



PatientAdvocacy.Academy

Powered by Healthcare Education Institute

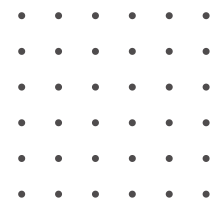


PATIENT ADVOCACY ACADEMY 2023

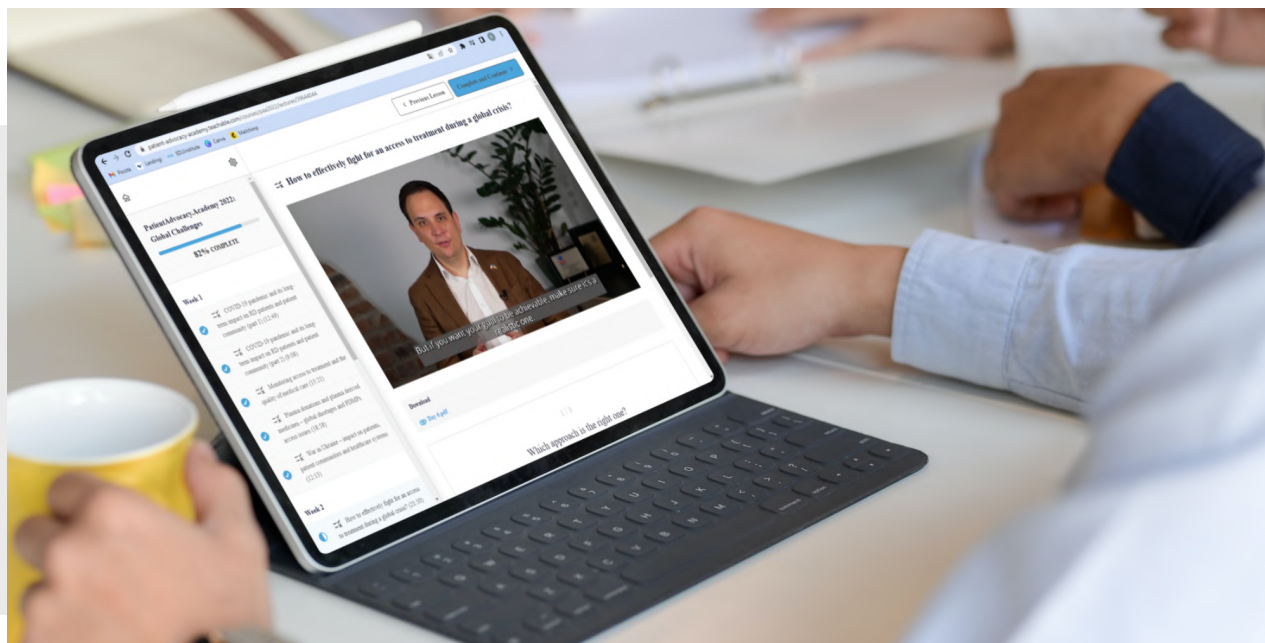
STRONG ORGANIZATION,
POWERFUL ADVOCACY



Healthcare Education Institute
The Foundation



What exactly the PatientAdvocacy.Academy is?



PatientAdvocacy.Academy is an online video training organized by the Healthcare Education Institute since 2018. It is addressed to **leaders of patient organizations** who are actively working to improve the situation of rare disease patients in their countries. Through the course, we want to give them resources that will allow them to fight for patients' rights even more effectively, express their needs more loudly and constantly increase public awareness of these diseases.

Each year, PAA has a different topic, based on suggestions from participants and the biggest challenges faced by leaders of patient organizations.

The first editions of PAA were attended primarily by **patient advocates operating in the field of plasma-derived medicinal products** (hemophilia, primary immunodeficiencies, hereditary angioedema and alpha-1 antitrypsin deficiency). This year we also hosted representatives of patient organizations dealing with other rare diseases, such as Fabry disease.

So far, PAA participants represented **50 different patient organizations operating in 32 countries on four continents** (Europe, Asia, North America and Africa).

Previous editions of the PatientAdvocacy.Academy

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

Every edition of the course means **impressive numbers, measurable results.**

6

editions



32

countries



50

patient
organizations



118

participants



79

video
lectures



general evaluation
of all editions

Why "**strong organization, powerful advocacy**" was the main topic?

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

Both those who are at the beginning of their adventure with managing a patient organization, as well as "veterans" who have been involved in its activities for many years, want it to be "strong". **Because a strong organization means more patients saved, better treatment and fuller, more normal lives for people with rare diseases.** In order to build such an organization, you need to be aware of what elements are necessary and with what tools to combine them.



And the most important task of every patient organization (and at the same time the most difficult) is **the fight for patients' rights, including access to treatment.** How can it be done efficiently and effectively? How can anyone become an expert in powerful advocacy?

In this edition of PatientAdvocacy.Academy, we wanted to teach participants **how to build a strong and credible organization with a well-planned budget and effective fundraising, which has dedicated and committed volunteers.** And, equally important, how to effectively conduct public policy advocacy activities. We focused on issues related **to communication with stakeholders, HTA, access to treatment and improving the quality of life of patients.**



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

21
participants

14
countries



3
continents

5
rare diseases

Main goals for this edition of the Academy

Our main goal was **to equip leaders with the practical skills needed by every patient advocate**. Thanks to the course, participants had the opportunity to:

- learn why it is so important **to build the credibility of the organization** and how to do it
- gain knowledge on how to communicate the achievements of their organization
- learn how **to plan the organization's budget**, according to the possibilities and needs
- find out what can and must be done and what cannot be done when raising funds
- learn how **to write a letter to a minister** or other important person which will be effective
- find out how to use the legal possibilities in their countries in the fight for patients' rights
- gain knowledge how **to effectively fight for access to modern therapies**
- learn how POs can be involved at different stages of medicine introduction to the market

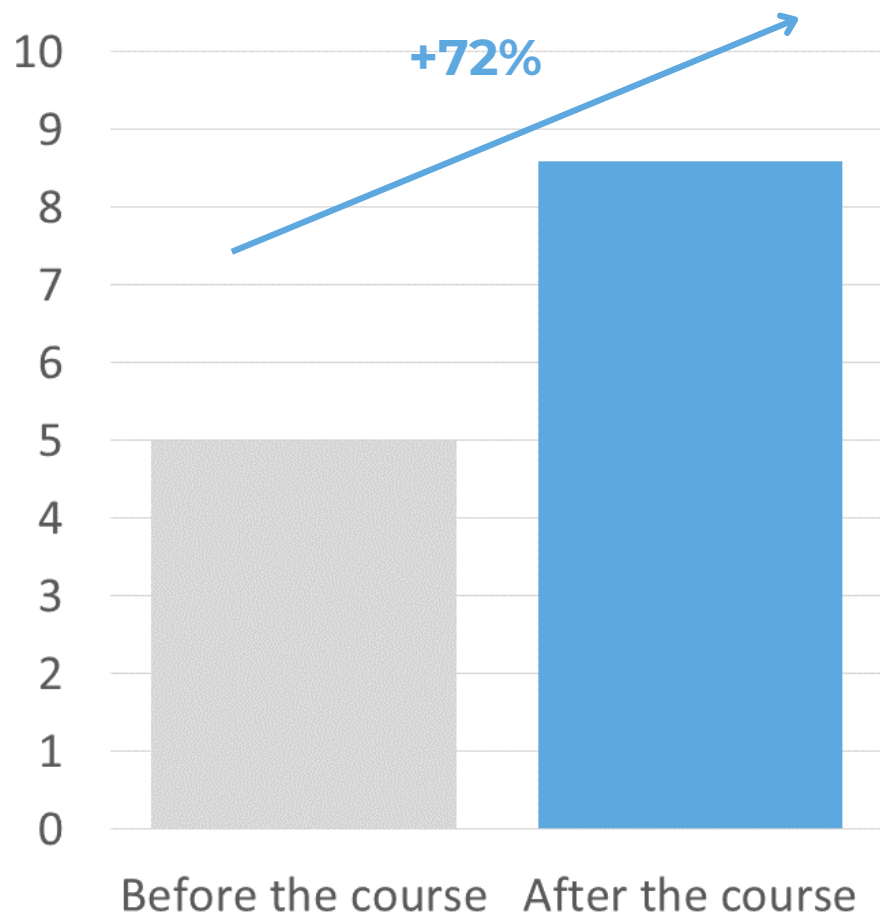


Assessing the achievement of the main goals

An important element in checking the effectiveness of the Academy is always conducting surveys before the start of the course and after its completion. Thanks to this, we can assess whether the assumed goals have been achieved.

As you can see in the chart, this year, academy participants rated their patient advocacy skills much better after completing the course compared to before. **So our goals have been achieved.**

The overall skills assessment, according the self-report of the participants, before the course was 5,0 (on a scale of 1 to 10) while after the course – 8,6. **It's a 72% increase** of their own skills assessment. We will discuss the survey results in detail later in the report.





Meet the trainers

PatientAdvocacy.Academy 2023 was run by three trainers from our foundation. We participated in 1-on-1 preliminary meetings, recorded lectures for participants, conducted an online video circle and supported them on Slack, answering all emerging questions.



Adrian Goretzki

Former leader of the Polish Association for Patients with Primary Immunodeficiencies 'Immunoprotect' and a member of the executive board of 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 2023. Professional lawyer, advisor, and keynote speaker. Fascinated with opportunities given by new technologies in the field of education.



Bernadeta Prandzioch-Goretzki

Psychologist experienced in working with patients with rare diseases, active in this area since 2014. At the HEI, 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.



Kamila Rzepka

A lawyer by profession, she gained experience in working with patient groups primarily as a project manager in the Polish Association for Patients with Primary Immunodeficiencies 'Immunoprotect' in 2014-2017. At the Healthcare Education 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.

1-to-1 preliminary online meetings

Since last year's innovation in the form of 1-to-1 preliminary meetings turned out to be a success, we also started the Academy in this way this year. It brought many benefits to both us, the organizers, and the participants.

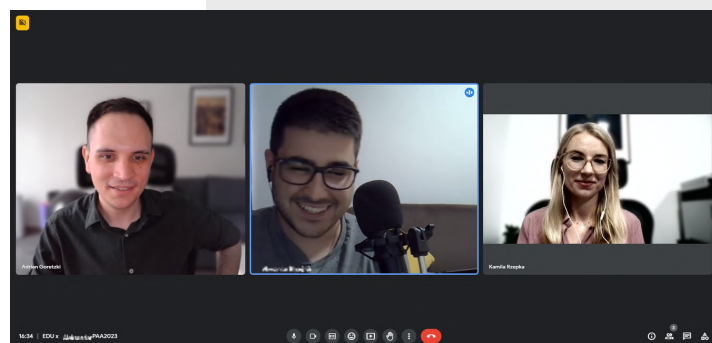
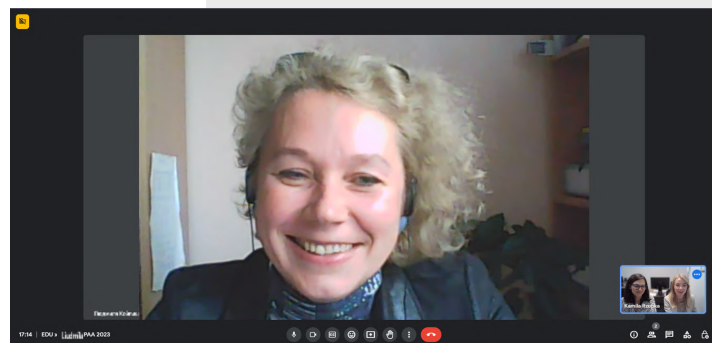
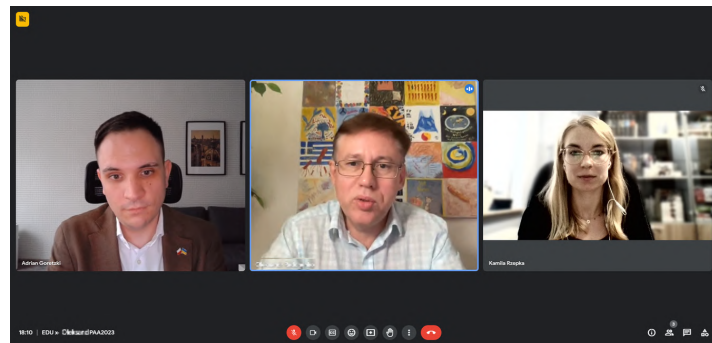
Each meeting lasts about 15 minutes, but **it allows us to get to know each participant better**, increase their commitment and build understanding between us.

During the conversation, we learn more about the situation of patients in a given country and the challenges faced by the patient organization. We ask participants about **their personal experience and what expectations they have regarding participation in PatientAdvocacy.Academy**.

Based on the information obtained, we select topics for online video circles that take place during the Academy.

We also see that **thanks to the introduction of these conversations, participants are more active during the course**, more willing to ask questions and engage in discussions with other patient advocates. Especially if this is the first edition they participate in.

In the case of returning participants, the interviews are a great opportunity to find out what activities have been undertaken and what changes have been introduced in the organization over the past year based on knowledge from the PAA.





How did the PAA2023 look in practice?

1. Videos full of knowledge, case studies & practical examples

The main element of the course were **10 video lectures**, 15-20 min. each, covering the most important issues related to the topic of this edition of the course, such as planning the organization's budget, writing a letter to the Minister of Health or fighting for access to treatment.

We took care of **the subtitles in English** so that each participant can understand the content, even if their English language skills are limited.

Additionally, at the request of some participants, we also created **a video transcription in Russian** for Russian-speaking participants.

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

As we can see in the course viewing statistics, participants often paused the recordings **to take a closer look at additional information**.





3. Online video circles to discuss the most challenging issues

Online video circles are always an opportunity during the Academy to discuss the biggest challenges participants face in their patient organizations. We select topics for online coaching circles based on information from 1-on-1 conversations.

Due to the specificity of the topics, this year **we decided to work in smaller groups**. We also asked some participants **to prepare short presentations and share their success stories** during coaching circles. Thanks to this, together we were able to develop ready-made solutions for each of the participants.

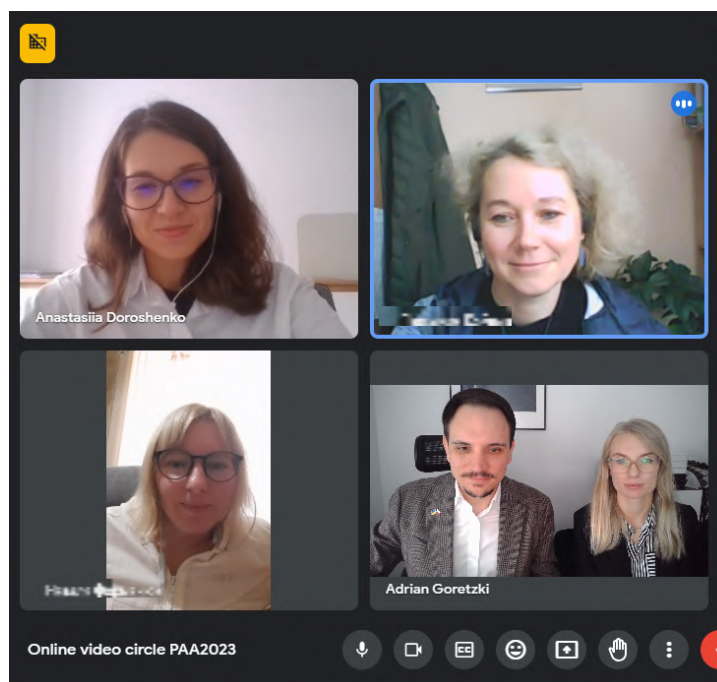
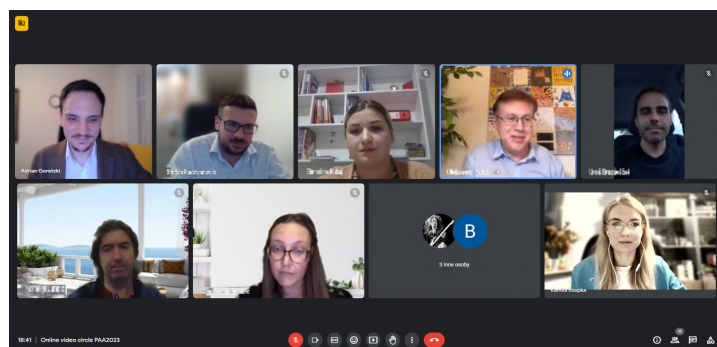
The main topic of the first online circle was **building the involvement of volunteers to strengthen the patient organization**. We discussed how to:

- Attract new volunteers and maintain their engagement
- Provide volunteers with opportunities to learn and develop
- Reward them for their hard work

During the second online circle, we discussed **what to do if the Ministry of Health doesn't want to talk with patient organizations**. We talked about:

- Allies that can be gathered around the cause
- Legal possibilities of action
- The role of media in patient organization's fight

Each online coaching circle has also been summarized in the form of notes with solutions ready to use.

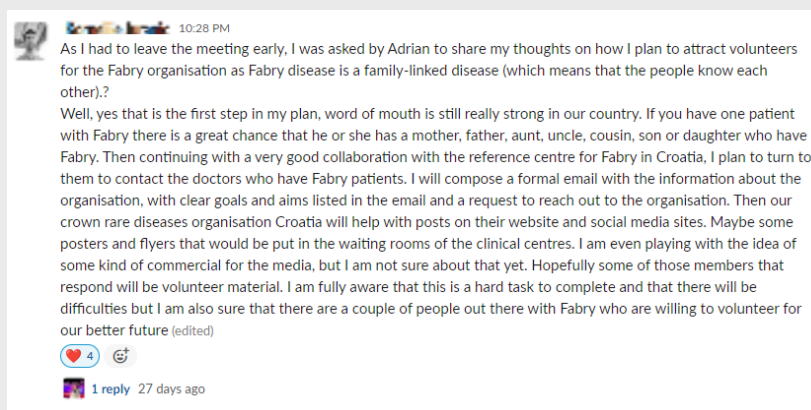
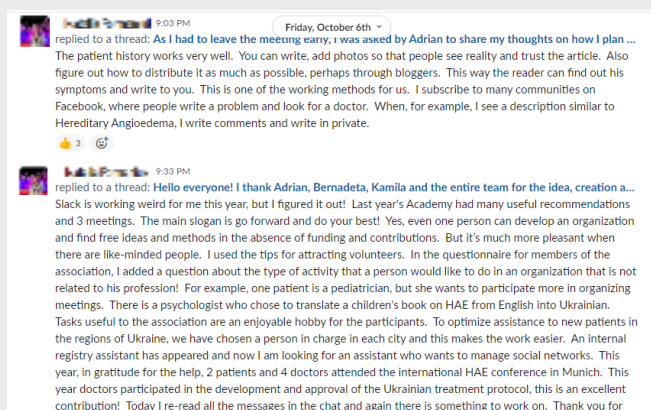
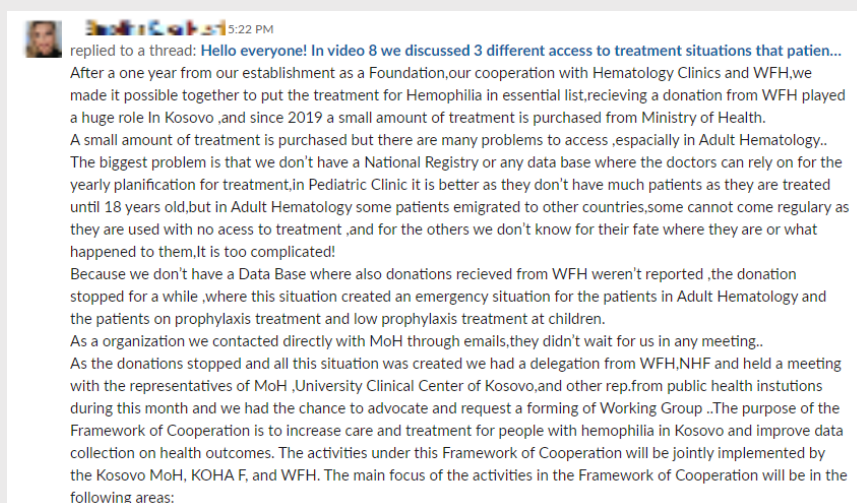


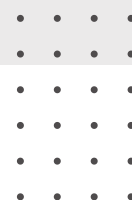
4. Ongoing communication on Slack group

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

This year, discussions on some topics were lively, as evidenced by the fact that participants wrote almost 100 posts. Some of them were really long and full of valuable content!

But it is also a place for after-hours discussions - about interests, private life or the places we come from.





How skills of the participants have improved

As previously mentioned 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 overall skills assessment before the course was 5,0 (on a scale of 1 to 10) while after the course – 8,6. **It's a 72% increase.** But we observe increase in each area listed in the survey. The increase ranged **from 43% to as much as 146%.**

Significant increase in three categories is worth mentioning:



1) "I know how to effectively raise funds for the activities of my organization" – Before the course the overall score was 3,5, after – 8,6. Increase was 146%.

Collecting funds for activities is, on the one hand, an extremely difficult task, as PAA participants often mention, and on the other hand, without financial resources it is impossible to effectively conduct patient advocacy activities. Therefore, we are glad that the participants feel that they have gained new skills in this area.



2) "I can effectively recruit volunteers and then keep them engaged in the activities of my organization." – Before the course the overall score was 4,3 after – 8,2. Increase was 91%.

A similar situation applies to recruiting volunteers. A patient organization cannot be a one-man army. But managing people, matching tasks to their competences and building commitment is not a piece of cake. Again, it's great that participants feel more competent in this area after the course.



3) "I know how to involve as a patient organization at various stages of the introduction of medicines to the market." – Before the course the overall score was 4,3, after – 8,0. Increase was 86%.

This is a highly specialized topic. There is little information tailored to the perspective of patient advocates, so we are pleased that we could partially fill this gap.

The next page shows detailed results for each category in the survey.

How skills of the participants have improved



1. I know how to build the credibility of my organization.	5,3	8,7	64%
2. I can effectively communicate the achievements of my organization.	6,3	9,0	43%
3. I can plan my organization's budget well in accordance with its capabilities and needs.	5,3	8,0	51%
4. I know how to effectively raise funds for the activities of my organization.	3,5	8,6	146%
5. I can effectively recruit volunteers and then keep them engaged in the activities of my organization.	4,3	8,2	91%
6. I can communicate with the ministry or other important people.	5,8	9,1	57%
7. I know the legal possibilities in my country to fight for patients' rights.	4,9	8,5	73%
8. I have a necessary knowledge on how to effectively fight for access to modern therapies and improve the patients' quality of life.	5,3	8,4	58%
9. I know how to involve as a patient organization at various stages of the introduction of medicines to the market.	4,3	8,0	86%
10. I know where I can obtain the knowledge I need and develop myself as a patient advocate.	5,1	9,4	84%

Participants' assessment of this year's Academy

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

We are glad that **the Academy again received a very high rating! All opinions and suggestions will be used to prepare even better training next year!**



9,8

Usefulness
of the
information



9,7

Choice
of the
subject



9,6

Communi-
cation with
us



9,5

Online
video
circle



Participants' assessment of this year's Academy

In the survey participants indicated the 3 most valuable aspects of PatientAdvocacy.Academy:

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

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

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

Would you like to attend a course like this in the future?

Definitely yes
85%



Rather yes
15%

It's very important to us that **all respondents to this question answered that they would like to participate in such a course in the future.** 85% answered "Definitely yes" and 15% "Rather yes".

Participants' assessment of this year's Academy

Participants repeatedly emphasized that they liked the form of the course. Below you can read selected opinions they shared in the survey.



"This is my first time participating in the PatientAdvocacy.Academy. I really liked the format of the training and meetings. In my opinion it is very effective!"

Anonymous opinion from the survey

"(...) I found our circle meetings to be extremely enriching. Hearing from fellow participants and sharing our experiences and thoughts added a unique dimension to the learning experience."

Anonymous opinion from the survey



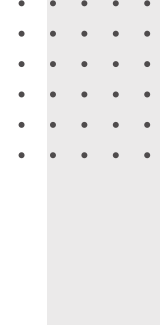
"I thoroughly enjoyed the video lectures as they provided valuable insights and knowledge (...)"

Anonymous opinion from the survey

"(...) it truly was inspirational and informative and very applicable. loved the freshness of the course and how the course was presented."

Anonymous opinion from the survey





Grant competition

Each PatientAdvocacy.Academy – apart from learning – is also an opportunity **to win funds for activities of the patient organization**. Thanks to the money grantees can immediately implement their plans! In this edition, participants had to complete **two tasks**:

The first was to prepare a competition entry on a selected topic from the following:

- **Plan a one-day training program for volunteers** with at least four different lectures/workshops to help build their commitment and briefly describe the content of each lecture or training. Additionally, prepare **a cost estimate** for the event for max. €5,000.
- Imagining that there is no reimbursement for the treatment of adult patients with a given disease in the country, **write a letter to the Ministry** on this matter, using ALL the elements described in video 6.



The second task was to send us three completed exercises for video lectures 3, 5 and 7.

This year we received a lot of valuable works and choosing the winner was not easy. Nevertheless, we are pleased to announce that the winner was **Uroš from Slovenia!** Congratulations!

Participants' opinion about this year's Academy



"I just want to thank (...) for another amazing workshop! The videos were more than interesting, and also most relevant (and practical). I truly enjoyed it!"

Stefan Radovanović
Serbian Haemophilia Society

"I thank (...) the entire team for the idea, creation and successful development of the academy."

Natalia Formaniuk
Ukrainian Patients Association
for Hereditary Angioedema



"This is I think my third Patient Advocacy Academy and I am coming back because I always learn something new and get new ideas for our advocacy campaigns."

Uroš Brezavšček
Krvni bratje, Slovenian association of patients
with blood clotting disorders

Participants' opinion about this year's Academy



“First of all, it was a great experience and opportunity for me to be part of PAA 2023 again. The videos were so helpful for me as I'm working on my personal development for FR, especially for budget planning purposes and Volunteer Engagement. Once again, it was great to participate!”

Elmedina Kukaj

Kosovo Hemophilia Foundation

“I truly enjoyed the format of the Academy, as well as the engaging and informative content. (...) I was particularly impressed with the video lectures. They were exceptionally well-executed, with excellent audio, video quality, and a professional presentation of the material. If there are more Academies like this in the future, our organization will eagerly participate!”



Oleksandr Radchenko

Ukrainian Alliance for Haemophilia
and Related Disorders

Sponsors of the PatientAdvocacy.Academy 2023

A huge thank you to the course sponsors!

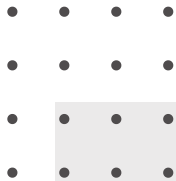
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Thanks to their support, the 6th edition of PatientAdvocacy.Academy was possible, as a result of which the patient community gained well-equipped advocates.





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