

# Building Centres of Expertise

## The Dutch Model

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Dutch Steering Committee on Rare Diseases and Orphan Drugs

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# The Dutch Landscape

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- eight university hospitals
- twenty-six large teaching hospitals, providing highly specialised medical care
- approximately 6-8% of the European population is affected by a rare disease in the course of life: in the Netherlands about one million people

# Mission Dutch Steering Committee

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- the Steering Committee is architect and booster of the policy on developing expertise centres for rare diseases
- work plan 2008-2011: to establish
  - high level care for rare diseases
  - development of health care pathways
  - improvement of information
- a consultation document made by the Committee will be discussed with the stakeholders

# Timelines (1)

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2008-2009 *top-down*

- consultation document with criteria for expertise centres and expert teams, derived from criteria in European documents

2010-2011 *bottom-up*

- consultation round with different stakeholders (a.o. professionals, treatment centres, patients) to gain support for the plans
- financial paragraph in consultation with relevant authorities

# Timelines (2)

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2011

The Dutch Steering Committee will advise the Minister of Health about

- the organisation of expertise centres
- a model for financing the multidisciplinary high-level care for rare diseases
- a proposal on monitoring the quality of expertise centres in the future

# General starting points

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- improvement of quality of life
- long term care (transition from child to adult care and secondary prevention)
- multidisciplinary teams
- central registration of data to improve research, care and treatment
- development of health care pathways
- participation in European networks
- implementation of new techniques (e-health)

# Dutch model

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- *expertise centre*  
combination of fundamental research, professional education, cure and care by an multidisciplinary team with international networks  
(some may get the status of European expertise centre)
  - *expert team*  
local treatment centre offering high-level care and clinical research in association with expertise centre
- Not every rare disease will have an expertise centre in the Netherlands (small country / few patients)

# Main criteria Expertise centre

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- multidisciplinary team
- offering long term care, i.c. secondary prevention and transition of care (child to adult)
- minimal number of patients
- setting up databases
- consultation centre for professionals and patients
- development of health care pathways
- performing fundamental research (international)
- translation of research into new treatments and care
- training and education of professionals

# Conclusions

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- Expertise centres and expert teams for rare diseases are important to improve
  - longitudinal treatment and care
  - knowledge of rare disorders
  - stimulation of research
  - quality of life of these patients
- National supervising organ will indicate expertise centres and audit the quality of centres in the Netherlands