Rare Diseases Working Group

Tartu, Estonia, September 2014
Rare diseases WG

- Established in 2011

- 2012/13: Survey on the awareness of RD in Europe

- 2014: Position Paper of the Rare Diseases working group of the European Federation of Internal Medicine
Rare diseases WG

• 2014: EFIM appointed as one of the 4 representative of the professional organisations and scientific societies in Commission Expert Group on Rare Diseases of the EU Commission
Commission Expert Group on Rare Diseases of the EU Commission

• Instituted by the Commission Decision 2013/C 219/04 of 30 July 2013

• Replace the EUCERD
Mission of the group:

- assist the Commission in the drawing up of legal instruments and policy documents, including guidelines and recommendations;
- advise the Commission in the implementation of Union actions and suggest improvements to the measures taken;
- advise the Commission in the monitoring, evaluation and dissemination of the results of measures taken at Union and national level;
- advise the Commission on international cooperation;
- provide an overview on Union and national policies;
- foster exchanges of relevant experience, policies and practices between the Member States and the various parties involved.
Composition of the group

- **Member States' competent authorities (28)**
  + Icelandic Ministry of Welfare, State Diagnositc and Counselling Centre; Norwegian Ministry of Health and Care Services

- **Patients’ organisations in the field of rare diseases (4)**
  EURORDIS – European Organisation for Rare Disease; The Network of European Federations of rare diseases; EGAN – European Genetic Alliances’ Network; The Network of National Alliances of rare disease patients’ organisations

- **European associations of producers of products or service providers relevant for patients affected by rare diseases (4)**
  European Association for Bioindustries – EuropaBio; European Biopharmaceutical Enterprises; The European Diagnostic Manufacturers Association; The European Social Insurance Platform

- **European professional associations or scientific societies acting in the field of rare diseases (4)**
  The European Federation of Internal Medicine; European Society of Human Genetics; European Hematology Association; European Academy of Paediatrics

- **individual experts (4)**
  Domenica Taruscio (I); Katharine Bushby (UK); Milan Macek (CZ); Ségolène Aymé (FR)
Commission Expert Group on Rare Diseases of the EU Commission

Activities

• EFIM is the contact point for Professional Societies
  
  – The European Federation of Internal Medicine
  – European Society of Human Genetics
  – European Hematology Association
  – European Academy of Paediatrics
Activities

• European Reference networks status of the implementation of the Art 12 of the Directive 2011/24/EU on patients’ rights in cross-border healthcare

• Rare diseases codification

• New Joint Action on rare diseases

• Rare diseases registries

• Research infrastructures in the field of RD research
Rare Diseases Working Group

European Federation of Internal Medicine
Rare Diseases Working Group
Proposed activities for the EFIM Rare Disease WG

Proposed activities

• EU survey on how internists deal with rare diseases
• EU School for rare diseases
• Childhood to Adulthood transition project (with EAP)
Proposed activities for the EFIM Rare Disease WG

Proposed activities

MARIE SKŁODOWSKA-CURIE ACTIONS

THE FRAMEWORK PROGRAMME FOR RESEARCH AND INNOVATION
HORIZON 2020

European Commission

EFIM

European Federation of Internal Medicine
Rare Diseases Working Group

Thank you