

# 6 WEEKS OF HOPE

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REPORT ON HUMANITARIAN  
AID FOR UKRAINIAN RARE  
DISEASE PATIENTS



*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 a recent history. A war in which there are no rules, in which civilian objects, homes, kindergartens and hospitals are bombed and shelled. A war in which the victims are innocent Ukrainians civilians – mothers, children, the sick ones.

A war that has already forced **more than 4 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 whether they will be able to escape and whether anyone will support them in their evacuation and secure their treatment.

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

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

# 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 worldwide population.

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 known rare diseases such as haemophilia or primary immunodeficiencies, 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.**



RD affect  
3.5%–6%  
of worldwide  
population



RD affects  
<1:2000  
people

There is over

6000

different RD



80% of RD  
are genetics

# How we support rare disease patients from Ukraine?

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

## 1. Helping patients fleeing the war in Ukraine

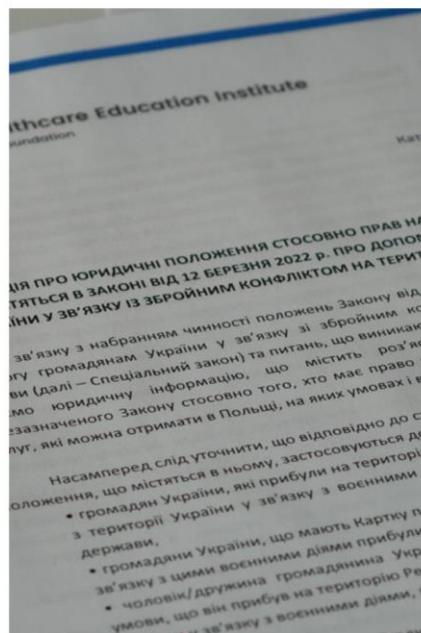
We provide patients with support at every stage of their journey to Poland or transit to other EU countries, including faster transport across the border and we organize accommodation and access to treatment in Poland.

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

We organize the transport 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.



# Helping patients fleeing the war in Ukraine

- We provide patients with support at **every stage** of their journey to Poland
- We organize humanitarian corridors to ensure faster border crossings for patients in serious condition
- We take care of **the initial accommodation** of the patient's family
- We provide access to treatment in Poland (we cover all procedures, **arrange the first visit to a specialist in a given field** or hospitalization)
- In the case of transit to other EU countries, we provide contact to a patient organization in each country, **as well as to a medical clinic treating a given disease**



*This is Yegor, 11 yo XLA patient receiving immunoglobulins in Polish hospital*

So far, we have managed to help over 50 families of patients with rare diseases from Ukraine.

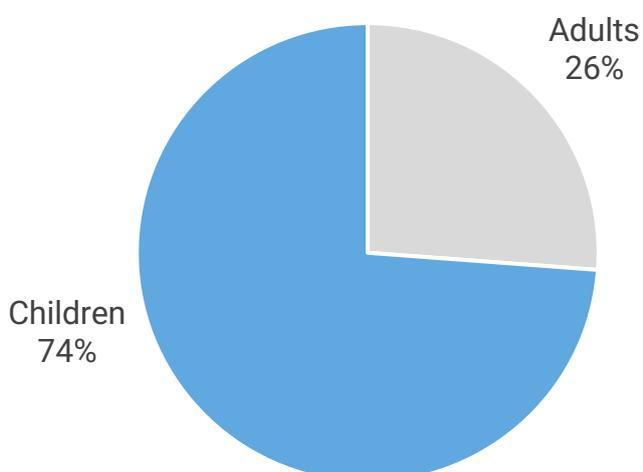
# Helping patients fleeing the war in Ukraine

So far, we have helped **over 50 families of patients with rare diseases**, including primary immunodeficiencies, epidermolysis bullosa or such rare cases as KIF1A.

In the case of patients in a difficult condition, we made sure **to create a fast track for them** so that they would not have to wait in long lines at the border. In the first days of the war, the queues required even several days of waiting, so it was crucial to speed up the procedures for RD patients.

Most of the patients we helped were children. But a quarter of them are adults, most often with **very serious forms of the disease**, requiring advanced treatment outside Ukraine, including transplantations.

**Rare disease patients we helped  
– adults vs. children**



6 of these patients were qualified for transplantation: 4 bone marrow transplantations and 2 liver transplantations.

# Helping patients fleeing the war in Ukraine

Patients whom we helped cross the border and receive treatment in Poland 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 of Ukraine patients whom we have helped

Autoimmune lymphoproliferative syndrome (ALPS)
Combined immunodeficiency due to DOCK8 deficiency
Common variable immunodeficiency (CVID)
DiGeorge syndrome
Epidermolysis Bullosa (EB)
Hepatopulmonary syndrome (HPS)
Hyper IgD Syndrome (HIDS)
Hyper IgE Syndrome (HIES)
Hypo-IgM Syndrome
KIF1A-Related Disorder
Leukocyte adhesion deficiency type-1 (LAD-I)
Nijmegen breakage syndrome (NBS)
Severe combined immunodeficiency (SCID)
Wilson's disease
X-linked agammaglobulinemia (XLA)

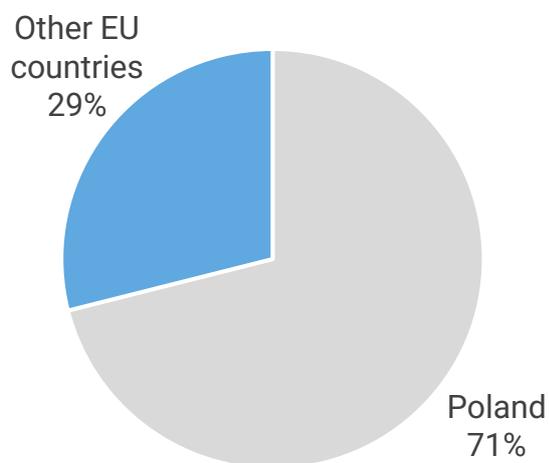
# Helping patients fleeing the war in Ukraine

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



In the case of patients who decided to travel further to other EU countries, we contacted them with patient organizations operating in a given country, we obtained information on which medical center they should go to or we contacted doctors in a given place directly.

# On-site support for the Ukrainian patients and medical community



Transport of medical equipment to Lviv's hospital (a truck full of goods!)

- We are in constant contact with hospitals treating patients with rare diseases in Ukraine and we collect from them the needs for medicines and medical equipment
- In response to needs, we organize transports of medicines and medical equipment to specific hospitals
- If the situation requires it, we finance the purchase of medicines on the spot
- We are in contact with patient organizations in Ukraine

The total value of medicines and medical equipment that we shipped to Ukraine or bought on site so far is around \$30,000.

# On-site support for the Ukrainian patients and 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, e.g. in Ivano-Frankivsk, Lviv, Poltava, Ternopil, Vinnitsa, Zaliztsi.

When it comes to OTC drugs, medical equipment and personal protective equipment, we organize the purchase and transport 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, Polish Medical Mission or Red Cross **or we finance purchases of specialized medicines on the spot.**



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

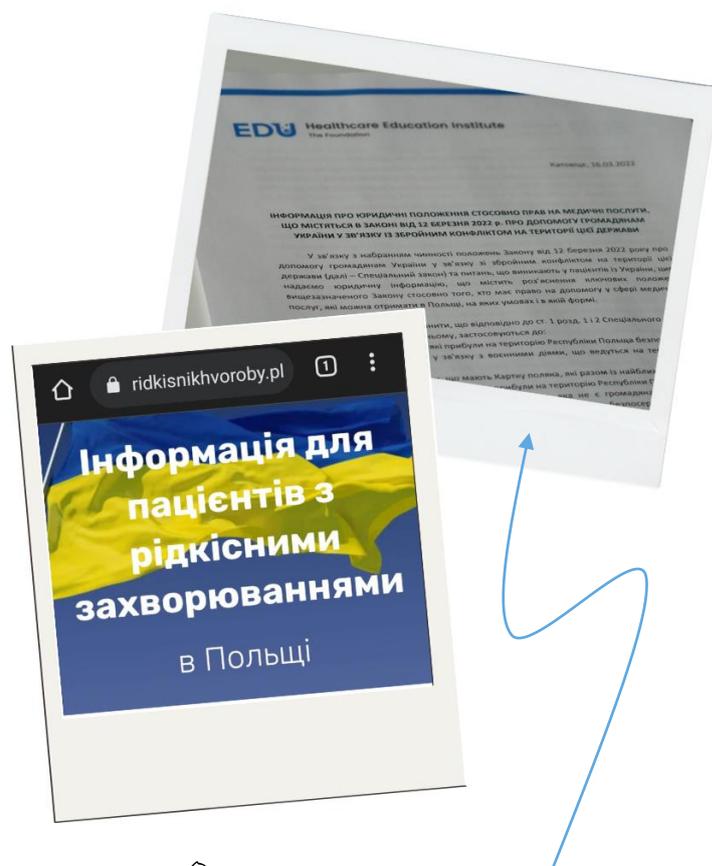
# Information and legal support for patients

- We run websites with information for RD patients:

[www.ridkisnikhvoroby.pl](http://www.ridkisnikhvoroby.pl)

[www.imunodefitsyt.pl](http://www.imunodefitsyt.pl)

- We prepare legal opinions on regarding access to therapy for Ukrainian patients with chronic diseases and staying in Poland
- We create printed materials for patients from Ukraine and doctors in Poland who treat them
- We organize translations of medical documentation 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.)



*Our legal opinion indicating that Ukrainian refugees have a right to free-of-charge medical care in almost all cases, including therapies for rare diseases.*

We have 5 translators on 2 continents who translate patients' medical records to ensure they receive appropriate medical care.

# Information and legal support for patients

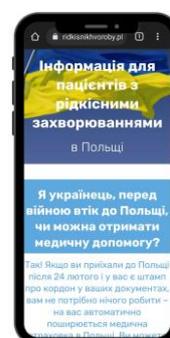
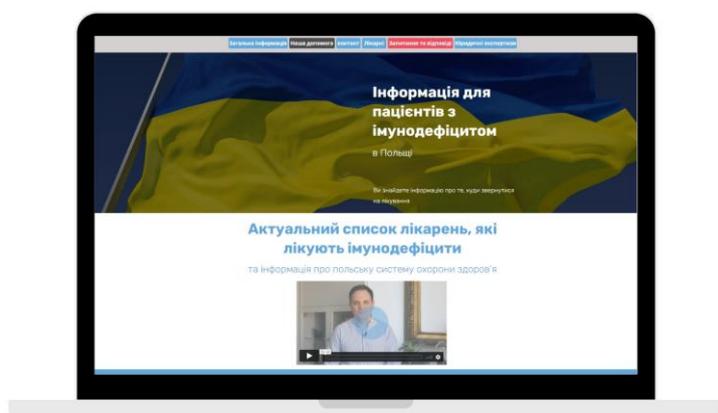
## 1. Websites with information for RD patients

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 of hospitals treating primary immunodeficiencies
- Contact details for Polish verified rare disease patient organizations
- **Comprehensive FAQ section with answers to 20 questions** regarding access to therapy for Ukrainian patients with chronic diseases 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.

## 2. Printed materials

We are currently preparing two printed brochures for patients. One is a simple way of discussing the medical care system in Poland from the perspective of RD patients, and the other 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.



*You can visit our websites, by clicking on the pictures!*

# Cooperation with other entities

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

- We are in constant contact with patient organizations supporting RD patients at the national and international level
- We participate in meetings of RD umbrella organizations
- We meet with representatives of international and domestic humanitarian organizations
- We also participated in the meeting of **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 Commission** on the necessity of supporting patients with rare diseases from Ukraine and possible methods of action.

Dear Member of the European Parliament,

At the best of times, the 30 million people living with rare diseases in Europe require specific actions and support to achieve equitable access to health and social needs. In times of crisis, relief efforts must include specific consideration for the needs of this vulnerable population.

**In Ukraine, an estimated 2 million people live with a rare disease.** Many of those affected by a rare disease require frequent and complex care and specialised treatments. Many also have disabilities that make movement very difficult. As a result of the war in Ukraine and in particular of the already fragile and increasingly decentralised healthcare system in the country, vulnerable populations such as those with rare disease are faced with two difficult options: leaving to neighbouring countries and navigating access to care and treatment as a refugee or struggling to access critical and life saving treatments and medical supplies in a war setting. **Classic humanitarian efforts are currently very limited and do not have the needs of the rare disease community on their radar.**

Those who remain within Ukraine are struggling to access care with **shortages of medicines and supplies** now widespread in the country and with the health system struggling to cope with civilian and military casualties that often overshadow the less prominent and vulnerable rare disease community. To get out of the country, those on the most vulnerable end of the spectrum need **end-to-end support to be transported** out of the country. Those who have managed to leave need **extra support once in Europe to navigate the healthcare system**. In Poland there are already signs the healthcare system needs extra support to avoid a shortage of medicines and supplies that would endanger the people who depend on those treatments.

Actions of solidarity have multiplied over the past few days to help people access basic healthcare services in Ukraine and to welcome refugees with specific health conditions (cancer for instance) in several European countries. Given the peculiar needs of people living with a rare disease in terms of healthcare but also mobility and social care, the Network of Parliamentary Advocates for Rare Diseases and EURORDIS-Rare Diseases Europe invite you to **join an online briefing** to discuss the most urgent challenges for this community and avenues for parliamentary actions. The webinar will welcome **patient organisations from Ukraine and from neighbouring countries** to provide MEPs with first-hand evidence.

They count on your support!

**Frédérique Ries, MEP**  
Co-Chair of the Network of Parliamentary Advocates for Rare Diseases

Draft Programme  
Wed 23, March | 13:30-15:15

*The situation in Ukraine – Vitaliy Matyushenko, President of Ukrainian Foundation "Children with Spinal Muscular Atrophy"*

*The situation in Poland – Adrian Goretzki Healthcare Education Institute Foundation*

*Coordinating the response through the European Reference Networks - Pr Héliène Dollfus, Head of the Medical Genetics Department at the HUS Strasbourg*

*EURORDIS: needs and response of the rare disease community – Michael Wilbur, Chief Operating Officer at EURORDIS*



To:

Ursula von der Leyen, President of the European Commission  
Janez Lenarčič, Commissioner for Crisis Management  
Olívér Várhegyi, Commissioner for Neighbourhood and Enlargement  
Stella Kyriakides, Commissioner for Food and Health Safety

6th April, 2022

**Subject: Call to protect and support the Ukrainian people living with a rare disease**

Dear President von der Leyen,  
dear Commissioner Lenarčič,  
dear Commissioner Várhegyi,  
dear Commissioner Kyriakides,

As Members of the European Parliament and on behalf of the Network of Parliamentary Advocates for Rare Diseases, **we wish to bring to your attention the tragic situation of the Ukrainian people living with a rare disease, and call upon you to make sure their specific needs are given due consideration by the Commission's humanitarian and emergency response.**

**In Ukraine, an estimated 2 million people live with a rare disease.** At the best of times, people living with a rare disease require specific actions and support to achieve equitable access to health and social needs. In times of crisis, relief efforts must also include specific consideration for the needs of this vulnerable population.

Ukrainian patient organisations report that people living with a rare disease in Ukraine are struggling to access critical life-saving care due to **shortages of medicines and other medical supplies**, and that the health system is not able to cope with the less prominent and vulnerable communities as they are overshadowed by civilian and military casualties. Once again, people living with a rare disease are left behind. Leaving the country is also challenging for those on the most vulnerable end of the spectrum who require **end-to-end support to be transported out of the country**. Families who have managed to flee need to **rapidly access highly specialised care in the host country and extra support to navigate health care systems in Europe**. In Poland, there are already signs that the healthcare system needs extra support to avoid a shortage of medicines and supplies, and overcrowding of specialised care centres.

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# Every patient story is an unique story...

## Meet Emily (Емілія)!

**Emilia** and her parents come from near Lviv. The girl was born with a rare genetic disease: severe combined immunodeficiency (SCID). This is a very serious type of primary immunodeficiency that most often requires a bone marrow transplant in the early months of life.

Emilia was also waiting for it, but in the first days of war the hospital in Kiev where the procedure was to be performed was bombed. Thanks to our efforts, Emilia came to Poland with her parents and was taken under the care of doctors in a pediatric hospital in Bydgoszcz. She will undergo a transplant in the coming days.



**There are many more patients like Emily who needs our help.**

## 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, „Zblizenia”, 15.03.2022

– Emily and her mother in hospital in Bydgoszcz

## Patients about our actions



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 дітей!

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.*

# Doctors about our actions



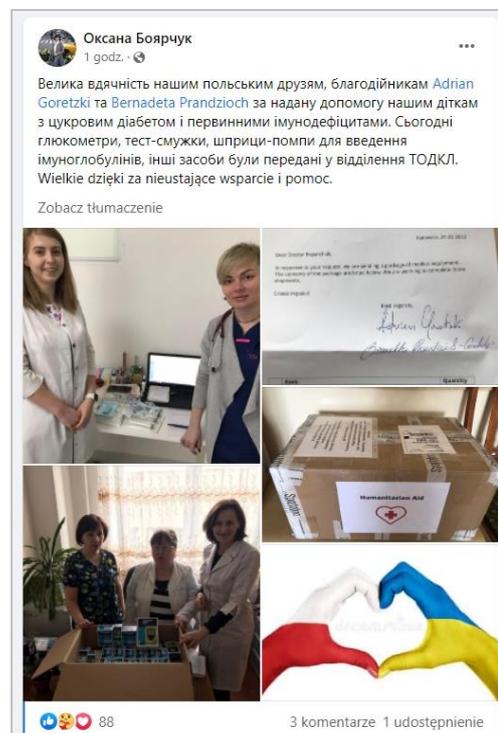
"The war has changed everyone's life! Yet, we are all fighting for the better life! **Some people defend us on the frontline, while others provide us with the necessary aid regarding health issues.** What is really important for us is the support we get from people who deeply care about the Ukrainians.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

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



# Cooperation and Support

## Industry Donors



## Non-profit organizations



You can also become our partner and support 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, a person with XLA and 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, 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 USA to Ukraine working together to ensure patients' safety and access to treatment.

You can read more about our everyday work on: [eduinstitute.org](https://eduinstitute.org).

## Board of Directors



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

In years 2010-2018 leader of Polish Association for Patients with Primary Immunodeficiencies 'Immunoprotect', former member of executive board of international umbrella association, the International Patient Organization for Primary Immunodeficiencies (IPOPI). **For his successful patient advocacy Goretzki has been given Luciano Vassali Award in 2014 and the University of Silesia Rector's Award in 2020.** In 2021 he was shortlisted for the EURORDIS Patient Advocacy Award in 2021. Professional lawyer, advisor and keynote speaker. Fascinated with opportunities given by the new technologies in the field of education.



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

Psychologist experienced in working with patients with rare diseases, active in this area since 2014. In the Institute she is responsible for the scientific part of our job, focusing herself on coordinating studies and reports. Researching the area of quality of life of patients with rare diseases. Author of the handbook for patients with primary immunodeficiencies 'The fullness of life'. **Successful TEDx speaker (over 350k views on YouTube)**, author of many scientific publications on international conferences and articles popularizing psychological knowledge.

# We raised more than \$100 000 since the war began. Support us and join those for whom **rare means exceptional, not unimportant.**

You can support our actions and 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 an agreement, 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 you would like to support our activities in different way – please contact us:

## Healthcare Education Institute. The Foundation

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