

6 MONTHS OF SUPPORT

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 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.

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

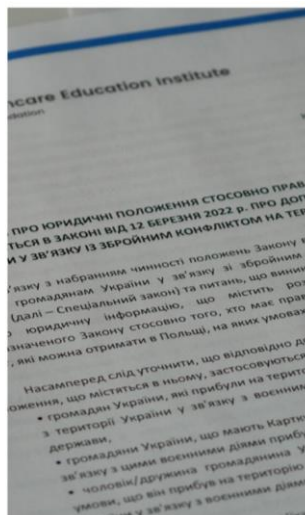
We organize the transportation of medicines and medical equipment to hospitals treating patients with rare diseases in Ukraine and we also finance the purchase of medicines on the spot.

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 condition
- 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**)
- 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 70 families of patients with rare diseases from Ukraine.

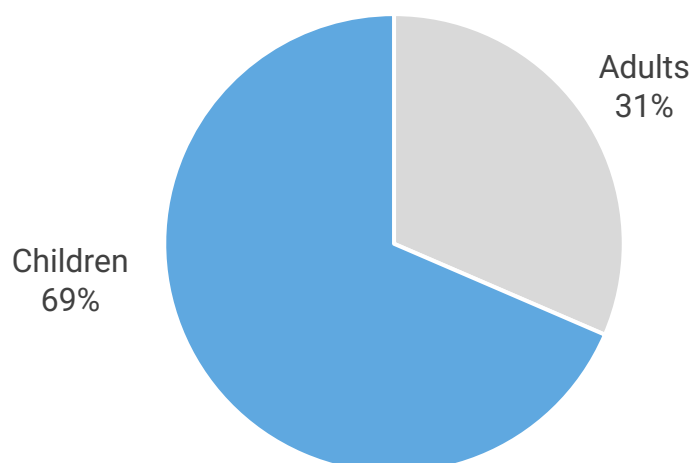
Helping patients fleeing the war in Ukraine

So far, we have helped **over 70 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 more than 30% 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 helped:
adults vs. children



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

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

Autoimmune lymphoproliferative syndrome (ALPS)
Combined immunodeficiency due to DOCK8 deficiency
Common variable immunodeficiency (CVID)
DiGeorge syndrome
Epidermolysis Bullosa (EB)
Glut1 deficiency syndrome (Glut1DS)
Hepatopulmonary syndrome (HPS)
Hyper IgD Syndrome (HIDS)
Hyper IgE Syndrome (HIES)
Hypo-IgM Syndrome
Kabuki syndrome
KIF1A-Related Disorder
Leukocyte adhesion deficiency type-1 (LAD-I)
Myasthenia gravis (MG)
Nijmegen breakage syndrome (NBS)
Severe combined immunodeficiency (SCID)
Wilson's disease
X-linked agammaglobulinemia (XLA)

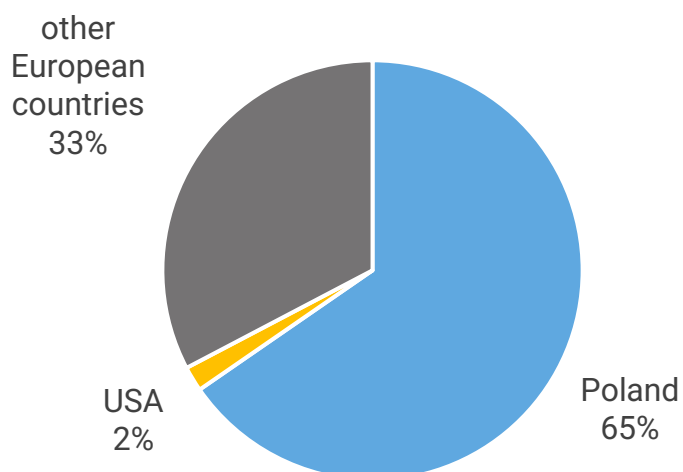
Helping patients fleeing the war in Ukraine

When Poland was the target country, we first 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.

On-site support for Ukrainian patients and the medical community



- 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.

So far, we have organized 20 shipments of medicines, medical equipment, and other necessities

The total value of medicines and medical equipment that we shipped to Ukraine or bought on site so far is over \$45,000.

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, e.g. in Ivano-Frankivsk, Kyiv, Lviv, Poltava, Ternopil, Vinnitsa, and Zaliztsi.

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

On-site support for Ukrainian patients and the medical community

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

Thanks to the support of one of our partners, in the coming months, patients with primary immunodeficiencies from Ukraine will receive infusion pumps that will allow them to administer immunoglobulins at home. Pumps will also be used in hospital departments. The biggest advantage is that they are mechanical pumps which do not require electrical power and can be used for both intravenous and subcutaneous infusions.

The first pumps and infusion sets have already been delivered to hospitals in Lviv, Ternopil, Kiyv, Vinnitsa, and Ivano-Frankivsk. Physicians from these hospitals participated in a special online training on the operation of these pumps so that they could train their patients in the near future.



The first patient is already using an infusion pump

Training for physicians



On-site support for Ukrainian patients and the medical community

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

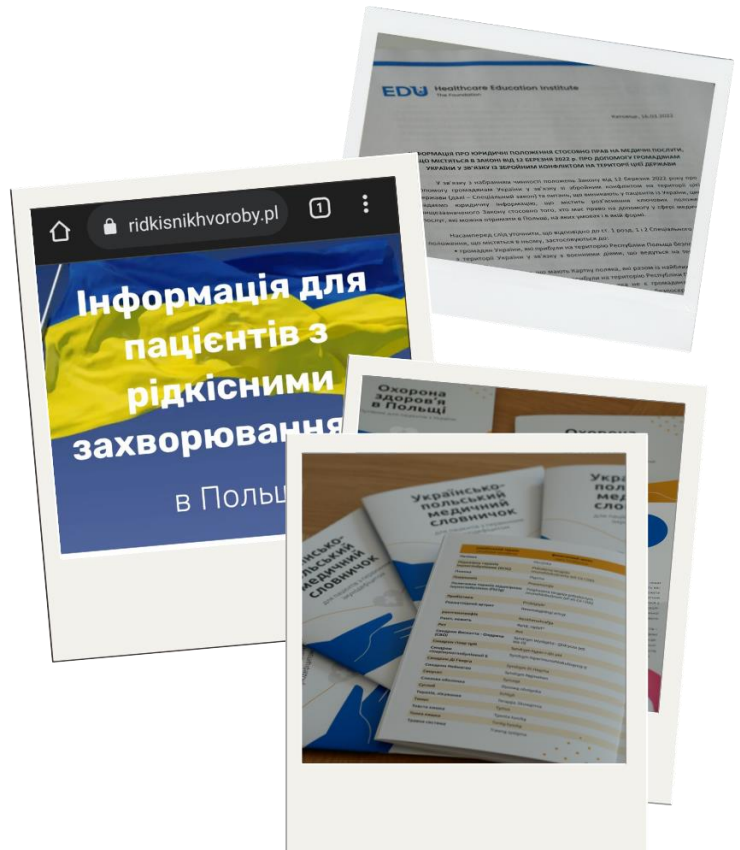
Information and legal support for patients

- 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 printed materials for patients from Ukraine and the physicians in Poland who treat them.
- 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.).
- We contact the appropriate offices in Poland to receive necessary information and answer questions from patient.



*a Ukrainian-Polish
medical dictionary for patients
with primary immunodeficiencies*

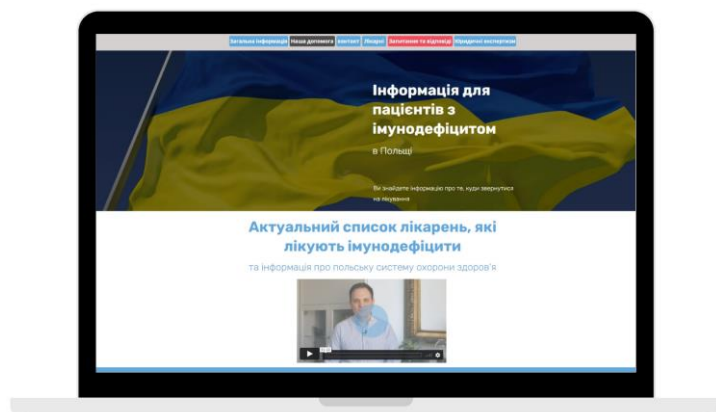
We have 5 translators on 2 continents who translate patients' medical records to ensure they receive appropriate medical care.

Information and legal support for patients

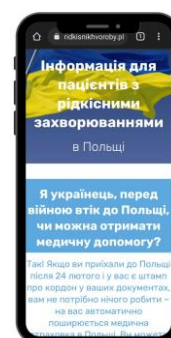
1. Websites with information for RD patients

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 for hospitals treating primary immunodeficiencies
- Contact details for Polish verified rare disease patient organizations
- **A frequently updated comprehensive FAQ section with answers to more than 30 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!



Information and legal support for patients

2. Printed materials

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

- First is a simple way of discussing the medical care system in Poland from the perspective of RD patients
- 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
- We are currently working on another brochure that will discuss matters related to social assistance and social benefits

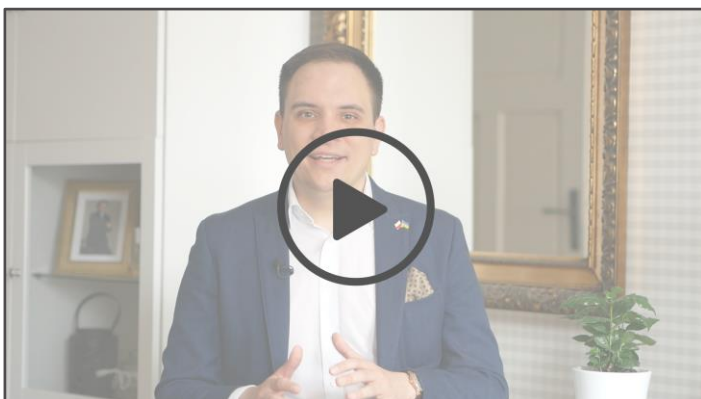


Raising awareness about the situation of RD patients from Ukraine

- 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)
 - We gave a speech to the Canadian Immunodeficiencies Patient Organization (April 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)

On October 11-12, we will be talking about Ukraine during the Plasma Protein Forum.

In the coming weeks, we will also be recording a series of video testimonials with the participation of RD families from Ukraine who currently live in Poland to raise awareness of their situations.



Click to listen to
the podcast

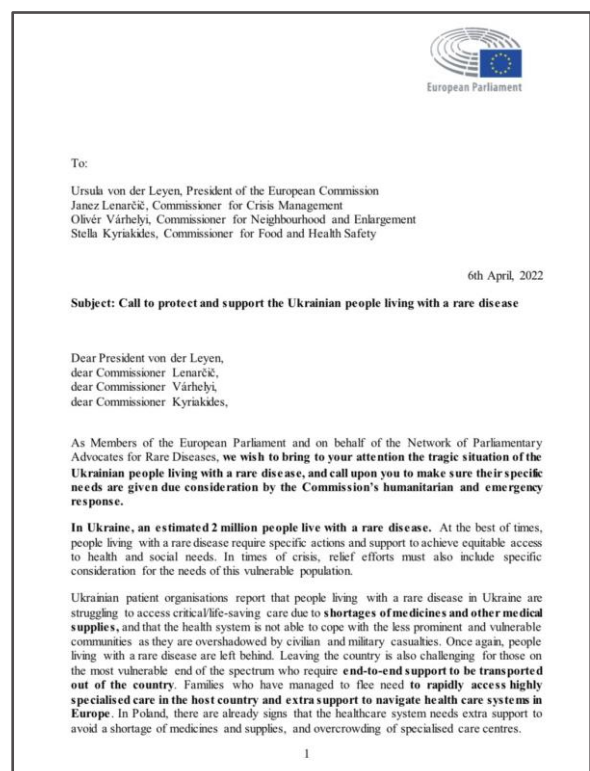
Cooperation with other entities

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 Commission 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



Every patient has a unique story...

Meet Emilia (Емілія)!

Emilia and her parents come from near Lviv. She was born with a rare genetic disease: 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 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 care of by doctors in a pediatric hospital in Bydgoszcz.

Emilia has undergone a successful transplant in the last few weeks. She feels fine and is recovering surrounded by family.



But there are many more patients like Emilia who need 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, "Zbliżenia", 15.03.2022

– Emilia and her mother in the hospital in Bydgoszcz

Hearing from 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.

Physicians about our actions



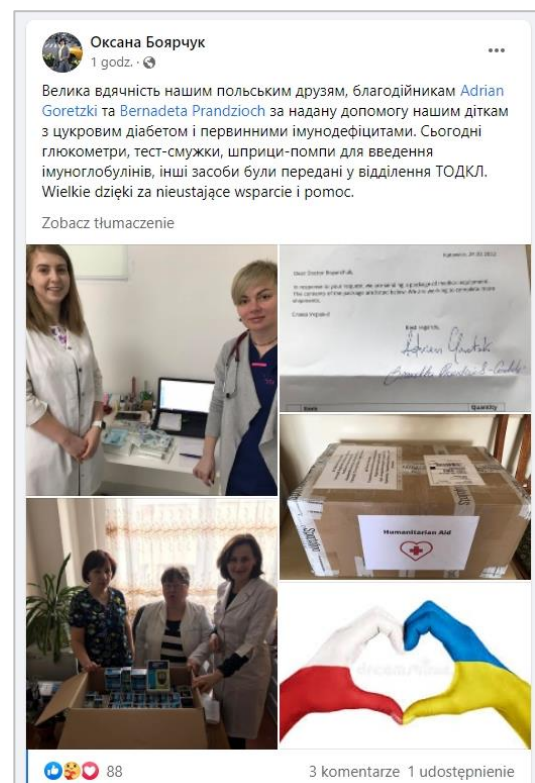
"The war has changed everyone's life! Yet, we are all fighting for the better life! **Some people defend us on the frontline, while others provide us with the necessary aid regarding health issues.** What is really important for us is the support we get from people who deeply care about the Ukrainians.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

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



NGOs and hospitals about our actions



"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

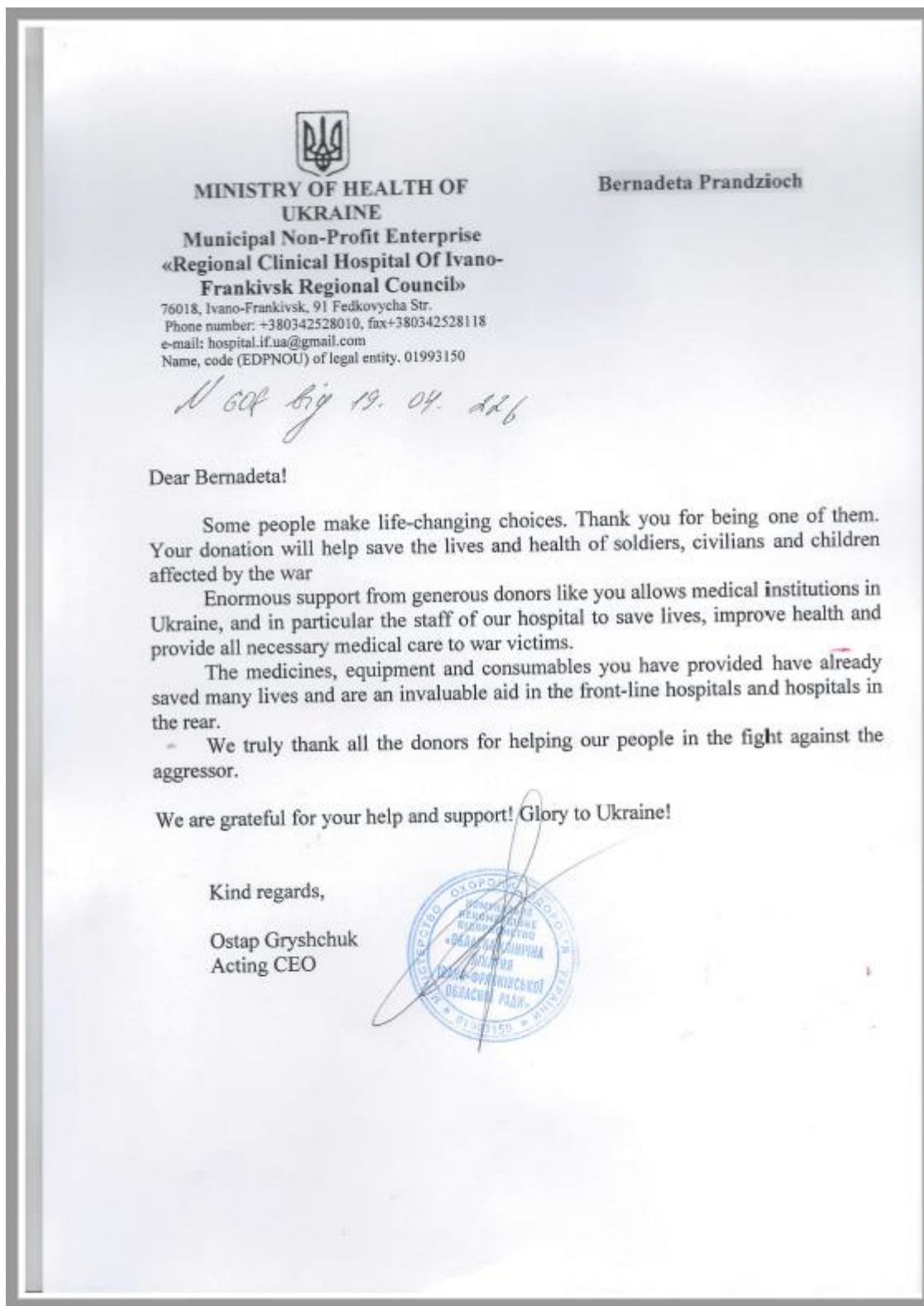
"The administration and the entire team of the Ternopil Regional Children's Clinical Hospital, TOR, express their sincere **thanks to our benefactors Healthcare Education Institute from Katowice, Poland** (...) for the charitable assistance provided to the children who are being treated at our medical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



Hearing from hospitals about our actions



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

New employee on board

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

Industry Donors



Non-profit organizations



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 former 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 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 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 (over 350k views on YouTube)**, author of many scientific publications and articles popularizing psychological knowledge, and participant in international conferences.

We've 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 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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