

ELF Patient Organisation Networking Day 2026

Dismantling the divide: patients and professionals as one team

Saturday 5 September 2026

10:00 – 17:30 CEST

Room 3C and online

*Fira Gran Via (Halls 1 to 3), Carrer de les Ciències, s/n, Hospitalet de Llobregat, 08908
Barcelona.*

Host: Dimitris Kontopidis, ELF Chair

Co-chairs:

- Stefano Pavanello, Union of Transplant Patients of Padova, Italy
- Eleonora Volpato, University of Graz, Austria and ELF Mental Health Working Group
- Carlos Pons, Respiralia Foundation, Spain
- Hilary Pinnock, University of Edinburgh and ERS Education Council Chair

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

09:45	<i>In person attendees only - Arrivals and registration (15 min)</i>
10:00	<i>In person attendees only - Welcome to attendees in Barcelona & networking introduction</i> Dimitris Kontopidis (10 min)
10:10	<i>In person attendees only - networking with patient organisations, patient advocates and ELF and ERS Leadership including ERS President & ERS President Elect. (50 mins)</i>
11:00	Welcome to all attendees from Dimitris Kontopidis, ELF Chair (10 min)
11:10	Introduction to session 1 (5 min) Stefano Pavanello & Eleonora Volpato
11:15	ERS President address (10 min) Joanna Chorostowska-Wynimko, ERS President Marc Miravittles, ERS President-Elect

- 11:25 **Introducing the ELF Award winner 2026 & Partnership in practice: patient-professional testimonial video (10 min)**
Kindly featuring experiences from:
- Daphne Raad, Vapen #JouwKeuze - Vaping #yourchoice
 - Clare Lyon, LifeArc Rare Respiratory Disease Centre and LAM Action, UK
 - Eleni Stamouli, ELF Pulmonary Fibrosis Working Group, Greece
 - Andy Bush, Royal Brompton Hospital, UK
 - Professor Daiana Stolz, University Hospital Basel, Switzerland
- 11:35 **Keynote speech: Patients and Professionals as One Team in Bronchiectasis Research and Care (20 mins)**
- Eliza Kompatsiari, ELF Bronchiectasis Patient Advisory Group
 - James Chalmers, University of Oxford and Chair of EMBARC - European Bronchiectasis Multicentre Audit and Research Collaboration
- 11:55 **Panel discussion: Partnership in Action: How to build better care side by side (30 min)**
Chairs: Stefano Pavanello & Eleonora Volpato
Panellists:
- Eliza Kompatsiari, ELF Bronchiectasis Patient Advisory Group
 - James Chalmers, University of Oxford, UK and Chair of EMBARC - European Bronchiectasis Multicentre Audit and Research Collaboration
 - Jean-Michel Fourier, Pulmonary Fibrosis Association France
 - Éric Salone, Association Josiane Salone, Everyone United Against COPD, France
 - Michael Kreuter, Lung Center Mainz, Mainz University Center and Marienhaus Clinic Mainz, Germany
- 12:25 **Q&A with the audience (15 min)**
- 12:40 **Group photo, lunch and networking (60 minutes)**

- 13:40 **Introduction to session 2 (5 min)**
Carlos Pons and Hilary Pinnock
- 13:45 **Report from Primary Care Day – the patient chair’s perspective (10 min)**
Debra Montague, Lung Cancer Europe and ELF Patient Advisory Committee
- 13:55 **Panel discussion: Partnership in Action: Addressing systemic barriers through collaboration (30 min)**
Chairs: Carlos Pons and Hilary Pinnock
Panellists:
- Haneefa Alam, Asthma + Lung UK
 - Oksana Kulish-Skåra, Pulmonary Hypertension Ukrainian Rare Disease Association, Ukraine
 - Marion Wilkens, Alpha-1 Germany
 - Ourania Koltsida, Sotiria General Hospital, Athens, Greece
 - Alba Ubide, European Pulmonary Fibrosis Federation, Belgium
- 14:25 **Q&A with the audience (15 min)**
- 14:40 **How are patient organisations driving partnership? – Video reel (10 min)**
- Liliya Belenko Gentet, French Federation of Associations of Patients with Respiratory Insufficiency or Handicap, France
 - Fernanda Aspilche Ferro, Alpha-1 Europe Alliance, Belgium
 - Blanca Angulo Muñoz, Bronquiectasias Grupo Apoyo, Spain
 - Breathe Easy Nottingham West Support Group, UK
- 14:50 **Comfort break (20 min)**



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- 15:10 **Introduction to session 3 (5 min)**
Carlos Pons and Hilary Pinnock
- 15:15 **Break out group discussions (80 min)**
Attendees will participate in small-group discussions, addressing the following topics
1. Sharing what works: best practice, tools and real-life examples.
 2. Reaching seldom-heard groups: inclusion, language, access and trust.
 3. Supporting involvement: how patient organisations can help with research, service design and quality improvement.
- 16:35 **Plenary (45 min)**
Facilitated by Carlos Pons and Hilary Pinnock
- 17:20 **Closing words and handover to the new ELF chair (10 min)**
Dimitris Kontopidis, ELF Chair and Phil Taverner, ELF Chair-Elect
- 17:30 **Event ends**
- 17:45-20:00 **ERS Congress Opening Session: Ceremony and networking session**
You are warmly invited to join ELF at the ERS Congress Opening Session in room 1A for food, networking with healthcare professionals and catching up with other patient advocates.