European Respiratory Patient Academy

13–16 NOVEMBER 2025
PRAGUE

EVENT REPORT

European
RESPIRATORY
PATIENT
Academy

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Executive Summary

4
days

12
sessions

24
countries

21%
average learning increase

70
attendees

The **European Respiratory Patient Academy** took place in Prague **from 13–16 November 2025**, bringing together advocates from across Europe for intensive training and collaboration. The Academy strengthens Europe-wide respiratory advocacy by **equipping patient leaders with the skills, confidence, and shared frameworks** needed to influence policy, support research, and improve access to care.

Uniting **seven European respiratory organisations,** representing hundreds of national groups and more than 600,000 patients, the Academy builds a stronger, collective patient voice. In 2025, it **empowered 42 advocates** with practical tools and evidence-based methods that are already being applied in national advocacy planning and cross-country collaboration.

Governance

The Academy is led by the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) and co-developed with a Steering Committee of leading patient organisations. The Steering Committee guides the Academy's strategic direction, ensuring the content is relevant, patient-centred, and aligned with the needs of respiratory communities across Europe.

Steering Committee Members

Marcia Podesta, European Federation of Allergies and Airways Diseases Patients' Associations (EFA) - **CHAIR**

Frank Willersinn, Alpha-1 Europe Alliance

Hilde Dekeyser, Cystic Fibrosis Europe (CF-E)

Liam Galvin, European Pulmonary Fibrosis Federation (EU-PFF)

Hall Skaara, Pulmonary Hypertension Association Europe (PHA-E)

Debra Montague, Lung Cancer Europe (LuCE)

Paul Sommerfeld, Tuberculosis Europe Coalition (TBEC)

About the event

Impact at a glance

100%

sessions resulted in a knowledge increase, with gains ranging from 11% to 37%

100%

rated the overall content positively

93%

rated the overall programme positively

96%

reported being better prepared and more confident in their advocacy role

9

respiratory disease areas strengthened their cross-disease solidarity

communication, research literacy & stigma reduction identified as the strongest skills to apply immediately.

clear, actionable advocacy priorities and **mapped national-level stakeholders** developed.

enhanced organisational knowledge of **governance, funding, and sustainability.**

Feedback combined quantitative scores and qualitative comments. Trainees completed on-site self-assessments, and 28 participants submitted post-event evaluations.

Strategic value

Chronic respiratory diseases affect more than 80 million people in the WHO European Region, with millions more undiagnosed, based on a report from the World Health Organisation and the European Respiratory Society published in 2025.

In this context, the Academy directly responds to **EU-level priorities**, including Health Technology Assessment (HTA) implementation, disease prevention, digital health integration, and reducing health inequalities, by equipping advocates with skills to influence these policy areas at national and European levels.

The Academy strengthens **national-level advocacy** by providing participants with frameworks to map decision-makers, analyse system gaps, and align national strategies with broader EU policy developments. Through shared learning, the Academy unites diverse disease areas for collective impact, supports the development of consistent, reinforced messages that resonate across Europe.

Participants were assessed before and after the training sessions to capture baseline levels of knowledge and confidence, as well as the progress made following the training. The results showed a statistically significant increase in knowledge across all 29 topics, from moderately confident to quite confident demonstrating a clear and meaningful learning effect.

Setting the scene

The European Respiratory Patient Academy is a dedicated learning platform that empowers respiratory patient advocates across Europe, strengthening their role as equal partners in healthcare, research, and policy-making.

70 attendees from 24 countries, the event brought together a diverse community of respiratory patient advocates and leaders

42 patient advocates trained and equipped with practical tools to launch campaigns, lead organisations, and influence policy

12 expert-led sessions that strengthened core skills across advocacy, research involvement, leadership, and organisational sustainability

1st cross-disease training for lung conditions, strengthening collaboration between umbrella patient organisations

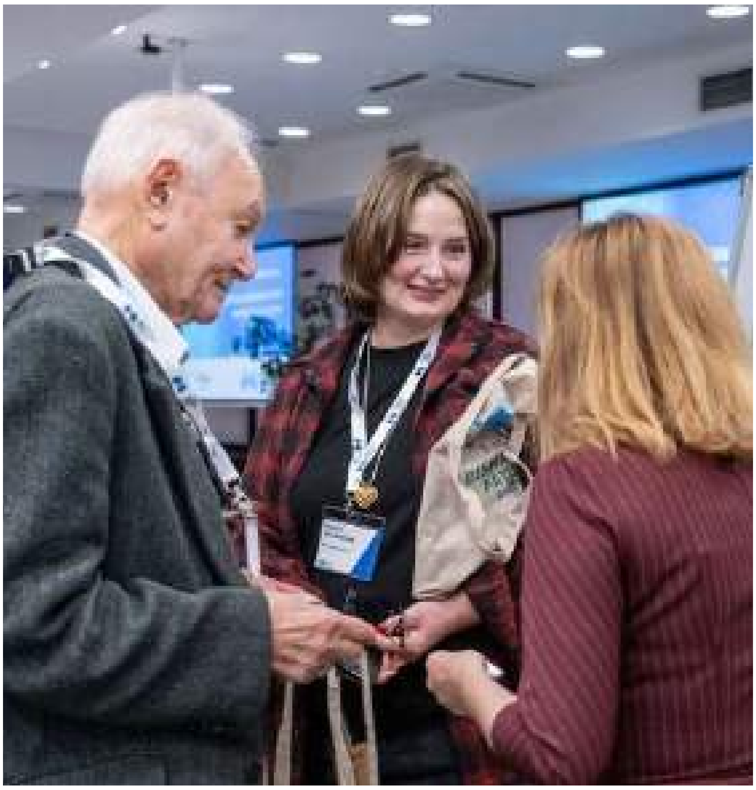
After the Academy, participants will be able to:

- Influence policymakers through evidence-driven messaging.
- Develop and sustain multidisciplinary coalitions.
- Drive national advocacy efforts more strategically.

Outcomes and key learnings

Welcome

> “We want our patient community to remain powerful beyond the Academy, so we place a strong emphasis on collaboration, peer support, and shared experiences.”
>
> **Marcia Podesta, EFA President**



Strengthened Advocacy Capacity

What participants gained

- Improved ability to identify disparities and set clear advocacy goals.
- Enhanced problem-solving and negotiation skills.
- Strengthened leadership, strategic thinking, and resilience.
- Greater capacity to manage organisations through governance, and sustainability.

> This gave great insights and will help my organisation in the future.
>
> **Trainee**

Strengthened Advocacy Capacity

Evidence of self-reported competency increase

22% confidence in setting advocacy goals

17% ability to apply leadership tools

15% ability to identify and diversify funding opportunities

17% ability to assess organisational governance structures

Trainees used on-site self-assessment forms to rate knowledge pre- and post-session.

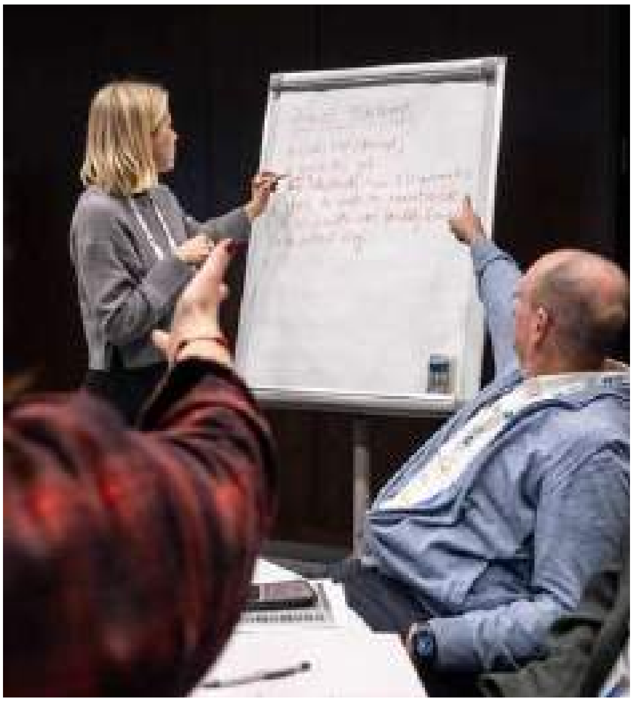
> As most relevant, I'm an advocate but not always effective. Here, I got some tips to use to be more effective, and will at least try to use tips and advice.

Trainee

Strengthened Understanding of Healthcare Systems, Policy and Access

What participants gained

- Deeper understanding of European healthcare system structures and decision-making.
- Ability to identify barriers and inequities in access across Europe.
- Improved capacity to engage policymakers using evidence, economics, and system insights
- Strengthened ability to analyse regional disparities and map stakeholders.
- Higher confidence to collaborate with policymakers, HCPs, and industry.



> Again, like a lot of you, to get that really good understanding of what European HTA is, and what the national drivers and leaders need to do… I think that was a great session.

Trainee

Strengthened Understanding of Healthcare Systems, Policy and Access

Evidence of self-reported competency increase

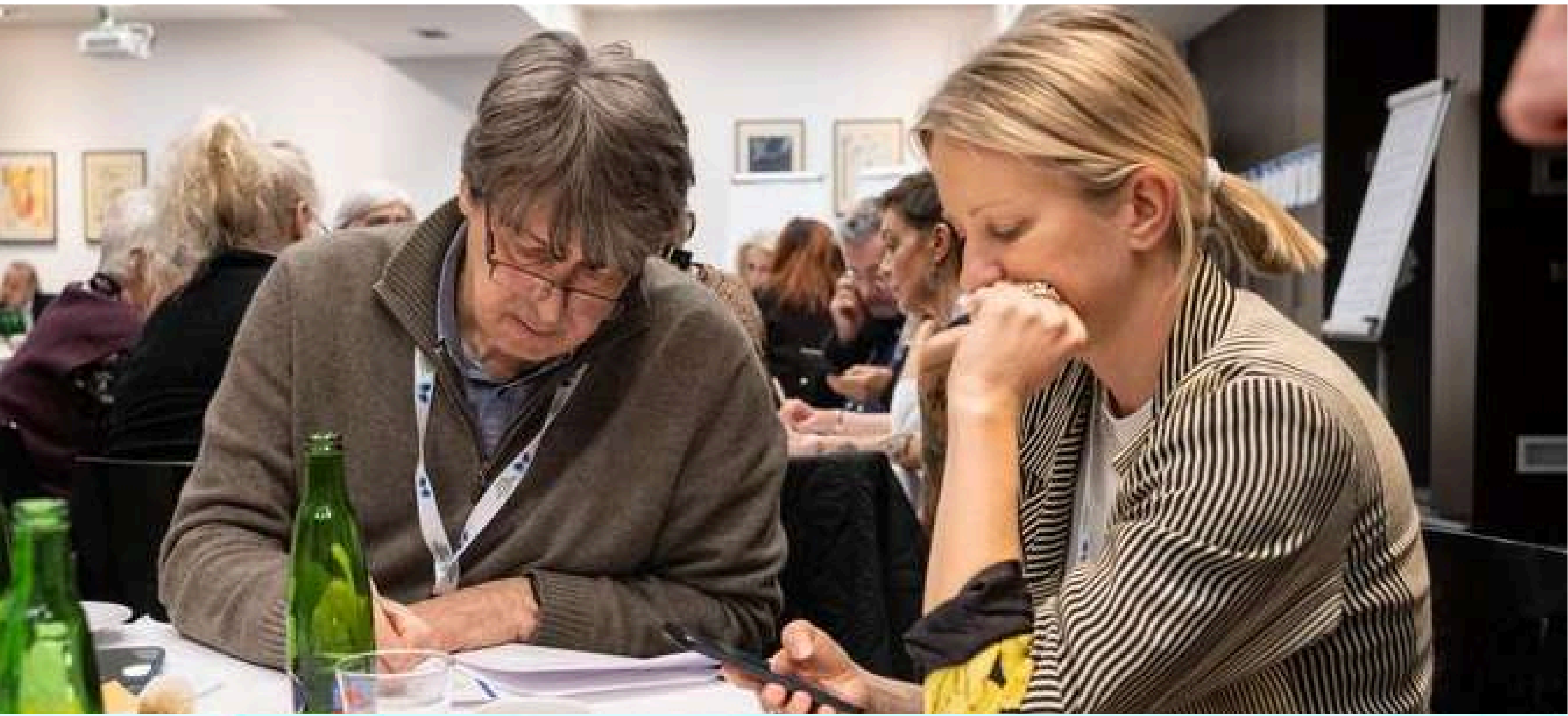
21% confidence in analysing disparities in healthcare access

34% increased understanding of structures and decision-making in healthcare systems

27% ability to engage effectively with stakeholders at both national and European levels

25% confidence engaging cross-sector stakeholders

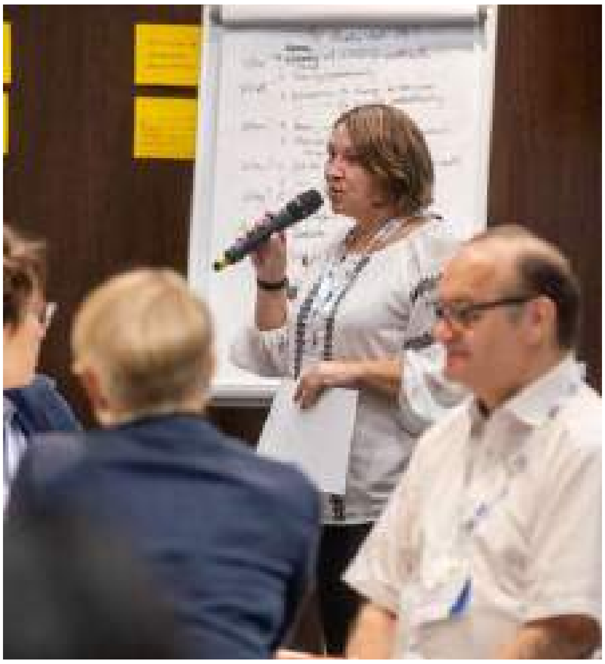
Trainees used on-site self-assessment forms to rate knowledge pre- and post-session.

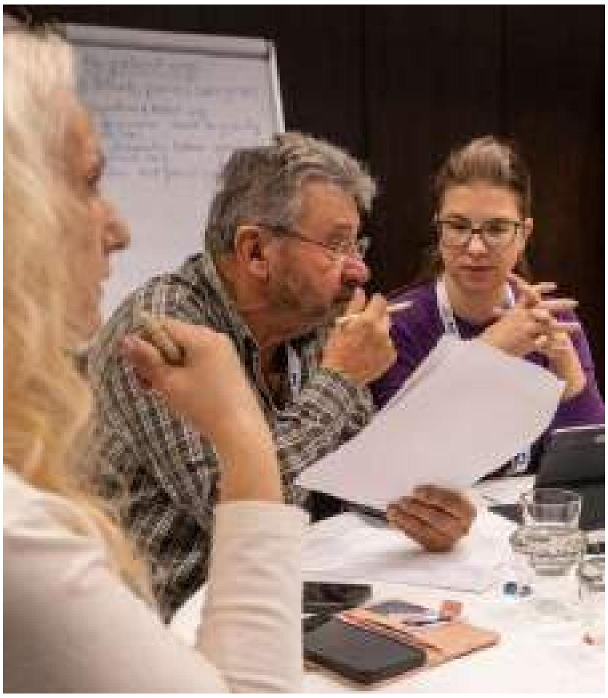


Strengthened Research and Data Literacy

What participants gained

- Improved ability to read, interpret, and understand scientific evidence.
- Increased capacity to advocate for patient-centred research.
- Better understanding of the role of patients in shaping research agendas.
- Ability to link scientific findings to real-world needs.





> It was interesting to take away just from looking at the clinical papers. I've got a background in pharmaceuticals, and I picked up some key learnings and new pieces of information today, which was great.
>
> **Trainee**

Strengthened Research and Data Literacy

Evidence of self-reported competency increase

20% ability to critically assess the quality and relevance of research for patient advocacy

19% confidence interpreting scientific studies

17% confidence understanding patient-centred research

15% ability to identify opportunities for patient involvement across different stages of the research process

Trainees used on-site self-assessment forms to rate knowledge pre- and post-session.

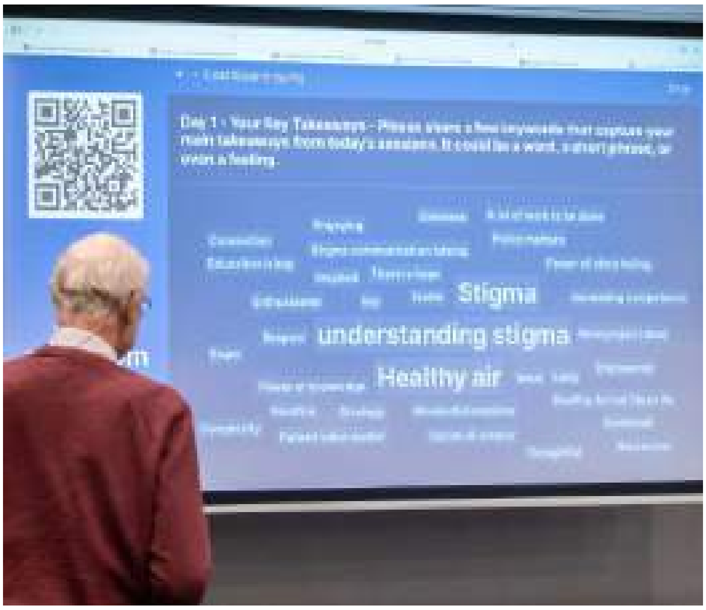
> “The problem is that the patient is not included from the first time… because sometimes you see us review the research, and then when the research goes out you see that your opinion is not important for that.”

Trainee

Strengthened strategies to reduce stigma and raise public awareness

What participants gained

- Strategies to reduce stigma across different settings (home, work, school, public).
- Ability to craft stigma-reducing communication.
- Higher confidence addressing misconceptions in respiratory diseases.
- Understanding of how stigma shapes behaviour, self-perception, and systems of care.
- Capacity to integrate stigma-reducing approaches into advocacy campaigns.
- Improved ability to craft audience-tailored messages.



> Everything depends on how communication goes to other partners and the public. A very inspiring session.
>
> **Trainee**

Strengthened strategies to reduce stigma and raise public awareness

Evidence of self-reported competency increase

38% confidence in planning prevention and awareness campaigns

29% ability to promote healthy behaviours in communities

31% confidence in communicating effectively to reduce stigma

20% confidence in leading with resilience, adaptability, and clear communication

16% ability to craft clear, persuasive, and audience-tailored advocacy messages

Trainees used on-site self-assessment forms to rate knowledge pre- and post-session.

> “Stigma follows people everywhere: at home, at work, at university. So, we need actions in all these settings.”

Trainee

Voice of advocates

> We came from different countries and diseases, but we worked as one community. That was really powerful.

Trainee

> I thought I was a small fish in a big ocean, but now I see the diversity of respiratory diseases and the value of working together.

Trainee

> I realised how important advocacy is and that I need to be braver and take this role more actively.

Trainee

Networking Evening

The Networking Evening created space for advocates to build meaningful connections across disease areas, exchange real-life experiences, and learn from one another. It fostered peer-to-peer support and opened doors for future collaboration beyond the Academy.

100% **of participants rated the Networking opportunities as excellent**

Feedback Summary

100% of participants would recommend the training

What participants valued most

- Clarity, practicality, and relevance of sessions.
- Trainers simplify complex topics and link them to real advocacy work
- Opportunities for meaningful connection.
- Participants value the Academy and support its annual offering.

> “Salvatore was incredible in translating a dry, complex topic into understandable pieces with fun.”
>
> **Trainee**

> “This has been a great platform, and I hope it becomes an annual event.”
>
> **Trainee**

Top-rated sessions

Salvatore Pirri – Understanding and influencing healthcare systems

Alfonso Aguarón – Advocacy essentials: strategies for driving meaningful change

>95% of participants classified both sessions as **Excellent/Good**.

28 participants completed the post-event evaluation forms, combining quantitative and qualitative questions

What participants want to see in the next Academy

Participants expressed a strong interest in expanding the programme with **more research content**, more hands-on **toolkits** to support practical advocacy work, and dedicated sessions on social media, digital skills, and the **use of AI** to strengthen organisational capacity.

Key takeaways identified by participants

Participants identified **communication** as the strongest learning and the key element they plan to apply in their advocacy work, and highlighted **stigma** as the most relevant topic due to its importance for patient advocacy, communication, and understanding patient viewpoints.

Future improvements

We will work to adopt cleaner, **more accessible slide designs** with reduced text and larger fonts to support clearer listening and learning.

We will make our best efforts to **streamline presentations**, helping participants follow the content without feeling overloaded.

We are committed to ensuring **better-distributed discussion areas in the same room**, improving participants' ability to hear, engage, and contribute comfortably for the future editions.

Impact beyond the event

The impact of the Academy extends well beyond the four-day training. Participants developed practical skills and created tools that they will continue applying at a national and international levels long after the Academy.

Focused advocacy goals

Each participant defined a SMART advocacy goal, mapped key stakeholders, and outlined first steps for targeted campaigns.

> “I’m going home with concrete actions: using the economic learnings, applying the SMART forms, and strengthening coalitions.”
>
> **Trainee**

From awareness to concrete micro-actions

Trainees created tailored anti-stigma actions and messages for different stakeholders, supported by ready-to-use tools like a stigma-mapping framework.

> “Hearing patient voices and stigma experiences was eye-opening. I’ll take this back to my clinicians.”
>
> **Trainee**

Strengthened patient involvement in research

Attendees learned to use patient-centred evidence in discussions with clinicians and policymakers, and to extract key messages from scientific data for advocacy.

> Knowledge is power. This Academy showed why data matters for real advocacy impact.

Trainee

Strengthening long-term partnerships and collaboration

Participants identified key peers from the Academy to reconnect with after the event and planned future coalition activities, strengthening the European respiratory advocacy network.

> Meeting other advocates showed me I'm not alone. I'm taking these contacts with me.

Trainee

Building future engagement for next editions

Building on the learnings of the Academy, the Steering Committee members are reviewing outcomes, gathering trainee feedback to inspire future attendance, and discussing possible follow-ups for 2026.

> You came here from different countries and disease areas, but you worked as one community of patient advocates (...) and showed what a united respiratory patient movement in Europe can look like.

Marcia Podesta, EFA President

Thank You

The success of the **European Respiratory Patient Academy 2025** was only possible thanks to the commitment of the organisers, the dedication of the Steering Committee, and the generous support of sponsors.

Together, we built a platform that not only trained but also connected respiratory patient advocates across Europe, paving the way for stronger, united advocacy in the years ahead.

Platinum

AstraZeneca

GSK

Gold

sanofi | REGENERON

OM PHARMA

Silver

MENARINI group

Roche

Chiesi

MSD

Boehringer Ingelheim