



## **EUCERD Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases in Member States**

On the 24 October 2011, during the third meeting of the European Union Committee of Experts on Rare Diseases, the EUCERD Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases in Member States were unanimously adopted by the 51-member EUCERD.

There are around 6000 rare diseases and most are unknown to healthcare professionals so rare diseases patients suffer from not knowing where to consult. To overcome this, some Member States have established centres specialised in some rare diseases/groups of rare diseases which have proven to be very efficient in improving quality of care. In order to help other countries elaborate similar processes, the EUCERD has established this set of Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases in Member States.

The development of centres of expertise and European Reference Networks in the field of rare diseases is encouraged in the Council Recommendation on an Action in the Field of Rare Diseases (2009/C 151/02) (8 June 2009) and more recently in the Directive on the application of patients' rights in cross-border healthcare (2011/24/EU) (9 March 2011) as a means of organising care for the thousands of heterogeneous rare conditions affecting scattered patient populations across Europe. In order to share knowledge and expertise more efficiently, the EUCERD recommendations seek to introduce harmonious standards of quality practices by elaborating criteria for the Member States to incorporate into their process to designate centres of expertise, especially in the context of national plans/strategies for rare diseases which the Council has urged all Member States to elaborate by 2013.

EUCERD, formally the EC Rare Diseases Task Force, has already issued a series of reports investigating the state-of-the-art in the field. The 45 Recommendations build upon these previous achievements and will serve to assist the Member States in developing their healthcare pathways at both the national and EU levels in the field of rare diseases. The recommendations cover the mission and scope of the centres of expertise at Member State level; the criteria for designating centres of expertise in Member States; the process of designating and evaluating centres of expertise in Member States; and the European dimension of centres of expertise.

The Recommendations are available on [www.eucerd.eu](http://www.eucerd.eu) here:

<http://www.eucerd.eu/upload/file/EUCERDRecommendationCE.pdf>

Translations into other languages can be found via the '[Recommendations](#)' tab of the site.