



PatientAdvocacy.Academy

Powered by Healthcare Education Institute

PATIENT ADVOCACY ACADEMY 2022

GLOBAL CHALLENGES

5th edition

Report issued by the
Healthcare Education Institute

What exactly the **PATIENTADVOCACY.ACADEMY** is?

PatientAdvocacy.Academy is an online video training for **leaders of patient organizations** who are actively working to improve the situation of patients in their countries, especially in advocacy groups in the area of plasma-derived therapies.

So far we have focused on **4 rare therapeutic areas**:

- Primary immunodeficiencies (PID),
- Hemophilia,
- Hereditary angioedema (HAE),
- Alpha-1 antitrypsin deficiency (A1AD).



The course is addressed primarily to representatives from **Europe**, but also leaders from other geographic areas are welcome. In this year's edition we hosted representatives from Kyrgyzstan and the United States who shared their unique perspectives

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



Every edition of the
PATIENTADVOCACY.ACADEMY means
impressive numbers, measurable results



94

PARTICIPANTS

5

EDITIONS

40

PATIENT
ORGANIZATIONS

11.750€

AWARDED
GRANTS

PATIENTADVOCACY.ACADEMY 2022: Global Challenges

Recent years, months or even weeks have brought patient advocates – especially those operating in the area of plasma-derived products – many **challenges**.



1

First, we experienced the COVID-19 pandemic **which strongly affected the healthcare systems in many countries, access to treatment and appropriate diagnostics, as well as the approach to rare disease patients.**

2

Also, drops in plasma donation caused by the pandemic resulted in shortages of drugs for patients fully depending on them. In some countries there are **temporary medicines availability problems**, in others the pandemic has become an excuse to cut back on spending on rare disease patients.

3

In February, Ukraine was attacked by Russia and the war began - the first such large armed conflict since the WWII. **The war has an obvious impact on Ukrainian rare disease patients, but also on healthcare systems across Europe.**

Therefore, during the PatientAdvocacy.Academy 2022, we took up all relevant topics from the PAG perspective in the context of **Global Challenges**, such as an **access to treatment, online education and plasma awareness**. We wanted to initiate the exchange of experiences and develop solutions that will help to effectively meet the needs of patients in the near future.

The 5th edition of PATIENTADVOCACY.ACADEMY was a great journey for all of us!

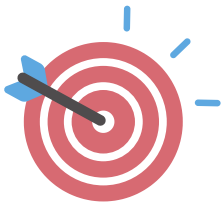
This edition was attended

by **20** participants
from **16** countries
located on **3** continents
representing **4** rare diseases



The presence of representatives of Ukrainian patient organizations was especially important for us. We greatly admire their care for each patient and their willingness to learn, even in times of war.





MAIN OUTCOMES OF THIS EDITION:

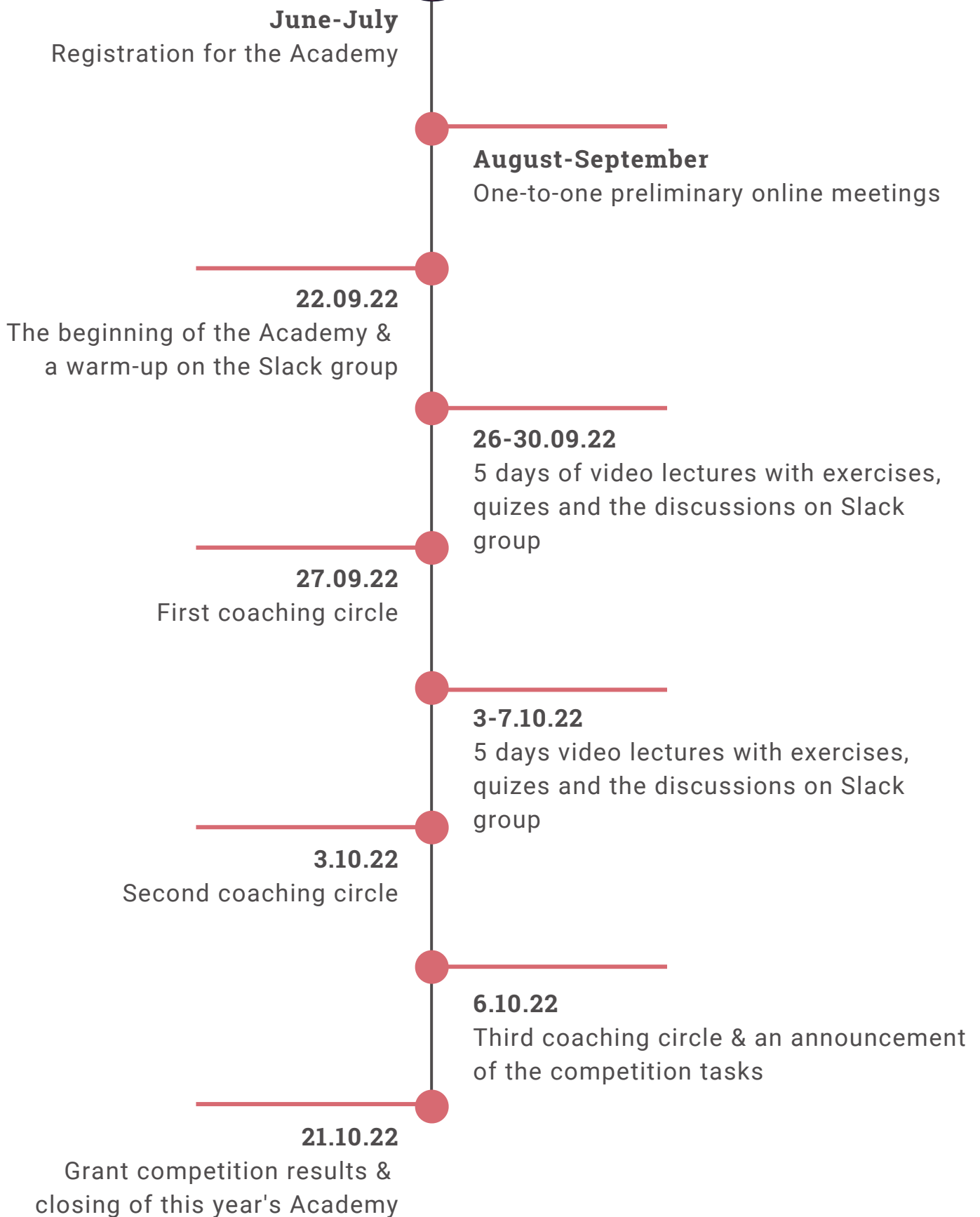
- Gaining knowledge about the long-term impact of a **COVID-19 pandemic** on patients
- Gathering information about **plasma donations** and **PDMPs**
- Learning how to effectively fight for an **access to treatment**
- Finding out how to improve comfort and take care of **newly diagnosed patients**
- Learning how to prepare **interesting meetings** and **conferences** for patients
- Getting to know how to start preparing valuable **podcasts** and **video materials**
- Finding possible ways of supporting **Ukrainian patients** in a long-term perspective

“

Advocacy Academy has helped me a lot in the past. Every time there is something new to learn and I hope we learn lots of new things from each other.

”

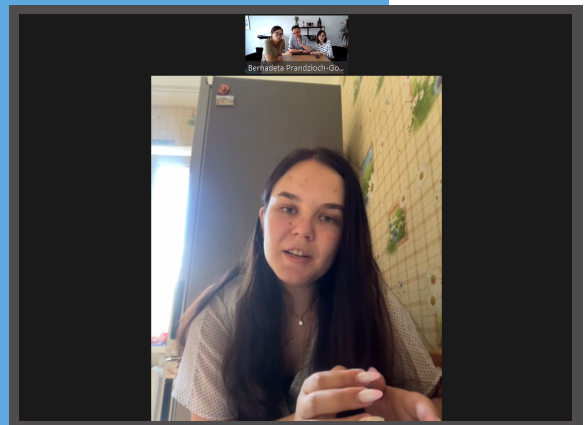
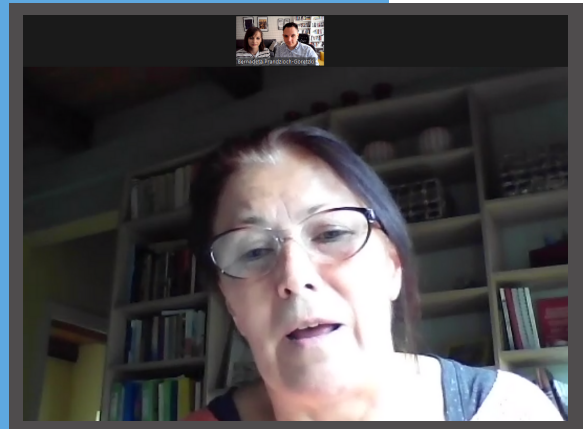
Schedule



We started this year's edition with **1-to-1 preliminary online meetings** with registered participants to learn about the situation in their countries regarding treatment and access to care, and to find out what challenges they are currently facing as patient advocates. It allowed us to adjust the topics of our online circles to their most urgent needs.

4 MAIN PROBLEMS FACED BY PARTICIPANTS

- No reimbursement of drugs for their disease or insufficient number of products available in their country
- Shortages of plasma-derived medicines as a consequence of the covid-19 pandemic
- Health insurance not covering all expenses related to treatment and rehabilitation
- Problems with the long-term engagement of volunteers in the activities of the patient organization



" I'm so excited for this given opportunity as I will have a chance to share my challenges, experiences, doubts as a new organization and to find helpful solutions from all of you. "

How does PATIENTADVOCACY.ACADEMY look in practice?

1. Videos full of knowledge with many case studies & practical examples




This year we created **10 video lectures**, 10-15 min. each, covering the most important topics related to global challenges.




We also took care of **the subtitles** so that each participant can understand the content, even if he or she is not fluent in English.

Each video also consisted of many additional **screens, charts and infographics** to make learning easier and more enjoyable.

How to prepare your guests for what they can expect?

-  Send a **list of questions or topics** for discussion
-  Arrange a **short phone call or video call** before recording
-  Ask a guest to complete a **short questionnaire on Google Forms**

 Inform your guest before recording **what equipment they'll need** – a quiet room and headphones with a microphone


2. Educational materials to support learning and putting knowledge into practice


For each video lesson, **additional educational materials** were prepared, which allowed participants to consolidate their knowledge and immediately translate it into practical solutions for their patient organizations.

Exercises
in PDF files



A short 3-question quiz
for each lesson

PRACTISE PAGE  PatientAdvocacy.Academy
Powered by Healthcare Education Institute VIDEO 3

 THE ANNUAL PATIENT QUESTIONNAIRE AS A FORM OF MONITORING ACCESS TO TREATMENT

? After today's lesson, you already know how important it is to regularly monitor access to treatment, even in a situation where we feel that everything is fine and patients have access to treatment. Try to prepare 4-5 questions for the annual patient questionnaire you are in contact with to make sure nothing worrying is going on. What will you ask?

- 1
- 2
- 3
- 4
- 5

! Remember that in the future you can use simple solutions such as a [Google Forms](#) for this type of activity!

1 / 3

What action will you take when you get a call from a patient saying he/she is being refused treatment?

incorrect

I will go to the media so that everyone will know about this situation ✘

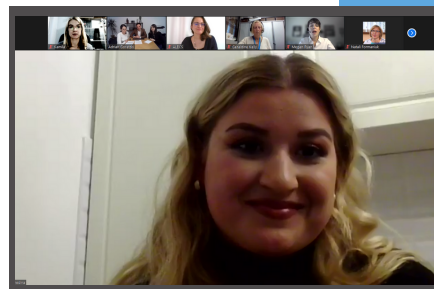
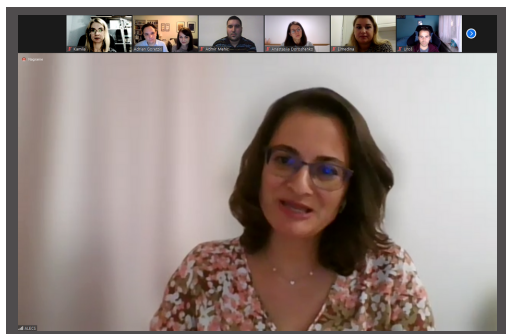
I will get as much information as possible from the patient, I will try to verify it with the other party, for example a hospital or a physician, if confirmed, I will intervene in the Ministry, if the Ministry doesn't want to cooperate I will go to the media

I will wait until I receive similar information from other patients, then I will call the Ministry's hotline to report the problem

Continue >

3. Online video circles to discuss the most challenging issues

During this edition there were **3 online video circles**. We looked at the challenges the participants face on a daily basis in their patient organizations and discussed possible solutions. We shared experiences, showed examples of good practices and inspired each other!



“ Thank you all for these interactions! It was such a pleasure to hear and learn from all of you! ”

1

How to engage volunteers into patient organization’s activities?

We showed some examples of well-organized cooperation between a patient organization and its volunteers. We answered to the question of what makes volunteers unwilling to get involved in the activities of the organization and how to avoid such situations.

2

What to do when there is no reimbursement or there are medicines shortages in your country?

We looked at some case studies of the organizations that dealt with such situations in the past. We talked about the current problems related to access to treatment in their countries and together we found possible solutions ready-to-use.

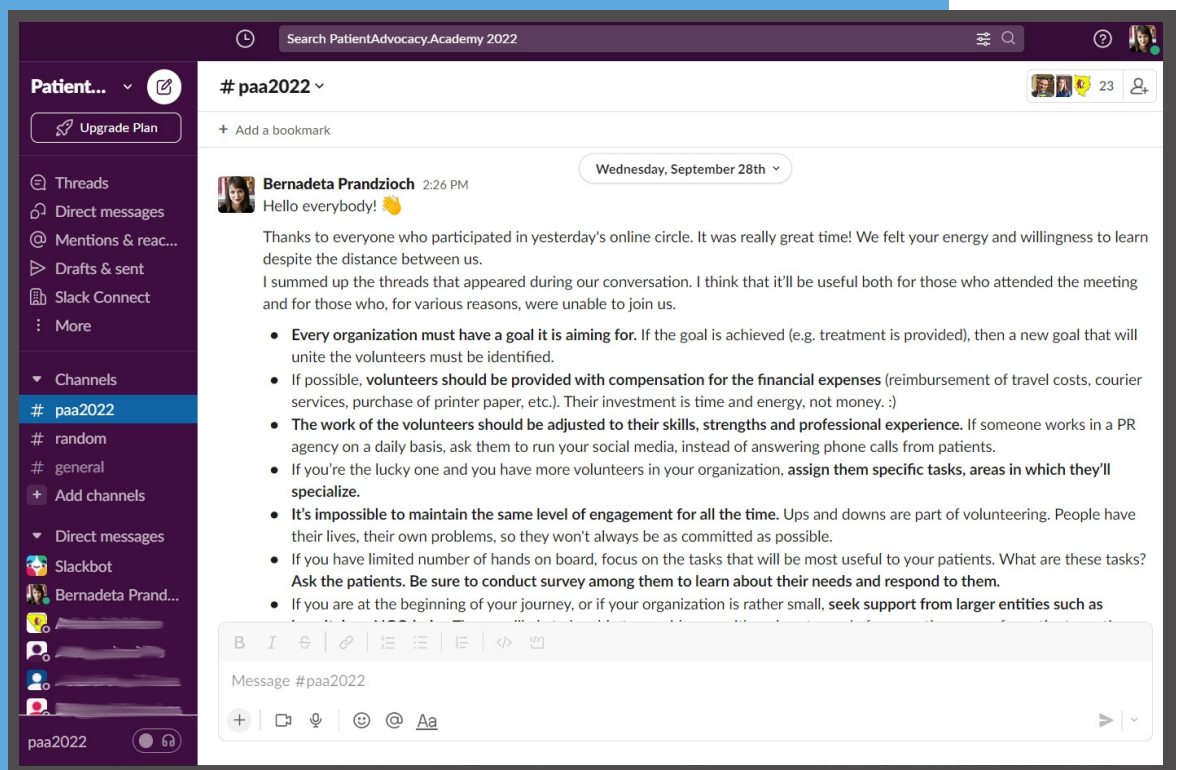
3

What is the situation of Ukrainian rare disease patients? How we as a community can help them?

We discussed the situation of refugees in different countries and tried to find the best way to help them as a community.

3. Ongoing communication on Slack group

To get to know each other even better, we launched a **Slack group** for all participants of the Academy. This is where we commented on each lesson, shared our successes in the area of patient advocacy and inspired each other for further actions.



“Yesterday I was thinking about a new approach involving volunteers from our patients. I plan to conduct a new survey and analyze the education and abilities of each. (...) Thanks everyone for the ideas, it's helpful.”

GRANT COMPETITION

Every year PatientAdvocacy.Academy is an opportunity not only to learn, but also **to win a prize** – an unrestricted grant for the activities of participants' patient organizations.

There were two grant competition tasks to complete.

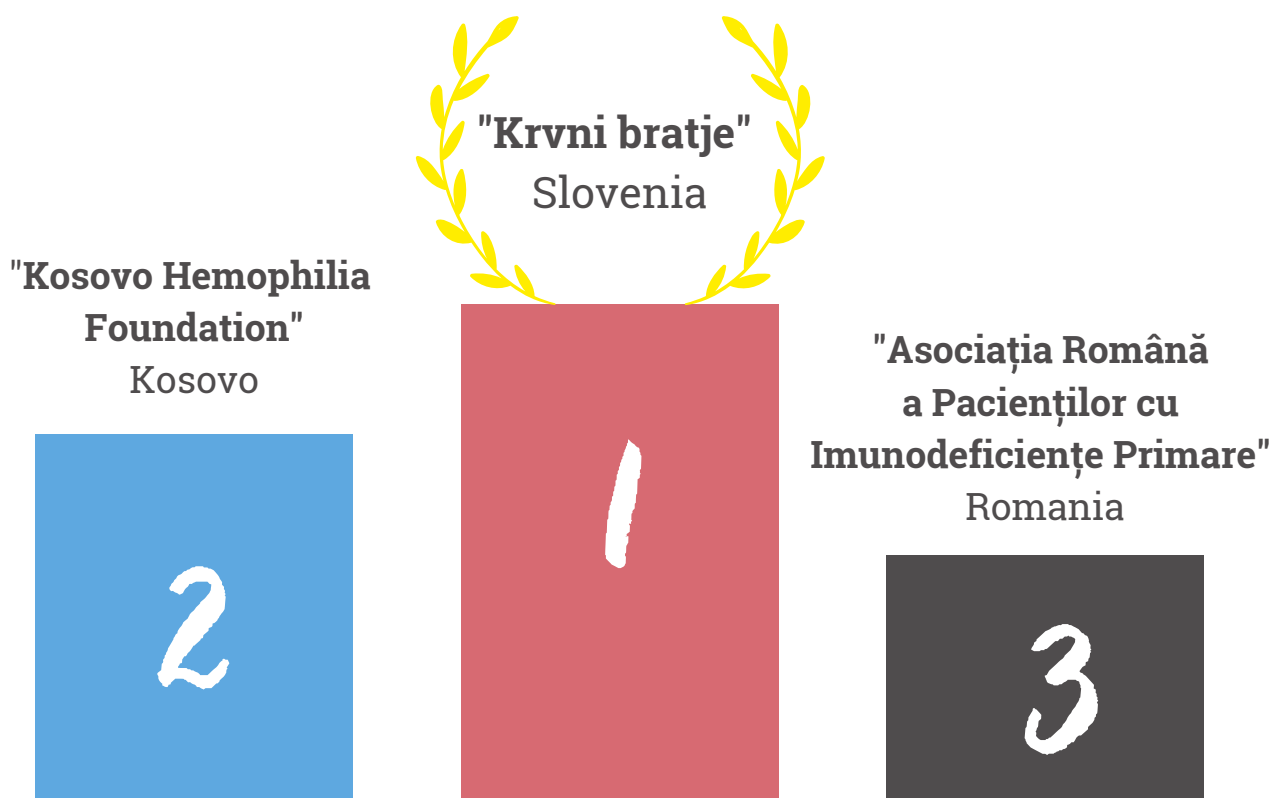
In the first task participants had to send us **3 filled Practise Pages**. In the second task they had to think about **the biggest challenge for their patient organization at the moment**, to **describe the problem** and **create an action plan**: how they will try to change the situation step by step.

The best projects were chosen by the Healthcare Education Institute board members and granted with a support:

1st place – 1000 €

2nd place – 800 €

3rd place – 600€



Participants' assessment of this year's Academy

We conducted **the survey** among participants after the end of the Academy to hear about their experiences and how they evaluate various aspects of this year's edition.

We are proud to say that **once again the participants rated PatientAdvocacy.Academy very highly**. This is the best reward for us and motivation to continue working on the next editions.

9,8

Choice of
the subject



9,8

Usefulness of
the information

10

Interesting way of
presentation

9,5

Additional elements supporting
learning – quizzes and exercises

9,0

Online meetings
on Zoom

In the survey, we also asked the participants **which topics of this year's academy were most important to them**. The vast majority marked two topics:

- How to effectively fight for **an access to treatment** during a global crisis?
- **New trends in education** – how to use it in patient organization?

We also asked them **what information or sentence they heard during the course was most important or useful to them**. Here are some answers:

“

Video about monitoring access to treatment and the homework gave me an idea how could we more efficiently get an idea what is happening with our community regarding the treatment our patients are receiving (...)

”

“

Leaflets and brochures, everything about website. Now I know how necessary is to make short videos for patients (...)

”

And when asked **if they would like to participate in such a course in the future**, everyone answered:

**DEFINITELY
YES**



Participants' opinion about this year's Academy

We have already placed some of the participants' opinions and comments on the previous pages of the report, but here you can read **some thoughts from the survey after the Academy:**

“

*Thank you very much! **It was very interesting and useful.** We have taken a lot of new ideas for our patients, website and volunteers.*

”

“

***Everything was incredible,** and I learned to many thing, especially it was a bit challenging for me to do practise pages, but so fun!*

”

“

***Great job,
thank you very much!***

”



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Thanks to the generous support of our Sponsors
there have been 5 editions of the
PatientAdvocacy.Academy.

Each of them means **many hours of learning,
exchanging experience and acquiring
new skills**. Each of them means **new well-
equipped patient advocates**.

Together we can build a great community of
incredible Leaders of patient advocacy groups!