

2022

ANNUAL REPORT

REVIEW OF ACTIVITIES AND ACHIEVEMENTS
OF THE HEALTHCARE EDUCATION INSTITUTE



Report prepared by:



Healthcare Education Institute. The Foundation
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Katowice, 2023

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Photos:

The following photos were used in the report:

- cover, p. 15, p. 16, and p. 25 – photos taken during the "Plasma saves lives" conference in Warsaw, **photographer: Piotr Bławicki**
- p. 20 and p. 26 – photos taken during The Access to Care Conference in Vienna, **Boehringer Ingelheim** / **photographer: Mila Zytka**
- p. 27 – photo taken during "The World for Ukraine Summit" in Rzeszów, **Polish Rescue Organization**
/ <https://www.facebook.com/photo?fbid=232623945756079>

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

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01

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 over 10 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 cooperate closely with stakeholders to shape changes that will have a positive impact on the quality of life of patients in different countries.



“ —

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.

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

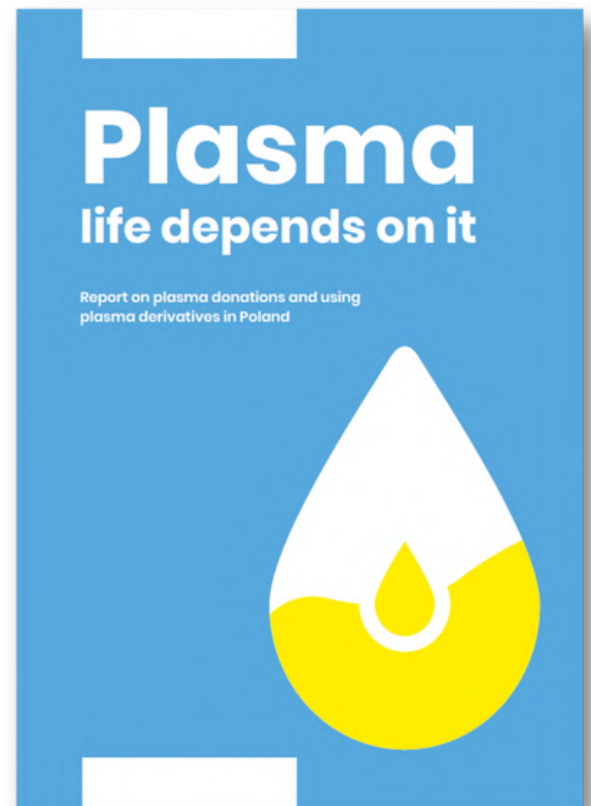
We support the pursuit of providing the best therapies and medical care, focusing both on the health and quality of life of patients. We advocate for changes that allow patients to live normal, full lives.

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.

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.



02

Letter from the President

This year was unique, unpredictable and full of challenges. We needed not only to continue working on our planned projects, but also adapt to the current situation.

The Russian invasion of Ukraine changed everything. On the 24th of February, we decided that we need to help Ukrainian refugees with rare diseases. We had to learn quickly how to effectively manage such a crisis and I believe we succeeded. Over 80 displaced patients with rare diseases received highly specialized therapies thanks to our efforts. Moreover, we sent humanitarian aid worth \$45,000 to Ukraine in order to support the rare diseases community there.

Besides this, we continued our projects in the area of patient advocacy like the PatientAdvocacyAcademy online video course. In this year's edition, we trained 20 patient advocates from 16 various countries.

Our work has been internationally recognized. I had the honor to receive Global Genes' RARE Champion of Hope award in September and in December I was informed about being awarded with EURORDIS Black Pearl Award.

In this report, you can learn more about our initiatives and project conducted this year. I feel that we did a fantastic job – thanks to the engagement of our team members, thanks to the support of our donors and sponsors and many volunteers helping us in the humanitarian part of our job. Thank you and... see you in 2023!



ADRIAN GORETZKI
PRESIDENT OF THE FOUNDATION



03

New employees on board

With each year of our foundation's activity, the number of projects and challenges increases. In 2022, the time came to expand our team – in March, Kamila Rzepka joined us, and in August, in response to the needs related to humanitarian aid to patients from Ukraine, Anastasiia Doroshenko began her work.

Kamila Rzepka, LL.M.

A lawyer by profession with experience in working with patient groups. In 2014-2018 she worked as a 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

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.



Medical Advisory Board

In 2022, we established the Medical Council at our foundation, which consisted of four experts with whom we have been cooperating for years, and we wanted this cooperation to become more formal. Our priority is for the foundation's activities to respond to the needs of the medical and patient community.

The Medical Council allows us to exchange experiences and respond more efficiently to emerging challenges. We invited specialists from various centers in Poland, as well as a representative of the medical community in Ukraine. In the future, the Council will certainly be expanded to include more specialists treating people with other rare diseases, also from outside Poland.

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.



Prof. Larysa Kostyuchenko MD, PhD

Director of Western Ukrainian Centre of Children's Immunology in the Specialized Children's Medical Center in Lviv, Ukraine; professor of Danylo Halyckyy Lviv Medical University, Medical Council at the Ministry of Health of Ukraine, member of the group of experts of the Ministry of Health of Ukraine.



Monika Mach-Tomalska MD

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





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 in Ukraine. We help them both in Ukraine and after reaching Poland.

Our foundation has never dealt with either humanitarian aid or direct assistance to individual patients, but when the war broke out beyond our eastern border, we knew we really had no choice. There was only one thing to do – help as many patients as possible.

It is particularly important, as patients with rare diseases are often overlooked. War only makes it worse. And it adds more problems into the mix. That is why, 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 have supported them in many ways here in Poland, in Ukraine and in different European countries.

In 2022, helping Ukrainian patients was our top priority, which is why there were fewer other activities, like in the field of patient education or advocacy.



The project in numbers

over

80

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

20

transports of medicines, medical equipment and other necessities organized by our foundation

26

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

6

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

over

\$45,000

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

What does our help look like? What do we focus on?

1. We provide access to treatment for patients who have left Ukraine and are staying in Poland or another European country, and we support them at various stages of their journey.
2. We support patients staying in Ukraine. We organize the transportation of medicines and medical equipment to Ukrainian hospitals treating patients with rare diseases.
3. We provide information and legal support for Ukrainian rare disease patients.
4. We raise awareness about the situation of rare disease patients from Ukraine to draw attention to their needs and encourage others to act.



“It's 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.

mother of one of our patients



So far, we have helped over 80 families of patients with rare diseases, including primary immunodeficiencies, epidermolysis bullosa, or rare cases such as KIF1A.

Most of the patients we have helped are children, but over 30% of them are adults, usually with very serious forms of their diseases and requiring advanced treatment outside Ukraine, including transplantations.

Patients have often suffered from very rare diseases. Some of them, like LAD-I, only occur in 1 in 500,000 births. KIF1A-related disorder is even rarer: there are only 150 diagnosed patients worldwide. All of them require a very specialized approach.

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

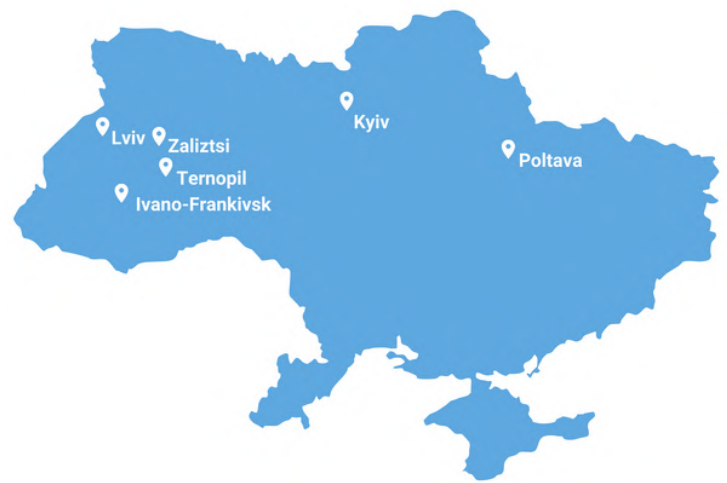
We are in constant contact with hospitals treating patients with rare diseases in Ukraine and we determine their needs for medicines and medical equipment. In response to needs, we organize the transportation of medicines and medical equipment to specific hospitals.

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.

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 Children's Clinical Hospital in Poltava 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.

"Pumps for Ukraine" project

Our assistance to patients staying in Ukraine includes not only emergency action, such as the purchase of medicines, but also more long-term initiatives, such as "Pumps for Ukraine" project. Currently, there is a lack of infusion pumps in Ukraine, but thanks to the support of



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

our donors, patients with primary immunodeficiencies from Ukraine receive infusion pumps and medical equipment that allow them to administer immunoglobulins at home. The infusion pumps are also used in hospital departments.

“

Many thanks to our Polish friends and 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. (...)

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

Transports of medicines, medical equipment and other necessities to Ukraine



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).
- We offer patients and their family members free psychological care in Ukrainian.
- In the case of transit to other European countries, we provide contact to a patient organization in each country as well as to a medical clinic treating a given disease.



Information and legal support for patients

Websites for rare diseases patients

In the first weeks of the war, we prepared two websites: www.ridkisnikhvoroby.pl for patients with rare diseases and www.imunodefitsyt.pl for patients with primary immunodeficiencies.

They can find there:

- contact details for hospitals treating primary immunodeficiencies,
- contact details for Polish verified rare disease patient organizations,
- a frequently updated comprehensive FAQ section with answers to almost 40 questions regarding access to therapy, social assistance work and education in Poland,
- legal opinions,
- educational materials like brochures, infographics or videos.

Brochures & other educational materials

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



- The first one presents the healthcare system in Poland from the perspective of RD patients.
- The second is a Ukrainian-Polish medical dictionary for patients with primary immunodeficiencies.
- The latest brochure is about the social benefits available in Poland for RD patients or their caregivers

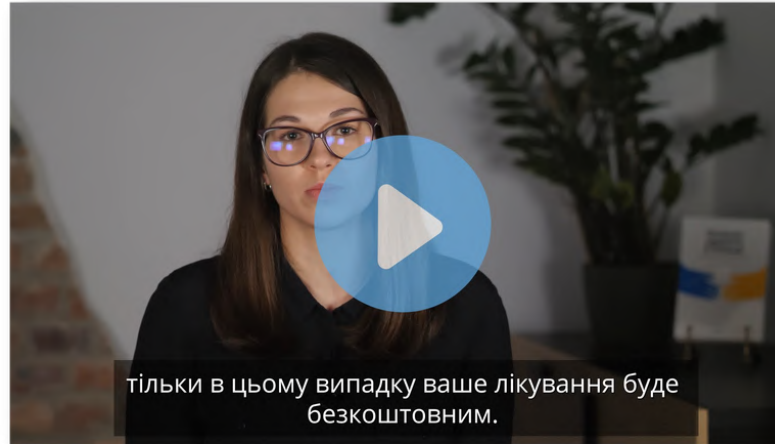
We have also created an infographic about vaccinations and roadmaps, which describes how to obtain a certificate of disability in Poland.

Video guides

We have prepared a series of video guides for Ukrainian patients with rare diseases who currently live in Poland, in which we discuss important topics such as access to healthcare, vaccinations and social benefits available to refugees from Ukraine.

Video tutorials are published on our YouTube channel:

www.youtube.com/@eduinstituteorg



Raising awareness about the situation of Ukrainian patients

We appear in front of an international audience to raise 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. We also prepared a video message for participants of the BIO International Convention in San Diego (13-16.06.2022) and Plasma Protein Forum in Washington (11-12.10.2022).

During the World for Ukraine Summit, together with participants from all over the world, we discussed better humanitarian, social and economic solutions to help Ukraine.

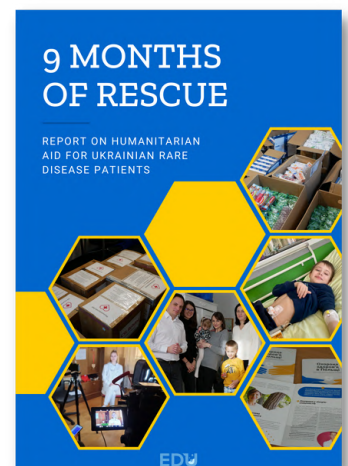


Close cooperation with many other entities

Our work would not be possible without cooperation with other entities. We are in touch with Ukrainian patient organizations supporting RD patients. We meet with representatives of international and domestic humanitarian organizations and we work together to provide patient care. We closely cooperate with EURORDIS as a part of the "Razem z Ukrainą" (Together with Ukraine) project aimed to meet the critical needs of Ukrainian families living with a rare disease who are currently in, coming to, and/or going through Poland.

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.

If you want to learn more about our humanitarian activities, read our report by clicking on the cover on the right





The situation of patients with rare diseases from Ukraine who fled the war – a report

Patient-focused studies are a very important part of our work. Exploring patients' needs, asking them about their preferences, challenges and burdens related to the disease allows us to support patient communities more effectively. Therefore, in order adjust our humanitarian activities to the needs of patients, in July 2022, we conducted survey research in a group of Ukrainian patients and patient caregivers whom we helped and who are currently residing in various European countries.

The respondents were asked about such subjects as:

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

The report which we have prepared on the basis of the collected responses is available in Ukrainian and English.

What are the main conclusions from the research?

- The vast majority of respondents have received medical assistance in the country where they're currently staying (89%). The countries receiving people fleeing the war in Ukraine are effectively responding to their needs in the field of medical care.
- Even people who, due to their illnesses, need highly specialized and costly medical procedures, such as surgeries or even transplantations, are guaranteed them in the countries they came to.

- As many as 61% of respondents indicated that one of the greatest difficulties related to their disease that they had to face after leaving Ukraine was the language barrier in contact with physicians. Therefore, it seems right to create educational materials in Ukrainian and to undertake other initiatives aimed at facilitating communication between physicians and patients.
- Almost 80% of respondents indicated that they had received financial assistance in the country where they're currently staying, but in the majority, it was only a one-time financial assistance for refugees. It seems necessary to think about more long-term forms of support for refugees with rare diseases in the countries that host them.

If you want to know more about the research, read our report by clicking on the cover on the right



06

Patient advocacy

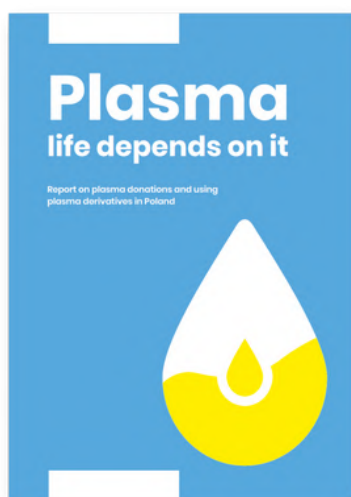
Ongoing activities in patient advocacy

For years, we have been participating in advocacy activities at both the national and European level. Also in 2022, in order to meet the needs of patients treated with plasma-derived medicinal products (PDMPs), we continued our advocating activities to increase the collection of plasma and take actions related to the safety of blood and plasma.

We were panelists at the International Plasma Protein Congress 2022 in Berlin, where we discussed the current situation of plasma and PDMPs availability in Poland.

In October, we also participated in the discussion on plasma at the "Plasma saves lives" conference in Warsaw, with the participation of Radosław Sierpiński – President of the Medical Research Agency and the Plenipotentiary of the Prime Minister for the development of the biotechnology sector and Poland's independence in the field of blood products. This event accompanied the celebration of International Plasma Awareness Week.

All these activities are a continuation of our work in this area, initiated by the foundation's report "Plasma – life depends on it. Report about plasma donations and plasma-derived medicines in Poland" (2021).



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



Foundation representatives during
"Plasma saves lives" conference in Warsaw



07

PatientAdvocacy.Academy 2022: Global Challenges



PatientAdvocacy.Academy
Powered by Healthcare Education Institute

The idea of the PATIENTADVOCACY.ACADEMY

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. The course takes place every year and lasts around three weeks. It consists of many different activities, such as video lectures, online coaching circles, Slack chat group and 1-to-1 meetings.

Each year, we choose a different main topic of the course, adjusting it to the current situation and the suggestions of the participants.

PATIENTADVOCACY.ACADEMY 2022: Global Challenges

This year we discussed global challenges - the post-pandemic landscape, medicine shortages, the war in Ukraine – these are big issues that patient advocates around the world have to deal with.

We are all the more pleased that in this year's edition of the course we hosted representatives from many different countries on three continents.

We even had participants from Kyrgyzstan and the United States, who shared their unique perspectives. The presence of representatives of three different Ukrainian patient organizations was especially important for us. We greatly admire their care for each Ukrainian patient and their willingness to learn, even in times of war.

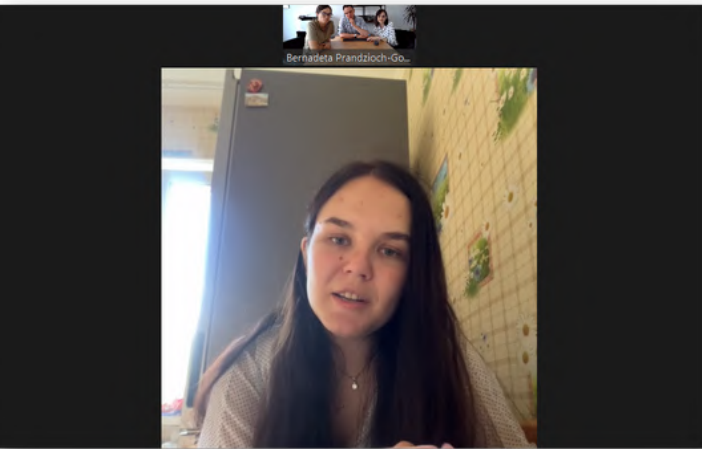


Countries of origin of participants from this edition

This edition was attended:

by **20** participants
from **16** countries
located on **3** continents
representing **4** rare diseases

How did PATIENTADVOCACY.ACADEMY 2022 look in practice?

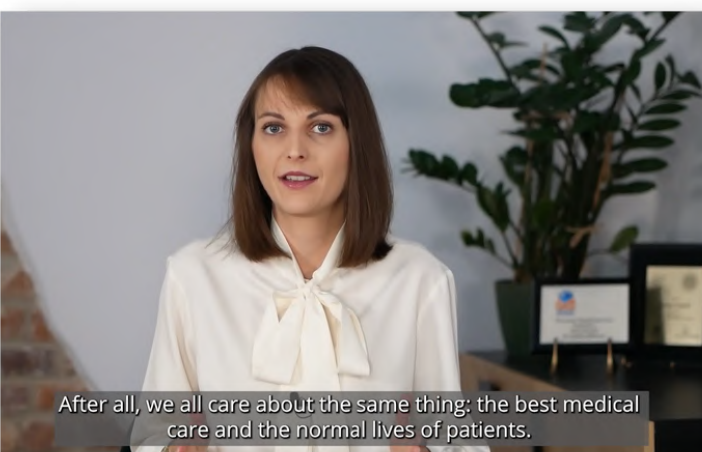
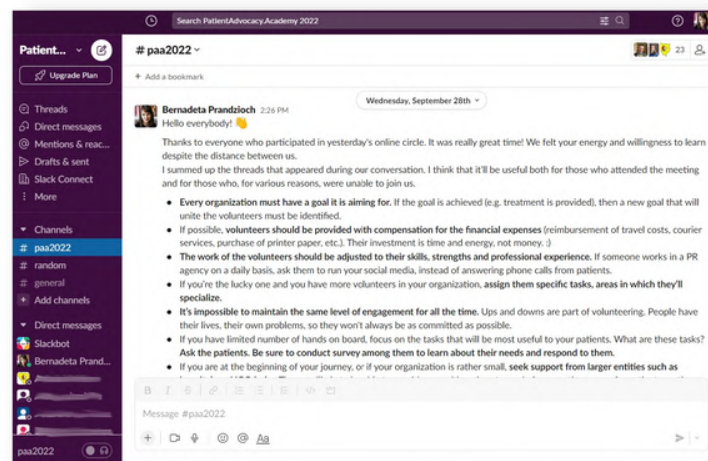


1-to-1 preliminary online meetings

We started with 1-to-1 preliminary online meetings with registered participants to learn about the situation in their countries regarding treatment and access to care, and to find out what challenges they are currently facing as patient advocates. It allowed us to adjust the topics of our online circles to their most urgent needs.

Ongoing communication on Slack group

To get to know each other even better, we launched a Slack group for all participants of the Academy. This is where we commented on each lesson, shared our successes in the area of patient advocacy and inspired each other for further actions.



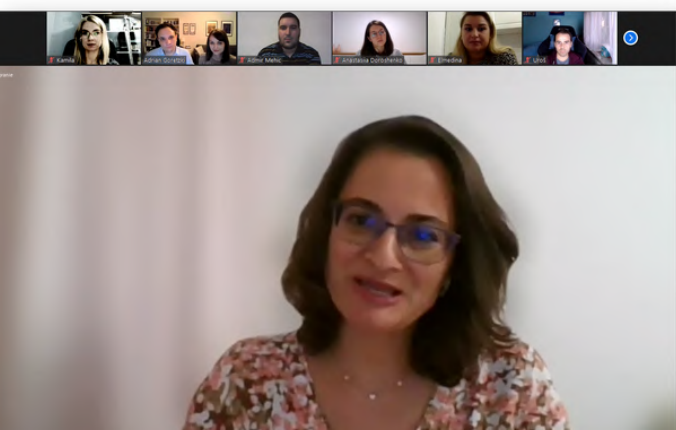
After all, we all care about the same thing: the best medical care and the normal lives of patients.

Videos full of knowledge with many case studies & practical examples

We created 10 video lectures, 10-15 min. each, covering the most important topics related to global challenges. We also took care of the subtitles so that each participant can understand the content, even if he or she is not fluent in English. Each video also consisted of many screens, charts and infographics to make learning easier and more enjoyable.

Educational materials to support learning and putting knowledge into practice

For each video lesson, additional educational materials were prepared, which allowed participants to consolidate their knowledge and immediately translate it into practical solutions for their patient organizations: exercises in PDF files and a short 3-question quiz for each lesson.



Online video circles to discuss the most challenging issues

There were 3 online video circles. We looked at the challenges the participants face on a daily basis in their patient organizations and discussed possible solutions. We shared experiences, showed examples of good practices and inspired each other.

Grant competition

Every year PatientAdvocacy.Academy is also an opportunity to win a prize – an unrestricted grant for the activities of participants' patient organizations. The best projects are chosen by the foundation board members.

This year, first place was won by a representative of "Krvni bratje" from Slovenia, the second place from "Kosovo Hemophilia Foundation" and the third place from "Asociația Română a Pacienților cu Imunodeficiențe Primare" from Romania.

If you want to know more about the PAA2022, read our report by clicking on the cover on the right



“

I want to thank the organizers of this awesome online training and the instructors for their intellectual teachings. I was so elated from the beginning to the end of the training. I hope to participate next time in an online training like this. I learned a lot from it. (...)

Elmedina Kukaj from Kosovo Hemophilia Foundation

08

Education in patient advocacy

We continue our activities aimed at strengthening the voice of patients in making decisions for better access to treatment and healthcare in Central and Eastern Europe. That is why we participated, together with leaders of patient organizations from various therapeutic areas from different European countries, in the Access to Care Conference in Vienna.

The main theme of this two-day conference was the fight for access to treatment. Among the experts were people dealing with pharmacoeconomics and health technology assessment.

In addition to lectures, during which problems and challenges faced by patients in the fight for access to treatment were discussed, there were also workshop sessions that allowed participants to share their experience and work together on specific solutions.



During his speech, Adrian Goretzki talked about the fact that, despite the lack of a specific legal framework for patient advocacy, it is still possible to influence decisions on drug reimbursement and what tools are needed to achieve this goal.

Together with other participants, he also talked about improving policy framework and early inclusion of patients in policy discussions and strategic collaboration between patient organizations and healthcare professionals organizations.



09

Testimonials of patients with Fabry disease

One of the goals of our foundation is to constantly increase the awareness of rare diseases in society. That is why, since 2021, we have been implementing a film project commissioned by Amicus Therapeutics. We present the stories of patients with Fabry disease from various European countries.

The films show the path of patients with Fabry disease to diagnosis, what their lives looked like before starting treatment and how their everyday life changed after its implementation. Patients share stories about the challenges they face and how the disease affects their private and professional lives.

These stories aim to raise awareness of this rare disease. The films are presented to a wide audience at many medical congresses in Europe.



We started the project in 2021. Back then, we recorded the stories of two patients with Fabry disease from Poland and one patient from Slovakia. In 2022, we created another 2 films with the stories of a patient from Hungary and a patient from the Czech Republic.

We hope to continue this important project in 2023 because we know that many other interesting stories of patients with Fabry disease in different countries are waiting to be told in order to raise awareness of the disease among physicians.

10

Meetings & events in 2022

The year 2022 was filled with various types of meetings, conferences and events, both stationary and online, in which we participated as panelists and listeners.



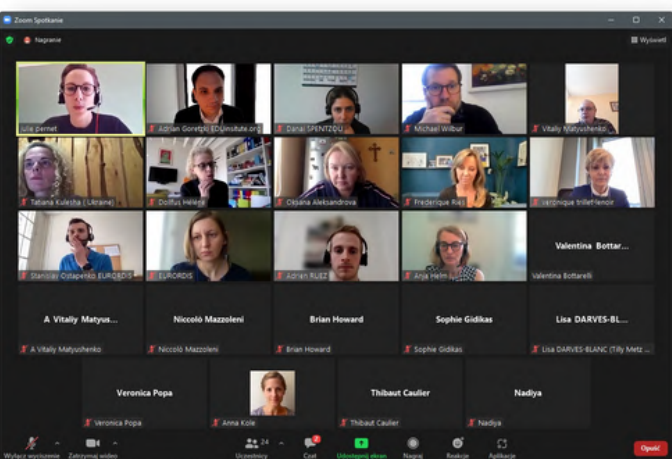
Rare Disease Day 26.02.2022, Łódź, Poland

During a conference organized at the Central Teaching Hospital of the Medical University of Łódź for Rare Diseases Day, Adrian Goretzki gave a speech on "Primary immunodeficiencies in adults. The voice of the long-term president of the association – what has changed, what else do we need to do?"

VII Health Challenges Congress 3-4.03.2022, Katowice, Poland

We were present at the VII Health Challenges Congress. We listened attentively to the sessions on rare diseases, during which, i.a., the implementation of the Plan for Rare Diseases (2021-2023) in Poland was discussed, as well as the diagnosis and treatment of selected rare diseases in Poland – cystic fibrosis, autoinflammatory diseases, Duchenne muscular dystrophy and SMA.





Parliamentary Advocates for Rare Disease of European Parliament 23.03.2022

The March meeting of the Parliamentary Advocates for Rare Disease of the European Parliament group was devoted to the unprecedented situation faced by patients with rare diseases from Ukraine. Two MEPs participated in the meeting.

As a result of the meeting, an appeal was made to the President of the European Commission for the necessity of supporting patients with rare diseases from Ukraine and possible methods of action.

Meeting with Ukrainian patient organizations, EURORDIS and the Singapore Red Cross 20.04.2022, Warsaw, Poland

The subject of the meeting was to identify the key problems faced by Ukrainian patients with rare diseases, as well as to create a plan of long-term assistance for this most vulnerable group. We talked about the challenges faced by displaced Ukrainians with RD and about the greatest needs of patients staying in Ukraine.

One of the results of the meeting was the creation of the "Razem z Ukrainą/Together with Ukraine" coalition under the leadership of EURORDIS.



2022 International Plasma Protein Congress (IPPC) 14-15.06.2022, Berlin, Germany

At the International Plasma Protein Congress, we met with policymakers, scientists and industry representatives to discuss the need of increasing plasma collection in Europe to secure patient access to plasma-derived medicinal products (PDMPs).

Adrian Goretzki was a speaker in the session "EU Pharma Strategy – Europe's industrial policy Progressing From Plasma to Product Establishing Successful Fractionation Plants: Lessons from the Past and Present."



The 11th European Conference on Rare Diseases & Orphan Products 28.06.2022

During the online session entitled "Mobilising the Rare Disease Movement for Ukraine: EURORDIS and Our Allies' response to the war in Ukraine", Adrian Goretzki spoke about the current needs of Ukrainian refugees with rare diseases and how to respond to them.

2022 RARE Patient Advocacy Summit 12-14.09.2022, San Diego, CA, USA

The 2022 Rare Disease Patient Advocacy Summit, organized by the American non-profit Global Genes, is one of the world's largest gatherings of rare disease patients, caregivers, advocates, healthcare professionals and researchers. This year, the board members of our foundation, Bernadeta Prandzioch-Goretzki and Adrian Goretzki, took part in this event.

The summit sessions provided us with information on the latest innovations in rare diseases, best practices in advocacy at individual and organizational levels, and practical strategies.



Meeting of "Together with Ukraine" project members 19.09.2022, Warsaw, Poland

Our project managers, Kamila Rzepka and Anastasiia Doroshenko took part in the meeting of EURORDIS' coalition "Razem z Ukrainą/Together with Ukraine".

We had a chance to exchange experiences with other members of the coalition and present our achievements so far in the field of supporting Ukrainian patients with rare diseases.



“Plasma saves lives” conference 7.10.2022, Warsaw, Poland

"Plasma saves lives" – this was a theme of the conference that took place in the Children's Memorial Health Institute in Warsaw.

Adrian Goretzki had a chance to take part in it as a panelist, talking about the necessity of increasing the security of Polish patients in the area of plasma-derived therapies.

The PPTA Business Forum 11-12.10.2022, Washington, D.C., USA

We were present online at this year's Plasma Protein Therapeutics Association Business Forum, during which we talked about humanitarian aid for Ukrainian patients with rare diseases.



Bernadeta Prandzioch-Goretzki
Vice President of the
EDUInstitute.org foundation



European Society for Immunodeficiencies congress 2022 12-15.10.2022, Gothenburg, Sweden

Adrian Goretzki and Bernadeta Prandzioch-Goretzki took part in ESID 2022 congress, the topic of which was "Dysregulation and hyperinflammation in inborn errors of immunity (IEI)".

We deepened our understanding of primary immunodeficiencies (PIDs) by listening to experts from around the world who presented and discussed significant developments in diagnostics, clinical management, genetics and immunobiology of inborn errors of immunity.



The Access to Care conference 25-26.11.2022, Vienna, Austria

The Access to Care conference in Vienna was attended by representatives of patient organizations and patient access experts from 14 countries involved in strengthening the voice of patients in the decision-making process for better access to treatment and care in Central and Eastern Europe.

Adrian Goretzki had the opportunity to give a speech on how to win a reimbursement case despite the lack of a specific legal framework for patient advocacy.

The World for Ukraine Summit (W4UA)

7-9.12.2022, Rzeszow, Poland

During the international conference devoted to the reconstruction of Ukraine organized by the W4UA foundation, Adrian Goretzki took part in a discussion panel on the future of Ukrainian healthcare.

Together with other panelists, he was looking for solutions and endeavors which, by virtue of improving the healthcare infrastructure in the war-ravaged country, will contribute to the goal of providing universal healthcare in a free Ukraine. In this discussion, he presented the perspective of patients with rare diseases.



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For the patients. Together!

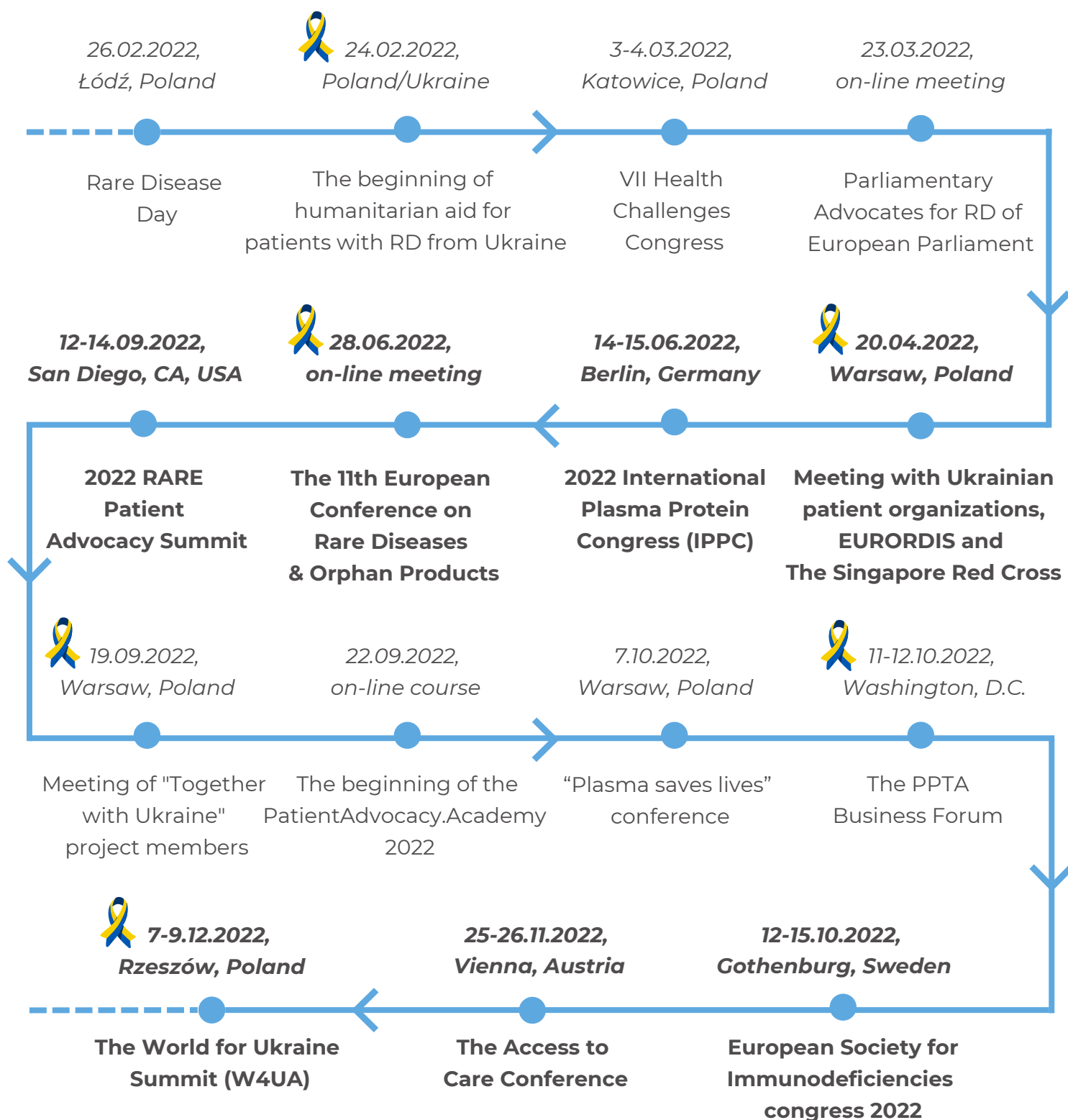
From the right: Adrian Goretzki, Oleksii Iaremenko, Ukrainian Deputy Minister of Health for European Integration and other panelists during the World for Ukraine Summit (W4UA) in Rzeszow, Poland



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



2022 on the timeline



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Awards for the President of the HEI

Our successes and actions have also been noticed in the international arena. In 2022, the president of the foundation, Adrian Goretzki, received two awards for his activities for the community of patients with rare diseases: RARE Champion of Hope and EURORDIS Black Pearl Award.



RARE Champion of Hope

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

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

Our foundation was also nominated for this year's title of RARE Champion in Advocacy – Foundation.

The EURORDIS Black Pearl Award

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

At the end of 2022, we received very happy information that the winner of the Black Pearl 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.

It is worth mentioning that Adrian was already nominated and shortlisted for this award two years ago and this time he was awarded.

The award ceremony will take place on February 21, 2023 in Brussels.



“

Among Adrian's achievements, EURORDIS wishes to particularly recognise his successful campaign for SCIG home therapy reimbursement for adults with primary immunodeficiencies, his advocacy for patients with rare immunodeficiencies, as well as his commendable work in support of the Ukrainian rare disease community, offering patients both legal and practical assistance.

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Media about us

Every year our activities and projects are in the area of media interest. Below we present some of the most important press materials from the past year regarding the foundation's work.

"Rare Revolution Magazine"

An extensive interview with Adrian Goretzki recognized by the Rare Revolution Magazine as "Rare inspiration" in recognition of his successes in the field of patient advocacy and humanitarian aid for Ukrainian patients.

[Click on the graphic to the right to read the full interview.](#)



"RARECast" The Global Genes Podcast

A podcast where Adrian Goretzki discusses "the needs of Ukrainians with rare diseases, what our organization has been able to do to help those fleeing the war, and why the humanitarian crisis for these rare disease patients will last beyond the current hostilities."

[Click on the graphic to the left to listen to the podcast.](#)



"The Source" Magazine by PPTA

An article about the humanitarian activities of our foundation for Ukrainian rare disease patients.

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



"Serwis Zdrowie" Educational portal of the Polish Press Agency (PAP)

An article that appeared after the conference "Plasma saves lives" with Adrian's statement about plasma deficits in Poland.

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

"Zbliżenia" Polish Television (TVP)

TV report in the TVP3 program "Zbliżenia", in which Emilia, a patient with severe combined immunodeficiency from Ukraine, and her mother are featured. She is the first patient from Ukraine whom we helped after the start of the war.

Click on the graphic on the right to watch the material.



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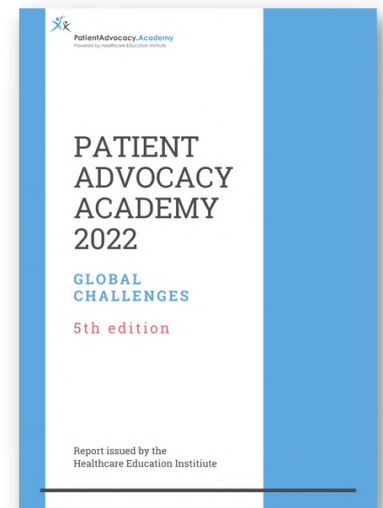
5th anniversary of our foundation

The year 2022 is also the time of the first summaries for us. Although the truth is that we did not have time to celebrate our fifth anniversary because – primarily due to humanitarian aid – it was the most intense year for us so far. Nevertheless, at the end of this report, we want to stop for a moment and celebrate what we have achieved over the last 5 years. Here are the five projects we are most proud of.



5 editions of the PatientAdvocacy.Academy (2018-2022)

PatientAdvocacy.Academy is the first and most beloved of our projects. It was an idea that we had in mind even before establishing the foundation. And we are glad that it has been with us for five years. Every year we meet amazing leaders of patient organizations who want to learn and develop during our online course. This project has grown with us and we believe that it gets better every year.



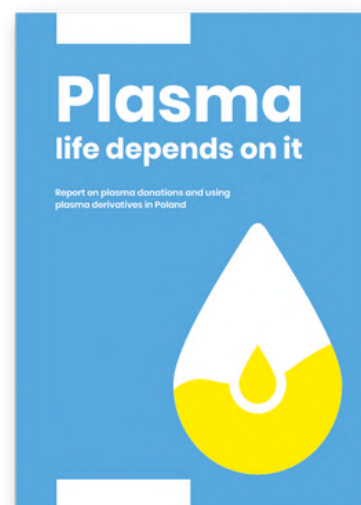
"The quality of life and treatment preferences of patients with primary immunodeficiencies in Poland" (2020)

Patients' quality of life, therapy tailored to their needs and preferences – these are topics that have always been important to us. Therefore, whenever we have the opportunity, we give a platform to the patients themselves, asking about their feelings. In 2020, we carried out a large research project among PID patients in Poland. The situation on the Polish plasma-derived medicines' (PDMPs) market has changed significantly since the previous research in 2015. Therefore, in order to determine the direction in which further efforts related to access to treatment should go, it was important to know the opinions of patients in Poland.



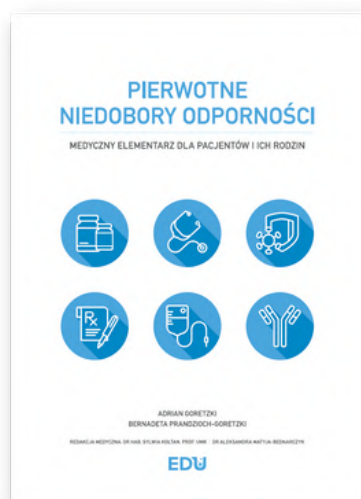
"Plasma – life depends on it" – report (2021)

In 2021, we published the report "Plasma – life depends on it" on plasma donations and the use of plasma derivatives in Poland. The report presents the current situation in Poland: we discuss the Polish system of plasma collection compared to neighboring countries, we indicate groups of patients for whom PDMPs treatment is crucial and needs to be reimbursed. We also show what the situation in Europe looks like, what the trends are for the coming years, and therefore what challenges Poland faces in order to be able to provide patients with life-saving treatments. The most important outcome of the report, however, was that its appearance initiated a broad discussion in Poland on the subject of plasma donations and use of PDMPs.



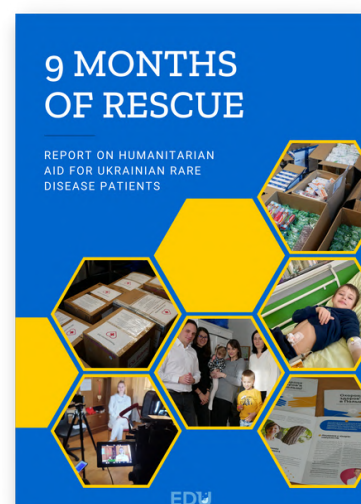
"Primary immunodeficiencies. A medical handbook for patients and their families" (2021)

Patient education is no easy task. It might seem that access to information is almost unlimited in the age of the Internet and there is no need to create new educational materials anymore, but nothing could be further from the truth. Especially in the flood of information, it is very important for patients to receive reliable information about their disease, so that they know how to act and how to live. We tried to keep this in mind when creating this project. It's a guide to the most important issues for every PID patient in Poland. And all this in maximally simple language, with many explanations and an extra glossary at the end of the book.



Humanitarian aid for Ukrainian rare disease patients (2022-)

This may be the most important project we have ever implemented in our foundation. While our work often results in saving lives or improving someone's existence, in this case it is even more tangible. It is also a project for which we were completely unprepared, doubly: not believing that such terrible things can happen in the 21st century in the center of Europe, and because we have never dealt with humanitarian aid. But feeling that it was necessary and that it was the only right way, we continue learning day after day. And when yet another patient is safe in a new place and has access to treatment has been and is the best reward for us.



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Partners, donors & sponsors

Our work would not be possible without the support of other entities. Therefore, we would like to thank our sponsors, donors and partners in a special way. We thank those who supported our projects and who made our humanitarian efforts possible. We would also like to thank the non-profit organizations with whom we had the pleasure of working last year. We are convinced that together we can do more!

Industry:



Non-profit organizations:





Healthcare Education Institute

The Foundation

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