



ELF

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ELF patient organisation networking day 2026

Dismantling the divide: patients and professionals as one team

Saturday 5 September 2026

11:00 – 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.

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| 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 | Partnership in practice: patient-professional testimonial video (10 min)
<i>Kindly featuring experiences from:</i> <ul style="list-style-type: none">• 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) <ul style="list-style-type: none">• 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: |



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- 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 Fourrier, Pulmonary Fibrosis Association France
- Éric Salome, Association Josiane Salome, 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 Comfort break for all attendees (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)

- Blanca Angulo Muñoz, Bronquiectasias Grupo Apoyo, Spain
- Theresa Burgoyne, Breathe Easy Nottingham West Support Group, UK
- Lila Martinez Ucha, Alpha-1 Europe Alliance, Belgium and Lovexair, Spain
- Liliya Belenko Gentet, French Federation of Associations of Patients with Respiratory Insufficiency or Handicap, France

14:50 Comfort break (20 min)

15:10 **Introduction to session 3** (5 min)
Carlos Pons and Hilary Pinnock

15:15 **Break out group discussions** (30 min)



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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.

15:45	Plenary (15 mins) <i>Facilitated by Carlos Pons and Hilary Pinnock</i>
16:00	Break out group discussions continued (60 min)
17:00	Plenary (20 min) <i>Facilitated by Carlos Pons and Hilary Pinnock</i>
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