# Patient Organisation Networking Day 2024

# Overview report

## Introduction

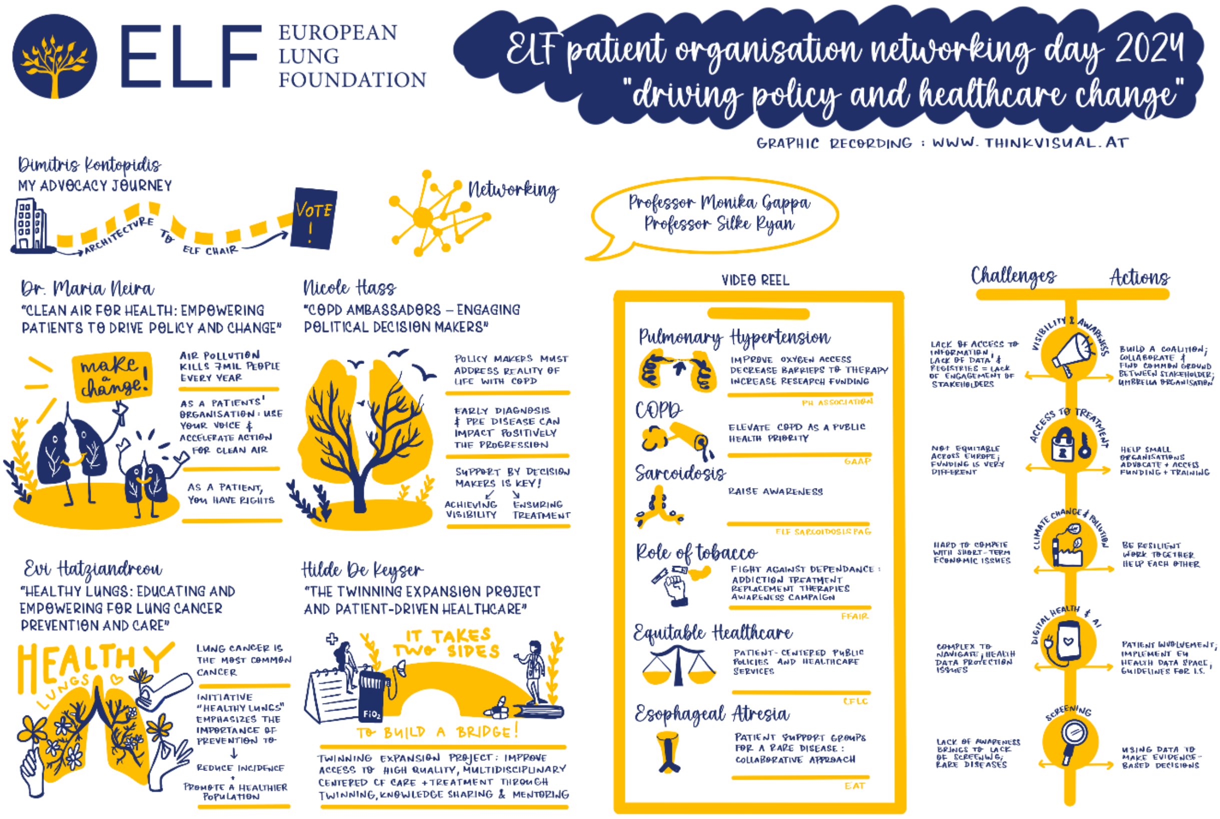
ELF Patient Organisation Networking Day 2024 was held on Saturday 7 September both in Vienna, Austria and online. This was the 9th time the event has been held, and the second time that it ran as a hybrid online and in-person event.

The programme had as its theme ‘Driving policy and healthcare change’. It included keynote and patient organisation speakers, interactive breakout groups and question and answer plenaries.

[Recordings from the event are available on the ELF website.]

In this report statistics are tracked up to 5 December 2024.

Illustrations are provided by a graphic artist who attended the day.



**Attendance Overview**

89 individuals attended the event in person with 4 people attending online.  They came from 29 countries. The livestream had 550 unique participants from 81 countries, with an average watch-time of 25 minutes.

**Networking activity**

Based on feedback from last year, we included a dedicated networking activity at the start of the event to provide wider opportunities for attendees to meet and talk together.

**Presentations**

The keynote talk was on ‘Clean Air for Health: Empowering Patients to Drive Policy and Change’ and was delivered by Dr Maria Neira, Director of Department of Environment, Climate Change and Health, World Health Organization (WHO). Three talks were given by patient organisation representatives and highlighted successful projects on the theme. A summary of each presentation is set out below and full recordings of all presentations are available.

**Keynote: Clean Air for Health: Empowering Patients to Drive Policy and Change**
*Dr Maria Neira, Director, Environment, Climate Change and Health, World Health Organization*

- Air pollution kills around 7 million people per year with 9 out of 10 people living in areas where air pollution exceeds WHO global air quality guidelines.
- Role of health workers extends beyond the clinic – they are a trusted voice for their patients. Raise questions to healthcare professionals to motivate them and use your political power.
- In 2023, COP28! held a health day for first time – 50 Ministers of Health attended. Aim to endorse COP28 health-climate declaration. Want to bring patient organisation voice to COPs in the future.
- Patients organisations can use their voice to drive clean air policy and make change:
  - Integrate air pollution as risk factor for respiratory diseases within your agenda.
  - Organise awareness campaigns and education opportunities.
  - Demand for action to local and national decision-makers.
  - Participate in other sectors activities.
- WHO Global Conference on Air Pollution and Health takes place 25-27 March 2025.

GRAPHIC RECORDING : WWW.THINKVISUAL.AT

**COPD Ambassadors – engaging political decision makers**

*Nicole Hass, Spanish patient organisation of COPD (APEPOC)*

- Campaign to raise awareness of COPD due to low awareness and under-diagnosis in Spain.
- Held 135 regional meetings with political party decision makers about burden of COPD on patients; provided health data and talked about health costs.
- Some were more engaged than others e.g. good press coverage and this support was recognised by giving them each an award.
- Important for policymakers to address reality of life with COPD – stressed importance of prevention through early diagnosis which can impact positively on disease progression.
- Most important communication channel was the media, social networks and the internet.

**Healthy Lungs: Educating and Empowering for Lung Cancer Prevention and Care**

*Evi Chatziandreou, FairLife Lung Cancer Care, Greece*

- FairLife Lung Cancer Care is the first, and only non-profit organization in Greece, exclusively dedicated to lung cancer.
- Healthy Lungs initiative emphasises the importance of preventive health measures including smoking cessation and screening. Ensures individuals can make informed decisions about their health. Advocating for policies that support preventive care.
- Created full day public health events in major cities inviting academics, politicians, influencers to talk about health lung topics.
- Offered free lung cancer screening, wellbeing activities and a website.
- Had a strong presence on social media including creation of podcasts, videos and an App.
- Next steps to hold more events in more areas and cities in Greece with a high prevalence of smoking and vaping.

### The Twinning Expansion Project and patient-driven healthcare

*Hilde De Keyser, Cystic Fibrosis Europe, Belgium*

- One aim of CF Europe is to strengthen the CF community in Europe and they run several projects to help achieve this.
- It takes both sides to build a bridge – and both sides need trust and to work together in openness and in real co-operation.
- Twinning Expansion Project was started by CF Europe and European CF Society working together to improve access to high quality, multidisciplinary centred CF care and treatment.
- Project includes twinning, mentoring and knowledge sharing activities among CF centres and patient organisations in Europe. Has grown from 9 to 21 twinning partners.
- Important to gather unmet needs and unlock knowledge by translating resources, sharing them on line, conferences, exchanges etc.
- “When I is replaced by We, even illness becomes wellness” (Louise May Alcott).

### Patient Organisation video presentation

This year we asked those who had applied to give a presentation and were not selected, to record a short 2-minute video about their organisational activities around driving policy and healthcare change. These were compiled and shown as 2 video reels during the event. There were 6 videos included which enabled a wider number of experiences and projects on the theme of the day to be shared. The videos were made by the following people and organisations:

1. **Caroline Love** from Esophageal Atresia global support groups (EAT) and Tracheo-Oesophageal Fistula Support (TOFS)
2. **Tonya Winders**, Global Allergy & Airways Patient Platform (GAAPP)
3. **Karolien Verheyen**, Patienten Rat + Treff VoG, Belgium
4. **Liliya Belenko Gentet**, French Federation of Association of Patients with Respiratory Insufficiency or Handicap (FFAAIR)
5. **Katie Kroner**, Pulmonary Hypertension Association, USA
6. **Martha Herrera**, Colombian Foundation for lung cancer, asthma, COPD and other respiratory and oncological diseases (INSPIRAT)

You can watch the video reels on the recording of the event.

**Interactive breakout groups**

Participants took part in 2 breakout discussion sessions, with groups focusing on different themes:

- Disease visibility and awareness
- Access to treatment
- Digital health and AI
- Climate change and air pollution
- Screening

The first breakout session discussed the challenges that organisations face. The second explored steps that organisations, or ELF could take to push forward health policy and healthcare changes in the above topic areas.

Each group selected one point from each session to share during the plenary session.

A summary of the breakout discussions can be found on the ELF website.

**Event evaluation**

All registered attendees were sent a feedback survey. 20 people completed the survey: 19 attended the whole event; 1 attended some sessions. Of those completing the survey, all attended in person in Vienna.

Event ratings and feedback

- 45% rated the event as 'Excellent' overall; 40% as 'Good' and 10% as 'Quite Good'. One person rated it as 'Poor'.
- 90% said they would attend Patient Organisation Networking Day again.
- 70% said they had learned something new during the day and that they planned to:
  - Set up some new contacts for future cooperation.
  - Make it easier for members to get involved in raising awareness and talking about their illness.
  - Contact politicians directly at a regional level instead of national level.
  - Try to get more patient information translated into non-European languages, especially South Asian languages and Arabic.
  - Contribute to World Health Organisation (WHO).
  - Consider exploring air quality as an area of research when addressing health disparities.
  - Consider incorporating mentor-mentee relationships in care centres similar to CF Europe.
  - Incorporate more storytelling.
  - Work with ELF to support the work of ERS Assemblies.

People attended the event for a range of reasons:

- 95% to network with other patient organisations
- 60% to share their / their organisation's experience

- 55% to learn more about the topic of the day
- Other reasons given were: to hear patient voices; learn from others

Speaker presentations

- All speakers received ratings of 85%-95% for combined ratings of 'Good' or 'Excellent'.
- Feedback included: "Programme was varied and speakers were engaging" and "Some speakers should talk more clearly - the articulation and the speaking rate".
- Video reels comments: "Liked the video reels and they were a good way to bring additional opinion" and "Videos a bit too short or difficult to link to the main topic."

Networking

- 53 % were 'Very satisfied' with the networking opportunities; 37% were 'Satisfied' and 11% were 'Not satisfied'.
- Comments included: "Sharing problems is fine but I lacked solutions for them" and "Could have a little longer at the start to meet/greet" and "I really enjoyed it" and "Well organised."

Breakout discussion sessions

- The afternoon discussion groups were rated: 61% 'Excellent'; 17% 'Good', 17% 'Fair' and 5% 'Poor'.
- Comments: "These worked really well and allowing each table to participate made for better engagement" and "Very interesting" and "The same topic for multiple tables to find a solution" and "In our group the work was not easy, mostly due to language issues."

Venue

- Several comments were made about the temperature of the room being too cold and that this affected concentration. Also that the catering could have provided healthier options. Ease of access was an issue for some with long distances to walk Long distances to walk and mobility scooters/golf buggies should be considered to be booked in advance.

Information received before the event

- Respondents rated the information received from ELF about the event beforehand as 58% Excellent, 37% Good and 5% Fair. Comments included: Excellent, but please send a reminder to be prepared for the cold of the room on Saturday", "Most was clear and on the event everything became clear", "Having a list of the attendees at the breakout sessions in advance would have been nice" and "Perhaps too much email".
- No issues were reported in registering for the event.

What attendees most enjoyed about the event

- The majority of people highlighted the networking opportunities and meeting with people. Two people mentioned the breakout discussions and 2 people mentioned meeting the ELF team. A few people mentioned the speakers and focus on important topics. Comments included: "It was an amazing networking day"; "Met expectations and benefitted from the high level of speakers sharing experience"; "Well done, lot of exchange and interaction".

- Suggestions for improvement included: “The meet was okay but important to provide interactions between patient representatives and all other stakeholders present at ERS Congress (doctors, researchers, assemblies etc)”. Another comment received was “Repetitive format, not very engaging, time too tight for discussions and comparisons” and “Prefer more patients and not patient organisation representatives to be involved.”

- It was suggested that follow-up notes and key take-aways could be distributed to attendees with summary by graphic artist to be distributed after the event.

**Future planning**

ELF will take the feedback received from participants into consideration when planning future events for the patient organisation network.