

EURORDIS ACTIVITIES ON EU AND NATIONAL POLICIES

EUCERD Recommendations on Centres of Expertis

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Eurordis Membership Meeting 2012

EUCERD Recommendations on Centre of Expertise



INTEREST IN RARE DISEASES (RD) HAS GROWN SIGNIFICANTLY OVER THE LAST DECADE IN EUROPE.

Rare Diseases were recognised as a health policy priority in the first Programme of Community Action on Rare Diseases (1999-2003) and confirmed as a priority in the Public Health Programme (2003-2008).

The Commission White Paper Together for Health: a strategic approach for the EU 2008-2013 of 23 October 2007 establishing the second Programme of Community action in the field of health (2008-2013) **identified Rare Diseases as a public health priority of action.**



RDTF, the Rare Diseases Task Force was established by Commission Decision 2004/192/EC of 25 February 2004 on the programme of Community action in the field of public health (2003 to 2008) – **to assist and advise the Commission on how best to implement the EU Public Health Programme in the field of Rare Diseases**

EUCERD, the European Union Committee of Experts on Rare Diseases was set up by Commission Decision 2009/872/EC of 30 November 2009

(art. 2) The Committee acting in the public interest shall assist the Commission in formulating and implementing the Community's activities in the field of RD, and shall foster exchanges of relevant experience, policies and practices between the Member States and the various parties involved.



CENTRES OF EXPERTISE for RARE DISEASES (CoE) **(a Key area for priority action)**

Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases in Member States were adopted by EUCERD on 24 October 2011.

(Art. IV (11) of the Council Recommendation on an action in the field of Rare Diseases 2009/C/151/02 of 8 June 2009 - *Identify appropriate centres of Expertise throughout Member State national territory by the end of 2013, and consider supporting their creation*)

Background

THE EUCERD RECOMMENDATIONS ON COE IN THE FIELD OF RD ARE THE RESULTS OF A LONG PATHWAY:

- **RDTF** (Reports September 2005 – September 2006 – July 2008)
- **HLG** High Level Group on Health Services and Medical Care (Report November 2005)
- **Commission Communication** on Rare Diseases: Europe's challenges (11.11.08),
- **Council Recommendation** on an action in the field of rare diseases (08.06.09),
- **Recommendations for National Plans and Strategies for Rare Diseases** (Europlan)
- **Cross Border Health Care Directive** (09.03.2011) art 12-13



EURORDIS PLAYED A KEY ROLE IN THE PROCESS FOR THE ADOPTION OF THE RECOMMENDATIONS ON CENTRES OF EXPERTISE

RDTF Report “Centres of Reference for RD in Europe: State of the Art” (2006)

- **Rare Diseases Patients Solidarity – RAPSODY Project (European Workshop Prague June 2007)**
- **Specific Contribution regarding CoE to the Public Consultation “Rare Diseases: Europe Challenge” (Feb. 2008)**



- Declaration of *“Common Principles on Centres of Expertise and European Reference Networks for Rare Diseases”*, in order to improve patient care throughout Europe. (2008)
- **The Voice of 12,000 patients: Experience and Expectations of RD patients on diagnosis and care in Europe (March 2009)**
- **Policy FACT SHEET - Centres of Expertise**
- **Policy FACT SHEET - European Reference Networks of Centres of Expertise**
- **ECRD 2007 Lisbon, ECRD 2010 Kracow (Session on Coe & ERNs)**
- **EUROPLAN (WP 8) – EUROPLAN 2**



EUCERD RECOMMENDATIONS

EUCERD Recommendations on quality criteria for CoE for Rare Diseases are intended to help the Member States in their policy regarding the development of National Plans and strategies for Rare Diseases

The Recommendations cover the Mission and Scope of the Centres of Expertise; the Criteria for designating Centres of Expertise; the Process of designating and evaluating National Centres of Expertise; and the European Dimension of Centres of Expertise



EUCERD Recommendations are intended to assist Member States in their policy developments concerning National Plans and Strategies for RD when addressing the issue of organisation of healthcare pathways at national and European level.

The Recommendations cover a wide range of criteria for the designation of CoE.

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EUCERD Recommendations on Centre of Expertise

THE MAIN CRITERIA INCLUDE:

- A multidisciplinary approach integrating, medical, paramedical, psychological and social need.
- High level of expertise and experience
- Capacity to manage RD patients and provide expert advise
- Participation in clinical trials
- Contribution to state-of-the-art research
- Assure e continuity between child and adult care
- Assure continuity of care between all stages of the disease
- Collaboration with patient organisations

(<http://www.eucerd.eu>)



PATIENTS EXPECTATIONS

**IDENTIFY THE APPROPRIATE HEALTH CARE RESEOURCE FOR THEIR CARE
IN THEIR PROXIMITY**

**OBTAIN EARLY DIAGNOSIS AND HIGH QUALITY HEALTH AND SOCIAL
CARE FOR ALL RARE PATIENTS**

**ACCESS TO SOCIAL SERVICES TO IMPROVE THE QUALITY OF
LIFE**

**MEMBER STATES ADOPT POLICY SUPPORTING THE DEVELOPMENT OF
NATIONAL PLANS FOR RARE DISEASES AND FOSTER THE
IDENTIFICATION OR CREATION OF CENTRES OF EXPERTISE WITH
ADEQUATE AND SUSTAINABLE FINANCIAL SUPPORT**



Thank you!

