

Proposal to develop a Rare Diseases Working Group - EFIM

Chair: Prof. Francois Maillot – French Society of Internal Medicine

Objectives:

- ✓ To promote the study of rare diseases (RD) in Europe
- ✓ To share common European strategies to improve knowledge and management of patients with RD.
- ✓ To define which categories of RD should be prioritized by the RD working group

Specific primary aims of the RD Working Group of EFIM are:

- ✓ To gain and share scientific knowledge about RD;
- ✓ To increase the awareness on RD among Internists across Europe;
- ✓ To create specific curricular tracks on RD for medical students and Internal Medicine residents;
- ✓ To implement the development of European research projects on RD;
- ✓ To gather data on RD in European Internal Medicine departments;
- ✓ To possibly coordinate future European multicentric clinical trials on RD.
- ✓ To collaborate with European Reference Networks (ERN)

General and future aims of the Working Group will be:

- ✓ To implement the comprehensive approach in RD, which is peculiar to Internal Medicine;
- ✓ To support the development of appropriate EU public health policies for RD;
- ✓ To increase international cooperation in scientific research among EFIM members, including links to other international scientific societies;
- ✓ To coordinate studies aimed at developing new approach to RD;
- ✓ To support campaign aimed at raising public awareness of RD in the EFIM Countries;
- ✓ To provide comprehensive quality information to RD community;
- ✓ To strengthen relationships with patients' organizations with RD.