EUROPEAN
LUNG
FOUNDATION

Patient Organisation Networking Day 2025

Saturday 27 September 2025, Amsterdam

Report summary

Introduction

ELF Patient Organisation Networking Day 2025 was held on Saturday 27 September in Amsterdam as a hybrid event. This was also the 10th anniversary of Patient Organisation Networking Day.

The theme for the day was 'Improving respiratory health – thinking globally, acting locally'. The programme included keynote and patient organisation speakers, interactive breakout groups and question and answer (Q&A) plenary sessions.

A recording of the event can be viewed on the ELF website at https://europeanlung.org/en/get-involved/events/patient-organisation-networking-day-2025/. To watch the talks and videos summarised below in full, please view the recording.

In this report statistics are tracked up to 8 December 2025. There have been 49 views of the event recording to date.

Attendance

106 individuals attended the event in-person from 24 countries.

There were also 21 online registrations from 10 countries with nine participating in the breakout discussion groups.

The livestream had 81 unique participants from 34 countries, with an average watch-time of 106 minutes.

Networking

Based on the positive response to last year's opening networking activity, a 50-minute networking session was included before virtual attendees joined. Members of ELF and ERS leadership including the ERS President and ERS President Elect were present.

Welcome

Dimitris Kontopidis, ELF Chair, opened the event with a warm welcome to all attendees and highlighted that this is the 10th year of holding this event. He thanked the working group members that helped to plan the agenda and then spoke about his 3 highlights from the year:

2. European Parliament event in Brussels with the MEP Lung Health Group.
3. Joining a global audience in Cartagena, Colombia at the World Health Organisation's (WHO) Second Global Conference on Air Pollution and Health.
4. The founding of an umbrella association for lung health in Greece.

Morning session

The morning session was co-chaired by Liam Galvin, EU-PFF board member and Chair of ELF Patient Advisory Committee and Louise Bouman, President of the Dutch Pulmonary Hypertension Association and board member of the Alliance for PH.

ERS President and President-Elect speeches

Professor Silke Ryan, ERS President focused on the commitment and dedication of the collaboration that exists between people living respiratory disease and respiratory professionals. A highlight of her ERS presidency has been the interactions with patients including at the Sleep and Breathing Conference where she learnt a lot.

Professor Joanna Chorostowska-Wynimko, ERS President-Elect, spoke about the issues that we can work on together in the future and how the voices of patients are invaluable and that in working with ERS we have the power to change things.

Keynote speeches

The first keynote speech of the day - **'Our Kids' Climate: Building parent power for clean air'** was delivered by Maya Mailer, co-director of Our Kids' Climate, an anchor organisation for the global movement of parents, grandparents and concerned adults taking action to protect children from the impact of the climate crisis. Maya shared how they build parent power for clean air through supporting community leaders to develop locally driven campaigns addressing air pollution and its health impacts.

Our Kids' Climate was awarded the 2025 European Lung Foundation (ELF) Award for its outstanding contribution to safeguarding children's respiratory health worldwide.

The second keynote speech was entitled **'Science Under Threat: What it means for patient rights and public health'** given by Professor Barbara Hoffman, Chair of the European Respiratory Society (ERS) Advocacy Council. Barbara highlighted current threats to science which included mis-information and deliberate dis-information; censorship; funding cuts and data access restrictions. The impacts on patients were explored such as decreased access to accurate information; increased scepticism towards vaccines; psychological effects; health insurance not reimbursing certain medical services and overall worsening of health outcomes.

A panel discussion and Q&A followed.

Patient Testimonial Video 1

An ELF video demonstrated how a range of issues and challenges are affecting people with lung conditions across the world and how patient advocacy can be impactful. The video featured experiences from: Sandra Baxendell, Australia; Maria Clara Castellões de Oliveira, Brazil; Dicky Sudrajat, Indonesia; Asunción Manríque, Mexico; Adnan Wshah, Jordan; Tom Bermingham, Ireland; Nancy Elena Rivas Elizondo, Costa Rica; Glenn Kitchener, Canada; Maria Alioto, USA; Resty Musigula, Kenya and Dhiraj Agarwal, India.
View video at: https://youtu.be/p0ZMPTlwclE

ELF Patient Organisation Network presentations on advocacy initiatives

The first talk on '**Clean Air Healthy Lives Campaign'** was given by Shane Fitch, President of Lovexair Spain. The campaign empowers communities and policymakers with data, tools and actions to advance respiratory health worldwide. Information about the digital tool Check@ir was shared which provides an online questionnaire, available in three languages, and provides a personalised report by email and a lung health guide for practical steps for self-care and protection. Trends will be analysed in the future.

The second talk was on **'Crop Phenomenon: A model of persistent advocacy to boost childhood vaccination and respiratory health'** delivered by Dr Ghulam Mustafa of the Helping Hands Foundation, Pakistan. They discovered that children in the community were not being vaccinated even though there were centres providing this. The challenge identified was how to motivate people. A programme was devised using local women to speak with families about vaccination issues and to deliver good health messages around maternal health. It took several rounds before progress and success was seen and the message learned was to be persistent.

Patient Testimonial Video 2

An ELF video was showed which focused on different activities and campaigns from patient organisations around the world and featured: Carlos Pons, Respiralia Foundation, Spain; Dr Arno Vermeulen, Dutch Post-infectious Bronchiolitis Obliterans

(PIBO) Foundation, Netherlands; Nicole Hass, Spanish patient organisation of COPD, Spain; Justine Hamaïde, Non-Tuberculosis Mycobacteria Association, Mon Poumon Mon Air, France and Satu Mustonen, The Organisation for Respiratory Health in Finland. **View the video:** https://www.youtube.com/watch?v=ZhNIriv0A-k&feature=youtu.be

A panel discussion and Q&A followed.

Afternoon session

The afternoon session was co-chaired by Marion Wilkens, leader of the Alpha-1 German association and Luca Roberti, founder of Italian sleep apnea patient association and member of Sleep Patient Advisory Group who opened the post-lunch session.

The afternoon session focused on break-out discussion groups with an opening talk on the '**WHO Lung Health Resolution'** by Mr José Luis Castro who is the WHO Director-General Special Envoy for Chronic Respiratory Diseases.

José stressed that the Resolution is just the starting point and for change to happen these commitments must become clinics or medicines and lead to healthier lives. Just as patient voices carried them this far, now patient demands must be carried into parliaments, into budgets and into law.

Read the full WHO lung resolution at https://apps.who.int/gb/ebwha/pdf_files/WHA78/A78_R5-en.pdf

Break-out discussions

Attendees took part in break-out discussion sessions focusing on the WHO Lung Health Resolution. Discussions explored what it means to patient communities and what organisations are currently doing to address the points in the Resolution.

ELF provided a summary of the key points from the Resolution and a Personal Action Plan for each participant which included suggestions from the advocacy team on actions patient organisations can take to help put the Resolution into practice. Participants were encouraged to add their own notes, reflections and actions to take away with them.

A summary of the break-out discussions can be found at https://europeanlung.org/wp-content/uploads/2025/12/Patient-organisation-networking-day-2025-breakout-discussion-report.pdf

ERS International Congress 2026:

Professor Hilary Pinnock as chair of the ERS Education Council will oversee the programme for the ERS Congress 2026 and introduced the Congress theme for 2026 - **'United for Better Breathing: partnership between patients, clinicians and researchers'** and the 3 priority topics that will shape the programme:

1. Co-creating care: patients as equal partners
2. Listening first: identifying and acting on unmet needs
3. Discovering together: advancing science through collaborative research

Hilary stressed that collaboration is going to be key for the success of the 2026 Congress and asked people to share their innovative ideas with ELF at info@europeanlung.org and clinical colleagues from ERS Assemblies.

Celebration of 10 years of Patient Organisation Networking Day!

Mikaela Odemyr, past Chair of ELF Patient Advisory Committee, shared her reflections of attending Patient Organisation Day over the past decade. Mikaela shared some of the inspirational friendships she has made over the years which encouraged her to get more involved. Her observations included that more patient organisations are getting involved each year and the benefits of learning from each other and sharing our challenges and achievements. Mikaela thanked everyone for the planning of the event over the years.

The talk concluded with a video which took a visual celebratory look back at the last 10 years of Patient Organisation Networking Day.

ELF chair closing remarks

Dimitris Kontopidis, ELF chair, closed the event. Dimitris thanked theh ERS President and President- Elect on emphasising the role of patients and congratulated Our Kids Climate on their wonderful initiative. He also thanked WHO for working with patients and for the discussions today that have linked the resolution with patient experience. He called for the inclusion of youth voices for future success, to map the knowledge we have and to continue to work collaboratively.

Watch the full Patient Organisation Networking Day event:

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