

INTEREST GROUP ON RHEUMATIC AND MUSCULOSKELETAL DISEASES (RMDs)

Policy issues and challenges in the treatment and care of rare diseases

European Parliament (Altiero Spinelli Building, Room 1G2)
6 December 2016, 12:30 - 14:30

Goal

The aim of the meeting is to discuss key issues and challenges in addressing rare diseases in Europe. In particular, the meeting will focus on the development of therapies against rare diseases as well as on the problems faced by people with rare diseases in getting health care. While general issues about rare diseases will be discussed, the meeting is expected to provide specific examples of rare diseases in the field of Rheumatic and Musculoskeletal Diseases (RMDs).

Draft agenda

Chair: **Takis Hadjigeorgiou MEP**, Vice-Chair of the Interest Group on RMDs

- 12:30 – 12:45 Welcome & Introduction by **Takis Hadjigeorgiou MEP, Vice-Chair of the IG**
- 12:45 – 12:55 Data barriers for clinical research and development for the treatment of rare diseases, **Dr. Ana Rath, Coordinator Scientific Secretariat, International Rare Diseases Research Consortium (IRDiRC) and Director of Orphanet**
- 12:55 – 13:05 The contribution of the EU to address rare diseases – Strategy and policy developments, **Jarosław Waligóra MD PhD, Policy Officer, DG Sante, Unit C1- Programme Management and Diseases**
- 13:05 – 13:15 Rare Rheumatic and Musculoskeletal Diseases – Current situation and challenges, **Prof. Marta Mosca, Rare CONNective and musculoskeletal diseases NETWORK (ReCONNET)**
- 13:15 – 13:25 Patients' perspectives on improving access to care and therapies for people with rare RMDs, **Kirsten Lerstrøm, Lupus Europe**
- 13:25 – 13:35 Comments, by **Karin Kadenbach MEP**
- 13:35 – 13:55 Discussion with participants, chaired by **Karin Kadenbach MEP**
- 13:55 – 14:00 Conclusions by **Takis Hadjigeorgiou MEP, Vice-Chair of the IG**

A light lunch will be provided.