

EU-IPFF Parliamentary Meeting  
Kindly hosted by MEP Elena Gentile (S&D, IT)

## **A FORWARD-LOOKING AGENDA FOR RARE DISEASES: BRINGING EUROPE CLOSER TO ITS PEOPLE**

### *Agenda*

*European Parliament, Brussels  
Room ASP 3H1  
Tuesday, 20 November 2018  
11:00 – 13:00*

- 11:00 – 11:10**     **Welcome and Introduction: EU-IPFF's growth and strengthening path**  
**Elena Gentile**, Member of the European Parliament (S&D, IT)
- 11:10 – 11:20**     **EU-IPFF President thanks MEPs for longstanding support**  
**Carlos Lines Millán**, President of EU-IPFF
- 11:20 – 11:30**     **Keynote Speech: how can the Commission ensure that rare diseases remain a priority?**  
**Annika Nowak**, Member of the Cabinet Andriuskaitis, European Commission
- 11:30 – 11:40**     **EU-funded research contributing to the goals of the International Rare Diseases Research Consortium (IRDiRC)**  
**Iiro Eerola**, DG RTD Health, European Commission
- 11:40 – 11:55**     **Position Paper: EU-IPFF important work in knowledge development and sharing - key results**  
**Francesco Bonella**, Chairman of the EU-IPFF Scientific Advisory Board, Ruhrlandklinik, Essen
- 11:55 – 12:10**     **How to scale-up successful initiatives within the European Reference Networks (ERNs)**  
**Franz Schaefer**, Chair of the ERNs Coordinators Group
- 12:10 – 12:30**     **Benchmarking Report: key results and call to action**  
**Steve Jones**, EU-IPFF Board Member and Action for Pulmonary Fibrosis Trustee
- 12:30 – 12:40**     **Exchange of views with other MEPs**
- 12:40 – 12:55**     **Q&A with audience**
- 12:55 – 13:00**     **Closing remarks**  
**Elena Gentile**, Member of the European Parliament (S&D, IT)