

ORAL PRESENTATION

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Building centres of expertise according to the Dutch model?

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Establishing the expertise for rare diseases started in the Netherlands by an inventory on existing expertise in 500 rare diseases at the Dutch Medical University Centres. The outcome of this survey was a vast list of persons with special knowledge of one or several of these rare diseases. The Dutch Steering Committee on Rare Diseases and Orphan Drugs concluded that differentiation within this list was needed by defining more specialised criteria for expertise. The criteria are based on European directives and are in line with a future perspective to improve quality of care. The highest distinguished level of expertise is an Expertise Centre where basic research, scientific output and professional training result in multidisciplinary high level care for people with complex rare diseases. Alongside this, Expertise Teams provide applied clinical research and high level care in local treatment centres. Currently, the Steering Committee is consulting professional groups, treatment centres and other stakeholders to gain support for this plan.

In 2011, the Steering Committee will advise the Ministry of Health about the organisation and the quality monitoring of the Centres of Expertise and Teams for various rare diseases. This advice will also contain a paragraph on a financing model concerning the organisation of care for rare diseases in the Netherlands.

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