

ELF Patient Organisation Networking Day 2025
“Improving respiratory health – thinking globally, acting locally”

Saturday 27 September 2025

10:30 – 17:30 CEST

Room 5A, Hall 5 and online

RAI Amsterdam, Europaboulevard, 1079 MW Amsterdam

Host: Dimitris Kontopidis, ELF Chair

Co-chairs:

- Liam Galvin, ELF Patient Advisory Committee Chair and CEO European Pulmonary Fibrosis Federation
- Louise Bouman, Dutch Pulmonary Hypertension Association
- Marion Wilkins, Alpha-1 Germany
- Luca Roberti, Italian Sleep Apnoea Patient Association

Timings are in Central European Summer Time (CEST). Online attendees please adjust for your time zone.

- 10:15 ***In person attendees only - Arrivals and registration (15 min)***
- 10:30 ***In person attendees only - Welcome to attendees in Amsterdam & networking introduction***
Dimitris Kontopidis (10 min)
- 10:40 ***In person attendees only - networking with patient organisations, patient advocates and ELF and ERS Leadership including ERS President & ERS President Elect (50 mins)***
- 11:30 **Welcome to all attendees from Dimitris Kontopidis, ELF Chair (10 min)**
- 11:40 **Introduction to morning session**
Liam Galvin and Louise Bouman (5 min)
- 11:45 **ERS President address (10 min)**
Professor Silke Ryan, ERS President
Professor Joanna Chorostowska-Wynimko, ERS President-Elect
- 11:55 **Keynote speech: Our Kids' Climate: Building parent power for clean air (10 min)**
Maya Mailer, co-director, Our Kids' Climate
- 12:05 **Keynote speech: Science Under Threat: What It Means for Patient Rights and Public Health (10 min)**
Professor Barbara Hoffman, Chair of the European Respiratory Society Advocacy Council and Professor of environmental epidemiology, University of Düsseldorf



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- 12:15 **Panel discussion and Q&A (10 min)**
Liam Galvin, Louise Bouman, Professor Silke Ryan, Professor Joanna Chorostowska-Wynimko, Maya Mailer and Professor Barbara Hoffman
- 12:25 **Comfort break (15 min)**
- 12:40 **Patient testimonial video (10 min)**
Kindly featuring 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
Dhiraj Agarwal, India
- 12:50 **Clean Air Healthy Lives Movement (10 min)**
Shane Fitch, Lovexair Spain
- 13:00 **Crop Phenomenon: A Model of Persistent Advocacy to Boost Childhood Vaccination and Respiratory Health (10 min)**
Dr Ghulam Mustafa, Helping Hands Foundation, Pakistan
- 13:10 **What are patient organisations doing around the world? – Video reel (15 min)**
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
Satu Mustonen, The Organisation for Respiratory Health in Finland
- 13:25 **Panel discussion and Q&A (15 min)**
Liam Galvin, Louise Bouman, Shane Fitch, Ghulam Mustafa
- 13:40 **Group photo, lunch break and networking (60 min)**

- 14:40 **Introduction to afternoon session (5 min)**
Luca Roberti and Marion Wilkens
- 14:45 **WHO Lung Health Resolution & Break out group discussions (50 mins)**
José Luis Castro, World Health Organization (15 min)
Discussion (35 min)
- 15:35 **Plenary (10 mins)**
Luca Roberti, Marion Wilkens, José Luis Castro
- 15:45 **Comfort break (15 min)**
- 16:00 **Break out group discussions: call to action planning (40 min)**
Introduction (5 min)
Discussion (35 min)
- 16:40 **Plenary (15 min)**
Luca Roberti, Marion Wilkens, José Luis Castro
- 16:55 **Congress Theme for 2026 (5 min)**
Professor Hilary Pinnock, ERS Education Council Chair
- 17:00 **10 years of ELF Patient Organisation Networking Day (10 min)**
Mikaela Odemyr, Swedish Asthma and Allergy Association and former ELF PAC Chair
- 17:10 **Closing words**
Dimitris Kontopidis, ELF Chair (5 min)
- 17:15 **Networking (15 min)**
Attendees are welcome to continue networking in the room until 17:30.
- 17:45-20:00 **ERS Congress Opening Session: Ceremony and networking sessions, Auditorium**
You are warmly invited to join ELF at the ERS Congress Opening Session for food, networking with healthcare professionals and catching up with other patient advocates.

ELF staff will guide you to the Auditorium at 17:30.