



ELF Patient Organisation Networking Day 2023

Saturday 9 September 2023

10:45 – 16:30 CEST

Room Coral 1 and online

MiCo Milan Convention Centre, Italy

Co-Chairs for the event are:

Kjeld Hansen, ELF Chair

Hilde de Keyser, CEO of Cystic Fibrosis Europe

Mikaela Odemyr, ELF Patient Advisory Committee Chair and Swedish Asthma and Allergy Association President

Liam Galvin, Volunteer Director of the Irish Lung Fibrosis Association and co-founder and CEO of the European Pulmonary Fibrosis Federation

Timings below are in Central European Summer Time (CEST) – online attendees, please adjust for your timezone

10:15 Arrivals, registration and networking in Milan

10:45 Welcome
Kjeld Hansen, ELF Chair (Norway)
(10 mins)

10:55 ERS President Address
ERS President, Professor Carlos Robalo Cordeiro (Portugal)
ERS President-Elect, Professor Monika Gappa (Germany)
(10 mins)

11:05 Session 1: Patient and public involvement in research
Introduction
Hilde de Keyser *(5 mins)*

11:10 Professor Michal Shteinberg, Carmel Medical Center, Haifa, Israel (20 mins):
Keynote: "Patient involvement in setting research priorities – the European Multicentre Bronchiectasis Audit and Research Collaboration experience"

- 11:30 **Anke Widenmann**, Esophageal Atresia Global Support Groups and European Reference Network for Rare Lung Disease (ERN Lung) (10 mins):
“Patient involvement in setting research priorities using a patient journey approach”
- 11:40 **Luca Roberti**, Apnoici Italiani, Italy (10 mins): “Co-design of a secondary prevention and research project for Sleep Apnoea with input from patients, health associations and health professionals”
- 11:50 **Panel discussion and question and answer** (20 mins)
- 12:10 **Comfort break** (10 mins)
- 12:20 **Interactive breakout group discussion** (40 mins)
- **Explanation and allocation into groups**
Kjeld Hansen (5 mins)
 - **Breakout discussion**
All participants (35 mins)
- 13:00 **Plenary** (20 mins)
- 13:20 – 14:05 **Lunch Break** (45 mins)
- 14:05 **Session 2: Mental health and lung disease**
Introduction
Liam Galvin (5 mins)
- 14:10 **Professor Andreas Von Leupoldt**, University of Leuven, Belgium (20 mins):
Keynote: “Mental Health & Respiratory Disease: Chronic Obstructive Pulmonary Disease as prime example”
- 14:30 **Dr Natalia Maeva**, Bulgarian society of patients with pulmonary hypertension, Bulgaria (10 mins): “Living with pulmonary arterial hypertension: navigating challenges and promoting adjustment”
- 14:40 **Professor Francesco Pagnini**, Università Cattolica del Sacro Cuore, Milan, Italy and Associazione Italiana Bronchiectasie (10 mins): “Breathing together: an online support group for people with bronchiectasis”
- 14:50 **Panel discussion and Question and Answer** (20 mins)
- 15:10 **Comfort break** (10 mins)

- 15:20 **Interactive breakout group discussion (40 mins)**
- **Explanation and allocation into groups**
Mikaela Odemyr (5 mins)

 - **Breakout discussion**
All participants (35 mins)
- 16:00 **Plenary (20 mins)**
- 16:20 **Welcome to ELF Chair Elect and closing words**
Kjeld Hansen, ELF Chair (Norway) and Dimitris Kontopidis, ELF Chair Elect (Greece) (10 mins)
- 16:30 **End**

Attendees in Milan are warmly invited to join ELF at the ERS Congress Opening session and welcome reception from 17:45 – 20:00, in room Gold, South Hall, MiCo Convention Centre.

