

Breath of Hope: Giving a future to patients living with rare pulmonary diseases

15 September, 10.30-12.15
European Parliament, Room 3H1

- 10:30 – 10:40** **Welcome and introduction**
Elena Gentile, Member of the European Parliament
- 10:40 – 10:50** **The European IPF Patient Charter**
Jean-Pierre Huybrechts, Belgische vereniging voor longfibrose
Rosalba Mele, AMA Fuori dal Buio
- 10:50 – 11:05** **Commission initiatives in the area of rare diseases**
Agnes Mathieu, Medicinal Products and Authorisation Unit, Health Systems and Products Directorate, DG Health and Food Safety, European Commission
- 11:05 – 11:20** **Iiro Eerola**, Innovative and Personalised Medicines Unit, Health Directorate, DG Research and Innovation, European Commission
- 11:20 – 11:35** **State of play of lung transplantation in Europe**
Arne Neyrink, Leuven University/ European Society of Organ Transplantation
- 11:35 – 11:50** **The role of education and training of doctors in the management of rare pulmonary diseases**
Peter Fsadni, Standing Committee of European Doctors
- 11:50 – 12:05** **The role of specialist nurses in disease management**
Ber Oomen, European Specialist Nurses Organisations
- 12:05 – 12:10** **The role of support groups in IPF management**
Daniela Magnani, AMA Fuori dal Buio
- 12:10 – 12:15** **Q&A and Wrap-up**
Elena Gentile

Refreshments

This event is funded through a grant from Roche