



Πανελλήνια Ένωση Σπανίων Παθήσεων  
Greek Alliance for Rare Diseases

# EUROPEAN REFERENCE NETWORKS

# RARE DISEASES

- More than 7.000 have been identified
- Most are genetic and affect children
- A disease is considered rare if it affects less than 5 in 10.000 people





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# EUROPEAN REFERENCE NETWORKS

- Must function with the following principles in mind:
  - Integrity
  - Independence
  - Respect
  - Equality
  - Transparency
  - Mutual Benefit



# EUROPEAN REFERENCE NETWORKS

- Should have at least three of the following objectives:
  - Innovation leading to potential
  - Contributing to the pooling of knowledge
  - Facilitating diagnosis and health-care
  - Maximising cost-effectiveness
  - Reinforcing research and training
  - Facilitating mobility of expertise
  - Encouraging the development of quality and safety
  - Helping Member States with insufficient numbers of patients and/or technology/expertise



# EUROPEAN REFERENCE NETWORKS

- Member states should facilitate the development of the ERN:
  - By connecting healthcare professionals throughout the country
  - By promoting the participation of healthcare professionals and centers of expertise in European Reference Networks



# CENTERS OF EXPERTISE

## Should provide:

- A multi-disciplinary approach
- Patient-centered Care
- Competence
- A link to European Reference Networks
- Safety for patients
- Autonomy for patients
- Access to Disease-specific social assistance



# CENTERS OF EXPERTISE

## Should also:

- Involve patients
- Exchange information with local professionals
- Share information with the public
- Train stakeholders
- Provide guidelines on patient care
- Promote research
- Ensure access to everyone





# CENTERS OF EXPERTISE

## Reality in Greece:

- Centers for

- Gaucher & Fabry
- Histiocytosis
- Hemophilia
- Pulmonary Hypertension
- Retinopathies
- Cystic Fibrosis
- Crohns Disease
- Sickle Cell Anemia
- Congenital Cardiopathies
- Keratoconus
- Prader Willi
- Hereditary Metabolic Diseases
- Rheumatoid Arthritis
- Primary Immunodeficiencies (Pediatric)
- Thalassemia
- Tuberous Sclerosis

- No Greek Centers Fully Adhere to the Standards defined by EUCERD



# CENTERS OF EXPERTISE

## Reality in Greece:

- Children to Adults transition only available for a few diseases (Thalassemia, Tuberous Sclerosis & Cystic Fibrosis)
- **Main Adherence Issues:**
  - Research
  - Education
  - Dissemination
  - Collaboration with Patient Organizations



# COLLABORATION BETWEEN PATIENTS' REPRESENTATIVES AND ERN MEMBERS

- Basic Principles for Patients:
  - Participation in governance
  - Offering valuable experience
  - Sharing information regarding actions
  - Contributing to the evaluation of the Network
  - Participation in training, research, clinical trials, pharmacovigilance, studies, sharing of information about bio banks, standards of care and diagnosis, social guidelines and helplines.





Κατερίνα Λάμπρου

Thank you for your attention!

