



PatientAdvocacy.Academy

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PATIENT ADVOCACY ACADEMY 2025

WELL-PLANNED ORGANIZATION

THE REPORT



THE 9TH EDITION OF PATIENTADVOCACY.ACADEMY – SUCCESSFUL FINISH!

The most recent edition of PatientAdvocacy.Academy was our most ambitious yet, bringing together a record-setting group of advocates for an intensive journey of growth and connection.



This edition set a new participation record, **bringing together 59 leaders — the largest group in the program’s history.** Representing a wide range of rare diseases from across the globe, participants shared their personal experiences and daily challenges while collaborating on potential solutions.

The group demonstrated **remarkable engagement, attending the online sessions and actively contributing to discussions.** Despite their diverse backgrounds, they quickly formed a sense of unity, highlighting the power of collective action in supporting people living with rare diseases.

We are proud of everything the participants achieved and grateful to have been part of this journey. On the following pages, you will find more information about this latest edition.

We wish you an enjoyable read!

Adrian & Bernadeta
PatientAdvocacy.Academy Team

FROM VISION TO ACTION: BUILDING WELL-PLANNED ORGANIZATIONS

This edition of the Academy was dedicated to effective planning of patient organization activities and the development of strategic growth plans. Each day, participants focused on strengthening a different area of planning. We aimed to empower participants with key insights and practical competencies applicable to their daily activities.



WHY DID WE CHOOSE THIS THEME?

Leading a patient organization means working **with limited resources, volunteer teams, and balancing advocacy, education, and patient support.** In this reality, clear planning is essential for effective, consistent activities.

That's why we focused on Well-Planned Organization. Good planning helps leaders **set realistic goals, manage daily work, and run projects that truly serve their communities.** It also makes it easier to handle challenges and prevent team burnout.

With the right planning skills, patient organization leaders **can do more with limited resources,** improve the quality and consistency of their work, and build a stronger foundation for long-term advocacy and patients' support.



WHAT GOALS DID WE SET FOR PARTICIPANTS?

Through the course, participants had the opportunity to:

- Learn why **structured planning helps maintain long-term stability** and impact;
- Discover strategies to **coordinate tasks** and improve organizational workflow;
- Learn how to **ensure lasting growth and effectiveness** in their organization.
- Gain knowledge how **to prepare successful media and awareness campaigns** from scratch;
- Develop effective ways to **educate and empower volunteers** for long-term success;
- Discover best practices for **designing resources** that resonate with an audience.



“I THINK IT WAS PERFECT. IT IS THE BEST TRAINING I ATTENDING THIS YEAR. I AM SO GLAD TO HAVE FOUND THIS ACADEMY.”

AN UNPRECEDENTED EDITION OF THE ACADEMY

A record number of 59 participants from five continents took part in this edition, representing 17 rare diseases and making it a truly global experience for collaboration and learning.



59
participants



30
countries



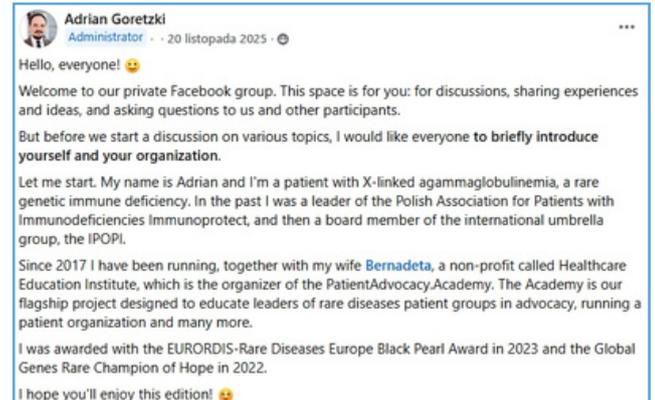
17
rare diseases



5
continents

AN INSIDE LOOK AT THE ACADEMY'S FRAMEWORK

We developed a 21-day program that blends a wide range of activities to deliver maximum value, while remaining flexible enough to fit alongside participants' daily responsibilities and work commitments.



1. PREPARING FOR THE JOURNEY: OPENING MEETINGS

Before the main program began, participants took part in a one-time online session held in small, welcoming groups of up to ten people.

During these sessions, they had the opportunity **to meet their trainers, build initial connections, and share their personal stories.**

The meetings also helped us **better understand participants' contexts**, including the healthcare environments in their countries and the specific challenges they face.

2. CONNECTING THE GROUP: CREATING COMMUNITY

The first days of the PatientAdvocacy.Academy were dedicated to fostering connections among participants.

We created a private discussion group where they can **introduce yourself, share more about their organizations, and talk about the condition their advocate for.**

This phase also covered technical steps like completing a pre-course survey and accessing the video platform.



“THANK YOU SO MUCH FOR YET ANOTHER FANTASTIC EDITION OF THE PATIENTADVOCACY.ACADEMY!”



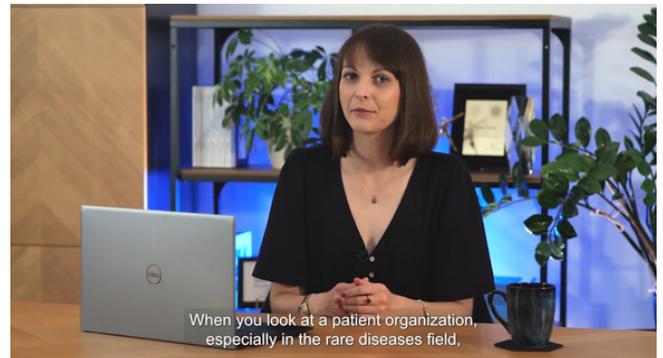
3. SELF-ASSESSMENT: KEY PLANNING SKILLS

To evaluate the Academy’s effectiveness, we conduct self-assessment surveys before and after the program. This year’s results reveal a marked improvement in leadership skills, with post-course ratings significantly exceeding initial benchmarks—clear evidence that our core objectives have been met.

Participants rated their leadership skills at an average of **5.8 (out of 10) before the course, rising to 7.8 upon completion. This represents a 34% increase** in self-assessed proficiency.

A detailed analysis of these findings is available later in this report (p. 7-8).

“IT WAS WONDERFUL AND USEFUL EXPERIENCE. I LEARNED A LOT AND I WILL RECOMMEND THE ACADEMY TO MY COLLEAGUES FROM ORGANISATION.”



4. EXPERT INSIGHTS: CORE VIDEO LECTURES

The curriculum consisted of **10 expert-led video lectures, each 15–20 minutes in length**, focusing on essential strategic planning skills.

Participants learned to create annual plans, set goals, and design projects such as awareness campaigns, educational programs, and volunteer training. The program also addressed the specific tools needed for patient advocacy, highlighting key differences between NGOs and business management.

To ensure maximum accessibility, all lessons were **delivered in English with subtitles**. Each module was supported by **supplementary materials**, including charts, infographics, and real-world examples designed to bridge the gap between theory and practice

★ **78%**

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

Exercise for Video B:
Defining the patient meeting format

Write down pros and cons of different patient meeting formats in the table below. Decide which format best fits your organization's current needs and explain why.

Scope	Pros	Cons
Local		
National		
Duration	Pros	Cons
One day		
Few days		

Which format best fits your organization's current needs and why?

1/5
What is the first step in planning a successful project?

Designing visual materials for the project

correct
Identifying the need

Writing a press release
Choosing volunteers

2/5
What is a call to action (CTA)?

correct
A public quote from a patient
A direct and simple instruction for the audience

A list of all campaign sponsors
A letter to the Ministry



5. THEORY IN ACTION: APPLIED PRACTICE TASKS

To deepen the learning experience, **each video lecture was paired with a suite of educational resources, including interactive quizzes and printable PDF workbooks.** These materials were designed for immediate practical application, allowing leaders to translate theoretical insights directly into the daily operations and long-term strategy of their patient organizations.

Leaders were challenged with **practical assignments**, such as:

- Selecting a core narrative for their 2026 advocacy campaign;
- Defining target audiences and drafting content for educational resources;
- Designing hands-on activities for volunteer training sessions;
- Establishing healthy professional boundaries to enhance focus and prevent burnout.



“WHILE WATCHING THE VIDEOS, I LEARNED SOME THINGS THAT ARE USEFUL FOR ME. AND THE QUIZ HELPED ME SEE WHERE I REALLY STAND.”

6. SHARED PERSPECTIVES: ONLINE DISCUSSION CIRCLES

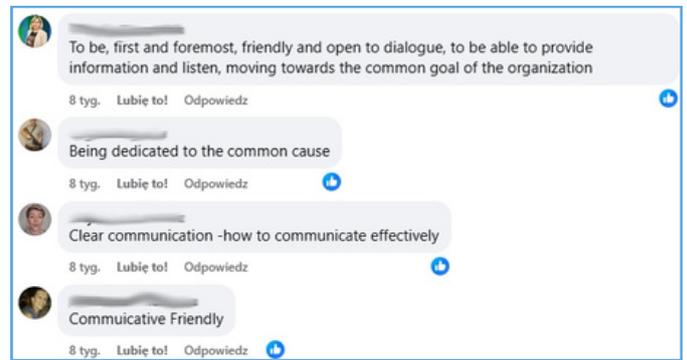
This year, we hosted five online circles, providing a space for real-time collaboration. Each participant joined **two sessions**, each lasting approximately two hours, to dive deep into strategic advocacy issues.

The first session focused on the **most pressing challenges regarding access to treatment** across different countries. **In the second, we shifted our focus to funding strategies** for patient organizations, exploring diverse revenue streams, expanding fundraising activities, and building a sustainable pool of sponsors.

The level of engagement was extraordinary. Participants did more than just seek answers; they became active contributors, **sharing proven solutions and peer-to-peer advice** on the challenges raised by the group.

★ **9,3/10**

AVERAGE RATING OF ADDITIONAL ELEMENTS SUPPORTING LEARNING



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 **to exchange ideas and share success stories.**

The most lively discussions focused on online tools for running a patient organization, key skills for volunteers, and examples of successful awareness campaigns.

Both trainers and participants shared **additional content**, including case studies of projects implemented by various patient organizations.

77%



OF RESPONDENTS CONSIDER THE MOST VALUABLE ASPECT OF THE ACADEMY TO BE THE FACT THAT IT EXPLAINS HOW TO RUN A PATIENT ORGANIZATION



“I FEEL SO SEEN AND SUPPORTED TO DO THE WORK I AM PASSIONATE ABOUT. THE TRAINING TIMELINES AND IDEAS SHARED WERE PERFECT.”

“THE CLASSES WERE REALLY EYE OPENING, DETAIL ORIENTED BACKED UP BY EXAMPLES FROM THE REAL WORLD.”

“I AM GRATEFUL AND PRIVILEGED TO HAVE BEEN A PART OF THIS. IT'S MY FIRST TIME ATTENDING PATIENTADVOCACY.ACADEMY, AND IT WAS ONE OF MY GOALS FOR THIS YEAR.”

RECOGNIZING COMMITMENT: GRANT AWARDS

To provide an additional motivational boost, every edition of the Academy – including this one – concludes with a grant competition.



This time, participants were asked to complete two tasks:

1. Record a two-minute video in English **sharing their plan for an advocacy campaign focused on access to therapy.**
2. Submit **completed exercises** from three out of the ten video lectures:
 - Planning the first quarter of the year;
 - Defining three concrete goals for 2026 using the adjusted SMART method;
 - Creating a small project idea.

The quality of the assignments was only one part of the overall evaluation. We also took into account participation in the online 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 **€1,650 to be used for statutory purposes.**

The winners are:



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



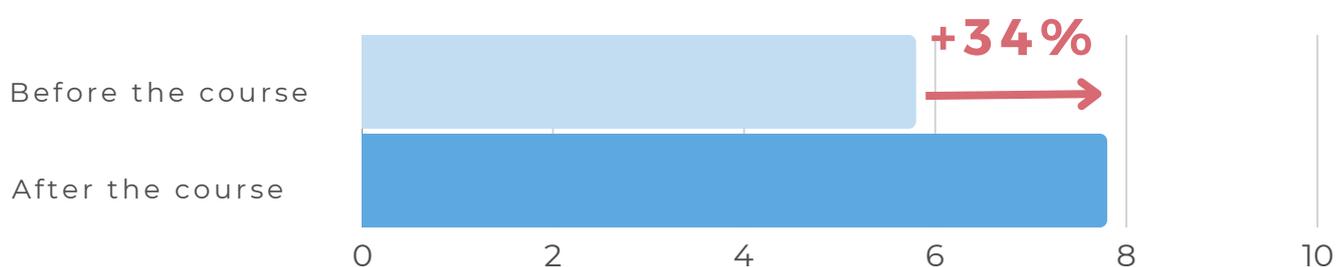
**Roussetia
NF Greece**
(Greece)



**Sofia
NF Patients United**
(the Netherlands)

THE GROWTH MAP: KEY SKILLS DEVELOPED

Our pre- and post-course surveys highlight a transformative learning experience. We recorded clear progress in all evaluated areas, with growth rates **peaking at 57%**. With an average overall improvement of 34%, **the Academy has effectively elevated the strategic toolkit of every participant.**



Top growth areas, where participants excelled:



Designing Engaging Volunteer Training (+57%)

Equipping volunteers with the knowledge and skills needed to deepen their commitment to the organization's mission.



Setting Strategic Goals (+51%)

Defining the direction of change and establishing clear objectives to support sustainable organizational growth.



Creating Impactful Media Campaigns (+42%)

Developing strategic media plans designed to boost public awareness and drive social change.

On the following page, you will find a detailed breakdown of the survey results, showcasing the professional evolution of our participants across all key competency areas.

PRECISION IN PRACTICE: ENHANCED PLANNING SKILLS



1. I know how to delegate responsibilities in my organization.	6.4	7.9	23%
2. I can create annual plans for my organization.	5.8	7.5	29%
3. I am able to set strategic goals to support the growth of my organization.	5.3	8.0	51%
4. I feel confident in creating project timelines.	6.6	7.8	18%
5. I am able to manage limited resources (time, budget and/or volunteers) efficiently.	6.7	7.8	16%
6. I feel confident in creating media campaigns.	5.2	7.4	42%
7. I know how to create practical educational materials.	5.8	8.2	41%
8. I am able to organize well-structured patient meetings.	5.9	8.3	41%
9. I know how to prepare engaging training sessions for volunteers.	4.7	7.4	57%
10. I feel confident in planning my organization's daily activities.	6.0	7.7	28%

B the survey before the course

A the survey after the course

 percentage increase in a given skill

EXCEPTIONAL RATINGS: HOW THE PARTICIPANTS SAW THE LATEST EDITION



9,4

**Overall
course
assessment**



9,5

Choice
of the subject



9,7

Interesting
way of
presentation



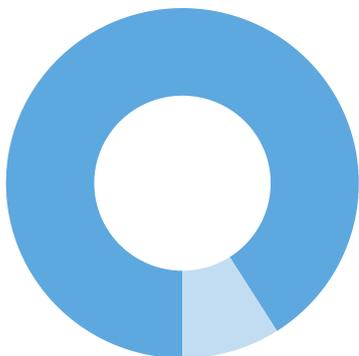
9,8

Communication
with
trainers

We couldn't be prouder! Every single respondent expressed interest in joining the PatientAdvocacy.Academy again - including a staggering 91% who are "Definitely" coming back.

DEFINITELY YES

91%



RATHER YES
9%



“THE ACADEMY HAS TRULY PROVIDED A SOLID ENTRY TOOLKIT FOR NEW ORGANISATIONS. THE STRUCTURE AND CLARITY HAVE TAUGHT ME A GREAT DEAL AND COME AT THE RIGHT MOMENT IN THE PROCESS OF ESTABLISHING ORGANISATIONS.”

PARTICIPANTS' FEEDBACK



*"I was honoured to be accepted onto the PatientAcademy.Academy 2025, an experience that was both **highly informative and professionally enriching**. As an ambassador for Nerve Tumours UK, the Academy equipped me with **valuable knowledge and practical skills that have significantly strengthened my ability to fulfil my role with greater confidence and effectiveness**. (...) The opportunity to engage with fellow participants further enhanced the experience, offering meaningful insights, shared learning, and the chance **to build valuable connections across the sector**."*

Georgia Baum
Nerve Tumours UK

*"...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**."*

Marvelous Ibiyemi
Nigerian Cardiac Community



*"**An outstanding program with skilled lecturers, amazing organizers, and a powerful learning structure. The content delivered clear messaging and practical skills every organization needs (...). The live sessions were a great opportunity for networking, exchanging experiences, and connecting with fellow advocates. This Academy doesn't just share knowledge - it builds confidence, collaboration, and real impact. Highly recommended.**"*

Maja Bartoszewicz-Moritz
MEF2C-related disorder community

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

SPONSORS AND PARTNERS OF THE PATIENTADVOCACY.ACADEMY 2025

We would like to extend our sincere **gratitude and thanks** to the Sponsors of the PatientAdvocacy.Academy 2025: Well-Planned Organization!



Komtur

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Your generous support was essential to the success of the 9th edition of PatientAdvocacy.Academy.

Thanks to your commitment, patient advocates from around the world were equipped with the skills, knowledge, and confidence to drive meaningful change in their communities.

We would also like to extend our heartfelt thanks to FH Europe for their partnership in this project and for their support in reaching outstanding leaders of patient organizations.



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Foundation**

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