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 State of play of lung transplantation in Europe
Arne Neyrink, Leuven University/ European Society of Organ Transplantation

11:20 – 11:35 The role of education and training of doctors in the management of rare pulmonary diseases
Peter Fsadni, Standing Committee of European Doctors

11:35 – 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

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