 11-12.10.2022)

On December 9, during **the WORLD FOR UKRAINE SUMMIT**, together with participants from all over the world, we discussed better humanitarian, social and economic solutions to help Ukraine.

RARECAST
The GLOBAL GENES® Podcast

Episode #385
How a Polish Rare Disease Organizations Is Helping Its Ukrainian Neighbors

With Adrian Goretzki, founder and president of the Healthcare Education Institute

The Russian invasion of Ukraine that began at the end of February has caused more than 5 million people to flee the country as the brutal assault has not spared civilian populations, schools, or hospitals. For people with rare diseases, the war has sent families in search of needed medications and care as they have crossed the border in search of help. Healthcare Education Institute, a Poland-base rare disease advocacy group, has been working to help Ukrainians with rare diseases get across the border, find accommodations, and connect them to medical care. We spoke to Adrian Goretzki, founder and president of the foundation, about the needs of Ukrainians with rare diseases, what his organization has been able to do to help, and why the humanitarian crisis for these rare disease patients will last beyond the current hostilities.

Click to listen to
the podcast

Raising awareness about the situation of RD patients from Ukraine

From the right: Adrian Goretzki, Oleksii Iaremenko, Ukrainian Deputy Minister of Health for European Integration and other panelists during the World for Ukraine Summit (W4UA) in Rzeszów, Poland

Adrian and Bernadeta (on the sides) with Ukrainian physicians – Khrystyna Lishchuk-Yakymovych (on the left) and Marianna Derkach (on the right) during ESID 2022 in Gothenburg, Sweden

Cooperation with other entities

We also make sure that we are up to date with all initiatives related to helping patients with rare diseases and participate in meetings with other organizations and decision-makers.

- We are in touch with patient organizations supporting RD patients at the national and international level.
- We participate in meetings with RD umbrella organizations.
- We meet with representatives of international and domestic humanitarian organizations.
- We also participated in the meeting of the network of Parliamentary Advocates for Rare Disease of European Parliament (23.03.2022). As a result of the meeting, an appeal was made to the President of the European Commision on the necessity of supporting patients with rare diseases from Ukraine and possible methods of action.
- We closely cooperate with EURORDIS as a part of the "Razem z Ukrainą" project.

Representatives of EURORDIS, Singapore Red Cross, Debra International, Rare Diseases Ukraine and EDUinstitute.org in Warsaw

Meeting of representatives of organizations cooperating under the project "Razem z Ukrainą" in Warsaw

"The situation of patients with RD from Ukraine who fled the war" – a report

In order to understand their situation even better and adjust our humanitarian activities to their needs, in July 2022, we conducted survey research in a group of about 30 Ukrainian patients and patient caregivers whom we helped and who are currently residing in various European countries. The report which we have prepared on the basis of the collected responses is available in Ukrainian and English.

The respondents were asked about such subjects as:

- the period of stay outside Ukraine
- received medical assistance related to their illness
- financial support received by refugees
- greatest difficulties faced abroad
- current housing and work situation
- plans for the future

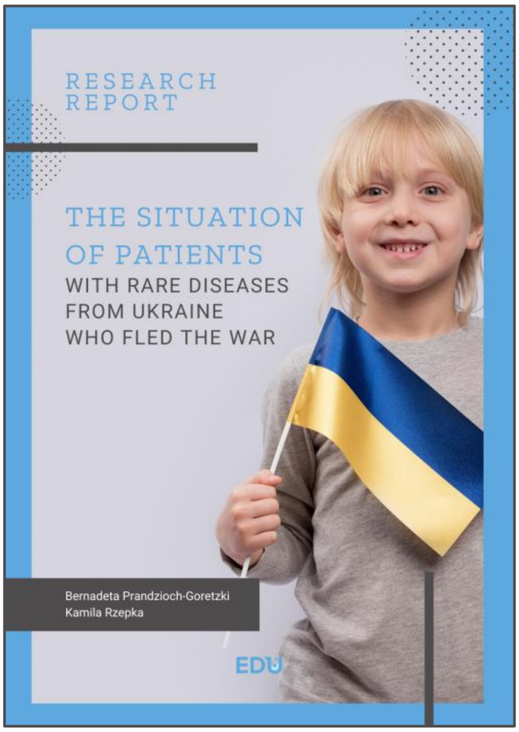
Click to read
the entire report

ЗВІТ ЩОДО
ДОСЛІДЖЕННЯ

СТАН
ПАЦІЄНТІВ
З РІДКІСНИМИ
ЗАХВОРЮВАННЯМИ
З УКРАЇНИ, ЯКІ ВТІКАЛИ
ВІД ВІЙНИ

Bernadeta Prandzioch-Goretzki
Kamila Rzepka

EDU



RESEARCH
REPORT

THE SITUATION
OF PATIENTS
WITH RARE DISEASES
FROM UKRAINE
WHO FLED THE WAR

Bernadeta Prandzioch-Goretzki
Kamila Rzepka

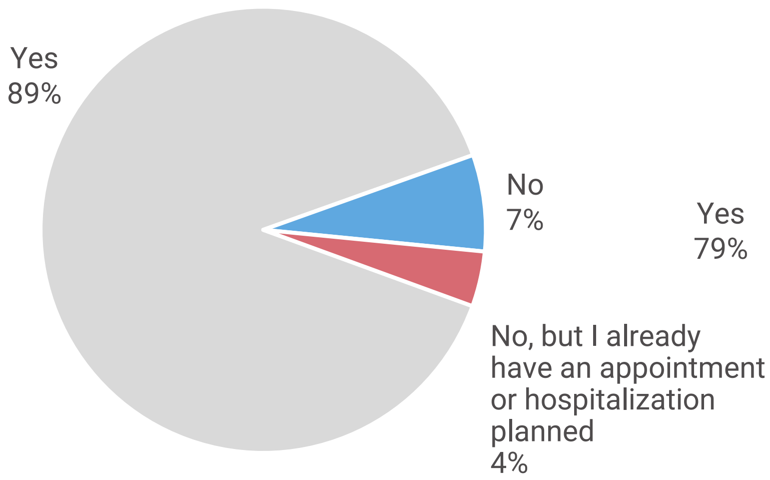
EDU

"The situation of patients with RD from Ukraine who fled the war" – a report

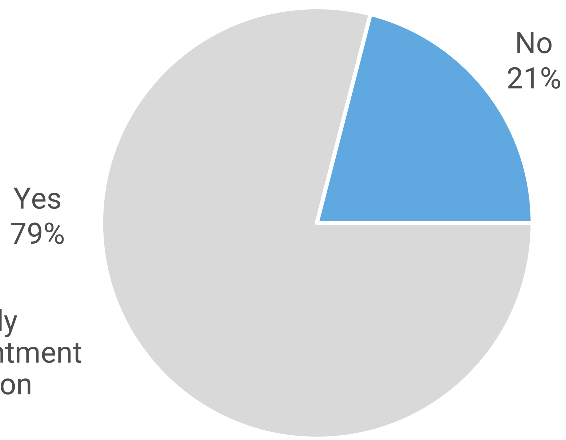
The most important conclusions from the research:

- The vast majority of respondents have received medical assistance in the country where they're currently staying (89%) which means that **the countries receiving people fleeing the war in Ukraine are effectively responding to their needs in the field of medical care**. Even people who, due to their illnesses, **need highly specialized and costly medical procedures**, such as surgeries or even transplantations, are guaranteed them in the countries they came to.
- As many as 61% of respondents indicated that **one of the greatest difficulties related to their disease that they had to face after leaving Ukraine was the language barrier in contact with physicians.** Therefore, it seems right to create educational materials in Ukrainian and to undertake other initiatives aimed at facilitating communication between physicians and patients.
- Almost 80% of respondents indicated that they had received financial assistance in the country where they're currently staying, but in the majority, it was only a one-time financial assistance for refugees. **It seems necessary to think about more long-term forms of support for refugees with rare diseases in the countries that host them.**

Receiving medical assistance while remaining outside Ukraine



Receiving official financial assistance in the country where a patient is staying



"Brave RARE Ukraine" is coming soon

For twelve months, since helping patients with rare diseases from Ukraine became the main part of our foundation’s activity, we have heard countless heartbreaking stories. We feel that each of these patients and each of these families are true warriors. Heroes no one has heard of. And we would like to change that.

Patients with rare diseases often remain in the shadows. Their stories rarely break through to the public. And it’s no different during war. That's why we came up with "Brave RARE Ukraine", a project in which we will tell the stories of those who, amidst the cruelty of war, still must struggle with their diseases and the challenges they pose.

We want to give a voice to patients, their families, doctors from Ukraine and representatives of patient organizations. We want to create a website where we will share their stories in the form of interviews, videos and podcasts.

Our foundation’s team and Brave RARE patients during the recordings

Every patient has a unique story (4)

Meet Vitaly (Віталій)!

Vitaly is from Kyiv. He has combined immunodeficiency due to LRBA deficiency, a very rare type of primary immunodeficiency. He lives with his wife Tanya, and they have been together for 12 years. Together they came to Poland after the start of the full-scale war. He also has two brothers back in Ukraine, who defend the country against Russian forces.

In addition to PID, Vitaly also has diabetes. When he was 16 he fell ill with Hodgkin's lymphoma. It was already an advanced stage, the third, and the bone marrow was already affected. His path to the diagnosis of immunodeficiency was long and complicated, and when it was established – it brought surprise but also relief. However, it didn't solve all his problems. Although immunoglobulin treatment was ordered, they weren't reimbursed in Ukraine at the time. Vitaly had to buy them on his own, borrowing money from family and friends.

Only about a year and a half ago, he started to receive immunoglobulins for intravenous administration as part of the program for people with immunodeficiency. For him it was a turning point in his life. He started to look into the future with a little more confidence. But then the war started.

On February 24, he and his wife were woken up by a very strong explosion nearby. They understood that something was wrong, opened up their messenger accounts, and immediately saw that the whole of Ukraine was on fire. Vitaly's first thoughts were about the medicines because on February 23 he placed an order for them and had to pick them up on February 24.

After some time he went outside despite the siren and everything was closed. Pharmacies were not working, people were

Every patient has a unique story (4)

panicking on the streets. **When he went to look for a pharmacy, he saw a large rocket flying 50 meters from their house, which didn’t explode.** It seems that anti-aircraft defense shot it down and it fell on a billboard.

He called the hospital, but he couldn’t get through. It was just there where the Russian Federation troops were attacking from the side of Belarus. Tanks were already coming from the Obolon direction.

He thought it would somehow get better, but a week passed, and he had a hard time getting to the hospital. Once he received medicine for a week and that was all. All the doctors told him that if there were some medicines, they were in the warehouses, and all the warehouses were closed and the logistics systems were completely shut down.

At that time, he had already decided that he would definitely go to Poland, but this was scary for him. “I thought, who needs emigrants, even sick ones, with such difficult diagnoses, with such expensive treatment. That's how it was in my head.”

"I thought, who needs emigrants, even sick ones, with such difficult diagnoses, with such expensive treatment. That's how it was in my head."

But after he and his wife came to Poland, he got treatment almost immediately. Now he goes to the immunology ward once a month or once every two months and receives subcutaneous immunoglobulins and injects them at home. “It was very unexpected and pleasant that the hospital helps with syringes, needles. I was given a pump for injections and everything that is necessary for this. (...) I feel so cared for (...) I can confidently say that now I have no problems with getting treatment here in Poland.”

As for his plans for the future, of course, the first dream is for the war to end as soon as possible and for the reconstruction of his country to begin.

Media about our actions

"Patient advocate and lawyer Adrian Goretzki, founder and president of the Healthcare Education Institute in Poland, has also helped families of rare-disease patients cross the border and arrange needed medical care.

His organization assists patients to get them quickly across the border, organizes medical care in Poland, translates medical documents from Ukrainian to Polish or English, and buys medicines and medical equipment for hospitals in Ukraine."

Erin Durkin, "National Journal", Washington DC, 4.04.2022

TVP, „Zbliżenia", 15.03.2022
– Emilia and her mother in the hospital in Bydgoszcz

PAGE 5 RARE INSPIRATION FEATURE

Extraordinary times...

Written by Nicola Miller
editor-in-chief, creative director
RARE Revolution Magazine

Extraordinary times call for extraordinary efforts. With an impactful early life of advocacy behind him, when the unimaginable happened in Ukraine, Adrian Goretzki was not only in the right place at the right time but had the necessary skills to play his part in stemming a humanitarian crisis for the PI community in the region.

This makes Adrian our RARE Inspiration

RARE Revolution eduinstitute.org

"Extraordinary times call for extraordinary efforts. With an impactful early life of advocacy behind him, when the unimaginable happened in Ukraine, Adrian Goretzki was not only in the right place at the right time but had the necessary skills to play his part in stemming a humanitarian crisis for the PI community in the region.

This makes Adrian our RARE Inspiration."

Nicola Miller, "RARE Revolution Magazine",
Autumn 2022

Click to read
the full article

Media about our actions

Click to read
the full article

”The Source. Winter 2022”, Magazine of the PPTA

SIX MONTHS OF SUPPORT:

HUMANITARIAN AID FOR UKRAINIAN RARE DISEASE PATIENTS

BY ALEXA WETZEL, PPTA DIRECTOR, LEAD FOR EUROPEAN PLASMA
ADRIAN GORETZKI, FOUNDER & PRESIDENT, EDUINSTITUTE.ORG FOUNDATION
BERNADETA PRANDZIOCH-GORETZKI, VICE PRESIDENT, EDUINSTITUTE.ORG FOUNDATION

Adrian Goretzki, a very active patient advocate and primary immunodeficiency (PID) patient himself, together with his wife Bernadeta Prandzioch-Goretzki, a psychologist experienced in working with rare diseases patients, started an incredibly challenging undertaking right after the war in Ukraine broke out. They decided to provide support to Ukrainian rare disease patients.

PPTA met with Adrian and his wife to talk about their humanitarian activities.

Can you tell us how you help Ukrainian rare disease patients?

The war in Ukraine is an unprecedented event in recent history. It is a war in which there are no rules and in which civilian objects, homes, kindergartens, and hospitals are bombed and shelled. A war in which the victims are innocent Ukrainian civilians, mothers, children, and the sick. A war that has already forced almost 5 million people to flee the country. Among them are also patients with rare diseases. Not to forget, the patients with rare diseases who stayed in Ukraine, uncertain of whether they will be able to escape and whether anyone will support them in their evacuations and secure their treatments.

Since the beginning of the war, we have been doing our best to prevent Ukrainian patients with rare diseases from feeling abandoned and left to deal with their difficulties alone. We support them in many ways. On one hand, we help them flee the war, and on the other hand, we provide them with treatment in Poland and other European countries. But we also offer legal assistance, provide information, and, finally, we arrange on-site support for Ukrainian patients and the medical community.

What started as an ad hoc project, forced by the situation, has turned into a well thought out support system with a dedicated team responsible for specific actions.

When we speak about rare diseases, how many people are affected in Ukraine?

As a whole, 80% of rare diseases are of genetic origin and are often chronic and life-threatening. In Ukraine, there are between 1.5 and 2.5 million people with rare diseases. Some of them suffer from more common and well-known rare diseases, such as hemophilia or primary immunodeficiencies, while others have conditions that affect only few persons in Ukraine.

8 THE SOURCE | WINTER 2022

> “SINCE THE BEGINNING OF THE WAR, WE HAVE BEEN DOING OUR BEST TO PREVENT UKRAINIAN PATIENTS WITH RARE DISEASES FROM FEELING ABANDONED AND LEFT TO DEAL WITH THEIR DIFFICULTIES ALONE. WE SUPPORT THEM IN MANY WAYS. ON ONE HAND, WE HELP THEM FLEE THE WAR, AND ON THE OTHER HAND, WE PROVIDE THEM WITH TREATMENT IN POLAND AND OTHER EUROPEAN COUNTRIES.”

Today, how are you organized and what actions are taken to support patients?

Our work is currently coordinated based on four main areas of activity:

1. First of all, we help patients fleeing the war. We provide patients with support at every stage of their journey to Poland or transit to other European countries, including faster transport across the border, organizing accommodation, and providing access to treatment.
2. We also provide support for Ukrainian patients and the medical community in Ukraine by organizing the transport of medicines and medical equipment to hospitals that treat patients with rare diseases, finance the purchase of medicines, and provide information and legal guidance to patients.
3. We have created dedicated websites with information for rare disease patients, legal opinions, printable materials, translations of medical records, and support for legal matters related to staying in the EU.
4. And most important, we raise awareness about the situation of Ukrainian rare disease patients. We speak at industry conferences and stakeholder meetings, give interviews, and take part in podcasts to draw attention to the needs of rare disease patients in Ukraine and to encourage others to act.

How many families are currently being cared for?

In the past six months, we have been able to help more than 70 families of patients with rare diseases, including primary immunodeficiencies, epidermolysis bullosa, and rare cases such as KIF1A-associated neurological disorders (KAND).

For patients with serious conditions, we make sure to create a fast track so they do not have to wait in long lines at the border. Especially in the first weeks of the war, the long lines required several days of waiting, so it was crucial to speed up the process for them.

Even though most of the patients we helped are children, we have also assisted more than 30 adults, most often with very serious forms of their diseases, that require advanced treatment outside Ukraine, including transplant operations.

The patients we have helped to cross the border and receive treatment in Poland were often affected by very rare diseases that required a specialized approach. That is why our activities are always focused on providing adequate medical care in a specialized medical center as soon as possible.

How did you proceed?

When Poland was the final destination, we first provided patients with support in finding accommodation and completing the necessary formalities obtain refugee status and a PESEL number (Polish acronym for “Universal Electronic System for Registration of the Population”). Then we provided them with appropriate medical care, making appointments with specialist physicians, or providing hospitalization in medical centers if their health conditions required it.

WINTER 2022 | THE SOURCE 9

When patients decided to travel to other countries, we worked with patient organizations operating in that given country, obtained information on which medical center they should go to, or contacted doctors directly. In some cases, patients first stayed in Poland, where they received appropriate treatment, and then decided to continue their journey to another country.

How is the situation in Ukraine now?

We are in constant contact with hospitals in Ukraine that treat patients with rare diseases to inform us about their urgencies for medicines and medical equipment.

According to patient needs, we organize the transport of medicines and medical equipment to specific hospitals. Many of these shipments contain specialized products and equipment needed to treat very specific rare diseases, such as primary immunodeficiencies, spina bifida, or cystic fibrosis.

If the situation requires it, we coordinate and finance the purchase of medicines on the ground. So far, we have organized 20 shipments of medicines, medical equipment, and other necessities.

The help and assistance we provide to patients in Ukraine does not only include emergency care but also more long-term projects. In the coming months, with the generous support of our partners, patients with primary immunodeficiencies will receive infusion pumps that will allow them to administer their immunoglobulins at home. These pumps will also be provided to hospital departments. The biggest advantage is that these mechanical pumps, which do not require electrical power, can be used for both intravenous and subcutaneous infusions.

Hospitals in Lviv, Ternopil, Kiyv, Vinnitsa, and Ivano Frankivsk have already received the pumps. Physicians from these hospitals participated in a special online training on how to operate them so that they can explain it to their patients accordingly. Not all medicines can be transported across the border to be delivered to Ukrainian hospitals, even as part of humanitarian aid. We have been confronted by some legal challenges, but this does not stop us. Thanks to the cooperation of a Ukrainian producer of plasma-derived medicines, we were eventually able to purchase immunoglobulins locally, which the manufacturer then delivered directly to the children’s hospital in Poltava by the manufacturer. Buying medicines on the ground is also an opportunity to support the Ukrainian economy, which is, of course, struggling due to the effects of the ongoing war.

How do you communicate and provide information to patients?

We have two websites that provide information to rare disease patients: www.ridkisnikhvoroby.pl (for rare diseases in general) and www.imunodefitsyt.pl (for patients with PID). For patients with chronic diseases who are in Poland, we have prepared legal opinions regarding access to therapy, created printed materials for patients and physicians, and organized translations of medical documents.

We also provide support for the bureaucratic steps related to their stay in Poland. We help contact the appropriate offices in Poland to receive necessary information and answer questions from patients.

Do you have support from other patient organizations?

10 THE SOURCE | WINTER 2022

> “THE PATIENTS WE HAVE HELPED TO CROSS THE BORDER AND RECEIVE TREATMENT IN POLAND WERE OFTEN AFFECTED BY VERY RARE DISEASES THAT REQUIRED A SPECIALIZED APPROACH. THAT IS WHY OUR ACTIVITIES ARE ALWAYS FOCUSED ON PROVIDING ADEQUATE MEDICAL CARE IN A SPECIALIZED MEDICAL CENTER AS SOON AS POSSIBLE.”

We exchange information about all ongoing initiatives related to rare disease patients and participate in meetings with other organizations, representatives from humanitarian organizations, and decision-makers on the national and international level. We were able to closely collaborate with EURORDIS as a part of the *Razem z Ukrainą* (Together with Ukraine) project.

In March, we participated in the European Parliament meeting of the network of Parliamentary Advocates for Rare Disease. As a result, an appeal was made to the president of the European Commission on the necessity of supporting patients with rare diseases from Ukraine and what possible actions can be taken.

If our readers would like to support you, what can they do?

Unfortunately, this war is not coming to an end and the needs are growing. We expect the next wave of rare disease refugees as the winter is approaching.

We encourage the readers to support our efforts helping Ukrainian patients with rare diseases. Please contact us for more details at adrian@eduinstitute.org or +4.860.936.3932. There’s also a page for individual donations at donations.eduinstitute.org

More information about the foundation’s general activity can be found on our website, eduinstitute.org. We have an international team of dedicated staff and volunteers working together to ensure patients’ safety and access to treatment. ●

EVERY PATIENT STORY IS ONE-OF-A-KIND

Emilia and her parents come from near Lviv, Ukraine. She was born with a rare genetic disease called severe combined immunodeficiency (SCID “the Bubble Boy disease”). This is a serious type of primary immunodeficiency that most often requires a bone marrow transplant in the early months of life. But in the first days of the war while Emilia was also waiting for her transplant, the hospital in Kiyv, where the procedure was to be performed, was bombed. Thanks to our efforts, she came to Poland with her parents and was taken care of by doctors in a pediatric hospital in Bydgoszcz. Emilia has underwent a successful transplant earlier this year. She feels better and is recovering surrounded by family.

WINTER 2022 | THE SOURCE 11

Physicians about our actions

Вероніка Кульчинська
17 godz.

The war has changed everyone's life! Yet, we are all fighting for the better life! Some people defend us on the frontline, while others provide us with the necessary aid regarding health issues. What is really important for us is the support we get from people who deeply care about the Ukrainians. There are so many kind people all around! We, on behalf of the staff and patients, especially little ones, would like to express our sincere emotions and say "Thanks" to all the great people who have sent such a significant support to us. Your understanding and kindness deserve the best praise.
Adrian Goretzki Bernadeta Prandzioch
❤️💙💛

"The war has changed everyone's life! Yet, we are all fighting for the better life! ***Some people defend us on the frontline, while others provide us with the necessary aid regarding health issues.*** *What is really important for us is the support we get from people who deeply care about the Ukrainians. There are so many kind people all around!*

We, on behalf of the staff and patients, especially little ones, would like to express our sincere emotions and say "Thanks" to all the great people who have sent such a significant support to us. Your understanding and kindness deserve the best praise."

Dr Veronika Kulchinska, MD, PhD,
hospital in Zaliztsi, 6.04.2022

*"****Many thanks to our Polish friends, philanthropists Adrian Goretzki and Bernadeta Prandzioch, for their help to our children with diabetes and primary immunodeficiencies****. Today, glucometers, test strips, syringes for the administration of immunoglobulins, other medical equipment were transferred to the department of TODCL. Many thanks for the constant support and help."*

Prof. Oksana Boyarchuk, MD, PhD,
hospital in Ternopil, 11.04.2022

Оксана Боярчук
1 godz.

Велика вдячність нашим польським друзям, благодійникам Adrian Goretzki та Bernadeta Prandzioch за надану допомогу нашим діткам з цукровим діабетом і первинними імунодефіцитами. Сьогодні глюкометри, тест-смужки, шприци-помпи для введення імуноглобулінів, інші засоби були передані у відділення ТОДКЛ.
Wielkie dzięki za nieustające wsparcie i pomoc.

Zobacz tłumaczenie

88 3 komentarze 1 udostępnienie

NGOs and hospitals about our actions

ГО "Об'єднання батьків дітей з Spina bifida і Гідроцефалією "Сяйво Духу"
7 godz. · 🌐

Для дітей з spina bifida Тернопільської області отримали засоби догляду і медикаменти. Висловлюємо щиру подяку Оксана Боярчук за постійну підтримку та увагу до дітей, благодійникам Bernadeta Prandzioch та Adrian Goretzkii за допомгу для дітей України у ці важкі часи.
www.syayvodukhu.com
#Spinabifida #Hydrocephalus #ukraine

27
1 udostępnienie

"Children with spina bifida in the Ternopil region received care products and medicines. We express our sincere gratitude to Oksana Boyarchuk for her constant support and attention to children and ***to benefactors Bernadeta Prandzioch and Adrian Goretzki for helping the children of Ukraine in these difficult times****.”*

NGO "Union of parents of children
with Spina bifida and Hydrocephalus”
"Сяйво Духу”, 15.08.2022

"The administration and the entire team of the Ternopil Regional Children's Clinical Hospital, TOR, express their sincere ***thanks to our benefactors Healthcare Education Institute from Katowice, Poland*** *(...) for the charitable assistance provided to the children who are being treated at our medical institution.*

We sincerely thank you for your support and caring attitude during a difficult time for Ukraine. *May your kindness and generosity return to you with the warmth of children's hearts.”*

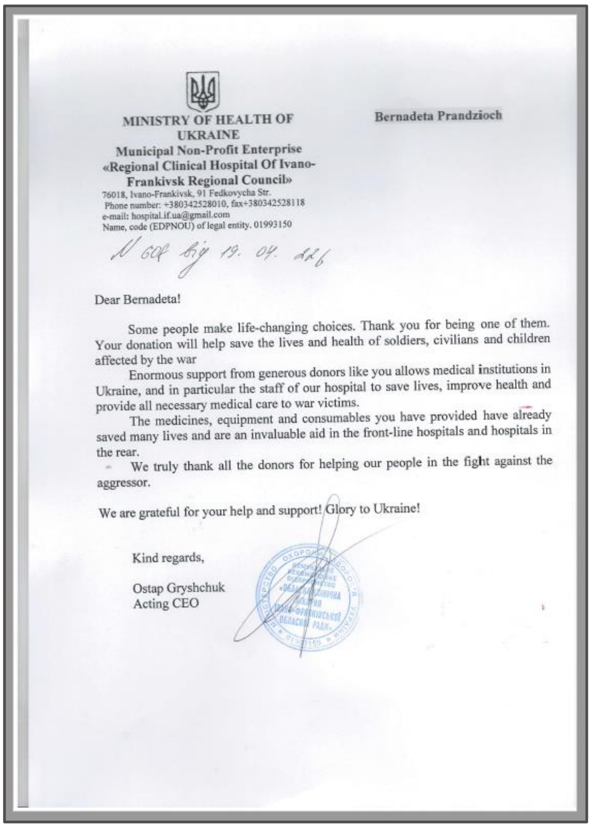
Ternopil Regional Children’s Clinical Hospital,
10.08.2022

КНП «Тернопільська обласна дитяча клінічна лікарня» ТОР
4 godz. · 🌐

🙏 Адміністрація та весь колектив КНП «Тернопільська обласна дитяча клінічна лікарня» ТОР висловлюють щирі слова подяки нашим благодійникам Healthcare Education Institute Katowice, Poland, а саме Adrian Goretzki та Bernadeta Prandzioch за надану благодійну допомогу для діток, котрі знаходяться на лікуванні у нашому медичному закладі.
🙏 Сердечно дякуємо Вам за підтримку та небайдуже ставлення у важкий для України час. Нехай Ваша доброта і щедрість повернуться до Вас сторицею та теплом дитячих сердець.

Adrian Goretzki i 22 innych użytkowników
2 udostępnienia

Hearing from hospitals and patients about our actions



MINISTRY OF HEALTH OF
UKRAINE
Municipal Non-Profit Enterprise
«Regional Clinical Hospital Of Ivano-Frankivsk Regional Council»
76018, Ivano-Frankivsk, 91 Fedkovycha Str.
Phone number: +380342528010, fax+380342528118
e-mail: hospital.if.ua@gmail.com
Name, code (EDPNOU) of legal entity. 01993150

Bernadeta Prandzioch

№ 608 від 19. 04. 22р

Dear Bernadeta!

Some people make life-changing choices. Thank you for being one of them. Your donation will help save the lives and health of soldiers, civilians and children affected by the war

Enormous support from generous donors like you allows medical institutions in Ukraine, and in particular the staff of our hospital to save lives, improve health and provide all necessary medical care to war victims.

The medicines, equipment and consumables you have provided have already saved many lives and are an invaluable aid in the front-line hospitals and hospitals in the rear.

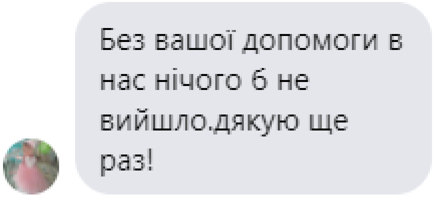
We truly thank all the donors for helping our people in the fight against the aggressor.

We are grateful for your help and support! Glory to Ukraine!

Kind regards,

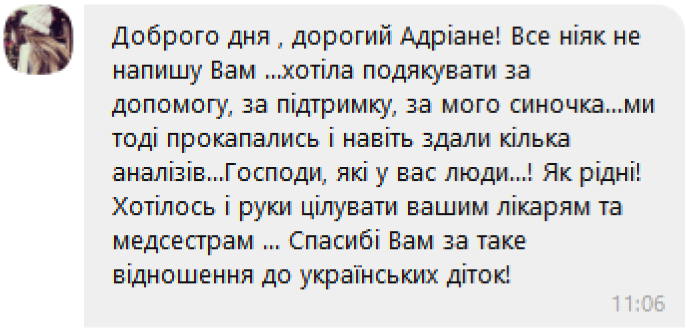
Ostap Gryshchuk
Acting CEO

Letter from Ostap Gryshchuk, CEO of the hospital in Ivano-Frankivsk with thanks for the provided medical equipment (19.04.2022)



Без вашої допомоги в нас нічого б не вийшло.дякую ще раз!

Without your help, we would not have succeeded. Thank you again!



Доброго дня , дорогий Адріане! Все ніяк не напишу Вам ...хотіла подякувати за допомогу, за підтримку, за мого синочка...ми тоді прокапались і навіть здали кілька аналізів...Господи, які у вас люди...! Як рідні! Хотілось і руки цілувати вашим лікарям та медсестрам ... Спасибі Вам за таке відношення до українських діток!

11:06

Good afternoon, dear Adrian! It is impossible to write everything... I wanted to thank you for your help, for your support for my son... (...) My God, what kind of people you are...! Like family. I also wanted to kiss the hands of your doctors and nurses... Thank you for this approach towards Ukrainian children.

RARE Champion of Hope 2022

Global Genes, an American non-profit organization dedicated to creating a globally connected community committed to meeting the challenges of rare diseases, has been awarding the RARE Champions of Hope since 2012, through which it honors and recognizes true champions of rare diseases.

This year, at the 2022 Rare Disease Patient Advocacy Summit in San Diego, CA, **Adrian Goretzki received the title of RARE Champion of Hope** for “a lifetime of dedication to helping get treatment to those in need and **especially for a work in helping patients cross the Polish/Ukrainian border in 2022, ensuring access to therapy and other medical care.”**

The EURORDIS Black Pearl Award 2023

Since 2012, **EURORDIS – Rare Diseases Europe** has organized The EURORDIS Black Pearl Awards to recognize the major achievements and outstanding commitment of patient advocates, patient organizations, policymakers, scientists, companies, and media who strive to make a difference for the rare disease community.

We are honored that **the winner of the Black Pearl Award 2023 is Adrian Goretzki**, our president. This award acknowledges his unwavering dedication to the rare disease community over the past years, but also his help for Ukrainian patients.

"Among Adrian's achievements, EURORDIS wishes to particularly recognise (…) his commendable work in support of the Ukrainian rare disease community, offering patients both legal and practical assistance."

The invaluable help of our Ukrainian-speaking project manager

Thanks to the financial support of one of our partners, we were able to hire **a new employee, Anastasiia Doroshenko, a physician specialized in pediatrics. She has extensive experience working with children in various environments and with various conditions, including rare diseases**.

As the project manager at the Foundation, **she is responsible for activities related to the comprehensive support of rare diseases patients from Ukraine fleeing war:** from support during their journeys and arranging accommodation to ensuring access to medical care and helping with formal matters.

She also coordinates humanitarian aid for Ukrainian hospitals treating rare disease patients.

Anastasiia Doroshenko, MD

Project Manager, Ukraine response

"Working with people has always been very close and important to me. It's especially valuable to help patients with rare diseases from Ukraine, because they need special attention in peacetime, even more so in such a difficult time for our country.

I'm very proud to be part of a team that does everything possible to help patients from Ukraine overcome difficulties and not feel alone with their problems."

Cooperation and Support

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ORID

You can also become a partner and support our activities securing the lives of patients from Ukraine – contact us!

About the Foundation

The Healthcare Education Institute was established in 2017 on the initiative of Adrian Goretzki, someone with XLA and a patient advocate with over 10 years of experience in working for patient communities. In our daily activities, we strengthen the voice of patient communities, educate patient group leaders, create reports, and conduct research and studies, all in order to ensure that patients with rare diseases are noticed and receive the best possible medical care.

Since the war broke out, we do everything to support RD patients from Ukraine. We now have an international team of dedicated volunteers from the USA to Ukraine working together to ensure patients' safety and access to treatment.

You can read more about our everyday work on: eduinstitute.org.

Board of Directors

Adrian Goretzki, LL.M.
Founder, President of the Foundation

From 2010 to 2018, served as leader of the Polish Association for Patients with Primary Immunodeficiencies 'Immunoprotect' and was a member of the executive board of the international umbrella association, the International Patient Organization for Primary Immunodeficiencies (IPOPI). **For his successful patient advocacy, Goretzki was given the Luciano Vassali Award in 2014, the University of Silesia Rector's Award in 2020, RARE Champion of Hope in 2022 and The EURORDIS Black Pearl Award 2023**. In 2021, he was shortlisted for the EURORDIS Patient Advocacy Award in 2021. Professional lawyer, advisor, and keynote speaker. Fascinated with opportunities given by new technologies in the field of education.

Bernadeta Prandzioch-Goretzki, M.Psy, B.Ed
Vice-President of the Foundation

Psychologist experienced in working with patients with rare diseases, active in this area since 2014. At the Institute, she is responsible for the scientific part of our job, focusing on coordinating studies and reports. Researching the area of quality of life in patients with rare diseases. Author of the handbook for patients with primary immunodeficiencies, *The Fullness of Life*. **Successful TEDx speaker (400k views on YouTube),** author of many scientific publications and articles popularizing psychological knowledge, and participant in international conferences.

Support us and join those for whom rare means exceptional, not unimportant.

You can support our actions and donate via PayPal.

Just use the QR code on the right or click HERE.

You can also donate directly to our bank accounts by entering *"Donation to help rare disease patients from Ukraine"* in the title of the transfer.

Details:

Healthcare Education Institute. The Foundation,
Gliwicka 74/4, 40-854 Katowice, Poland

SWIFT/BIC: PPABPLPK (BNP Paribas)

- PL (donations in PLN): PL45 1600 1055 1830 5274 2000 0001
- INT (donations in EUR): PL34 1600 1055 1830 5274 2000 0005
- INT (donations in USD): PL07 1600 1055 1830 5274 2000 0006

You can also become our Industry Donor or Business Partner.

If you or your company would like to make a corporate donation and it requires a contract, please let us know. We are a **non-profit & VAT-exempted foundation** based in Poland (a legal equivalent of US 501(c)(3) organization status).

If you have any questions or would like to support our activities in different way, please contact us:

Healthcare Education Institute. The Foundation

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☎ +48 609 363 932


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