



**ELF** EUROPEAN  
LUNG  
FOUNDATION

## **ELF Patient Organisation Networking Day 2022**

**Wednesday 31 August 2022**

**10:30 – 16:00 CEST**

**Online event**

Co-Chairs for the event are:

Kjeld Hansen, ELF Chair

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

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

- 10:30      **Welcome**  
Kjeld Hansen (Norway) and Mikaela Odemyr (Sweden)  
(15 mins)
- 10:45      **ERS President Address**  
ERS President, Professor Marc Humbert (France)  
ERS President-Elect, Professor Carlos Robalo Cordeiro (Portugal)  
(10 mins)
- 10:55      **Keynote Session**
- Introduction**  
Kjeld Hansen (Norway) (5 mins)
- Self-management in people with chronic lung disease: from theory to implementation**  
Dr Tanja Effing-Tijdhof, Flinders University and University of Adelaide (Australia) (15 mins)
- Patient perspective on self-management**  
Ilan, cystic fibrosis patient advocate and Israel Cystic Fibrosis Foundation (Israel) (15 mins)
- Question and Answer with keynote speakers (15 mins)**
- 11:45      **Laughter Yoga**  
Marian Reilly (Ireland) (10 mins)

11:55 **Break** (15 mins)

12:10 **Patient organisation Experiences across Europe**

**Introduction**

Mikaela Odemyr (Sweden) (5 mins)

**Tips and Trips with Self-Management**

Tessa Jelen, Asthma and Lung UK Westminster Support Group (UK) (10 mins)

**Italian Sleep Apnea Association, from Screening Web App project to Apno-Point the digital volunteer**

Luca Roberti, Apnoici Italiani (Italy) (10 mins)

**The evolving self-management needs of cystic fibrosis communities in Spain and Greece**

Carlos Pons, Respiralia Foundation (Spain) and Anna Spinou, Hellenic Cystic Fibrosis Association (Greece) (15 mins)

**Online respiratory physiotherapy programme**

Armando Ruiz, Spanish Federation of Allergy and Airways Diseases Patients' Associations (FENAER) (Spain) (10 mins)

**Question and Answer with all patient organisation speakers (20 mins)**

13:20 **Lunch Break** (45 mins)

14:05

**Interactive breakout groups**

**Explanation and allocation into groups**

Kjeld Hansen (Norway) *(10 mins)*

**Breakout discussion**

All participants *(50 mins)*

Breakout discussion questions:

1. What experience have you had with self-management in your patient community?
2. What are the barriers to self-management, and what solutions have you found to overcome them?
3. Have there been changes to self-management approaches in your patient community since the pandemic?

15:05

**Break** *(15 mins)*

15:20

**Plenary discussion**

Chairs: Kjeld Hansen (Norway) and Mikaela Odemyr (Sweden) *(30 mins)*

15:50

**Closing words, Kjeld Hansen, ELF Chair** (Norway) *(10 mins)*

16:00

**End**