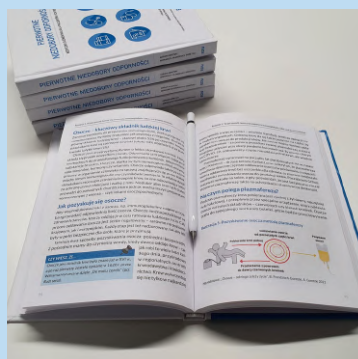


# 2017 - 2021

# SUMMARY REPORT

REVIEW OF ACTIVITIES AND ACHIEVEMENTS  
OF THE HEALTHCARE EDUCATION INSTITUTE



## Report prepared by:



**Healthcare Education Institute**  
The Foundation

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Katowice, 2022

## Photos:

The following photos were used in the report:

- p. 38 – photos taken during the conference "Recipe for the future of Europe in the face of social, economic and health challenges after COVID-19. European Union, Member States, civil society" in Warsaw (24.11.2021); event organizer: the Institute for Social Affairs Development (Instytut Rozwoju Spraw Społecznych - IRSS), photographer: Łukasz Kamiński

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 many 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 and the University of Silesia Rector's Award in 2020. 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 (300k 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 education

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.

## Patient advocacy

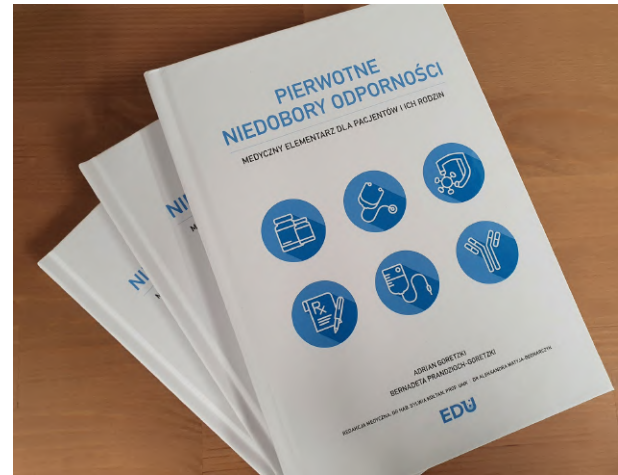
We support the pursuit of providing the best therapies and medical care, focusing both on the health and quality of life of patients. We advocate for changes that allow patients to live normal, full lives.

## Trainings

We created a proprietary program of series of training sessions focused on building satisfying relations with patients. We discuss patients' needs, develop the doctors' and nurses' ability to take a perspective of a patient and concentrate on proper doctor/patient and nurse/patient communication.

## 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

**When we established the Healthcare Education Institute we had one main goal: to empower rare disease community and make their voices louder.**

People with rare diseases are often overlooked by the healthcare system, they are underdiagnosed and public awareness of these diseases is far from sufficient. That is why we have made it our mission to support in every possible way those who are fighting for a better life for patients with rare diseases.

From the very beginning we focused our efforts on supporting patient advocates across Europe and creating reliable educational materials. We also dedicated ourselves to conducting research and preparing reports in the area of rare diseases.

This report summarizes our activities in 2017-2021. We're extremely proud of our flagship project: PatientAdvocacyAcademy which started in 2018 and takes place every year since then. When we started this online project was rather innovative. But then two of those years were marked by the COVID-19 pandemic and it was the only way to organize trainings. The pandemic slowed us down a bit and held our face-to-face activity, but during this hard time we worked even more hard to deliver valuable educational materials for rare disease patients like handbook for PID patients, video testimonials and some COVID-related leaflets.

In this report, you can learn more about all our initiatives and projects. Enjoy reading!



**ADRIAN GORETZKI**  
PRESIDENT OF THE FOUNDATION





| 2017

## 03

## A series of educational videos for Polish PID patients

Foundation was the executive producer of a series of educational videos for Polish PID patients, entitled "10 Experts for the 10th anniversary of the Immunoprotect Association" commissioned by the Polish Association for Patients with Primary Immunodeficiencies "Immunoprotect".

Nowadays the videos are the most efficient way of reaching the widest possible audience, including patients. That's why "Immunoprotect" decided to prepare a special birthday gift for Polish patients: a unique videoguide addressed to all the PID patients, consisting of ten short lectures (about ten minutes long each) devoted to the most important PID-related issues.

We are honored that at the beginning of our path we could become the executive producer of such a fantastic project, to which leading immunologists from the most important centers in Poland were invited.

The topics covered in the videos have been selected based on the most frequently asked questions by patients. Below you can find a list of the videos:

- Hygiene principles for people with PID,
- Immunoglobulins – what you should know about them
- PID and the respiratory system,
- Safe traveling with PID,
- School and PID,
- Vaccinations for people with PID,
- Sport and PID,
- PID and gastroenterological diseases,
- Work and PID,
- PID: how to build a good relationship with a doctor?



The videos are available on the YouTube channel of the "Immunoprotect" Association. [Click to watch them.](#)





## Photos from film sets during the production of the educational videos for PID patients



## 04

## Meetings & events in 2017

In 2017, we participated in many events to further develop our knowledge and skills in the field of patient advocacy. The most important events were STYPA and ESID.



### STYPA: Overcoming Discrimination 3-5.07.2017, Vienna, Austria

Adrian Goretzki took part in the 1st edition of The Skills Training Course for Young Patient Advocates (STYPA) organized by the European Patients Forum in Vienna. STYPA is aimed at young (18-30 years old) patient advocates who want to learn more about advocacy and develop their leadership skills. The theme of the first edition was: Overcoming Discrimination. Participants learned how to initiate changes in patient organizations to better fight discrimination and how to effectively influence change at the institutional level.

### European Society for Immunodeficiencies congress 2017 11-14.09.2017, Edinburgh, Scotland

Members of the foundation's board took part in the ESID 2017 congress. The theme of the meeting was "Autoimmunity & Inflammation in PID; Beyond the Paradox". Adrian and Bernadeta had the opportunity to get acquainted with the latest research and analysis in the field of immunodeficiency and breakthrough discoveries, as well as share knowledge and establish new contacts with people from the industry.







| 2018

## 05

## Training for leaders of the "Immunoprotect" association

In February 2018, we organized a 2-day training for the leaders of the Polish patient organization for PID patients "Immunoprotect".

The goal of the training was to equip them with practical skills and the necessary knowledge to manage a patient organization.

The first part of the training was devoted to the patient organization itself. We discussed issues such as: How to make a patient organization professional? How to identify patients' needs and respond to them effectively? How to build good relationships with people from the environment: doctors, key opinion leaders and other stakeholders? How to raise funds for your organization?

We talked about branding and its role in a patient organization, about engaging patients in the organization's activities – building a network of committed volunteers and creating long-term action plans.

We also discussed very practical issues, such as organizing meetings for patients or creating educational materials.

### Organizacja pacjencka

Jak sprawić, by była profesjonalna?  
 Jak odpowiadać na potrzeby pacjentów?  
 Jak budować dobre relacje?  
 Jak pozyskiwać środki na swoją działalność?



On the second day, we focused on practical exercises on self-presentation and preparing for meetings with important people. After the theoretical introduction, we worked with each person individually on creating their own elevator speech, planning public speeches, as well as conducting important meetings from the point of view of organization.

We suggested some tricks that increase self-confidence and help you find yourself in any situation, even if you are an introvert.

We believe that thanks to this, the leaders of the "Immunoprotect" association will be more effective in their work for patients with primary immunodeficiencies!

### Projekty organizacji pacjenckich – od pomysłu do realizacji



# PatientAdvocacy.Academy

## 2018: Trendy answer for real needs



PatientAdvocacy.Academy  
Powered by Healthcare Education Institute

### The idea of the PATIENTADVOCACY.ACADEMY

PatientAdvocacy.Academy is our flagship educational project, which we launched in 2018.

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 is addressed primarily to representatives from Europe, but also leaders from other geographic areas are welcome.

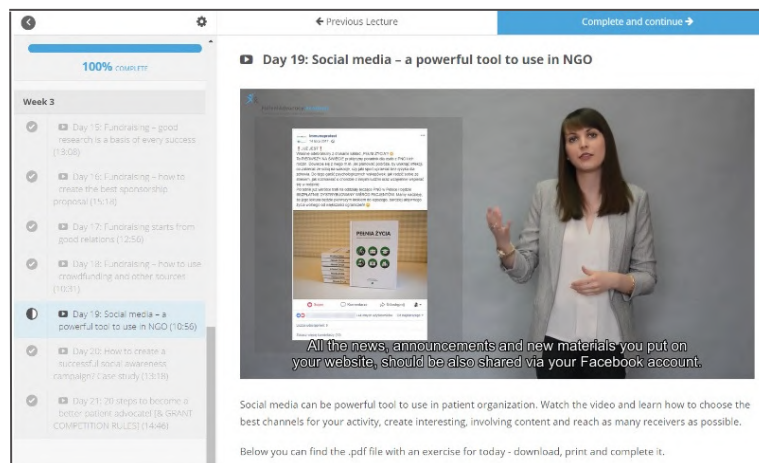
Each year, we choose a different main topic of the course, adjusting it to the current situation and the suggestions of the participants.

### The first edition of the course

The first edition of PatientAdvocacy.Academy in 2018 was addressed to **PAG representatives acting in the area of plasma-derived products**. These extremely engaged people face many obstacles: they often lack sufficient knowledge and experience to face the complicated, unfriendly and bureaucratic world of healthcare laws and policies. We wanted to give them practical knowledge on patient advocacy – effective tools, procedures and best known solutions.

The course was focused on:

- developing a professional NGO and building a team of engaged volunteers,
- effective public policy advocacy,
- efficient fundraising and creating financial strategy,
- building relations with media, doctors and other stakeholders.



### How did it look in practice?

The workshop lasted 21 days. Every day participants received an access to **a new video** (lasting about 15 minutes) and **a short exercise** which helped them to practically implement gained knowledge. They also had the opportunity to discuss the topic in **a special closed group**. The course ended with **a special live Q&A session and a live summary session**. Participants could ask any questions they still had and get extra tips.

In the first week, participants got to know how to manage a patient organization and how to plan its activities. In the second week, we drew their attention to patient education and effective patient advocacy. In the third week, they learned how to effectively collect funds for activities, as well as how to use social and conventional media to achieve goals.

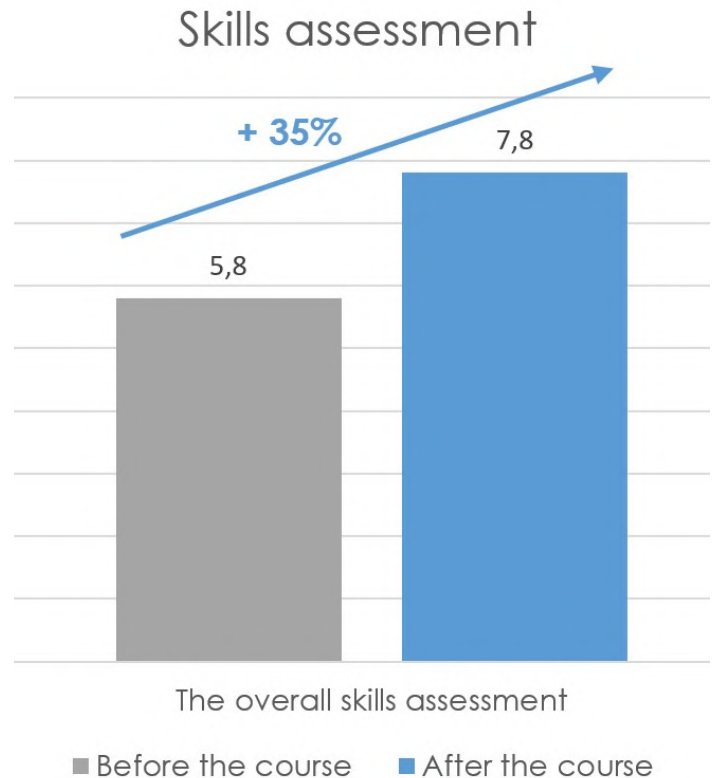
The course was complemented with **a grant competition**. It was an opportunity for PAG leaders to win an unrestricted donation for their activity.

## First edition – impressive results

The overall skills assessment, according to the self-report of the participants, before the course was 5.8 (on a scale of 1 to 10), while after the course – 7.8. That's a **35% increase in assessment of their own skills**.

The participants also assessed the course very highly. **The general evaluation was 8.5** (on a scale of 1 to 10). The choice of subjects was evaluated at 8.8, while the usefulness of the information – 9.0.

Moreover, the participants were asked if they would like to attend a course like this in the future. **66.7% of them answered "Definitely yes", while 33.3% "Rather yes"**. There were no other answers!



8,8

the choice  
of the subject

8,5

general evaluation  
of the course

9,0

usefulness  
of the information

## 07

## Trainings for physicians

Based on our many years of experience from patient organizations and conversations with doctors, we have created a proprietary training for physicians: **PATIENT PERSPECTIVE, PATIENT NEEDS.**

In the case of rare diseases, **the doctor-patient relationship, based on mutual understanding and trust, is extremely important.** Only in this way is it possible not only to treat effectively, but also to take care of all the patient's needs, including psychological and social ones. And without satisfying them, we cannot talk about a proper quality of life.

Therefore, in our training we focus on patients' needs and developing the ability to take the perspective of a patient. The participants practiced the acquired skills in order to make sure that everything is well understood and the physicians are ready to apply new knowledge in their everyday medical practice.

The training consisted of three parts:

- Patient perspective – preferences of patients regarding their treatment and medical care;

- Different people, different needs – discussing patient types, their behaviors, motivations and requirements;
- How to do it in the real world? – patient-physician conversation role-plays (including challenging cases) with feedback from a psychologist.

In 2018, we conducted 3 trainings for physicians, mostly immunology specialists:

- in Sopot (February 2018),
- in Olsztyn (May 2018),
- in Gdańsk (September 2018).

The participants assessed the trainings very highly – the overall results show that the training had fulfilled physicians' expectations. The general evaluation was 9.8 (on a scale of 1 to 10). The theoretical part was evaluated 9.7, while the workshops – 9.9.

**9,7**  
theoretical  
part

**9,8**  
general  
evaluation of the  
trainings

**9,9**  
workshops

## 08

## Medical conference and patient meeting in Minsk

At the invitation of the Belarusian patient organization "Save immunity", members of the Foundation's board had the opportunity to take part in a medical conference and meeting for PID patients in Minsk (April 19-21)

On 19-21 April, the 5th International Congress "Actual Problems of Primary Immunodeficiency" was held in Minsk. Among the invited guests were doctors and representatives of patient organizations, e.g. from Poland, Ukraine and Russia.

Adrian had the pleasure of speaking on the second day of the conference, talking about his activity as a patient advocate in Poland. He presented his greatest successes from 10 years of work in the "Immunoprotect" Association, but also the plans of the Foundation.

We were pleased to hear the speeches of people from other countries and we also established cooperation with doctors from Ukraine, which resulted in joint projects in the following years.



On the last day of our stay in Minsk, we participated in a meeting for patients with primary immunodeficiencies and their families from Belarus, organized by the "Save immunity" organization. We also visited the most important hospital treating patients with PID – the Center for Pediatric Oncology, Hematology and Immunology (РНПЦ дзіцячай анкалогіі, гематалогіі і імуналогіі).

We are grateful for the invitation and we hope that what we talked about inspired the participants of the meeting to fight for even better access to treatment for all PID patients across Belarus.





## 09

## Meetings & events in 2018

In 2018, we participated in many events to further develop our knowledge and skills. The most important events were ESID congress and Capacity Building Module On Empowering Leadership and Positive Governance organized by EPF.



### Capacity Building Module On Empowering Leadership and Positive Governance

**Bratislava 05.2018 & Warsaw 09.2018**

Adrian Goretzki took part in a training organized by the European Patients Forum for leaders of patient organizations, the aim of which was to strengthen their leadership and positive governance skills. The training was partly online and partly stationary – two weekend training sessions took place in Bratislava and Warsaw.

### European Society for Immunodeficiencies (ESID 2018), 24-27.10.2018, Lisbon, Portugal

Participation in lectures, educational workshops and interactive sessions was an ideal opportunity to get acquainted with the latest achievements in immunology, genetics and immunobiology of primary immunodeficiencies and to broaden knowledge about the diagnosis and treatment of immunological disorders.

During ESID 2018, our foundation had the opportunity to present two scientific posters: "The importance of physicians' education in the area of building long-lasting relations with PID patients" and "Effective public advocacy and fighting for the patients' rights – the meaning of training and education of PAG's leaders".



You can find one of the  
posters in large format  
on the next page



# One of the posters presented at ESID 2018: "Effective public advocacy and fighting for the patients' rights – the meaning of training and education of PAG's leaders"



**Healthcare Education Institute**  
The Foundation

Bernadeta Prandzioch-Górecka, Adrian Górecki  
Healthcare Education Institute. The Foundation

## EFFECTIVE PUBLIC ADVOCACY AND FIGHTING FOR PATIENTS' RIGHTS – THE MEANING OF TRAINING AND EDUCATION OF PAG'S LEADERS

Patient Advocacy Groups are very important part of the healthcare environment. Their fight for patients' rights and public policy advocacy guarantee a proper level of medical care. Meanwhile actions focused on patients' education and providing support lead to better quality of life among PID patients.

That is why we created PatientAdvocacyAcademy – 21-day online video training. The first edition was addressed to PAG representatives acting in the area of plasma-derived products. We wanted to give them practical knowledge on patient advocacy – effective tools, procedures and best known solutions.

### BACKGROUND

PatientAdvocacyAcademy took place in June 2018.

We conducted a survey among the participants **before the start of the course and after the end** to compare results and observe the outcomes of the training.

The statistics show that the assessment of all skills listed in the survey has raised.

### TRAINING

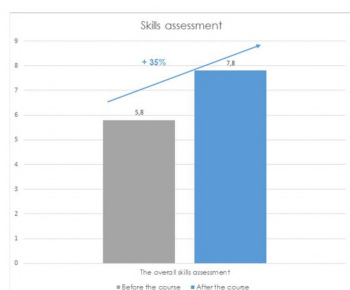
Training lasted 21 days, every day participants received an access to a new video (about 15 minutes) and a short exercise which was designed to help them to practically implement gained knowledge. They also had an opportunity to discuss the topic on a special closed group. The course ended with a special live Q&A session and a live summarizing session. Participants could resolve their last doubts and get extra tips.

The course was focused on:

- developing a professional NGO
- building a team of engaged volunteers
- effective public policy advocacy
- efficient fundraising and creating financial strategy
- building relations with media, doctors and other stakeholders

### THE OVERALL SKILLS ASSESSMENT

The overall skills assessment, according the self-report of the participants, before the course was 5,8 (on a scale of 1 to 10) while after the course – 7,8. It's a 35% increase of their own skills assessment.



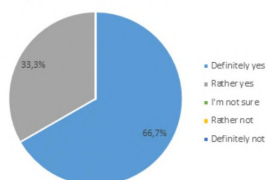
### SPECIFIC SKILLS ASSESSMENT

The ability to effectively fight for patients' rights – increase was 40%. Knowledge on fundraising – increase was 52%. The ability to create an effective public awareness campaign – increase was 56%. Moreover the self-confidence of the participants has increased 20%.



### FUTURE DEVELOPMENT

The participants were asked if they would like to attend a course like this in the future. 66,7% of them answered "Definitely yes", while 33,3% "Rather yes". There was no other answers.



### GENERAL TRAINING ASSESSMENT

The participants also assessed the course very high – general evaluation was 8,5 (on a scale of 1 to 10). The choice of subjects has been evaluated 8,8 while the usefulness of the information – 9,0.



**Bernadeta Prandzioch-Górecka** - psychologist, successful TEDx speaker, author of many scientific publications on international conferences and articles popularizing psychological knowledge. Co-author of a handbook for PID patients – "Fullness of life". Using professional skills and experience for the past few years engaged in a voluntary work with people with rare diseases.



**Adrian Górecki** – 'Immunoprotect' President, PID patient. In 2014 recognized with Luciano Vassalli Award. Former member of IPOPI executive board. Founder of Healthcare Education Institute, professional trainer, advisor and keynote speaker specialised in patients relations. Fascinated with opportunities given by the new technologies in the field of education.

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| 2019

## 10

## Campaign for therapy reimbursement

Our gratest policy advocacy achievement in 2019 was a campaign for therapy reimbursement for a patient with an extremely rare immunodeficiency in Poland. The case was about an off-label use of an interferon gamma product.

The issue was that this medicine was not registered for this specific immunodeficiency. As [there are just 9 patients with this disease described in scientific papers worldwide](#), there are no clinical trials performed for this specific indication, but the Ministry demanded results of double-blind tests.

After a few months of the battle, [we managed to persuade the Ministry of Health to change their negative decision on therapy reimbursement](#). How did we do it? We notified the media and we sent a request for support to the most important politicians in the country. We recalculated the numbers used by the public HTA agency to prove that the therapy is not too expensive as they previously stated and managed to convince them that they should ask for a Polish expert's opinion as there are no double-blind tests available.

Finally, the Ministry of Health, despite the previous refusal, accepted our arguments.

[In the "Intervention" program broadcast on one of the nationwide televisions, a material describing the case was published, in which Adrian Goretzki also appeared. To view the material, click on the graphic on the right.](#)



## 11

# PatientAdvocacy.Academy

## 2019: Public policy advocacy



PatientAdvocacy.Academy  
Powered by Healthcare Education Institute

Public policy advocacy was 2019's topic. It is one of the most demanding and complex areas of activity of patient organizations. It was clearly visible in the results of our survey from the first edition of the Academy. Fields of activity related to policy advocacy were indicated as the most tough ones.

In many countries, patients suffering from rare diseases are provided with inadequate care. Treatment is not refunded, not all the treatment options are available or there are no procedures available that would provide quick diagnostics. That is why it is so important that the leaders of patient organizations become effective patient advocates.

### PATIENTADVOCACY.ACADEMY

#### 2019 in practice

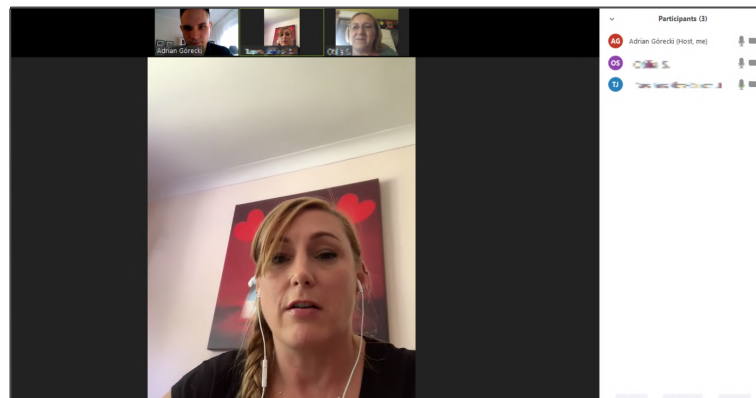
In this edition, the course's formula was a little bit different from the previous one. Taking into account the participant's feedback, we decided to design [a 14-day course with longer videos](#). So the overall time of the video material stayed the same, but we serve it in a more condensed form.

There were also [3 online video conferences – coaching circles](#) – where participants exchanged their views and experiences on the current topics of the course in order to find solutions of their own obstacles. It was also a time to ask all the questions to the trainer.

The course was also complemented with a grant competition. It was an opportunity for PAG leaders to win an unrestricted donation for their activity.



There were two grant competition tasks to complete. In the first task participants had to record 1-minute video with an elevator speech about their organization. In the second task they needed to write a letter to members of parliament in order to recruit valuable allies.



19

engaged users

9,6

general evaluation  
of the course

14

video lessons

3

online meetings

2.250€

awarded grants

## Most important skills

Participants had a chance to learn how to prepare a detailed plan of a public policy campaign. They should be able to recruit powerful allies from different environments: politicians, celebrities, social media influencers and physicians. They also got to know what is a proper timing of such activities: when to send official writings, when to start attracting media and – finally – when to announce a success.

Moreover, they are ready to engage themselves in a longer advocacy processes too – we underlined many times that sometimes it takes a long time to achieve a success here.

## Usefulness, technical aspect and declarations for the future

We conducted the survey among participants after the end of the course.

The participants assessed the course very high – **general evaluation was 9,6** (on a scale of 1 to 10). The technical aspect has been evaluated 9,0 while the usefulness of the information – 9,5.

Moreover, the participants were asked if they would like to attend a course like this in the future. **80% of them answered "Yes", while 20% "Rather yes"**. There was no other answers.

“

***The relevance and quality of the information is excellent. Also it is good to have real life examples of how some of the theory worked. I particularly liked the modules on running a campaign and dealing with a crisis. The modules are very well thought out and presented very well.***

*participant's opinion*

## 12

## Trainings for nurses

Nurses working in the area of rare diseases are the first contact for patients on many issues related to the disease and therapy. Therefore, it is extremely important that patients have good contact with nurses and their relationship should be based on mutual trust. To make this possible, it is crucial to focus nurses' attention on patients' expectations and needs and teach them how to communicate with patients properly.

In 2019 we conducted 2 trainings for nurses:

- in Wrocław (May),
- Toruń (November).

We focused on building satisfying relations with patients with rare diseases. We discussed long-term care which should meet patients' needs, developed communication between a nurse and a patient and equipped them with psychological skills which allow them to support patients. Every training session ended with a workshop to make sure that the nurses were ready to apply new knowledge in their everyday work.

The training course consists of four parts:

1. What are the patients' expectations and needs?
2. How to talk with patient about the disease
3. How to support patients and reduce their stress
4. Communication patient-nurse: building mutual trust and openness



The participants assessed the training course very highly – [the general evaluation was 9.5](#) (on a scale of 1 to 10). The workshops were evaluated at 9.5, usefulness of the information – 9.5 and selection of the issues involved – 9.7.



**62.5% of the participants declared that they *DEFINITELY* would like to attend similar training sessions in the future, while 37.5% – that they would *RATHER* like to.**



## 13

## Trainings for physicians

Due to the fact that the trainings for doctors focused on building satisfying relations with patients conducted in 2018 were very popular and were highly rated by the participants, we designed another training for physicians: **HOW TO BE UNDERSTOOD CORRECTLY.**

In recent years, there has been a surge of interest in factors that are responsible for therapeutic success. Research shows even up to 70% of them are non-medical ones. **One of the obstacles to treatment is bad communication between the doctor and the patient.** What causes difficulties? Doctors as highly qualified specialists often use a complicated, hermetic language called "med-speech". This makes patients feel lost, they do not understand what is really wrong with them and they cannot fully follow therapeutic indications.

In response to these difficulties, we created a training course aimed at sensitizing doctors to this issue and teaching them how to communicate with the patient in a clear, understandable way.

The training consists of three parts:

- What is med-speech and how can you avoid it in communication with patients?
- Say it easier, say it better – how to communicate difficult things in a simple way. Workshop on rephrasing our communication.

- Communication of a diagnosis – patient-physician conversation role-plays.

In 2019, we conducted two trainings for physicians, mostly immunologists:

- in Poznań (March 2019),
- in Wrocław (May 2019).

As previously the participants assessed the training course very highly. 75% of participants marked the workshop on patient-physician conversations as the most important part of trainings.



**75% of participants marked the workshop on patient-physician conversations as the most important part of trainings.**

## 14

## Meetings & events in 2019

In 2019, we participated in many events to further develop our knowledge and raise awareness about rare diseases. The most important events were 29th Economic Forum and ESID congress.



### 29th Economic Forum 3-5.09.2019, Krynica, Poland

Board Members of the Foundation participated in the 29th Economic Forum in Krynica. Adrian Górecki was one of the invited experts in the discussion panel on plasma donation and Polish system of plasma collection organized by Rzeczpospolita, a nationwide economic and legal journal.

### European Society for Immunodeficiencies congress 2019 18-21.09.2019, Brussels, Belgium

During 2019 Focused Meeting of the European Society for Immunodeficiencies (ESID 2019): Malignancy and PID, which took place in Brussels, our Foundation had the opportunity to present a scientific poster on "The importance of nurses' education in the area of communication and building long-lasting relations with PID patients".



You can find the poster  
in large format  
on the next page

Bernadeta Prandzioch-Górecka  
Adrian Górecki

**EDU** Healthcare Education Institute  
The Foundation

## THE IMPORTANCE OF NURSES' EDUCATION IN THE AREA OF COMMUNICATION AND BUILDING LONG-LASTING RELATIONS WITH PID PATIENTS

Nurses working in the area of PID are the first contact for the patients on many issues related to the disease and a therapy. Usually they spend more time with the patients than physicians and have the opportunity to talk with them about everyday problems as well as to dispel any doubts. They also watch over the formal side of implementing the therapy. Therefore, it is extremely important that patients have good contact with nurses and their relationship should be based on mutual trust. To make this possible, it is crucial to focus nurses' attention on patients' expectations and needs and learn them how to communicate with patients properly.

### BACKGROUND

In 2019 Polish immunology nurses took part in the one-day training on communication and building long-lasting relations with PID patients.

They were designed especially for them, taking into account specific issues related to the complex care of a patient with PID.

After the training nurses filled out a survey regarding the discussed matters.

### TRAINING

We focused on patient's needs and developing communication skills. Nurses practiced the acquired skills in order to make sure that everything is well understood and they are ready to apply new knowledge in their everyday work.

The training consists of the following modules:

- What are the patients' expectations and needs?
- How to talk with patients about the disease?
- How to support patients and reduce their stress?
- Communication patient-nurse: building mutual trust and openness

### MAIN BENEFITS OF THE TRAINING INDICATED BY PARTICIPANTS:

- ✓ Psychological tips on coping with patients' stress
- ✓ Opportunity to comment case studies
- ✓ Practical workshops
- ✓ Exchanges of experience and views

62,5%

of participants stated that they **definitely** would like to continue such trainings in the area of patient-nurse relations, while 37,5% - that **rather** yes.

### GENERAL TRAINING ASSESSMENT

Participants assessed the training very high – the overall results shows that the training had fulfilled nurses' expectations. The general evaluation was 9,5 (on a scale of 1 to 10). The usefulness of the information has been evaluated 9,5 while selection of the issues involved – 9,7.

9,5  
USEFULNESS OF  
THE INFORMATION

9,5  
GENERAL  
EVALUATION

9,7  
SELECTION OF THE  
ISSUES INVOLVED

It is extremely important to create an opportunity for the nurses to participate in such trainings to constantly improve their soft skills. As a result they will feel better, more self-confident and will increase their effectiveness. It is crucial as patients rely on them.



Bernadeta Prandzioch-Górecka - trainer, psychologist and successful TEDx speaker. Author of many scientific publications and articles popularizing psychological knowledge. Co-author of a handbook for PID patients – "Fullness of life". Engaged in educational activities for people with rare diseases.



Adrian Górecki – founder of Healthcare Education Institute, professional trainer, advisor and keynote speaker specialised in patients relations. PID patient himself, former 'Immunoprotect' President and member of IPOPI executive board. In 2014 recognized with Luciano Vassali Award.

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| 2020

## 15

## Research on the quality of life and treatment preferences of PID patients in Poland

The first research on the quality of life and treatment preferences of PID patients in Poland was conducted in 2015. However, access to treatment and the availability of various products on the Polish market have changed significantly since then. In 2020, we managed to repeat these studies.

The situation between 2015 and 2020 in Poland has changed significantly. **Most importantly, adult patients with PID were included in the drug program. Moreover, new treatment options became available for both adult and pediatric patients; the availability of subcutaneous medicines also increased.** Therefore, it was very important to repeat the research to observe the current situation of patients with PID, recognize their preferences, needs, expectations, what they think about specific treatment options and how their treatment affects their quality of life.

The study was in the form of anonymous questionnaires. They were carried out in February-March 2020 among patients of six centers treating patients with PID in Poland: **68 adult patients with PID and 60 caregivers of underage PID patients.**

The respondents were asked, among other things, about current and past treatment methods, preferred method of treatment, frequency of treatment, use of the rapid-push method, factors determining their choice of treatment. They assessed every treatment method available in the country. They also answered questions about the assessment of the current state of health, assessment of prospects for the future, psychological aspects of living with the disease, time and financial burdens related to it.

The collected results are a valuable source of knowledge about adult PID patients, as well as about juvenile patients. They will help to better understand the needs, preferences and motivations of PID patients and their families, which will translate into better, comprehensive medical and psychological care for this groups of patients.



## 16

## Survey on blood and plasma donation in Poland

For the purposes of the report "Plasma – life depends on it", which was published in 2021, we conducted a survey among people declaring interest in the subject of blood donation.

Social awareness of what plasma is, how often it can be donated, and above all, how it is used to save human lives is definitely insufficient in Poland. We were able to confirm it while analyzing the results of our research.

For the purpose of the report "Plasma – life depends on it" we have surveyed 538 people in the age between eighteen and fifty-four interested in the subject of blood donations. We asked them questions about donating blood and plasma and the purposes of plasma collection.

Full results of the research can be found in our report "Plasma – life depends on it", which we invite you to read. Here we want to present selected, most important results.

Among the study participants, 30.5% indicated

that they donate blood regularly, 25.1% donated blood more than once, and 6.5% donated blood once in their lifetime.

In the case of plasma, only 1.3% of respondents indicated that they donate it regularly, 4.6% that they donated plasma more than once, and 2.8% – once in their lifetime. It is worth noting that as many as 91.3% never donated plasma.

This also translates into knowledge in the field of blood and plasma donation. While 75.3% of the respondents correctly indicated the maximum frequency of blood donation in Poland, in the case of plasma only 8.7% of the respondents knew how often it can be donated. Only 14.5% of respondents knew what plasma is used for and 6.3% of participants indicated correctly the diseases treated with plasma derivatives.



**75,3%**

**of respondents know how often blood can be donated**



**8,7%**

**of respondents know how often plasma can be donated**

The graphics come from the report "Plasma - life depends on it" (2021).

## COVID-19 educational materials

The COVID-19 pandemic in 2020 took us all by surprise. In the first weeks, patients with primary immunodeficiencies were a particularly vulnerable group. Therefore, as soon as we could, we prepared special educational materials for them on disease prevention.

In March 2020 we prepared a set of 12 key principles for patients with primary immunodeficiencies. These recommendations were created in cooperation with prof. Sylwia Kołtan, Polish National Consultant for Clinical Immunology.

Since these were the first educational materials dedicated to patients with primary immunodeficiencies, patient organizations from other countries began to contact us with requests to translate the infographics also into other languages.

Finally, in cooperation with patient organizations, 5 more language versions were created - English, Ukrainian, Finnish, French and Russian.



Polish version of infographic have been printed and distributed among all the hospital wards in Poland treating patients with primary immunodeficiencies. They were also added to sets with subcutaneous immunoglobulins, which are taken home by patients.

Later this year also prepared a leaflet and social media graphics with the pandemic recommendations for Polish patients with Fabry disease in cooperation with Polish Association for Families with Fabry Disease. The content of the educational materials was reviewed by prof. Jolanta Sykut-Cegielska.



# PatientAdvocacy.Academy

## 2020: Young Leaders – future of a patient advocacy



PatientAdvocacy.Academy  
Powered by Healthcare Education Institute

This edition was designed for young patient advocates. We strongly believe that young adults can bring a new energy and new ideas to the rare disease community. They can also bring knowledge about new technologies and new forms of communication, influencing decision-makers to pay attention to the patient organization, but also the ability to respond to the needs of the young generation.

Many leaders in patient organizations acting in the field of plasma-derived medicines are people around or over 50 years old. They are the most experienced people in their organizations, they were the ones who often founded patient organizations in their country, but often there are no new leaders ahead.

Moreover, young people feel that they do not have enough skills and knowledge, so – as a result – they do not feel confident in patient advocacy. So they need a training to be equipped in crucial skills needed in the most important areas of patient advocacy such as public policy advocacy, fundraising, patient education or raising awareness.

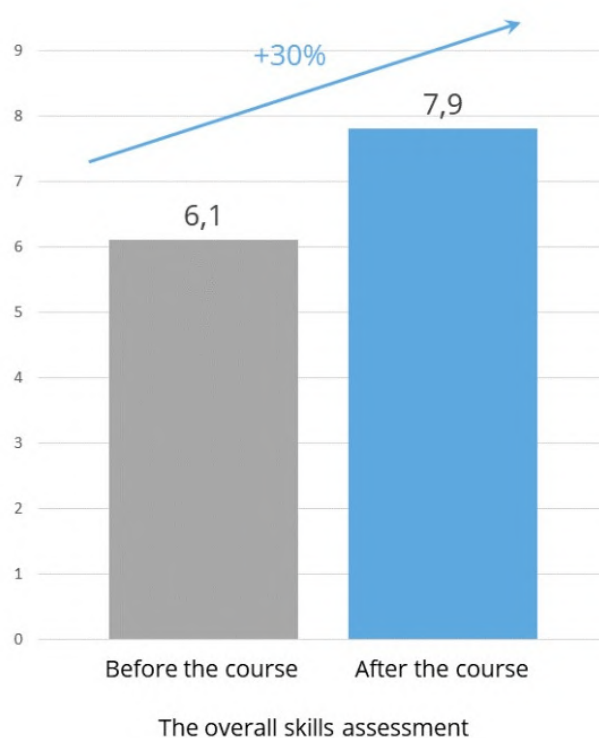
- Find their place in the patient organization and use their full potential
- Strengthen their position in PAG – will increase their self-confidence

Basing on the survey results and statistics of the course we can admit that **the main goals of the training were achieved**. The overall skills assessment, according the self-report of the participants, before the course was 6,1 (on a scale of 1 to 10) while after the course – 7,9. **It's a 30% increase of their own skills assessment.**

### Main goals for this edition of the academy

Thanks to the course the participants had an opportunity to:

- Gain knowledge how does a patient organization work
- Learn where to find needed information on healthcare system or PAG activities
- Gain knowledge about fundraising and yearly planning
- Learn how to prepare an awareness campaign or an educational project
- Learn the principles of organization's branding and communication

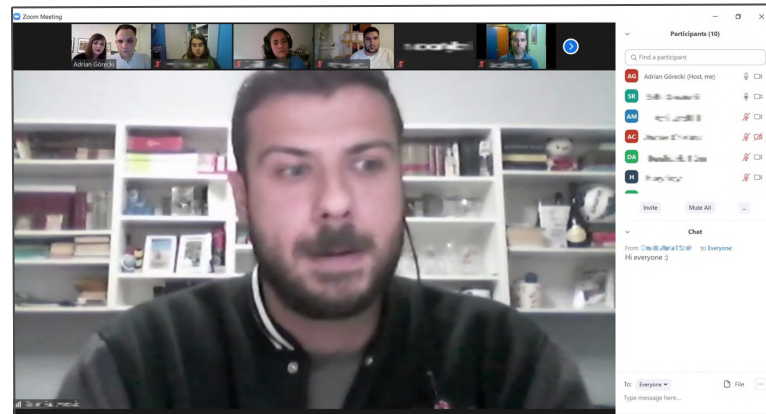
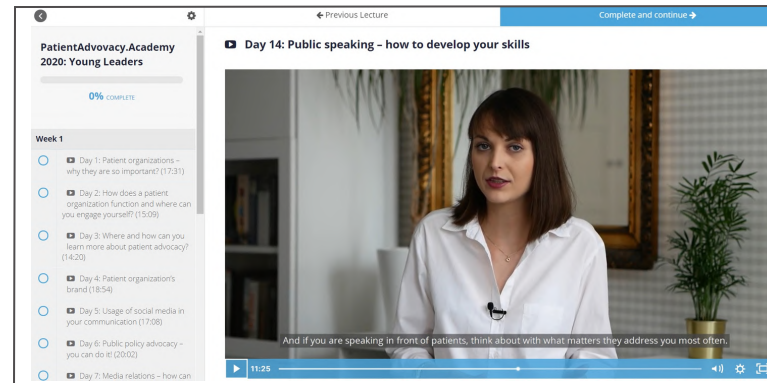


## PATIENTADVOCACY.ACADEMY 2020 in practice

2020 edition, as addressed to Young Leaders, was enriched with additional online activities and consists of 4 main elements:

- **14-day video course** with videos lasting about 15 minutes each – a dose of practical knowledge ready to be used in patient organization
- **exercises in PDF files** to each lesson allowing participants to consolidate the knowledge and immediately translate it in practical solutions for their patient organizations
- **dedicated Slack group** where all the participants exchanged experience, ideas and shared their successful actions in the area of patient advocacy
- **2 Zoom meetings** where participants had occasion to discuss specific issues related to treatment access, public policy advocacy and awareness. It was also a time to ask all the questions to the trainer

The course was also complemented with a **grant competition**. It was an opportunity for PAG's leaders to win an unrestricted donation for their activity.



## PATIENTADVOCACY.ACADEMY 2020 in numbers

18  
participants

106  
posts on Slack

9,3  
general evaluation  
of the course

14  
video lessons

2.250€  
awarded grants



## 19

## Award of the Rector of the University of Silesia for Adrian Goretzki

Adrian Goretzki was one of the winners of the 12th edition of the Awards of His Magnificence Rector of the University of Silesia, his *alma mater*. He was distinguished primarily for his social activities for the benefit of patient community.

Awards of His Magnificence Rector of the University of Silesia have been awarded since 2009. The main idea behind the awards is to promote active and creative attitudes that bring benefits to the academic community or society.

The winners have achievements in various fields, from artistic and sports, through social, cultural, scientific and popular science

activities, as well as in initiating and supporting student life.

2020 was exceptional in many ways. Unfortunately due to the pandemic, there was no gala during which the Rector's awards were presented, but the list of winners was announced and commemorative plaques were sent to the winners by courier.





| 2021



## 20

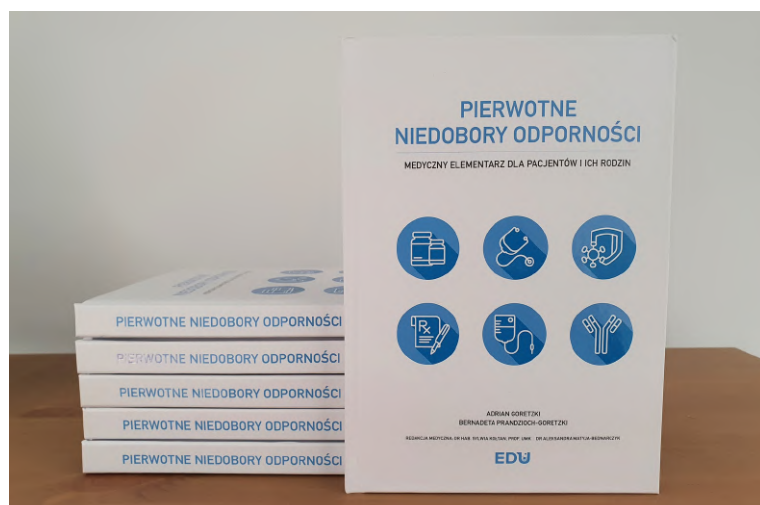
# "Primary immunodeficiencies. A medical handbook for patients and their families"

In 2021, we published a handbook for PID patients and their relatives. It's a guide to the most important issues for every patient.

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, nothing could be further from the truth. Especially in the flood of information, it is very important for the patients to receive reliable information about their disease, so that their know how to act and how to live.

And the second and equally key issue, is to tailor the message to the audience, or to put it simply, to make sure that the educational materials that go out to patients are written in a clear, straightforward and accessible way.

We tried to keep this in mind when creating our latest project: a medical handbook for patients with primary immunodeficiencies. We explain what PIDs are, discuss their most common types, present available treatment methods with special emphasis on

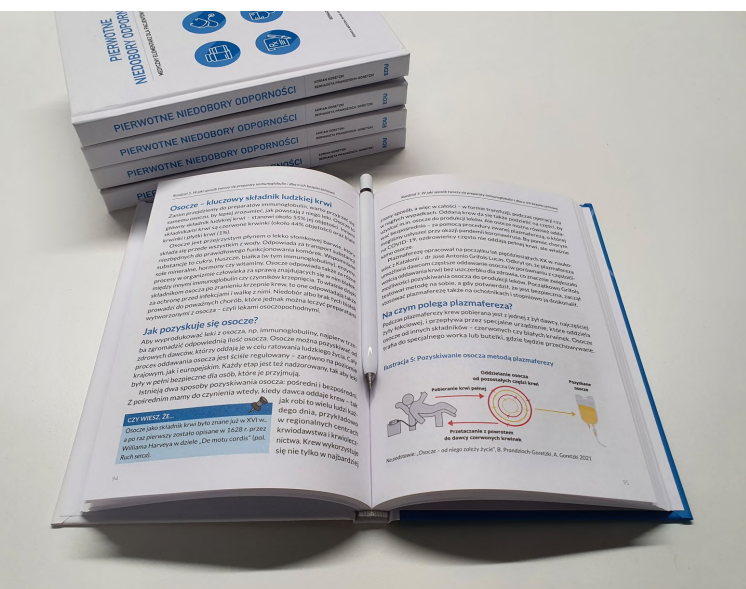


immunoglobulin therapy. We describe the most common co-morbidities and their warning signs. We also write about vaccinations, issues related to inheritance and care of a child with PID. We also provided many useful tips regarding everyday care and life management.

And all this in the simplest possible language, with many explanations and an extra glossary at the end of the book, because our main goal was to deliver the knowledge in an easy way, using simple language, translating from the language of medicine to the plain language, easy to understand by everybody.

The handbook is available in Polish and was distributed among PID-treating hospitals in Poland.

We hope that after reading, every patient will have a better understanding of their disease and will be able to cope with it even more effectively.



## 21

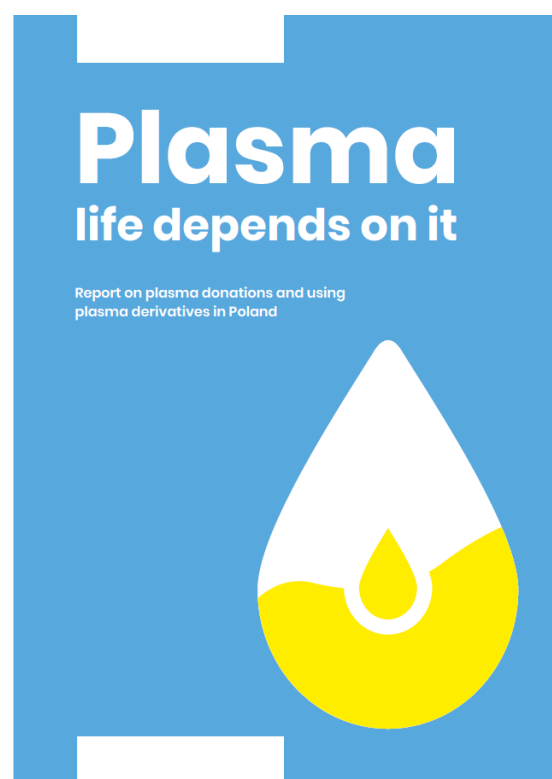
## "Plasma – life depends on it" – report

In 2021, after over a year of a hard work, 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.

This is the first publication of this type, presenting the situation in Poland compared to other countries, especially those with a similar socio-economic profile. For us, 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.](#)

You can download the report  
by clicking on the cover on  
the right!



“—

***An issue raised by the authors of this report (...) is extremely important. Their conclusions confirm observations made by specialists using plasma derivatives in their daily practice. Above all else it tells us that the clinical need for this kind of medicine is growing quickly while, especially in Poland, we can also experience bigger problems related to the system of plasma collection (...).***

*comment by prof. Maciej Siedlar, MD, PHD  
National Consultant for Clinical Immunology 2012-2019*

## 22

## Our plasma advocacy activities

Creating the report "Plasma – life depends on it" was just a beginning of an advocacy work in this area. In 2021, in order to raise awareness about importance of plasma collection, ways of improving the system of plasma donation and the needs of patients treated with PDMPs, we participated in many different meetings and discussions, both on national and international level.

We were panelists at [the 30th Economic Forum in Karpacz, Poland \(7-9.09.2021\)](#), where our report about plasma donations and plasma-derived medicines in Poland had its premiere and we discussed about security and self-sufficiency of the Polish healthcare system – the importance of plasma and other strategic resources.

We were speakers at [The PPTA Business Forum \(15.11.2021\)](#). This is an internal conference for all Plasma Protein Therapeutics Association (PPTA) members, where we talked about plasma donations and the PDMPs market in Poland and the CEE.

We also attended [The Global Plasma Summit \(16-18.11.2021\)](#), a worldwide virtual event bringing together industry leaders, patient advocates and public officials to get the latest news on the plasma protein therapeutics industry and plasma donation across the world.

We had the opportunity to be panelists also at [the conference about post-covid challenges in economics and healthcare in Warsaw \(24.11.2021\)](#), hosted by Instytut Rozwoju Spraw Społecznych. Our panel was an opportunity to talk about Polish patients' safety in this uneasy time of a global crisis. We underlined the need for securing supply of PDMPs and for raising the amount of collected plasma – a raw material needed to produce those life-saving medicines.





Adrian Goretzki during the conference about post-covid challenges in economics and healthcare, Warsaw (24.11.2021)



# PatientAdvocacy.Academy

## 2021: Public policy advocacy – real challenge for Young Leaders



PatientAdvocacy.Academy  
Powered by Healthcare Education Institute

PatientAdvocacy.Academy 2021 was addressed to Young Leaders of patient organizations who are actively working to improve the situation of patients in their countries, especially from advocacy groups in the area of plasma-derived products.

Public policy advocacy is one of the most demanding and complex areas of activity of patient organizations. It was also clearly visible in results of our surveys from previous editions of the Academy. Fields of activity related to policy advocacy were indicated as the most tough ones.

Patient advocates are usually aware of the need for changes in healthcare policy, but also do not have any experience or knowledge in this area.

Meanwhile, in the current situation, caused by the COVID-19 pandemic and potentially insufficient amounts of plasma on the market, it is even more important for patient advocates to be able to effectively fight for the rights of patients in their countries, including ensuring access to treatment, its safety and reimbursement.

### Well-educated Young Leaders

Our main goal was to equip Young Leaders with essential knowledge about public policy advocacy and practical skills needed to effectively fight for patients rights, access to treatment, reimbursement and so on.

The course provided the participants with the opportunity to:

- Gain knowledge how the European healthcare systems works
- Learn how to collect and use crucial data on patients and the healthcare system
- Strengthen position of their PAG by establishing and keeping relations with people responsible for healthcare policy
- Learn how conduct a public policy campaign step by step
- Gain knowledge on the health technology assessment (HTA) as well as pricing and reimbursement processes

“

**Participation in PatientAdvocacy.Academy made it easier for me to manage the Association (...). Overall, my impression is very positive because of the organization, subject and content. I would love to repeat it again!**

*participant's opinion*

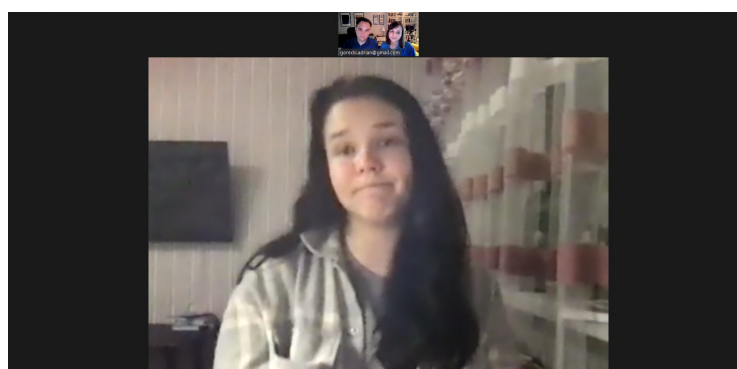
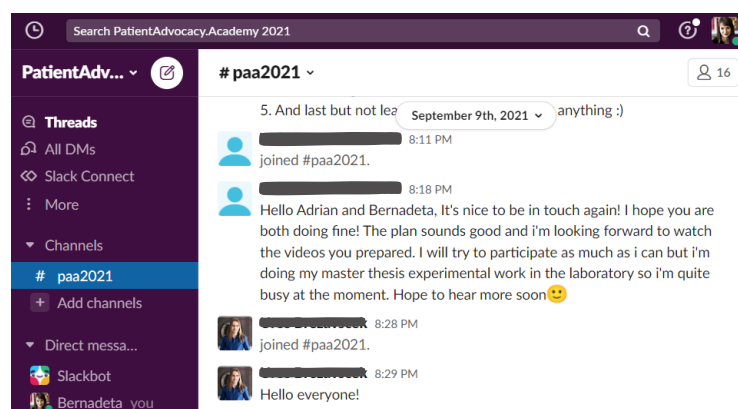
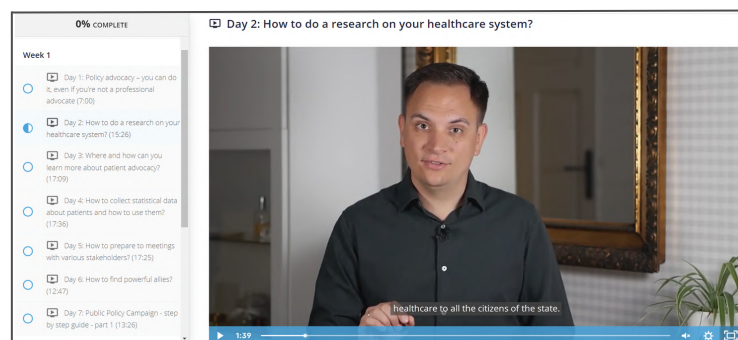


## How did PATIENTADVOCACY.ACADEMY 2021 look in practice?

Taking into account the participant's feedback, we decided to design a 21-day programme containing various activities:

- **10 video lectures** lasting about 15 minutes each covering most important topics related to policy advocacy
- **exercises in PDF files** to each lesson allowing participants to consolidate the knowledge and immediately translate it in practical solutions for their patient organizations
- **dedicated Slack group** – a place for ongoing communication about the Academy, but also for exchanging experience, ideas and shared their successful actions in the area of patient advocacy
- **one-to-one online sessions** where participants had occasion to discussed specific issues related to treatment access, public policy advocacy and awareness. It was also a time to ask all the questions to the trainer.

As in previous years, the course was complemented with a **grant competition** in which participants had to think about the most important policy advocacy issue in their country at the moment. Then they had to imagine getting a grant of € 1000 and describe how they will use it for activities related to policy advocacy.



“

***I love your work! I especially love the practical lectures and the concrete suggestions that you provide during your sessions. Thank you again for providing a patient community with much-needed knowledge and for sharing your valuable experience.***

*participant's opinion*



## 24

## Testimonials of patients with Fabry disease

Constantly increasing public awareness of rare diseases is of great importance to us. We are happy to engage in projects that aim to achieve this. In 2021, we started cooperation with Amicus Therapeutics in creating video testimonials of patients with Fabry disease .

For many patients with rare diseases, the path to diagnosis is difficult and bumpy. They often have similar experiences of being misunderstood, being sent from one specialist to another, accused of making up symptoms. Diagnosis and proper treatment changes a lot in their lives.

At the same time, each patient is a different, unique story.



These stories aim to raise awareness of Fabry disease, especially among healthcare professionals, as it can be insidious, not easy to diagnose, and requires a multidisciplinary approach because the symptoms come from many different organs and systems. Videos are presented on various medical meetings and conferences in Europe.

In 2021, we recorded three patients with Fabry disease: two from Poland and one from Slovakia. In the films, they talk about their childhood, the first symptoms, and the pain that accompanies them every day. At the same time, they share stories about their passions, sports that they practiced despite obstacles. They explain how their everyday life changed after implementation of treatment. Patients share stories about the challenges they faced and how the disease affects their private and professional lives.



## 25

## 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 2021 regarding the foundation's work.

During the Plasma Awareness Week, Adrian Goretzki took part in the podcast of Rzeczpospolita, a nationwide economic and legal daily, in which he drew attention to Poland's potential in the development of plasma-derived therapies.

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



Adrian Goretzki also took part in a debate organized by the cowzdrowiu.pl portal on how to ensure blood safety. In his speech, he emphasized how important it is that patients who have immunodeficiencies and have to undergo a procedure during which they will probably have blood components transfused, receive the safest possible blood components.

Click on the graphic to the left to watch the debate.

## Our President shortlisted to the EURORDIS Black Pearl Awards 2021

Our successes and actions have also been noticed in the international arena. In 2021, Adrian Goretzki was shortlisted to the EURORDIS Black Pearl Awards in category "Young Patient Advocate".

Since 2012, EURORDIS – Rare Diseases Europe has organized this event to honor the major achievements and exceptional commitment of patient advocates, patient organisations, policy makers, scientists, companies and media who are working to improve the lives of patients with rare diseases and their families.

Awards are given in several categories, including "Young Patient Advocate – for a young, outstanding individual (aged 30 or

under) who actively contributes to raising awareness of key issues for people living with a rare disease at a local, national, or international level".

In 2021, Adrian Goretzki was among the 3 finalists in this category. He was recognized for his involvement in activities to ensure access to drugs and reimbursement of treatment for patients with PID in Poland.



**VOTE FOR**

**THE YOUNG PATIENT ADVOCATE AWARD**

**ADRIAN GORETZKI**

“  
Adrian's involvement in advocating for access to medicine and reimbursement of treatments has improved the quality of life for patients with primary immunodeficiencies as well as their families and caregivers.

**EURORDIS Black Pearl AWARDS**

**24TH FEBRUARY 2021**



## 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 years. We are convinced that together we can do more!

### Industry:



### Non-profit organizations:



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**Healthcare Education Institute**

The Foundation

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