

Alpha-1 antitrypsin deficiency Patient Conference

Date: 5 November 2024

10:00 – 16:00 CET (9:00-15:00 GMT)

- **Audience:** Patient-focused but open to all e.g., carers, healthcare professionals etc.
- **Zoom platform with automated caption translation** available in 50+ languages
- **Chairs:** Patients and clinicians to introduce sessions
- **Timings are in Central European Time (CET)** : please adjust for your own timezone

Welcome

10:00 Welcome and Housekeeping – Pippa Powell, ELF Director 10 min

Session 1: Introduction to Alpha-1 antitrypsin deficiency

10:10 Introduction to session - Karen O'Hara 5 min
 10:15 Introduction to Alpha-1 Europe Alliance - Fernanda Aspilche Ferro 15 min
 10:30 Basics of Alpha-1 - Christian Clarenbach 30 min
 11:00 Q&A - Karen O'Hara (moderator) 15 min

Session 2: Living with Alpha-1 antitrypsin deficiency

11:15 Introduction to session - Fernanda Aspilche Ferro 5 min
 11:20 Patient stories – Marion Wilkens, Karen O'Hara & Elena Goyanes 15 min
 11:35 Mental health, psyche, breathing – Paul Köbler 25 min
 12:00 Q&A - Fernanda Aspilche Ferro (moderator) 15 min
 12:15 Exercise session for attendees – Nicole Hopkins 10 min
 12:25 Break 35 min

Session 3: Research and clinical trials

13:00 Introduction to session – David Parr 5 min
 13:05 EARCO registry update - Marc Miravittles 15 min
 13:20 Patient participation in clinical trials - Sandra Nestler-Parr 20 min
 13:40 Research in AATD - Alice Turner 25 min
 14:05 Q&A – David Parr (moderator) 15 min

Session 4: Diagnosis and clinical management

14:20 Introduction to session - Marc Miravittles 5 min
 14:25 Experience in diagnosis and treatment - Marion Wilkens 10 min
 14:35 Diagnosis and clinical management: lung disease - David Parr 25 min
 15:00 AATD-associated liver disease - Pavel Strnad 20 min
 15:20 Rare Alleles - Timm Greulich 20 min
 15:40 Q&A - Marc Miravittles (moderator) 15 min
 15:55 Closing comments – Karen O'Hara and Marion Wilkens 5 min
 16:00 End