



**PatientAdvocacy.Academy**  
Powered by Healthcare Education Institute

# PATIENT ADVOCACY ACADEMY 2024

A large, light blue speech bubble graphic with a tail pointing towards the bottom left, containing the text "MASTERING COMMUNICATION".

MASTERING  
COMMUNICATION

THE REPORT

**EDU**

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# THE 7TH EDITION OF PATIENTADVOCACY.ACADEMY IS BEHIND US!

Our latest edition of the innovative online course for leaders of patient organizations in the plasma-derived medicinal products field has wrapped up with incredible success! Let's explore the highlights of this edition and, most importantly, hear what the participants have to share!



## "MASTERING COMMUNICATION" - THE MAIN THEME OF THIS EDITION

Effective communication is essential for patient advocates, yet many struggle to convey their messages clearly to doctors, NGOs, and the public. Challenges include simplifying complex information, engaging with the media, and building public speaking skills. Recognizing this, the PatientAdvocacy.Academy 2024 focused on **sharpening these communication skills, empowering advocates to stand out and effectively connect with their audiences.** Participants left equipped to share their mission with impact and confidence.

“I WAS SUPER IMPRESSED BY THIS YEAR'S TOPIC, GREAT INFO FOR MY ORGANIZATION.”

“THIS YEAR THE COURSE WAS VERY USEFUL FOR ME, AS IT COVERED TOPICS THAT CONCERN ME.”

# GLOBAL LEADERS UNITE: MASTERING COMMUNICATION IN PATIENT ADVOCACY

Once again, the Academy has brought together passionate leaders of patient organizations from around the globe! Despite being thousands of kilometers apart, they collaborated to gain invaluable knowledge and skills in the art of communication.



## BENEFITS FOR PARTICIPANTS

In just 21 days, participants:

- learned how to turn different audiences into their allies,
- gained knowledge on effectively communicating the most important demands of their patient organization,
- discovered the secrets of media communication,
- learned how to prepare for every conversation and public appearance,
- enhanced their skills in public speaking,
- mastered the art of creating interesting and engaging presentations.



**22**  
participants



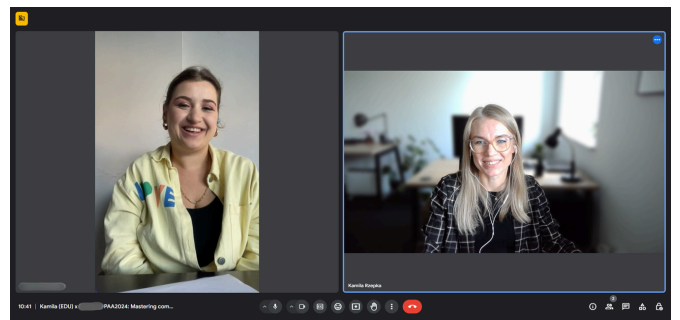
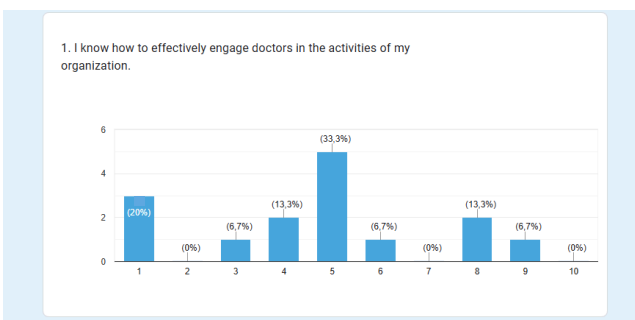
**17**  
countries



**3**  
continents

# HOW DID PAA 2024 ACTUALLY LOOK LIKE?

We have planned a 21-day program featuring a variety of activities designed to maximize benefits, while also allowing for participation that can be easily balanced with daily responsibilities and professional work. We regularly survey Academy participants about their preferences for specific course elements to ensure that the quantity and format meet their expectations.



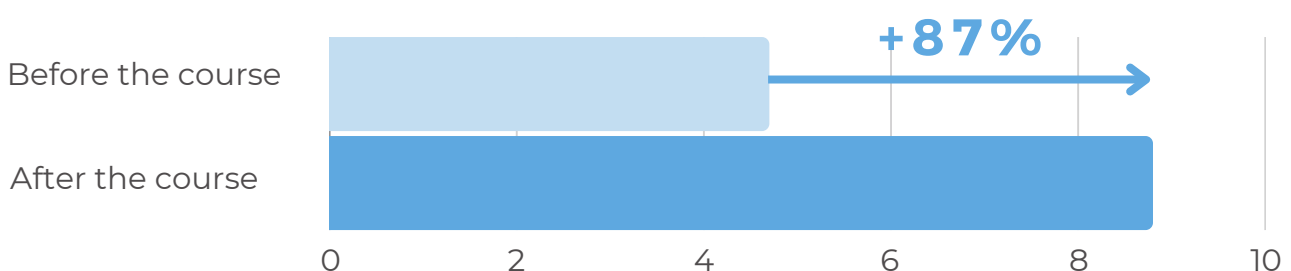
## 1ST STEP: SELF-ASSESSING OF COMMUNICATION SKILLS

To assess the Academy's effectiveness, we conduct surveys at the beginning and end of each course. This year's **results reveal a marked improvement in participants' communication skills.** Post-course ratings significantly exceeded pre-course ones, showing **our goals have been met.**

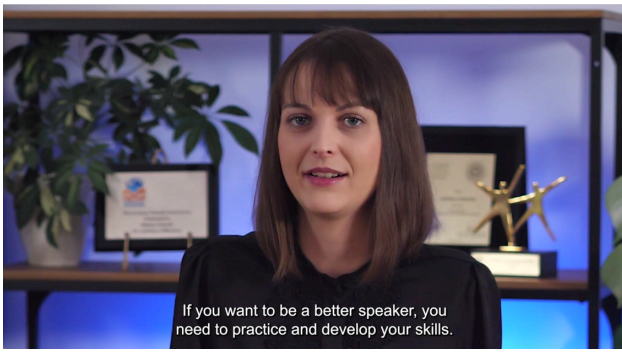
Participants rated their communication skills at 4.7 (out of 10) before the course and 8.8 after, indicating **a 87% increase** in self-assessed abilities. A detailed analysis of the survey findings will follow later in the report (p. 7-8).

## 1-TO-1 PRELIMINARY ONLINE MEETINGS

This year, we have once again conducted 1-to-1 preliminary meetings to boost participant engagement. These brief sessions allow us **to connect personally, understand challenges, and tailor the Academy's content** to address the most relevant issues. This personalized approach **encourages active participation**, especially from first-timers, while offering returning participants **a chance to reflect on their successes.** The success of these meetings has established them as a vital part of the Academy's ongoing impact.







Acquiring new sponsors		
Before the meeting	During the meeting	After the meeting
<ul style="list-style-type: none"> <li>✓ familiarize yourself with the company</li> <li>✓ prepare a description of yourself and your organization</li> </ul>	<ul style="list-style-type: none"> <li>✓ introduce your organization and briefly summarize its activities</li> <li>✓ ask questions</li> <li>✓ talk about specific projects</li> <li>✓ bring a ready-made paper offer</li> </ul>	<ul style="list-style-type: none"> <li>✓ send a follow-up email</li> </ul>

## ENGAGING VIDEO CONTENT

The PAA 2024 featured **10 video lectures**, addressing key communication issues. The videos covered both the theoretical foundations of communication with various individuals and entities, as well as practical skills in public speaking and self-presentation.

To enhance accessibility, we provided **English subtitles** and, at participants' request, added **Russian and Ukrainian dubbing using AI**.

Supplementary materials like charts and infographics enriched the learning experience, and participants often paused the videos to explore additional content, showcasing its practical relevance.

“I AM IMPRESSED BY THE ARTIFICIAL INTELLIGENCE (..). THIS IS AMAZING.”

**Natalia Formaniuk**  
Ukrainian Patients Association for Hereditary Angioedema

“...I GOT A WHOLE NEW APPRECIATION FOR THE VIDEOS YOU ALL PROVIDE, PROPS TO THE WHOLE TEAM, IT MUST HAVE TAKEN A LOT OF WORK TO GET TO THAT LEVEL!”

**Aleksandar Blagojevic**  
Serbian Haemophilia Society

**Exercise for Lecture 3: Presenting the case in the media**

Find an article on the Internet about the fight for reimbursement or the refusal of treatment. Read it, and note which elements are included - check them off on the list below:

- description of the crisis situation
- description of the disease
- statement from a medical expert
- statement from a patient organization representative
- patient story
- worst-case future scenario
- statement from the Ministry of Health or payer

Write down below what you missed the most in the article.

2 / 5

What should you do a month before your speech?

- Write the entire speech and memorize it
- Book a room for rehearsals
- Ask the organizer for details about the event and presentation
- Only prepare slides

correct

Back Continue

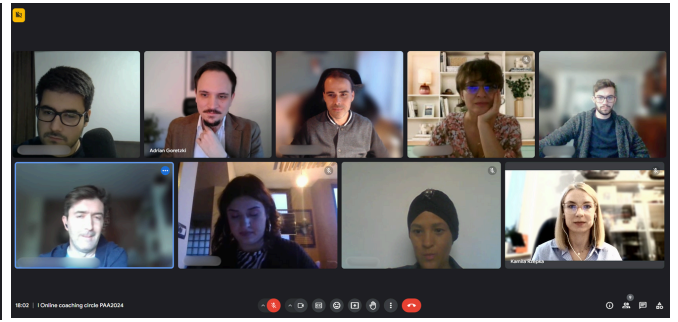
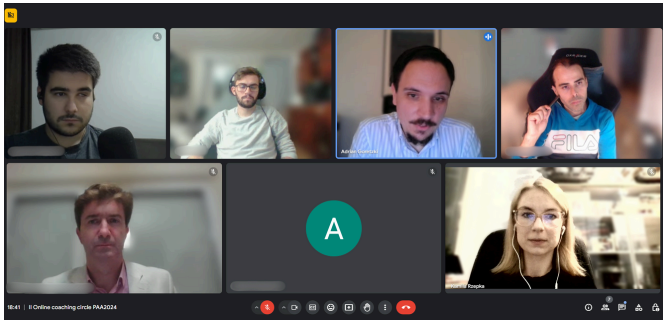
## EDUCATIONAL MATERIALS

Each video lecture included additional materials to help participants consolidate their knowledge and apply it in their patient organizations.

Under each video, participants found:

- A ready-to-print **PDF exercise**
- **A short quiz** with 5 questions

The exercises facilitated the creation of actionable solutions, while the quizzes provided an engaging way to test their knowledge and recap key concepts.



“THE ACADEMY UNITES THE ENERGY OF CREATORS AND PARTICIPANTS, WHICH INSPIRES NEW IDEAS.”

9,5/10 ★

AVERAGE RATING OF ONLINE COACHING CIRCLES BY RESPONDENTS

## ONLINE VIDEO CIRCLES

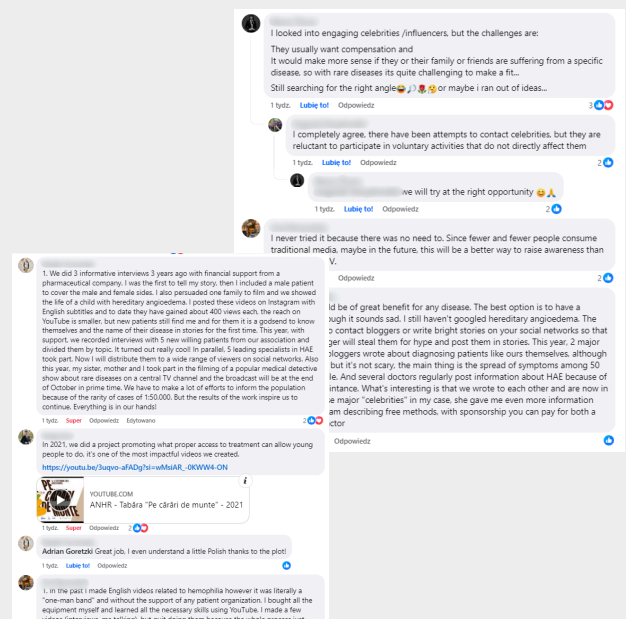
Thanks to online coaching circles, we created a significant sense of unity across the participants, who learned from each other, motivated themselves and provided others with valuable feedback. In this edition, we organized 2 online meetings:

In the first session, participants shared powerful **success stories and insights on mastering communication.**

The second session took it up a notch with a **1-minute "elevator pitch" challenge** - imagine running into the Health Minister at a conference. Participants and trainers provided constructive feedback, spotlighting each pitch's strengths and areas to polish.

## ONGOING COMMUNICATION ON FACEBOOK GROUP

An important part of each edition is the ongoing group discussions. By popular demand, we've switched from Slack to a private Facebook group, where participants exchanged experiences, discussed watched video lectures, added their thoughts and presented the achievements of their patient organizations.

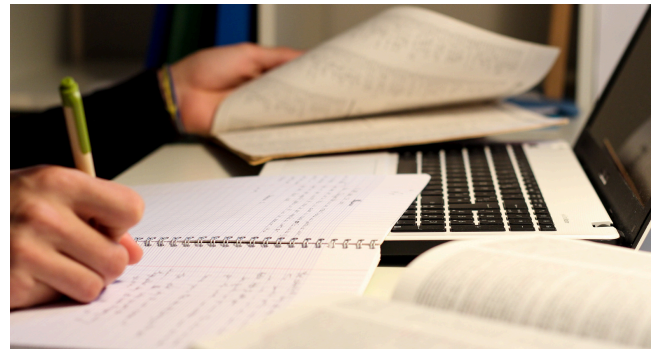




## INDIVIDUAL MENTORING SESSIONS

This year, participants benefited from **dedicated 1-on-1 mentoring sessions with trainers**, where they tackled real challenges faced by their patient organizations. These personalized meetings **allowed trainers to give each participant their full attention, collaborating on practical, tailored solutions.**

Adrian had the opportunity to meet one of the participants in person during the international conference held during the Academy (photo above).



## GRANT COMPETITION

Each PAA offers not only training but also **funding opportunities for patient organizations to implement new projects.** In this edition, participants completed two tasks:

1. Presented a **project proposal** (in a document or short audio/video) for a €1,500 grant, using communication skills learned in the Academy.
2. **Completed exercises** from two Academy videos.

We received many strong entries and are thrilled to announce the winners:

**1st place: Natalia from Ukraine**

**2nd place: Aleksandar from Serbia**

**3rd place: Aleksandra from Romania**

# 10/10

AVERAGE RATING OF  
COMMUNICATION WITH TRAINERS  
BY RESPONDENTS

**“...THE GRANT COMPETITION TASK WAS ESPECIALLY WELL DONE, IT PUSHED US TO REALLY THINK THROUGH WHAT WE’D LEARNED WHILE ALSO LETTING US BRING OUT OUR CREATIVITY. IT WAS A PERFECT BALANCE OF CHALLENGING AND INSPIRING!”**

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# TOP 4 AREAS OF GREATEST PARTICIPANT PROGRESS

We conducted a pre- and post-course survey among participants to compare results and assess the training's impact. **Each surveyed skill area showed growth, with increases ranging from 37% to an impressive 244%.**

Four categories, in particular, showed significant progress:



## ALLIES IN POLITICS

1) **"I know how to find allies among politicians."** – Before the course: 2.5, after: 8.6. **Increase was 244%.**

Finding political allies is challenging but vital for patient advocacy, offering resources and visibility to amplify impact. It's encouraging that participants now feel equipped to connect with these key supporters.



## INFLUENCER ENGAGEMENT

2) **"I can engage influencers and/or celebrities in the actions taken by my organization."** – Before: 3.0, after: 8.1. **Increase was 170%.**

Engaging influencers and celebrities can significantly boost advocacy, expanding reach and credibility. It's fantastic to see participants now confident in building these high-impact partnerships.



## CONNECTING WITH DECISION-MAKERS

3) **"I know ways to build and maintain relationships with decision-makers."** – Before : 3.3, after: 8.6. **Increase was 161%.**

Building relationships with decision-makers is key to advocacy and policy influence. With new skills, participants are now better equipped to foster lasting, impactful connections that advance their missions.



## SECURING SPONSORSHIPS

4) **"I can acquire new sponsors."** – Before: 3.5, after: 8.6. **Increase was 146%.**

Securing sponsorships is crucial for expanding advocacy efforts, though it can be challenging. We're excited to see participants now more confident in attracting sponsors to support their organizations' goals.

# IMPROVEMENTS IN COMMUNICATION SKILLS



1. I know how to effectively engage doctors in the activities of my organization.	4,7	8,8	87%
2. I know how to use the support of other non-governmental organizations.	4,7	8,5	81%
3. I can engage influencers and/or celebrities in the actions taken by my organization.	<b>3,0</b>	<b>8,1</b>	<b>170%</b>
4. I can communicate with patients in an understandable way.	6,8	9,3	37%
5. I know how to prepare educational materials tailored to the needs of the audience.	5,8	9,4	62%
6. I know how to interest the media in the issues we advocate for.	4,1	8,6	110%
7. I know how to find allies among politicians.	<b>2,5</b>	<b>8,6</b>	<b>244%</b>
8. I know ways to build and maintain relationships with decision-makers.	<b>3,3</b>	<b>8,6</b>	<b>161%</b>
9. I can acquire new sponsors.	<b>3,5</b>	<b>8,6</b>	<b>146%</b>
10. I can effectively build and maintain relationships with sponsors who regularly support my organization.	4,4	9,1	107%
11. I can conduct important and difficult conversations that affect the well-being of the patient or organization.	4,8	8,7	81%
12. I feel confident in public speaking situations.	5,5	8,8	60%
13. I know how to prepare for public speeches.	5,6	9,2	64%
14. I can create engaging content for speeches that is tailored to the audience.	5,9	9	53%
15. I can create visually attractive presentations.	5,7	8,8	54%

# PARTICIPANTS' ASSESSMENT OF THIS YEAR'S ACADEMY



**9,5**

**Overall course assessment**



**9,8**

Choice of the subject



**9,7**

Usefulness of the information

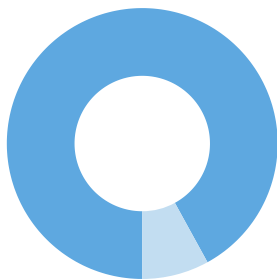


**9,4**

Interesting way of presentation

We're thrilled to report that every single respondent expressed enthusiasm for joining future courses! A strong 92% said "Definitely yes," with the remaining 8% saying "Rather yes."

**Definitely yes**  
**92%**



**Rather yes**  
**8%**

**"...THANK YOU FOR YOUR EFFORT AND ONE MORE GREAT ACADEMY! HOPE TO SEE YOU AGAIN NEXT YEAR!"**

**"I LOVE IT. SEE YOU GUYS NEXT YEAR."**



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# PARTICIPANTS' OPINIONS



*“Having watched the entire course in my native language, I want to note that this year the material was learned by 99 percent. The time was spent 2 times less compared to the previous year. I had the opportunity to listen to some lectures 2 times and take notes. Thanks to the creators of this course for valuable information and for the convenient delivery of lectures with AI.”*

**Natalia Formaniuk**  
Ukrainian Patients Association  
for Hereditary Angioedema

*“...thank you for all the great work you and the whole team did, to provide us with the invaluable knowledge we can use in our fight to be the best advocates we can!”*

**Aleksandar Blagojevic**  
Serbian Haemophilia Society



*“This was my second year in the academy. And I have the intention to continue applying for the academy, because the topics dealt in the academy are different every year. The videos are of great quality, and they are easy to follow. It is obvious how much experience Kamila, Bernadeta and Adrian have. (...) they answer all the questions you have and even find the time to make 1 on 1 meetings if someone has the need to discuss some additional topics or questions...”*

**Kornelije Juranić**  
Hrvatska Anderson Fabry udruga



*All anonymous opinions in the report are from surveys completed by participants after the Academy.*

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Your support made the 7th edition of PatientAdvocacy.Academy a reality - empowering the patient community with skilled, passionate advocates.



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