



PatientAdvocacy.Academy

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# PATIENT ADVOCACY ACADEMY 2025

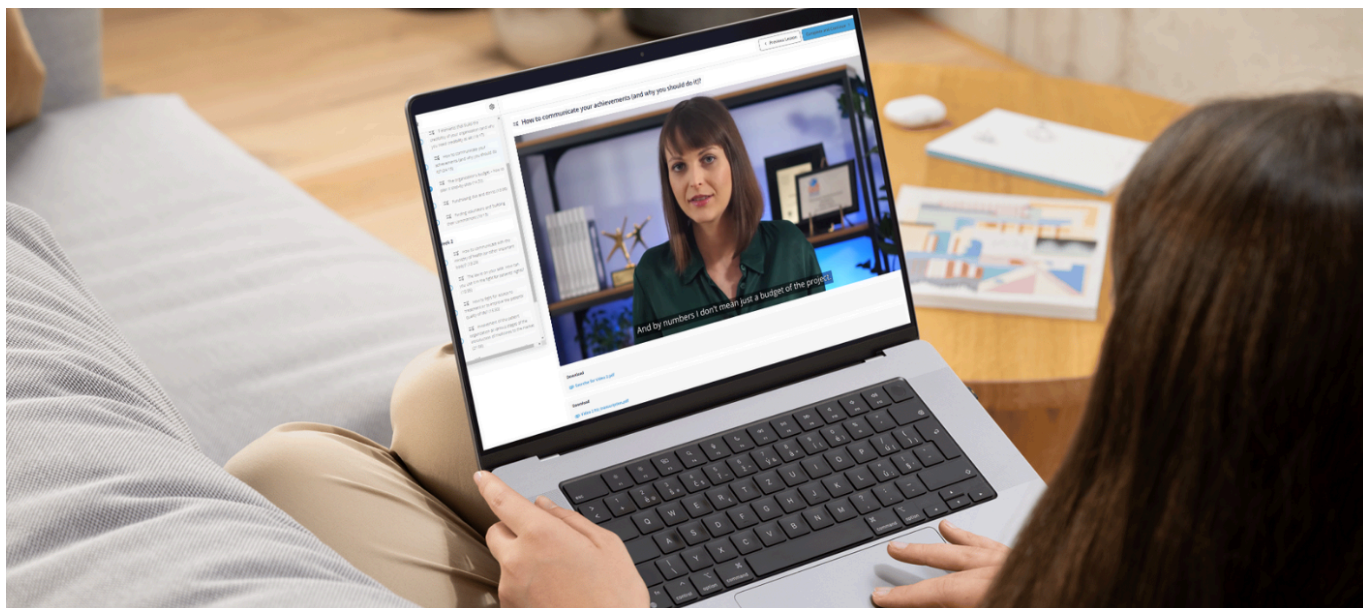
## RARE LEADERS

### THE REPORT



# THE 8TH EDITION OF PATIENTADVOCACY.ACADEMY – MISSION ACCOMPLISHED!

This year's edition of PatientAdvocacy.Academy marked a major step forward – with record participation, broad representation, and strong engagement.



This edition of the Academy set a **record for participation, with 30 people taking part** — the largest group in the program's history. Leaders representing **different rare diseases from numerous countries around the world** shared their experiences and everyday challenges, working together on possible solutions.

The group showed **great commitment, joining four sessions and actively taking part in discussions.** Despite their different backgrounds, they quickly built **strong unity and a spirit of collaboration**, proving how powerful it is to work together for people living with rare diseases.

**We are proud of the work accomplished by all participants.** We're happy to have been part of this process.

On the following pages, you'll find more details about this year's Academy. Enjoy the read!

Adrian, Kamila & Bernadeta  
PatientAdvocacy.Academy Team

# BUILDING A STRONG PATIENT ORGANIZATION

This edition of the Academy was dedicated to building patient organization. Each day, we focused on a different aspect essential for running an effective organization and advocating for patients' rights. Our goal was to equip participants with essential knowledge and practical skills they could immediately apply in their daily work.



## WHY DID WE CHOOSE THIS THEME?

A credible organization led by true representatives of the rare disease community is key to effective advocacy. A well-structured association or foundation improves patient care and access to life-saving therapies.

Beyond advocacy, leaders need skills in fundraising, strategic planning, and HR management. This edition of PatientAdvocacy.Academy equipped participants with **tools to build a strong organization, manage budgets, and engage volunteers.**

We also provided insights into **public policy advocacy, focusing on treatment access and stakeholder relations.**



## WHAT GOALS DID WE SET FOR PARTICIPANTS?

Through the course, participants had the opportunity to:

- Learn the importance of **building organizational credibility** and how to do it;
- Gain skills in **communicating organizational achievements**;
- Learn how to **plan a budget** based on needs and resources;
- Understand **fundraising** dos and don'ts;
- Learn how to **write effective letters** to key officials;
- Discover **legal tools** for advocating patients' rights;
- Gain insights on **securing access to modern therapies**;
- Learn how POs can be involved in the medicine introduction process.



**“ I AM PLEASED WITH THE TIME YOU GAVE US AND THE OPPORTUNITY TO LEARN THINGS THAT I HAD NO IDEA WERE IMPORTANT.”**

# A RECORD-BREAKING EDITION OF THE ACADEMY

In this edition, we gathered a record number of 30 participants from 5 continents, representing 11 rare diseases. It was an incredible opportunity for global collaboration and learning!



**30**  
participants



**26**  
countries



**11**  
rare diseases

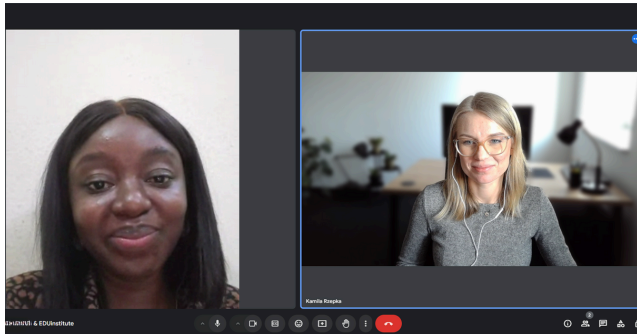


**5**  
continents



# LET'S TAKE A CLOSER LOOK AT KEY ELEMENTS OF THE ACADEMY

We have prepared a 21-day program with a wide range of activities to maximize benefits while allowing participants to balance their involvement with daily responsibilities and professional work.



## 1. PREPARING FOR THE JOURNEY: INITIAL MEETINGS

Once we selected the participants for the Academy, we scheduled a **short video call** with each of them.

We talked about the **specific challenges their organizations are currently facing**, the realities of rare disease patients in their countries, and what they hoped to gain from this particular edition of the Academy.

Many participants expressed a strong desire to strengthen their leadership skills, connect with peers from other countries, and learn practical tools for advocacy and fundraising.

## 2. ENGAGING THE GROUP: BUILDING COMMUNITY

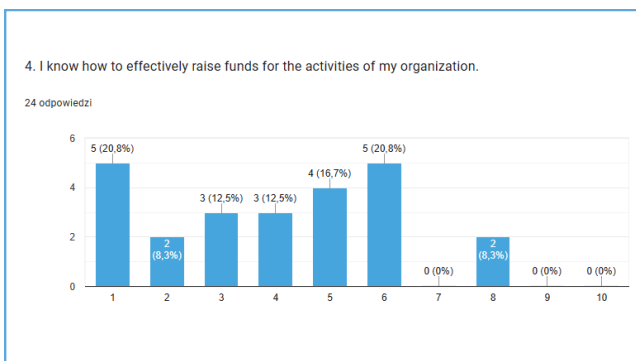
The first four days of the Academy focused on building connections within the group.

Participants introduced themselves in **the private discussion group**, sharing the story of their organization and the rare conditions they represent.

What stood out was **the genuine interest and engagement** – attendees actively commented on each other's posts, asked questions, and expressed support.



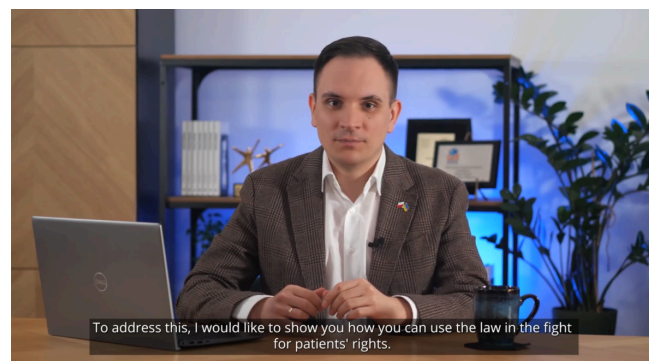
**“SINCERELY THANKING THE WHOLE TEAM FOR THEIR PRICELESS EFFORTS!”**



### 3. SELF-EVALUATION OF LEADERSHIP 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' leadership skills.** Post-course ratings significantly exceeded pre-course ones, showing **our goals have been met.**

Attendees rated their leadership skills at **5.2 (out of 10) before the course and 8.2 after**, indicating a **58% increase** in self-assessed abilities. A detailed analysis of the survey findings will follow later in the report (p. 7-8).



### 4. CORE KNOWLEDGE: VIDEO LECTURES BY EXPERTS

The course featured **10 video lectures**, each lasting around 15–20 minutes. **The lessons covered essential skills for building and managing patient organizations** — from establishing credibility and celebrating achievements, to planning budgets and mastering fundraising. They also focused on effective advocacy, volunteer management, legal tools for patient rights, influencing treatment access, and developing leadership for long-term organizational growth.

Lessons were provided **in English with English subtitles** to ensure accessibility for all participants. Each video featured **supplementary materials** like charts, infographics, and practical examples to reinforce key concepts.



**“...THE VIDEO MATERIALS WERE EXTREMELY HELPFUL AND PRACTICAL AND I LEARNED A LOT FROM THEM...”**

**Oana Voivod**

“The Together for Patrick Association” - the patient organization representing patients with Cystic Fibrosis from Romania

 **79%**

OF RESPONDENTS INDICATED THAT VIDEOS WERE THE MOST USEFUL ELEMENT OF THE COURSE



## 5. KNOWLEDGE APPLICATION: EDUCATIONAL CONTENT

Each video lecture was accompanied by **educational materials in the form of quizzes and printable exercises in PDF format**. Participants could immediately apply what they had learned to their patient organization's activities.

Leaders had to tackle **tasks** such as:

- Calculating the core costs of their organization;
- Formulating questions for a survey to help identify and meet patients' needs;
- Collecting information about ongoing or planned clinical trials of drugs targeting their specific condition;
- Creating an email thanking volunteers for their involvement.

## 6. COLLABORATIVE LEARNING: ONLINE DISCUSSION CIRCLES

This year, we met with Academy participants **four times via live online discussion circles**. We divided them into **two groups based on time zones** – we had participants from nine zones and the time difference was as much as 11 hours.

Every group had two sessions, each lasting two hours. In **the first session**, attendees explored the most pressing challenges faced by patients and patient organizations in their countries. In **the second session**, we worked together to identify and develop practical solutions to these issues.

**The participants' engagement was extraordinary**, as they not only sought answers to their questions but also actively participated in the discussion, providing examples of solutions to the problems raised by others.

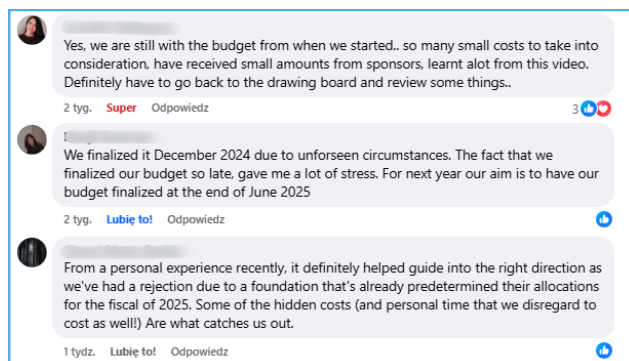


**“I ENJOYED THE ONLINE VIDEO CIRCLES VERY MUCH. ADRIANS TIPS AND TRICKS AND ALL KNOWLEDGE ARE SUPER HELPFUL...”**



**9/10**

AVERAGE RATING OF ONLINE DISCUSSION CIRCLES BY RESPONDENTS



## 7. SHARING KNOWLEDGE: DISCUSSION GROUP

The core principle of the Academy was that participants learned not only from the trainers but also from one another.

A **private discussion group** offered a space for participants to exchange ideas and share success stories.

**The most lively discussions** focused on challenges like finding and keeping engaged volunteers, planning a budget for the organization, and building its credibility.

Both trainers and the participants shared **additional content**, such as examples of successful projects implemented by different patient organizations.

86% 

OF RESPONDENTS CONSIDER THE MOST VALUABLE ASPECT OF THE ACADEMY TO BE THE FACT THAT IT COMBINES VARIOUS ELEMENTS

“...I REALLY ENJOYED  
THE INTERACTION WITH  
FELLOW PARTICIPANTS  
IN THE FACEBOOK  
GROUP; IT WAS  
INSPIRING AND  
MOTIVATING TO  
CONNECT WITH OTHERS  
(...)”

Maria Beekman-Kortekaas  
HAE the Netherlands

“...IT WAS INDEED VERY  
INFORMATIVE AND  
TRUTHFULLY INSPIRING  
TO MEET WITH PATIENTS  
AND CAREGIVERS FROM  
ALL AROUND THE  
WORLD (...)”

Cansu Kaya Kızılırmak  
Hemophilia Society of Türkiye

# RECOGNIZING COMMITMENT: GRANT AWARDS

To provide an additional motivational element, each edition of the Academy, including this one, concludes with a grant competition.



This time participants were asked to complete two tasks:

1. **Develop a one-day training program for volunteers** with a budget of 5,000 EUR, or **write a letter to the Ministry** regarding the lack of reimbursement for treatment costs for adult patients with their condition in their country.

2. **Send us the completed exercises that accompanied two of the ten video lectures:**

- Writing and calculating the core costs of their organization;
- Verifying whether the specific framework for POs presented in the video exists in their country and how they could use it to achieve their goals.

The quality of the completed assignments was just one part of the overall evaluation. We also took into account participation in the online

coaching circles, engagement in the discussion group, and the percentage of video lectures watched.

After carefully reviewing all submissions, we selected three winners. **Each organization will receive €1,000 to be used for statutory purposes.**

The winners are:



**Ayotunde  
Cardiac Community  
Advocacy and Support  
Initiative** (Nigeria)



**Daniel  
Czech Society of  
Hemophilia** (Czech  
Republic)

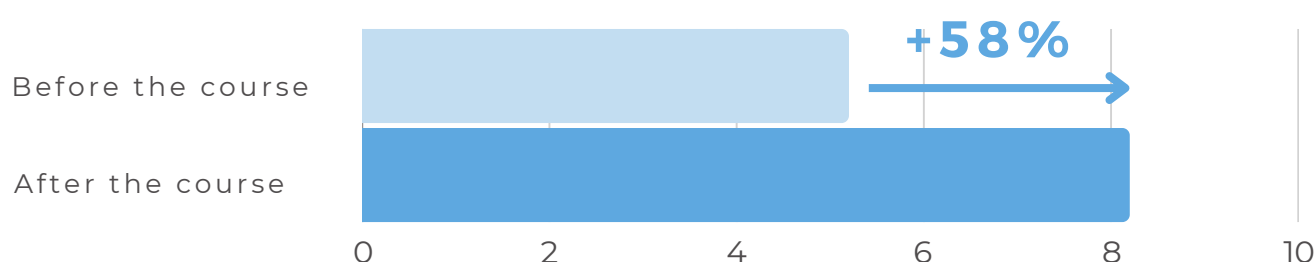


**Ganesh  
HAE Nepal** (Nepal)



# KEY AREAS OF PARTICIPANTS' GROWTH

To evaluate the impact of the training, we carried out surveys before and after the course. The results revealed clear growth across all skill areas, with improvements ranging from 35% to an impressive 105%. **The average increase in self-assessment across all skills was 58%.**



Areas of greatest skill improvement:



## **Fundraising (+105%)**

Knowing how to effectively raise funds for organizational activities.



## **Volunteer engagement (+93%)**

Recruiting and retaining volunteers successfully.



## **Budget management (+73%)**

Planning budgets aligned with needs and capabilities.



## **Self-development (+73%)**

Finding resources to grow as a patient advocate.

On the next page, you'll find detailed results from the survey, showing how participants of the PatientAdvocacy.Academy developed their skills across different areas.

# IMPROVEMENTS IN LEADERSHIP SKILLS



1. I know how to build the credibility of my organization.	5.8	8.6	48%
2. I can effectively communicate the achievements of my organization.	6.2	8.8	42%
3. I can plan my organization's budget well in accordance with its capabilities and needs.	4.8	8.3	73%
4. I know how to effectively raise funds for the activities of my organization.	4.0	8.2	105%
5. I can effectively recruit volunteers and then keep them engaged in the activities of my organization.	4.2	8.1	93%
6. I can communicate with the ministry or other important people.	5.6	8.4	50%
7. I know the legal possibilities in my country to fight for patients' rights.	5.5	7.4	35%
8. I have a necessary knowledge on how to effectively fight for access to modern therapies and improve the patients' quality of life.	5.5	7.8	42%
9. I know how to involve as a patient organization at various stages of the introduction of medicines to the market.	5.2	7.9	52%
10. I know where I can obtain the knowledge I need and develop myself as a patient advocate.	5.2	9.0	73%

**B** the survey before the course

**A** the survey after the course

 percentage increase in a given skill



# HOW PARTICIPANTS RATED THIS EDITION OF THE PATIENTADVOCACY.ACADEMY



**9,6**

**Overall  
course  
assessment**



**9,7**

Choice  
of the subject



**9,7**

Usefulness  
of the  
information



**9,7**

Communication  
with  
trainers

We're excited to share that all respondents expressed interest in attending future courses! A solid 86% answered "Definitely yes," while the remaining 14% chose "Rather yes."

**DEFINITELY YES  
86%**



**RATHER YES  
14%**



**"IT WAS AMAZING!  
THANK YOU ALL SO  
MUCH FOR ALL THE TIME  
AND ENERGY YOU  
INVESTED IN US!! I CAN'T  
THANK YOU ENOUGH.  
YOU HELPED ME BECOME  
A BETTER, STRONGER  
LEADER!"**

# PARTICIPANTS' FEEDBACK



*"...I want to thank you for everything you've done throughout this course. (...) I also really appreciated how active and engaging the Facebook page was; I read many interesting comments and found some valuable insights there as well."*

**Oana Voivod**

**"The Together for Patrick Association" -  
the patient organization representing  
patients with Cystic Fibrosis from Romania**

*"... I want to thank you and the rest of the team for providing this opportunity for us to learn and be great Rare leaders."*

**Ganesh Dahal**

**HAE Nepal**



*"...I would like to thank you all again for the very insightful last few weeks. I have gained so much knowledge on how to manage our MG Myasthenia Gravis Foundation Namibia (...) and how we can bring about change to assist those with MG in the country."*

**Corachia Ockhuizen**

**Myasthenia Gravis Foundation Namibia**

*"...I would like to take this opportunity to express my heartfelt gratitude to you for sharing your knowledge with us. The videos were incredibly educational, and I found Adrian's experiences and the tips he shared during the online video circles especially insightful and impactful."*

**Maria Beekman-Kortekaas**

**HAE the Netherlands**



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

# SPONSORS OF THIS EDITION OF THE PATIENTADVOCACY.ACADEMY

We would like to extend our sincere **gratitude and thanks** to the Sponsors of the PatientAdvocacy.Academy 2025!

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Your invaluable support made the 8th edition of PatientAdvocacy.Academy not only possible but truly impactful.

Thanks to your commitment, we were able to bring together an inspiring group of patient advocates from across the globe – equipping them with the skills, knowledge, and confidence needed to drive meaningful change in their communities.



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