2023
ANNUAL
REPORT

REVIEW OF ACTIVITIES AND ACHIEVEMENTS OF THE HEALTHCARE EDUCATION INSTITUTE

Report prepared by:

Healthcare Education Institute
The Foundation

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Photos:

The following photos were used in the report:

- cover, p. 29 and p. 35 – photos taken during The EURORDIS Black Pearl Award gala, **EURORDIS - Rare Diseases Europe**
- cover, p. 22, p. 23 and p. 33 – photos taken during The Access to Care Conference 2023 in Vienna, **Boehringer Ingelheim**
- p. 7 – photos taken during The Access to Care Conference 2022 in Vienna, **Boehringer Ingelheim / photographer: Mila Zytka**
- p. 32 – photos taken during The EJPRD Training on Leadership and Communication Skills in Gdańsk, **photographer: Paweł Sadura**

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

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Letter from the President

2023 was a year full of diverse and challenging activities for us. On the one hand, we continued humanitarian activities for Ukrainian patients with rare diseases, and on the other, we implemented the Foundation's planned projects.

I am truly proud that, despite limited resources we managed to assist over 100 families of Ukrainian patients with rare diseases. In many cases, this assistance was comprehensive and multi-dimensional, addressing not only medical issues but also transportation, accommodation, and support in formal and legal matters.

Additionally, we supported the medical community and patients in Ukraine by continuing to send humanitarian shipments, including specialized equipment such as infusion pumps or oxygen concentrators.

This year marked the sixth PatientAdvocacy.Academy, and I'm pleased that participants willingly engage in this event, sharing their experiences and acquiring new knowledge. This translates into more effective actions in their respective countries.

We had the pleasure of participating in numerous valuable events, conferences, and meetings this year. You can find detailed information about all our activities on the following pages of the report.

I would like to express my gratitude to the foundation's fantastic employees and volunteers, as well as our donors and sponsors. Without your commitment, all of this would not be possible. Thank you!

Adrian Goretzki

ADRIAN GORETZKI
PRESIDENT OF THE FOUNDATION

About the Healthcare Education Institute

The Healthcare Education Institute is a non-profit, non-governmental foundation established in Poland in 2017 on the initiative of Adrian Goretzki, a person with a rare disease and a patient advocate with almost 15 years of experience in working for rare disease communities. Our mission is to support those who are fighting for a better life for patients with rare diseases in every possible way.

People with rare diseases are often overlooked by the healthcare system, they are underdiagnosed and public awareness of these diseases is far from sufficient.

In our daily activities, we strengthen the voice of patient communities, educate patient group leaders, create reports, conduct research and studies, all in order to ensure that patients with rare diseases are noticed and receive the best possible medical care.

We collaborate closely with stakeholders to influence changes that will positively impact the quality of life for patients in various countries. This involves improving the time to diagnosis, enhancing access to treatment, and considering the specific needs of patients with rare diseases within the healthcare system. Ultimately, we strive to create a more inclusive and supportive healthcare environment for individuals affected by rare diseases worldwide.

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> ***Because we believe that rare means exceptional, not unimportant.***

Board of Directors

Adrian Goretzki, LL.M.

Founder, President of the Foundation

From 2010 to 2018, he 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 in 2023. Professional lawyer, advisor, and 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.

Medical Advisory Board

Our priority is to make the foundation's activities responsive to the needs of the medical community and patients. Therefore, there is a Medical Council at our foundation, which includes experts with whom we have worked for years.

Prof. Sylwia Kołtan
MD, PhD

Polish National Consultant in the field of clinical immunology, works in the Clinic of Pediatrics, Hematology and Oncology, University Hospital No. 1 in Bydgoszcz; Department of Paediatrics, Hematology and Oncology. Professor of Collegium Medicum of the Nicolaus Copernicus University in Toruń.

Aleksandra Matyja-Bednarczyk
MD, PhD

Specialist in internal medicine, clinical immunology and allergology, chief of Immune Diseases and Hypercoagulation Outpatient Department, University Hospital in Cracow.

Monika Mach-Tomalska
MD

Pediatrician and clinical immunologist, works in the Immunology Department of the University Children's Hospital of Cracow (UCH).

Prof. Larysa Kostyuchenko
MD, PhD

In October 2023, we received the news of the passing of Prof. Larysa Kostyuchenko, a member of our Medical Council, with great sadness. This is an irreparable loss, not just for us, but especially for the community of Ukrainian patients with primary immunodeficiencies. Prof. Kostyuchenko always prioritized their well-being, even while facing her own battle with the disease. We will remember her as someone dedicated to her work, tireless in the fight for higher standards of care, and always filled with optimism and warmth.

Foundation's Team

Kamila Rzepka,
LL.M.

Senior Project Manager

A lawyer by profession with experience in working with patient groups. In 2014-2018 she worked as an project manager in the Polish Association for Patients with Primary Immunodeficiencies "Immunoprotect".

At the Institute, she is responsible for coordinating ongoing projects and cooperation with patient organizations, mainly in matters related to reimbursement, access to treatment and the fight for patients' rights.

Anastasiia Doroshenko,
MD

Project Manager: Ukraine Response

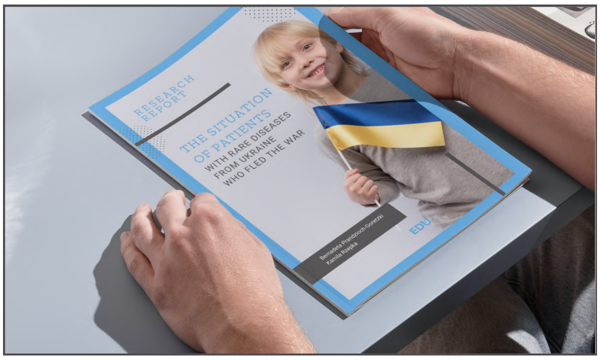
A physician specialized in pediatrics, with experience in working with children with rare diseases and their families.

At the foundation, she is responsible for activities related to the comprehensive support of rare diseases patients from Ukraine fleeing the war – from support during the trip, through arranging accommodation, ensuring access to medical care and helping with formal matters. She also coordinates humanitarian aid for Ukrainian hospitals treating rare disease patients.

What do we focus on?

Research & reports

In order to change reality, you need to understand the current situation, the needs of all parties involved and the possibilities of the system. That is why we focus on research and reports: to better understand patients' individual situations and find appropriate approaches and procedures to initiate a change.



Patient advocacy

We support the pursuit of providing the best therapies and medical care, focusing both on the health and quality of life of patients. We advocate for changes that allow patients to live normal, full lives.

Patient education & trainings

We show patient leaders how to effectively use the available tools and legal mechanisms in the fight for patients' rights. We share with them our experience gained over the years on a national and international level. We equip them with practical knowledge, effective tools and proven solutions.


I'm aware of the fact that being a leader of a patient organization is extremely time consuming.

Collaboration

We believe in teamwork. We know that for a change to take place, the involvement of all parties is necessary: patient advocates, doctors, stakeholders, pharma representatives. That is why we discuss, exchange views and share experiences – so that changes come faster.

Humanitarian aid for Ukrainian rare disease patients

In 2022, our activities focused almost entirely on humanitarian aid to Ukrainian patients with rare diseases who were fleeing the war in their homeland. We continued these actions throughout 2023, assisting them both in Poland and in Ukraine. Each time, we adapted them to the changing circumstances and needs of refugees, as well as medical community and patients on site.

A lot has changed in two years - patients' needs, the issues they contacted us about, the situation in Ukraine. One thing has not changed: patients and their families still needed support so as not to feel abandoned in the new situation. We tried to respond to these needs as best as we could.

Although our resources were rather limited, the numbers speak for themselves:

around

100

families of patients with rare diseases from Ukraine whom we directly helped

33

transports of medicines, medical equipment and other necessities for Ukrainian hospitals and NGOs

31

various rare or ultra-rare diseases that the patients we have helped suffer from

over

220

pages of medical documentation translated by our volunteers

over

$75,000

the total value of medicines and medical equipment that we shipped to Ukraine or bought on site

On-site support for patients and the medical community

Organization of transports of medicines and medical equipment to hospitals treating patients with RD in Ukraine

Thanks to the fact that we were in constant contact with hospitals treating patients with rare diseases in Ukraine, we knew exactly what medicines and medical equipment were in demand in a specific facility. In 2023, we organized a total of 19 transports of medicines and medical equipment.

Oxygen concentrators and nebulizers

Many of the shipments contained specialized products needed to treat specific rare diseases. We provided the NGO "Ukrainian Association of Patients with Pulmonary Hypertension" with medical equipment for patients with pulmonary hypertension from Ukraine, such as oxygen concentrators and nebulizers.

Power stations

One of the key things we delivered to Ukraine in the first days of 2023 was 8 power stations.

Power outages, caused by Russian shelling and regular damage to critical infrastructure, meant not only the lack of heating or the ability to cook a meal. For many patients, a power outage meant that devices that save their lives or help them function better simply didn't work.

Devices like oxygen concentrators, respirators or aspirators need to be powered continuously. Thanks to the power stations, rare disease patients can feel safer and more independent from external factors.

On-site support for patients and the medical community

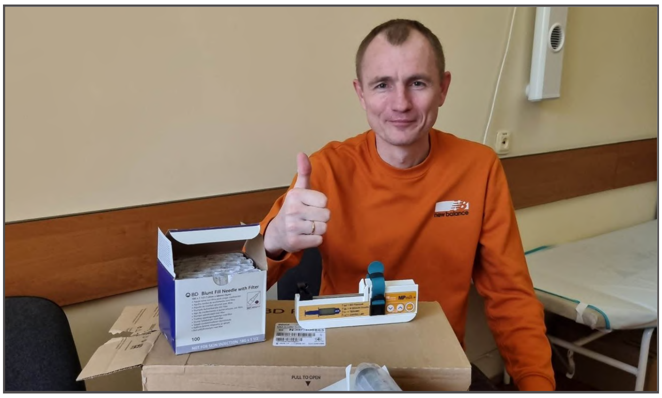
“Pumps for Ukraine” project

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

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

In 2023, we delivered 9 more infusion pumps along with the necessary medical equipment. Since the beginning of our activities, we have delivered a total of 17 such pumps.

Additionally, we have provided online training to doctors from these hospitals on how to use the pumps, enabling them to easily instruct their patients.



Hospitals in Ukraine for which we have delivered infusion pumps and medical equipment necessary for subcutaneous infusions.

On-site support for patients and the medical community

Information and legal support for patients

Brochures & infographics

In 2023 we prepared fourth printed brochure for Ukrainian patients in Poland. It is available at hospital wards where rare disease patients from Ukraine are treated.

The brochure is dedicated to Ukrainian patients with primary immunodeficiencies who are staying and receiving treatment in Poland. We discussed all the most important issues related to this: how the drug program works, what the rules of access to treatment are and what therapeutic options they can choose from in Poland.

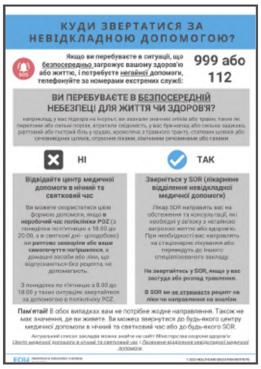
We also have created two more infographics. In the first one, we explain step by step where to turn in situations of sudden deterioration of health or life-threatening situations. In the second infographic, we present how to get to a specialist for a consultation.


Імуноглобулінотерапія для людей з первинними імунодефіцитами в Польщі

Посібник для пацієнтів

EDU

Click on the graphics to download educational materials.


КУДИ ЗВЕРТАТИСЯ ЗА НЕВІДКЛАДНОЮ ДОПОМОГОЮ?

Якщо ви перебуваєте в ситуації, що безпосередньо загрожує вашому здоров'ю або життю, і потребуєте негайної допомоги, телефонуйте за номерами екстрених служб: 999 або 112

ВИ ПЕРЕБУВАЄТЕ В БЕЗПОСЕРЕДНІЙ НЕБЕЗПЕЦІ ДЛЯ ЖИТТЯ ЧИ ЗДОРОВ'Я?

☒ НІ

Відвідайте центр медичної допомоги в нічний та святковий час

Ви можете скористатися цією формою допомоги, якщо в **неробочий час поліклініки POZ** (з понеділка по п'ятницю з 18.00 до 20.00, а в святкові дні - цілодобово) ви **раптово захворіли або ваше самопочуття погіршилося**, а домашні засоби або ліки, що відпускаються без рецепта, не допомагають.

З понеділка по п'ятницю з 8.00 до 18.00 у таких ситуаціях звертайтеся за допомогою в поліклініку POZ.

☑ ТАК

Зверніться у SOR (лікарняне відділення невідкладної медичної допомоги)

Лікар SOR направить вас на обстеження та консультації, які необхідні у зв'язку з негайною загрозою життю або здоров'ю. При необхідності вас направлять на стаціонарне лікування або переведуть до іншого спеціалізованого закладу.

Не звертайтесь у SOR, якщо у вас застуда або розлад травлення.

В SOR ви не отримаєте рецепт на ліки чи направлення на аналізи.

Пам'ятай! В обох випадках вам не потрібне жодне направлення. Також не має значення, де ви живете. Ви можеш звернутися до будь-якого центру медичної допомоги в нічний та святковий час або до будь-якого SOR.


ЯК ЗАПИСАТИСЯ НА БЕЗКОШТОВНУ КОНСУЛЬТАЦІЮ ДО ЛІКАРЯ-СПЕЦІАЛІТА?

1. У більшості випадків вам знадобиться направлення до спеціаліста! Якщо ви не отримали його, наприклад, разом із випискою з лікарні чи від іншого лікаря-спеціаліста, зверніться до свого сімейного лікаря (або педіатра у випадку дітей) у поліклініці POZ.

2. Якщо сімейний лікар (або педіатр) після проведення бесіди та необхідних аналізів вирішить, що вам потрібне лікування у спеціаліста, він випише вам направлення.

3. Отримавши направлення, ви самі вирішуєте, до якої спеціалізованої клініки звернутися. Для того, щоб отримати безкоштовну консультацію, ви повинні вибрати один з тих центрів, які уклали договір з NFZ. Якщо ви не знаєте, куди звернутися, запитайте в поліклініці POZ.

4. Направлення не має строго визначеного терміну дії. Воно є дійсним, доки ви його не використаєте або поки є причина для його видачі. Лише направлення на фізіотерапевтичні процедури необхідно зареєструвати в реабілітаційному центрі протягом 30 днів з дня видачі.

ВАМ НЕ ПОТРІБНО направлення до таких спеціалістів як:

- лікар-психіатр
- гінеколог і акушер
- онколог
- венеролог
- стоматолог

Ви можете пройти лікування в будь-якій спеціалізованій клініці без направлення, якщо:

- маєте довідку про тяжкий ступінь інвалідності
- маєте довідку про ступінь інвалідності разом із ознаками: потреба в постійному чи тривалому догляді чи допомозі іншої особи у зв'язку зі суттєво обмеженою здатністю до самостійного життя та необхідністю постійної участі опікуна дитини в процесі лікування, реабілітації та навчання на щоденній основі
- це стосується психологічних, психотерапевтичних та соціальних послуг для дітей та молоді

Пам'ятайте! Якщо ви хочете записатися на прийом до лікаря-спеціаліста приватно, вам не потрібне направлення. Вищезазначений спосіб стосується лише безкоштовного лікування за кошти NFZ (Національного фонду здоров'я).

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.

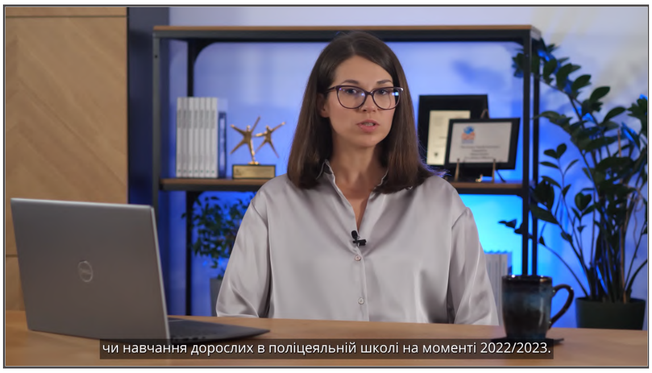
We published the first video in late 2022, the remaining seven were released regularly in 2023. All videos are available on our YouTube channel:

www.youtube.com/@eduinstituteorg

Click on the graphics below to go to the YouTube channel and watch the videos.


ОХОРОНА ЗДОРОВ'Я В ПОЛЬЩІ

Відеопосібник для українських пацієнтів з рідкісними захворюваннями та їхніх родин


чи навчання дорослих в поліцеальній школі на моменті 2022/2023.

Information and legal support for patients

Legal support for patients

From the very beginning, we have been supporting Ukrainian patients not only in matters directly related to treatment. Thanks to having a team of lawyers, we also provided them with legal assistance in issues concerning their stay in Poland, entitled benefits, and resolved problems they encountered. Our activities included, among others:

- Ongoing analysis of legal regulations concerning Ukrainian citizens covered by the special law and responding to patients' and their families' current questions.
- Support in obtaining a disability status for Ukrainian refugees covered by the special law.
- Assistance in obtaining care allowance for patients, including preparing documents and appeals against decisions of Municipal or Communal Social Welfare Centers.
- Correspondence with various Polish institutions (including ZUS, NFZ, the Ministry of Family and Social Policy, the Ministry of Finance, MOPS, GOPS) regarding available benefits for patients from Ukraine.
- Preparing applications for the right to a care allowance and issuing identification cards for person with a disability.

Raising awareness about the situation of RD patients from Ukraine

We launched 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 recorded the videos with stories of Ukrainian patients and their families.

More information about the project can be found on pages 24-27.

BRAVE
RARE
UKRAINE

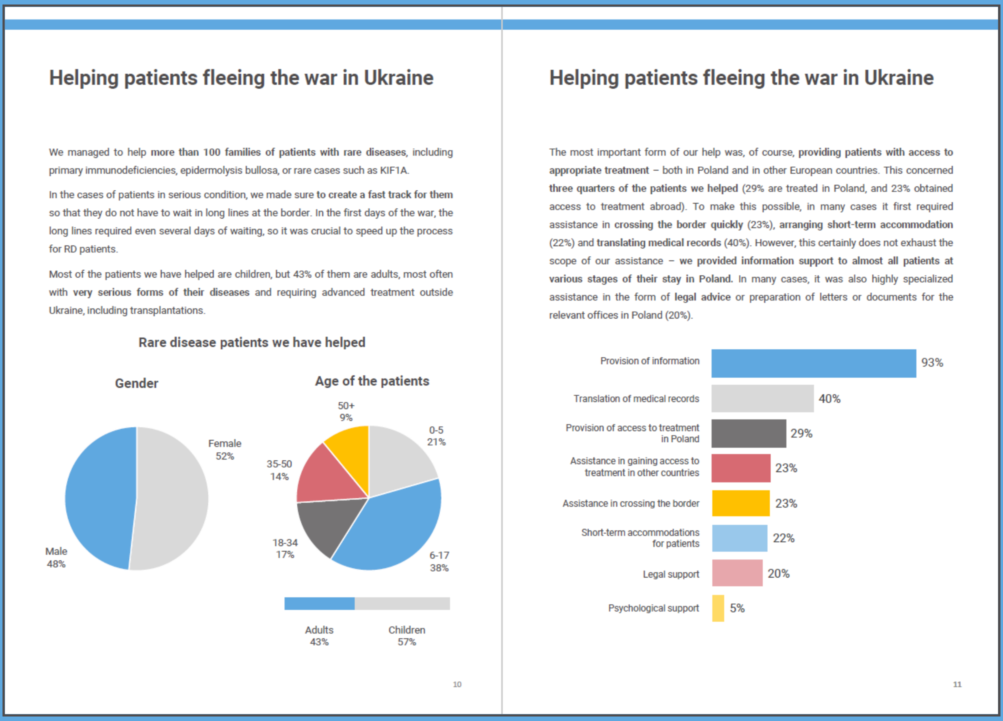
2 YEARS OF COMMITMENT:
Report on humanitarian aid for Ukrainian rare disease patients 2022-2023

If you want to learn more about our humanitarian activities, read the report by clicking on pictures below:

2 YEARS OF COMMITMENT

REPORT ON HUMANITARIAN
AID FOR UKRAINIAN RARE
DISEASE PATIENTS 2022-2023

EDU



Helping patients fleeing the war in Ukraine

We managed to help **more than 100 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 made 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 43% 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

10

Helping patients fleeing the war in Ukraine

The most important form of our help was, 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** (29% are treated in Poland, and 23% obtained access to treatment abroad). To make this possible, in many cases it first required assistance in **crossing the border quickly** (23%), **arranging short-term accommodation** (22%) and **translating medical records** (40%). 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 (20%).

11

List of legal acts for the platform on rare diseases in Poland

Adrian Goretzki and Kamila Rzepka have prepared a list of legal acts important for people with rare diseases in Poland, which can be found on the government website chorobyrzadkie.gov.pl.

In 2021, the Council of Ministers in Poland adopted the "Plan for Rare Diseases", the aim of which is to develop actions that should be taken to improve the quality of medical care for patients with rare diseases. In 2022, the Rare Diseases Information Platform was launched, serving as a comprehensive and reliable source of information on rare diseases and representing the implementation of one of the six areas outlined in the Plan for Rare Diseases.

At the invitation of the Scientific Council of the Information Platform "Rare Diseases," appointed by the Minister of Health, our Foundation had the opportunity to prepare a section devoted to legal acts regarding rare diseases.

We have created a list of almost 20 legal acts that affect the lives of people with rare diseases in Poland. They concern the health care system and pharmaceuticals, but also the social care system. The purpose of this list is to make patients more aware of their rights.

The list is available on the government website chorobyrzadkie.gov.pl.

We hope that this is just the beginning of our cooperation and that in the future, we will be able to prepare an accessible legal guide for people with rare diseases and their caregivers.

9.	Ustawa z dnia 6 września 2001 r. Prawo farmaceutyczne	*M.in. w zakresie w jakim:* • *reguluje kwestię dopuszczenia do obrotu produktów leczniczych* • *reguluje tzw. import docelowy, czyli sprowadzenie zza granicy i refundacja leku na wniosek pacjenta, poparty opinią lekarza prowadzącego i konsultanta krajowego, na podstawie pozytywnej decyzji Ministra Zdrowia* • *umożliwia pacjentowi, jego przedstawicielowi ustawowemu lub opiekunowi faktycznemu zgłoszenie działania niepożądanego produktu leczniczego*
10.	Ustawa z dnia 5 grudnia 1996 r. o zawodach lekarza i lekarza dentysty	*W zakresie w jakim reguluje odpowiedzialność zawodową lekarzy i obowiązki wobec pacjentów*
11.	Ustawa z dnia 10 maja 2018 r. o ochronie danych osobowych	*W szczególności w zakresie w jakim wprowadza szczegółowe zasady dotyczące ochrony prywatności i poufności danych osobowych, w tym medycznych, zgody na ich przetwarzanie, usuwanie, przenoszenie między placówkami medycznymi*
12.	Rozporządzenie Ministra Zdrowia z dnia 6 kwietnia 2020 r. w sprawie rodzajów, zakresu i wzorów dokumentacji medycznej oraz sposobu jej przetwarzania	*W szczególności w zakresie w jakim reguluje zasady udostępniania dokumentacji medycznej*

Ongoing activities in patient advocacy

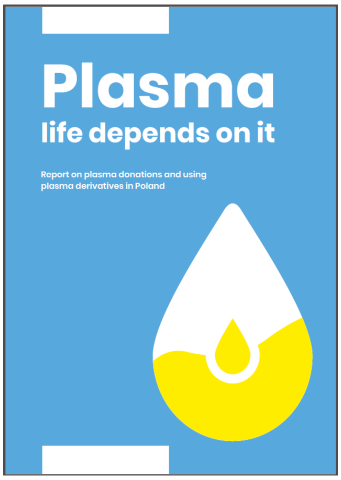
Our ongoing patient advocacy activities in 2023, at both the national and European levels, focused primarily on the needs of patients treated with plasma-derived medicinal products (PDMP) and the safety of blood components for immunocompromised patients.

The needs of patients treated with plasma-derived medicinal products (PDMPs)

In 2023, we continued our efforts to popularize activities that increase plasma collection.

At the invitation of the Plasma Protein Therapeutics Association (PPTA), Adrian Goretzki participated in a discussion panel at the International Plasma Protein Congress in Lisbon.

During the panel, he discussed how to increase the volume of collected plasma and, in turn, secure the availability of plasma-derived medicines for patients, especially those without any other therapeutic options. Additionally, he shared insights into various national initiatives aimed at increasing the number of plasma donors across Europe.



Plasma
life depends on it
Report on plasma donations and using plasma derivatives in Poland

And for those interested in the situation of plasma donations and PDMPs in Poland, you can download our report by clicking on the cover on the left.

The topic of plasma-derived medicines for patients was also part of the panel discussion during the CSL Behring regional meeting in Munich. Adrian Goretzki presented the perspective of patients with primary immunodeficiencies, arguing that immunoglobulin therapy, as a life-saving method, not only helps maintain basic life functions but also allows patients to lead a full life. He emphasized that immunoglobulin replacement therapy is beneficial not only from a humanistic perspective but also from a long-term government perspective in terms of spending.

Ongoing activities in patient advocacy

Safety of blood components for patients with immunodeficiencies

In 2023, we engaged in activities aimed at drawing attention to the safety of blood components, a crucial concern for immunocompromised patients.

Patients with primary and secondary immunodeficiencies require guaranteed access to pathogen-inactivated blood components for transfusion, as a weakened immune system may not effectively combat pathogens in contaminated preparations. Bacterial contamination, if it occurs, can lead to sepsis. Additionally, for many patients with immunodeficiencies, even common and usually harmless viruses such as CMV can pose a deadly threat.

These were the main issues that Adrian Goretzki highlighted during his presentation at the '"Blood Safety - Patient Safety" conference organized on September 29th in Warsaw by the HEMATOONKOLOGICZNI Association and Polish Press Agency.

It was also a topic at the conference "Moving Towards Optimal Blood Safety and Supply Continuity for Vulnerable Patients", organized in October by Cerus. Adrian Goretzki discussed proposed solutions in this area, such as the possibility of creating new guidelines for physicians regarding the treatment of patients with immunodeficiencies using blood components.

A frame from the video recording of the debate during the "Blood Safety - Patient Safety" conference, which is available at **the link**.

PatientAdvocacy.Academy 2023: Strong organization, powerful advocacy

PatientAdvocacy.Academy is our flagship educational project, which we have been carrying out since the beginning of the foundation's existence. It's an online video course for leaders of patient organizations who are actively working to improve the situation of patients in their countries.

This was already the sixth edition of PatientAdvocacy.Academy, and the pool of important topics that should be addressed to make running patient organizations easier, and to make the fight for patients' rights more effective, is still not exhausted.

In this edition of PatientAdvocacy.Academy, our aim is to educate participants on constructing a robust and reputable organization through careful budgeting and successful fundraising, complemented by the presence of dedicated and committed volunteers. And, equally important, how to effectively conduct public policy advocacy activities. We focused on issues related to communication with stakeholders, HTA, access to treatment and improving the quality of life of patients.

Once again, the PAA connected people from various therapeutic areas acting different parts of the world!

This edition was attended:

by 21 participants

from 14 countries

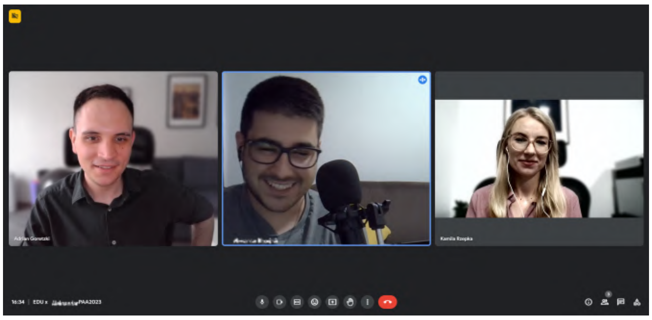
located on 3 continents

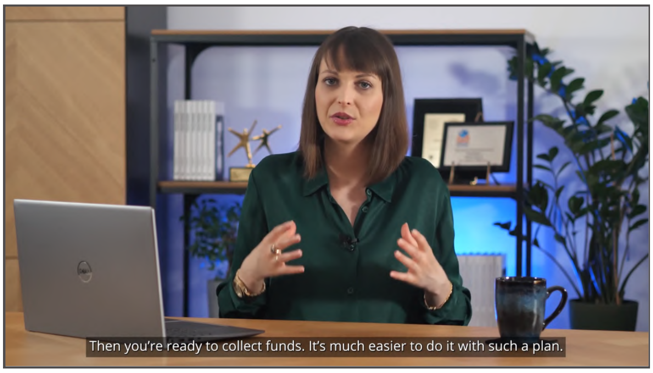
representing 5 rare diseases

Countries of origin of participants from this edition.

How did PatientAdvocacy.Academy 2023 look in practice?

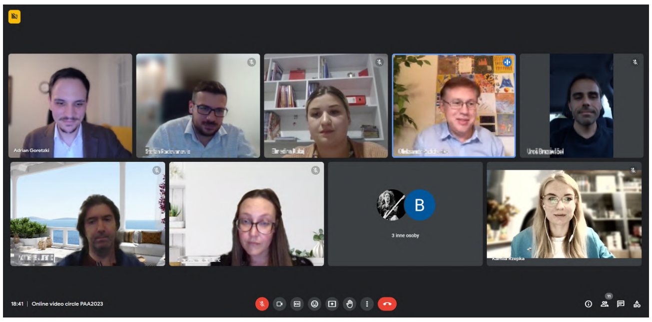
Since last year's innovation in the form of 1-to-1 preliminary meetings turned out to be a success, we also started the Academy in this way. It allows us to get to know each participant better, increase their commitment, build understanding between us and to adjust the topics of our online circles to their most urgent needs.

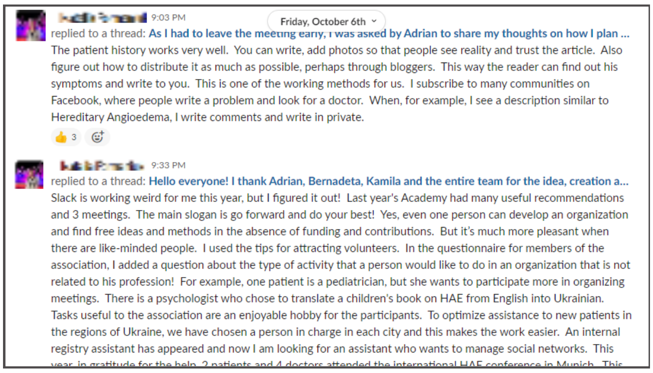




The focal point of the course comprised 10 video lectures, each spanning 15-20 minutes, delving into the crucial aspects associated with the theme of this course edition. We provided English subtitles, and, responding to the requests of certain participants, we crafted a video transcription in Russian. Each video was enriched with numerous supplementary screens, charts, and infographics to enhance the learning experience.

We select topics for online coaching circles based on information from 1-on-1 conversations. Due to the specificity of the topics, we decided to work in two smaller groups. We also asked some participants to prepare short presentations and share their success stories during coaching circles. Thanks to this, together we were able to develop ready-made solutions for each of the participants.





[redacted] 9:03 PM

Friday, October 6th

replied to a thread: **As I had to leave the meeting early, I was asked by Adrian to share my thoughts on how I plan ...**

The patient history works very well. You can write, add photos so that people see reality and trust the article. Also figure out how to distribute it as much as possible, perhaps through bloggers. This way the reader can find out his symptoms and write to you. This is one of the working methods for us. I subscribe to many communities on Facebook, where people write a problem and look for a doctor. When, for example, I see a description similar to Hereditary Angioedema, I write comments and write in private.

👍 3

[redacted] 9:33 PM

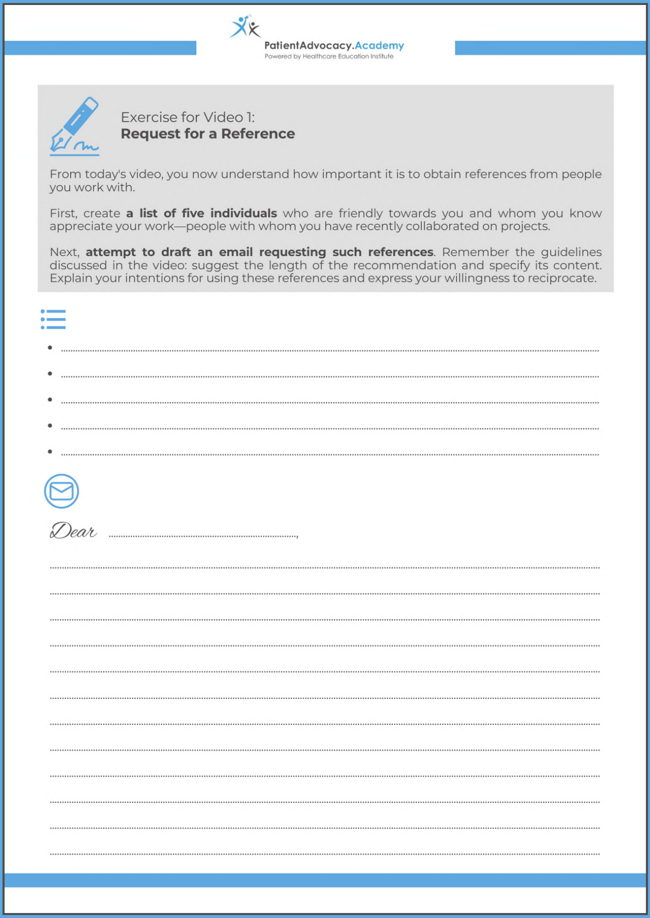
replied to a thread: **Hello everyone! I thank Adrian, Bernadeta, Kamila and the entire team for the idea, creation a...**

Slack is working weird for me this year, but I figured it out! Last year's Academy had many useful recommendations and 3 meetings. The main slogan is go forward and do your best! Yes, even one person can develop an organization and find free ideas and methods in the absence of funding and contributions. But it's much more pleasant when there are like-minded people. I used the tips for attracting volunteers. In the questionnaire for members of the association, I added a question about the type of activity that a person would like to do in an organization that is not related to his profession! For example, one patient is a pediatrician, but she wants to participate more in organizing meetings. There is a psychologist who chose to translate a children's book on HAE from English into Ukrainian. Tasks useful to the association are an enjoyable hobby for the participants. To optimize assistance to new patients in the regions of Ukraine, we have chosen a person in charge in each city and this makes the work easier. An internal registry assistant has appeared and now I am looking for an assistant who wants to manage social networks. This year, in gratitude for the help, 2 patients and 4 doctors attended the international HAE conference in Munich. This

During the entire Academy, a Slack group was available to all participants. It is a communication platform that enables ongoing discussion. Participants can exchange experiences, ask questions to trainers, and present the achievements of their patient organizations.

How did PatientAdvocacy.Academy 2023 look in practice?

Additional educational materials were prepared for each video lesson in the form of an exercise in a PDF file and a short 4-question quiz, which allowed participants to consolidate the acquired knowledge and immediately translate it into practical solutions for their patient organizations.



Exercise for Video 1:
Request for a Reference

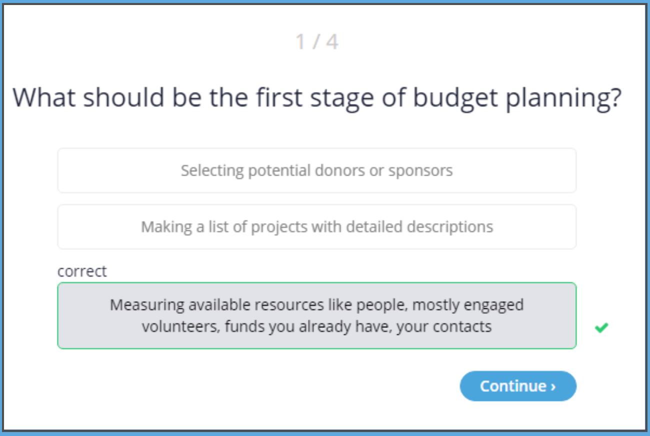
From today's video, you now understand how important it is to obtain references from people you work with.

First, create **a list of five individuals** who are friendly towards you and whom you know appreciate your work—people with whom you have recently collaborated on projects.

Next, **attempt to draft an email requesting such references**. Remember the guidelines discussed in the video: suggest the length of the recommendation and specify its content. Explain your intentions for using these references and express your willingness to reciprocate.

- ....
- ....
- ....
- ....
- ....

Dear ....,



1 / 4

What should be the first stage of budget planning?

Selecting potential donors or sponsors

Making a list of projects with detailed descriptions

correct

Measuring available resources like people, mostly engaged volunteers, funds you already have, your contacts ✓

1 / 4

Which legal regulation applies to all health care decision-making in most legal systems?

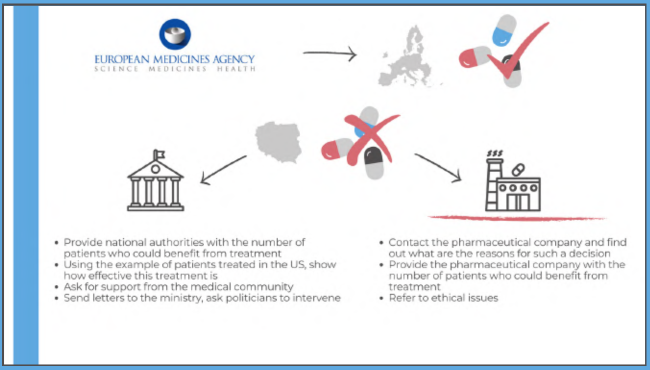
General Code of Patients' Rights

correct

General Code of Administrative Procedure ✓

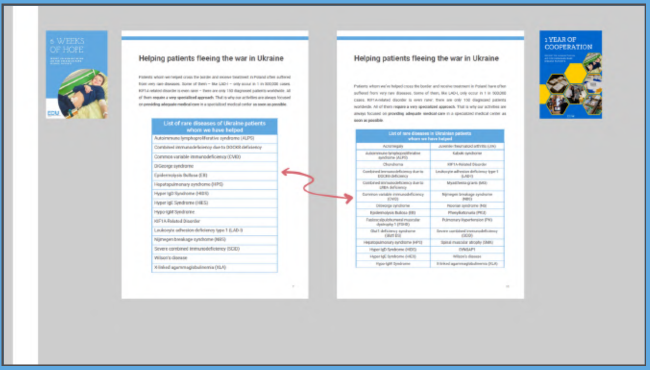
A Specific Code of Rights of Patient Organizations and Patients

Each video also consisted of many additional screens, charts and infographics to make learning easier and more enjoyable. We made sure to provide as many practical examples as possible to illustrate what we are talking about.



- Provide national authorities with the number of patients who could benefit from treatment
- Using the example of patients treated in the US, show how effective this treatment is
- Ask for support from the medical community
- Send letters to the ministry, ask politicians to intervene

- Contact the pharmaceutical company and find out what are the reasons for such a decision
- Provide the pharmaceutical company with the number of patients who could benefit from treatment
- Refer to ethical issues



Assessment and opinion of participants of this year's Academy

To learn the participants' opinions, after completing the Academy, we asked them a few questions about the course in the form of an anonymous survey.

We are glad that the Academy again received a very high rating! The overall course assessment was 9,3. All opinions and suggestions will be used to prepare even better training next year!

These three elements show what are - and should be - the foundations of PatientAdvocacy.Academy: tailoring content to participants, mixing various activities within one course and providing practical knowledge, ready to apply.

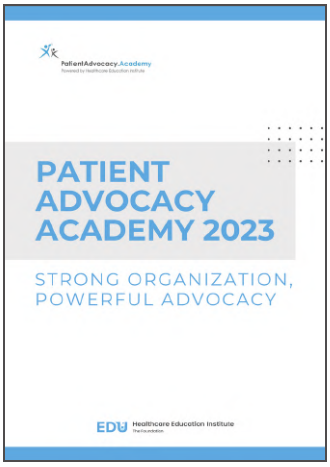
These elements also make course participants want to come back and gain new knowledge every year.

9,3

Overall course assessment

In the survey participants also indicated the 3 most valuable aspects of PAA:

1. The fact that it combines various elements (video, online meetings, exercises, discussion).
2. That it explains how to run a patient organization.
3. That it is based on examples from their therapeutic field.



PATIENT ADVOCACY ACADEMY 2023

STRONG ORGANIZATION, POWERFUL ADVOCACY

If you want to know more about the PAA2023, read our report by clicking on the cover on the left.

> ***“This is I think my third Patient Advocacy Academy and I am coming back because I always learn something new and get new ideas for our advocacy campaigns.”***
>
> ***Uroš Brezavšček***
> *Krvni bratje,*
> *Slovenian association of patients with blood clotting disorders*

Education in patient advocacy

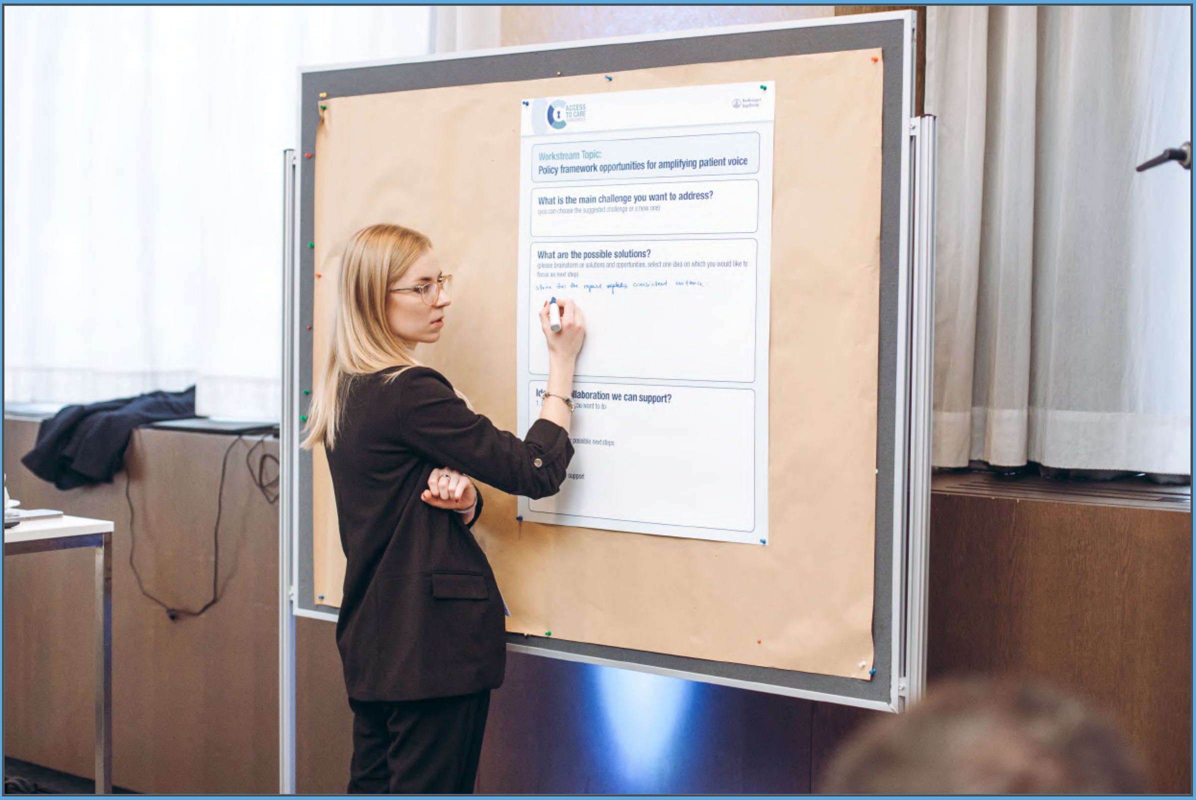
Our efforts have consistently focused on strengthening patient organizations and providing them with the necessary tools to more effectively advocate for patients' rights and access to treatment. This was also the topic of our presentation during the annual Access to Care conference in Vienna.

Access to Care is a conference attended by dozens of leaders from patient organizations in the Central Eastern Europe region. Over the course of two days, the conference features lectures and workshops addressing various topics related to the advocacy for access to treatment. These issues encompass not only medical and social aspects but also pharmacoeconomic and legal considerations.

This year, Kamila Rzepka spoke at the conference on behalf of the Healthcare Education Institute. In the first panel, she presented the legal and policy framework for patient engagement in CEE. This is part of our original project, gathering and presenting good practices from various countries in the region, while also encouraging out-of-the-box thinking in the context of patient advocacy. The aim is to inspire leaders of patient organizations to explore non-obvious solutions, adopt successful practices from other countries or therapeutic areas, and strive to implement beneficial changes in their own legal systems.

Kamila also took part as an expert in the workshop "Policy framework opportunities for amplifying patient voice", during which she discussed possible initiatives to overcome access barriers and improve patient treatment outcomes.

Kamila Rzepka at the annual Access to Care conference in Vienna



Raising awareness

Brave RARE Ukraine

BRAVE
RARE
UKRAINE

For almost two years, since helping patients with rare diseases from Ukraine became the main focus of our Foundation's activity, we have heard countless heartbreaking stories. We felt that each of these patients and each of these families are true warriors. Heroes no one has heard of. And we wanted to change that.

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

Additionally, we wanted to shed light on the stories of those who aspire to return to their homeland after the war but face uncertainty and lack of access to essential medical treatment, amplifying their plight and resilience.

We needed to give a voice to patients, their families and doctors from Ukraine. So **we created a dedicated website where we share their stories in the form of videos.**

The project was launched in August 2023. So far we have published five video testimonials with Ukrainian patients and their families staying in Poland, but more videos, including those featuring doctors from Ukraine, will be release soon.

You can read more details about patients' stories on the following pages.




Our Brave RARE patients during the recordings.

Masha, 2 years old, from the Zaporizhzhia region

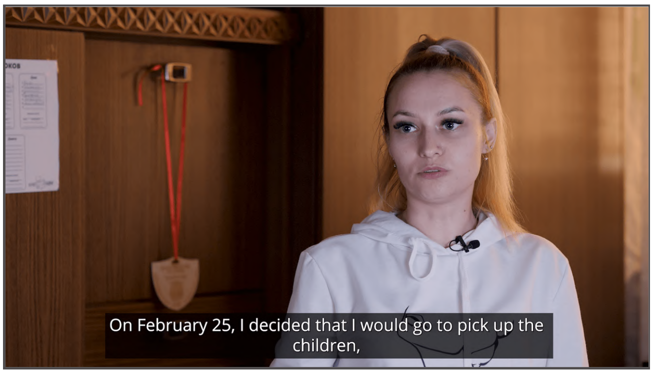
Nijmegen Breakage Syndrome

Masha and her family come from the Zaporizhzhia region. She was diagnosed with NBS at the beginning of the war. The poor conditions in bomb shelters – extreme humidity and low temperatures – aggravated her symptoms, and she became seriously ill. The family had to leave Ukraine and look for treatment in Poland.

Nastya, 7 years old, from Lysychansk

A rare set of gastroenterological diseases

Her family came from Lysychansk, which is currently in the temporarily occupied territories. They had to flee the war in dramatic circumstances. They left everything behind and lost everything. They are currently building a new life in Poland, focusing on providing Nastya with proper treatment.



Yehor, 10 years old, from Zviahel

X-linked agammaglobulinemia

In the case of Yehor's disease, interruptions in treatment can be extremely dangerous. Therefore, as soon as his family arrived in Poland, fleeing the war, it was crucial to provide him with access to life-saving treatment as soon as possible.

▶

Click on any photo
to watch the videos!

BRAVE
RARE
UKRAINE

Oleksandr, 18 years old, from Vinnitsa
Kabuki Syndrome

In 2021, he fell ill with Hodgkin's lymphoma, then he was diagnosed with Kabuki syndrome. He came to Poland in very serious condition, when his platelet count was approaching zero. At the University Hospital in Gdańsk, he immediately received proper treatment that allowed him to function normally.

Difficult conditions, because there we had to go down to the bomb shelter when he had a fever,

"All warehouses are closed and there is no way to get the medicines and give them to you."

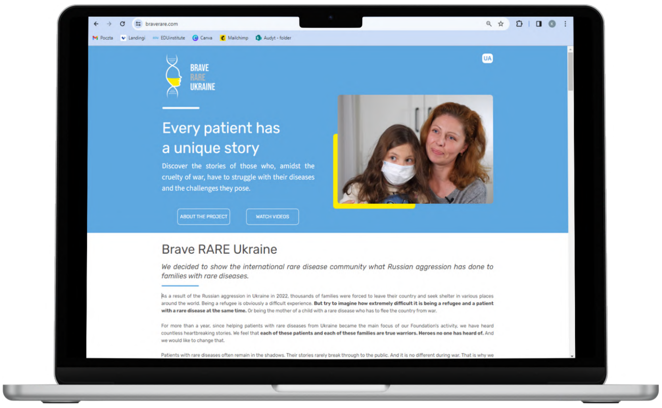
Vitaly, adult patient from Kyiv
LRBA deficiency

Vitalii suffers from an ultra rare disease. He was in Kyiv when the war began. He found himself in a besieged city, with no access to treatment - because both his hospital and the warehouses where the drugs were stored were directly on the front line. Therefore, he was forced to leave the country and look for opportunities to continue his therapy in Poland.

The project partners were: EURORDIS, Global Genes, Rare Diseases Ukraine, Rare Immune Diseases and Okhmadyt, the largest children's hospital in Ukraine, treating many patients with rare diseases. Our media partner was Rare Revolution Magazine.

This project is also an appeal to European policymakers to take into account the situation of Ukrainian patients with rare diseases when working on Ukraine-rebuilding programs.

There is a need for policies that facilitate the post-war repatriation of rare disease refugees who wish to return to their homeland but currently lack the guarantee of receiving treatment for their conditions.



Every patient has a unique story

Discover the stories of those who, amidst the cruelty of war, have to struggle with their diseases and the challenges they pose.

Brave RARE Ukraine

We decided to show the international rare disease community what Russian aggression has done to families with rare diseases.

As a result of the Russian aggression in Ukraine in 2022, thousands of families were forced to leave their country and seek shelter in various places around the world. Being a refugee is obviously a difficult experience. **But try to imagine how extremely difficult it is being a refugee and a patient with a rare disease at the same time.** Or being the mother of a child with a rare disease who has to flee the country from war.

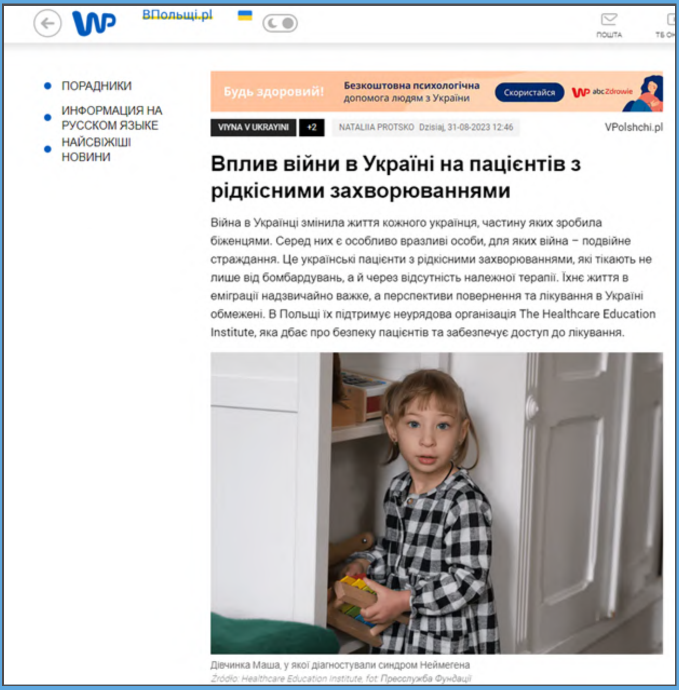
For more than a year, since helping patients with rare diseases from Ukraine became the main focus of our Foundation's activity, we have heard countless heartbreaking stories. We feel that **each of these patients and each of these families are true warriors. Heroes no one has heard of.** And we would like to change that.

Patients with rare diseases often remain in the shadows. Their stories rarely break through to the public. And it is no different during war. That is why we

You can read about the project on a special website::

braverare.com

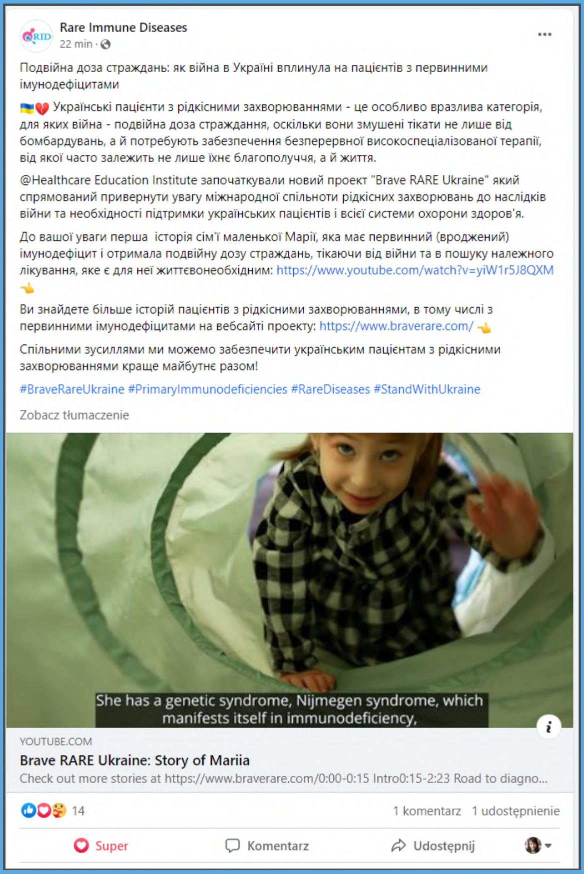
The project had also good media coverage and was widely shared on social media



Вплив війни в Україні на пацієнтів з рідкісними захворюваннями

Війна в Україні змінила життя кожного українця, частину яких зробила біженцями. Серед них є особливо вразливі особи, для яких війна – подвійне страждання. Це українські пацієнти з рідкісними захворюваннями, які тікають не лише від бомбардувань, а й через відсутність належної терапії. Їхнє життя в еміграції надзвичайно важке, а перспективи повернення та лікування в Україні обмежені. В Польщі їх підтримує неурядова організація The Healthcare Education Institute, яка дбає про безпеку пацієнтів та забезпечує доступ до лікування.

Дівчинка Маша, у якої діагностували синдром Неймегена
Źródło: Healthcare Education Institute, fot: Пресслужба Фундації



Подвійна доза страждань: як війна в Україні вплинула на пацієнтів з первинними імунодефіцитами

🇺🇦💔 Українські пацієнти з рідкісними захворюваннями - це особливо вразлива категорія, для яких війна - подвійна доза страждання, оскільки вони змушені тікати не лише від бомбардувань, а й потребують забезпечення безперервної високоспеціалізованої терапії, від якої часто залежить не лише їхнє благополуччя, а й життя.

@Healthcare Education Institute започаткували новий проект "Brave RARE Ukraine" який спрямований привернути увагу міжнародної спільноти рідкісних захворювань до наслідків війни та необхідності підтримки українських пацієнтів і всієї системи охорони здоров'я.

До вашої уваги перша історія сім'ї маленької Марії, яка має первинний (вроджений) імунодефіцит і отримала подвійну дозу страждань, тікаючи від війни та в пошуку належного лікування, яке є для неї життєвонеобхідним: https://www.youtube.com/watch?v=yiW1r5J8QXM 👈

Ви знайдете більше історій пацієнтів з рідкісними захворюваннями, в тому числі з первинними імунодефіцитами на вебсайті проекту: https://www.braverare.com/ 👈

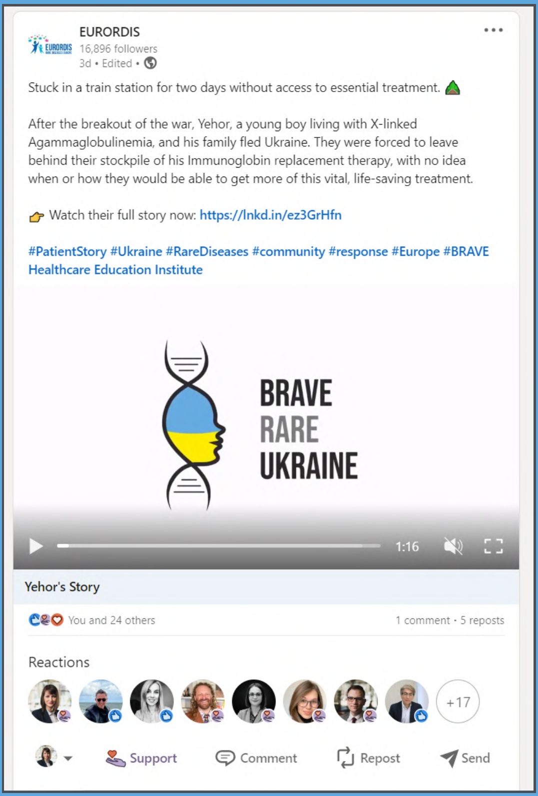
Спільними зусиллями ми можемо забезпечити українським пацієнтам з рідкісними захворюваннями краще майбутнє разом!

#BraveRareUkraine #PrimaryImmunodeficiencies #RareDiseases #StandWithUkraine

Zobacz tłumaczenie

She has a genetic syndrome, Nijmegen syndrome, which manifests itself in immunodeficiency,

YOUTUBE.COM
Brave RARE Ukraine: Story of Mariia
Check out more stories at https://www.braverare.com/0:00-0:15 Intro0:15-2:23 Road to diagno...



Stuck in a train station for two days without access to essential treatment.

After the breakout of the war, Yehor, a young boy living with X-linked Agammaglobulinemia, and his family fled Ukraine. They were forced to leave behind their stockpile of his Immunoglobin replacement therapy, with no idea when or how they would be able to get more of this vital, life-saving treatment.

👉 Watch their full story now: https://lnkd.in/ez3GrHfn

#PatientStory #Ukraine #RareDiseases #community #response #Europe #BRAVE Healthcare Education Institute

PRESS RELEASES

Double dose of suffering: how the war in Ukraine has affected patients with rare diseases

14 AUGUST 2023

Press Release: 09.08.2023, Katowice, Poland. Healthcare Education Institute. The Foundation

Among the refugees from Ukraine, there are particularly vulnerable individuals for whom the war means double suffering. These are Ukrainian patients with rare diseases who are fleeing not only from bombings but also due to the lack of appropriate therapy. Their life in exile is exceptionally difficult, and the prospects of returning and receiving treatment in Ukraine are limited.

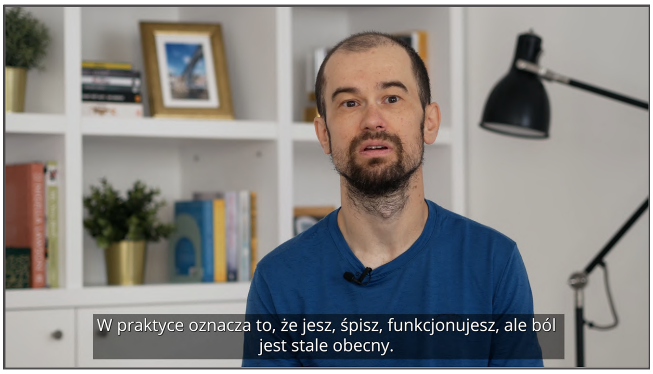
One of such individuals is Nastya, a seven-year-old girl with a rare set of gastroenterological diseases. Her family came to Poland from Lysychansk, in the Donbas region, which is currently in the temporarily occupied territories. They had to flee the war under very dramatic circumstances due to the worsening health condition of the girl. They left behind all their belongings and lost everything, including their newly built house. They became among the millions of refugees who left Ukraine after 24 February 2022.

Testimonials of patients with Fabry disease

In 2023, we continued the film project commissioned by Amicus Therapeutics, which was initiated in 2021. The project involves presenting the stories of patients with Fabry disease from various European countries. The main goal is to continuously increase awareness of the existence of Fabry disease, especially among doctors.

Fabry disease is difficult to diagnose because it can cause very different symptoms originating from many different organs and systems. That is why it is so important to increase awareness of this disease among doctors of various specialties.

The patient testimonials we have recorded over the last three years have been presented at many European medical congresses, with the aim of facilitating more accurate diagnoses.



Since 2021, we have documented the stories of six patients from five different countries. n the videos patients with Fabry disease talk about the challenging path they went through before receiving the correct diagnosis and how their lives changed after starting treatment. They share their everyday experiences with the disease, discussing the challenges they face and the impact the disease has on their family and professional life.

In 2023, it was time to share the story of a Fabry patient from Croatia. Additionally, we have prepared new language versions of two existing films so that they can reach a wider medical audience.

But, of course, many interesting stories of patients from other countries remain untold. Therefore, we hope that this project will continue in 2024.

Meetings & events in 2023

In 2023, we participated in numerous valuable meetings, conferences, and training sessions. Each of these events was an opportunity for us to share knowledge and experience, as well as to gain new perspectives. All of this was done with the aim of continually improving the situation for patients with rare diseases.

The EURORDIS Black Pearl Award gala

21.02.2023, Brussels, Belgium

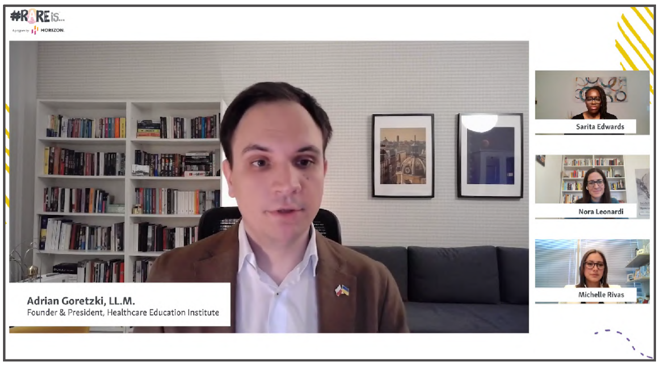
One of the most significant events for us in 2023 was the annual gala, The EURORDIS Black Pearl Award. During this event, our president, Adrian Goretzki, received the award in the category of "The EURORDIS Young Patient Advocate Award" for his activities on behalf of the community of patients with rare diseases. This is a significant honor for him personally and for the entire foundation, but also a commitment and tremendous motivation for further work.

Click on the photo above to watch the recording of the gala and Adrian Goretzki's speech (from 50:50).

Horizon's webinar on the occasion of Rare Disease Day

28.02.2023, on-line meeting

Every year on February 28, numerous events take place with the aim of drawing attention to the issues and challenges faced by patients with rare diseases. During the webinar organized by Horizon Therapeutics, Adrian Goretzki and other #RAREis Global Advocate Grant recipients discussed the ongoing efforts to support people living with rare diseases around the world.



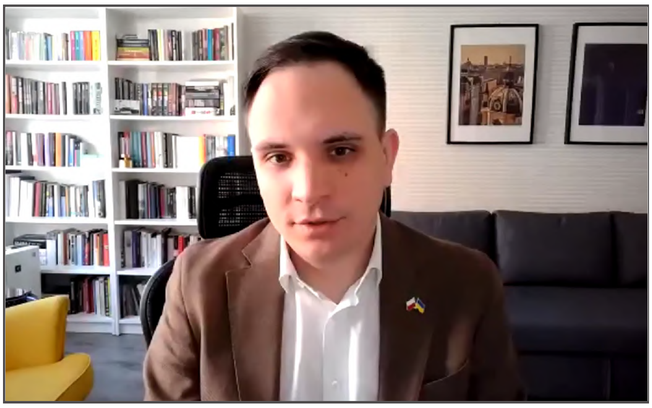
Click on the photo above to watch the webinar recording.

Meetings & events in 2023

The Conference on the occasion of Rare Disease Day

28.02.2023, Warsaw, Poland

Adrian Goretzki was a speaker at the conference organized in Warsaw on the occasion of Rare Disease Day, during which he spoke about the need for cooperation between patients, doctors and scientists in developing therapies for rare diseases. He also took part in a panel on the Plan for Rare Diseases in Poland.



The EURORDIS Membership Meeting 2023

25-27.05.2023, Stockholm, Sweden

Kamila Rzepka represented our Foundation at the EURORDIS Membership Meeting 2023 in Stockholm, taking part in workshops and networking moderated sessions on a holistic, lifelong approach and full social inclusion of people with rare diseases. It was a great opportunity to meet new people, share experiences, and gain new perspectives for future work.

The CSL Behring regional meeting

12-13.06.2023, Munich, Germany

During a panel discussion at the CSL Behring regional meeting in Munich, Adrian spoke about the importance of immunoglobulin therapy for patients with primary immunodeficiencies. He emphasized how these therapies can improve not just the health state but, equally important, the quality of life for patients.

Meetings & events in 2023

The Boehringer Ingelheim meeting

14-15.06.2023, Palma, Spain

During the Boehringer Ingelheim meeting, where the industry's cooperation with patient organizations was discussed, Adrian Goretzki conducted workshops that explored the potential of patient organizations and the importance of supporting their growth and development.

The International Plasma Protein Congress (IPPC)

19-21.06.2023, Lisbon, Portugal

At the invitation of the Plasma Protein Therapeutics Association (PPTA), Adrian Goretzki participated in a discussion panel at the International Plasma Protein Congress (IPPC) in Lisbon.

Summary of the Razem z Ukrainą (Together with Ukraine) project

23.06.2023, Warsaw, Poland

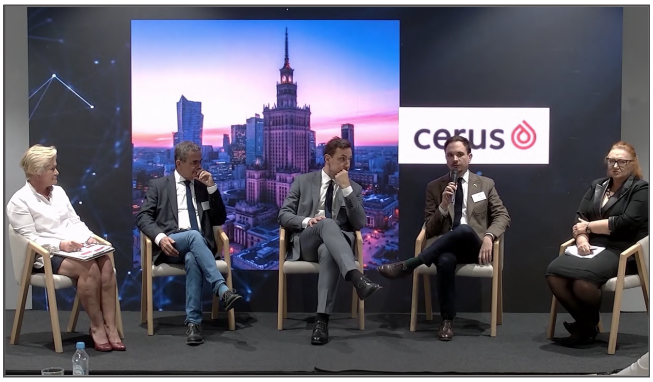
Our organization, together with other participants of the Razem z Ukrainą (Together with Ukraine) project organized by Eurordis, met to discuss the results of the project's annual activities, which focused on helping Ukrainian patients with RD who fled the war.

Meetings & events in 2023

The "Blood Safety - Patient Safety" conference

29.09.2023, Warsaw, Poland

Adrian Goretzki spoke during the 'Blood Safety - Patient Safety' conference organized by the HEMATOONKOLOGICZNI Association and Polish Press Agency, presenting the problem of blood safety from the perspective of patients with primary immunodeficiencies.



Moving Towards Optimal Blood Safety and Supply Continuity for Vulnerable Patients - conference

9-10.10.2023, Warsaw, Poland

Adrian was a speaker at a conference organized by Cerus, where he discussed proposed solutions in the area of blood safety from the perspective of patients with immunodeficiencies.

Training for patient representatives and advocates

26-27.10.2023, Gdańsk, Poland

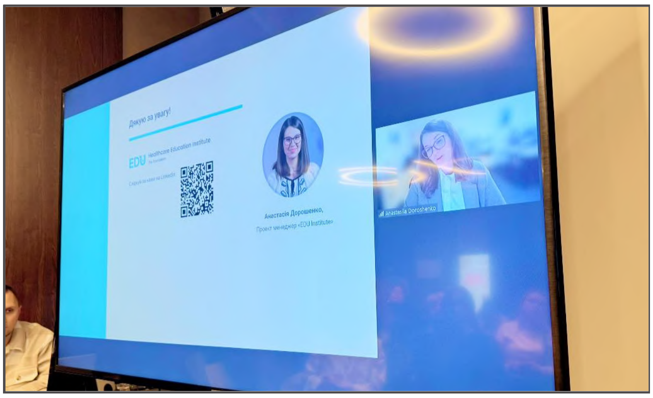
Kamila Rzepka participated in a course “Training for patient representatives and advocates on leadership and communication skills”, organized by EURORDIS in cooperation with the European Joint Program for Rare Diseases and Medical University of Gdańsk.

Meetings & events in 2023

The Access to Care conference

30.11-01.12.2023, Vienna, Austria

During the conference for patient advocates Kamila Rzepka presented the legal and policy framework for patient engagement in CEE and took part as an expert in the workshop "Policy framework opportunities for amplifying patient voice", during which she discussed possible initiatives to overcome access barriers and improve patient treatment outcomes.



The Anniversary International Medical Forum in Lviv

15.12.2023, Lviv

During the Anniversary International Medical Forum "Medicine of Ukraine and the world: basics, realities and strategic prospects", Anastasiia Doroshenko presented the humanitarian activities of our Foundation for Ukrainian patients with rare diseases affected by the war in Ukraine.

> ❝
>
> ***For the patients.***
> ***Together!***

2023 on the timeline

21.02.2023,
Brussels, Belgium

The EURORDIS
Black Pearl Award
gala

28.02.2023,
on-line meeting

Horizon's webinar
on the occasion of
Rare Disease Day

28.02.2023,
Warsaw, Poland

The Conference
on the occasion of
Rare Disease Day

25-27.05.2023,
Stockholm, Sweden

The EURORDIS
Membership
Meeting 2023

12-13.06.2023,
Munich, Germany

The CSL Behring
regional
meeting

14-15.06.2023,
Palma, Spain

The Boehringer
Ingelheim
meeting

19-21.06.2023,
Lisbon, Portugal

The International
Plasma Protein
Congress (IPPC)

23.06.2023,
Warsaw, Poland

The concluding
meeting of the “Razem
z Ukrainą” project

28.09.2023,
on-line course

The beginning of the
PatientAdvocacy.Academy
2023

29.09.2023,
Warsaw, Poland

The Blood Safety
- Patient Safety
conference

9-10.10.2023,
Warsaw, Poland

Moving Towards Optimal Blood
Safety and Supply Continuity for
Vulnerable Patients - conference

26-27.10.2023,
Gdańsk, Poland

EJPRD Training on
Leadership and
Communication Skills

30.11-01.12.2023,
Vienna, Austria

The Access
to Care
conference

15.12.2023,
Lviv, Ukraine

The Anniversary
International Medical
Forum in Lviv

The EURORDIS Black Pearl Award

Our successes and actions have also been noticed in the international arena. In 2023, the president of the foundation, Adrian Goretzki, received the EURORDIS Black Pearl Award for his activities for the community of patients with rare diseases.

Since 2012, EURORDIS – Rare Diseases Europe has organized The EURORDIS Black Pearl Awards to recognize the major achievements and 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 in the category "The EURORDIS Young Patient Advocate Award" 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.

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> **“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.”**

Media about our Foundation

Similarly to previous years, we shared our activities and projects in the media. Here are the most important press materials regarding the foundation's work.

#EurordisRareOnAir

Adrian Goretzki was a guest on the Eurordis podcast "Rare On Air." In the episode titled “War with a Rare Disease: Responding to the Invasion of Ukraine,” he discusses his experience working with Ukrainian contacts to ensure that people living with a rare disease receive the healthcare they need, despite the outbreak of the war.

Click on the graphic to the right
to listen to the podcast.

Odcinek podcastu

War with a rare disease: Responding to the invasion of Ukraine

Rare on Air

lut 2023 · pozostało: 6 min 8 sek.

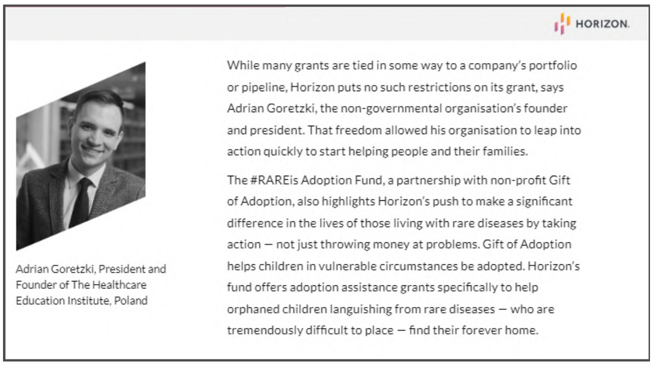
Opis odcinka

One year on from Russia’s full-scale invasion of Ukraine, Julien Poulain, Communications Manager at EURORDIS, speaks to those who have dedicated themselves and their organisations to supporting those Ukrainians living with a rare disease amid the crisis. Tetiana Kulesha, Chair of the Board of Orphan Diseases of Ukraine, joins the discussion to speak not only of her efforts to support patients impacted by the invasion, but also her efforts to make sure Ukraine keeps striving towards its pre-war goals in rare disease policy. Adrian Goretzki, and Katarzyna Świeczkowska also share how their organisations in neighbouring Poland have been supporting Ukrainians living with a rare disease and their families – both those who have remained in the country and those who have had to flee. Meanwhile, Anastasiia Saliuk, lead for the EURORDIS response to Ukraine, shares her research and findings on the situation for those with a rare condition affected by the invasion.
Email the podcast at **RareOnAir@eurordis.org**.

“The Economist“

In an article in Economist Impact, Adrian Goretzki explains how the grant, awarded to us twice under the #RAREis Global Advocate Grant program, enabled the organization to carry out humanitarian activities.

Click on the graphic to the left
to read the full article.



Adrian Goretzki, President and Founder of The Healthcare Education Institute, Poland

While many grants are tied in some way to a company’s portfolio or pipeline, Horizon puts no such restrictions on its grant, says Adrian Goretzki, the non-governmental organisation’s founder and president. That freedom allowed his organisation to leap into action quickly to start helping people and their families.

The #RAREis Adoption Fund, a partnership with non-profit Gift of Adoption, also highlights Horizon’s push to make a significant difference in the lives of those living with rare diseases by taking action — not just throwing money at problems. Gift of Adoption helps children in vulnerable circumstances be adopted. Horizon’s fund offers adoption assistance grants specifically to help orphaned children languishing from rare diseases — who are tremendously difficult to place — find their forever home.

“Financial Times“

An article in the 'Financial Times' covers our activities, made possible through securing a grant under the #RAREis Global Advocate Grant program."

Click on the graphic to the right
to read the full article.

#RAREis: empowering the rare disease community

The rare disease community is often overlooked, leaving many patients feeling helpless and frustrated. #RAREis provides a global platform where they can share their experiences and have their voices heard.

Partners, donors & sponsors

Collaboration with other entities is crucial in our work. Without the support of sponsors, partners, and other NGOs, many projects would not come to fruition. That's why we want to express our gratitude to all of them here! We appreciate your presence and collective efforts for patients with rare diseases around the world.

Industry:

Amicus Therapeutics
Boehringer Ingelheim
cerus
CSL Behring Biotherapies for Life®
HORIZON
IHS INNOVATIVE HEALTH SCIENCES™
octapharma
Ovid™ Therapeutics
PPTA Plasma Protein Therapeutics Association
SO CONNECT

Non-profit organizations:

debra Ukraine.
EBPolska Epidermolysis Bullosa
EURORDIS RARE DISEASES EUROPE
Razem z Ukrainą A EURORDIS INITIATIVE RARE DISEASES EUROPE
Global Genes® Allies in Rare Disease
immunoprotect Stowarzyszenie na rzecz osób z niedoborami odporności
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Public entities:

НАЦІОНАЛЬНА ДИТЯЧА СПЕЦІАЛІЗОВАНА ЛІКАРНЯ «ОХМАТДИТ»

Media:

RARE REVOLUTION MAGAZINE

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