

## **European Pediatricians collaborate in Care for Children with Rare Diseases**

### **Mission statement**

#### **European Pediatricians, working together, will**

1. Provide sufficient services for expert diagnosis or confirmation of diagnosis.
2. Ensure appropriate capacity and equal access to follow-up and management of children with rare diseases
3. Produce and adhere to good practice guidelines and implement outcome measures and quality control.
4. Use and demonstrate a multi-disciplinary approach in management of patients and families.
5. Document and maintain a high level of expertise and experience through publications, grants or honorary positions, teaching and training activities
6. Make a strong contribution to international research and support international trials in treatment of rare diseases.
7. Provide epidemiological surveillance, such as by registries, preferably at a European level.
8. Communicate with health authorities and policy makers in order to improve the finances for health care of patients with rare diseases.
9. Support, communicate with, and advise patient rare disease networks and organisations
10. Collaborate with initiatives of the European Commission Rare Disease Task Force, in developing national plans for integrated services and support for patients and families affected by rare diseases.