



GRAND-DUCHÉ DE LUXEMBOURG

Représentation permanente du Luxembourg  
auprès de l'Union européenne

# Implementing the Directive on crossborder healthcare to support patient mobility

## The national perspective Luxembourg

Anne Calteux

Attachée Santé, Pharma et Sécurité Sociale



# **1. Rare Diseases in Luxembourg: big challenges for a small country**

- a) A specific context
- b) The challenges

# **2. How to address these challenges**

- a) on a national level
- b) on an EU level



# 1. Rare Diseases in Luxembourg: big challenges for a small country

## a) A specific context

- **Small surface, limited population**
  - => absence of critical mass of patients
  - => lack of medical expertise for certain RDs
- **Border region**
  - => proximity of foreign medical infrastructure
  - => high referral of patients abroad



- **A contradictory situation**

  - => one of the highest per capita income – one of the poorest access to overall RD care

  - => one of the most generous social security coverage – treatment for many RD and interdisciplinary consultation not reimbursed

- **In comparison**

  - => RD at EU level: 29 million persons affected

  - => RD in Luxembourg: 20.000 persons affected; < 230 persons per RD; 7% population; 91 different RDs

    - 20% neuromuscular

    - 17,6% gastrointestinal

    - 5,9% spina bifida and neurodegenerative

    - 5,4% cystic fibrosis.



## **b) The challenges**

### **- Lack of overall medical expertise and scientific research in RD**

=> Difficult access to quick and valid diagnosis

=> lack of adequate guidance after diagnosis

=> lack of appropriate treatment and therapeutic care

=> high patient mobility (40% LU; 2% EU), difficult follow-up coordination



- **High financial impact**

=> time consuming search for correct diagnosis

=> high cost of orphan medicinal products

=> no systematic procedure for exceptional reimbursement

- **own expenditure by 38% patients**
- **renunciation of certain treatment**
- **unequal access to appropriate healthcare**



## 2. How to address these challenges

### a) On a national level

- Screening: pre- and neonatal screening since 1968, progressive extension until 2008 (MCAD)
- Patient associations: ALAN (1998)
- Awareness raising : European Conference on RD (2005)
- 2005: Interdisciplinary Study Group on RD



## **Mandate of the Study Group :**

- taking stock of the national situation
- assessing specific needs and shortcomings
- laying ground for RD Platform, national plan, RD registry
- raising public awareness
- enhancing equal access to healthcare





## Recommendations of the Study Group (May 2011):

- Creating a RD Platform
- Elaboration of a national plan on rare diseases
- Recognition/definition of RD
- Information and awareness raising
- Equal access to diagnosis, services and treatment
- Specific support for patients and families
- Implication of patient associations
- Ensure adequate financing
- Need to redirect patients to expertise in border countries : international cooperation for diagnosis, treatment and follow-up



## b) On the EU level

- Already done:
  - participation in EU expert networks (cystic fibrosis network (Goethe Univ., Germany); Orphanet)
  - Collaboration with AFM/Téléthon
  - participation in EU studies (Rapsody, EU Task Force, EU Health Programme)
- Yet to come:
  - Implementation of the crossborder healthcare directive (by October 2013)



## Implementation of the Directive

### - **Special interest for Luxembourg**

- ⇒ large dependency on foreign expertise: Directive facilitates access to foreign knowhow (art 12)
- ⇒ geographical situation (border region): Directive encourages cooperation of border regions (art 10)
- ⇒ lack of resources to implement strictly national measures : Directive provides for COM support (art 13)



## - **What to expect?**

- Facilitate **patient mobility**:

⇒ information on where to find high quality healthcare for specific RD and under what conditions (reimbursement, prior authorisation)

- Facilitate **expertise mobility**:

⇒ access to information, knowledge and capacity building on diagnosis and treatment of RD



## - **How to achieve an efficient implementation ?**

⇒ **Role of National Contact Points** (art 6)

⇒ **Participation in Centres of Reference** (art 12, 13)

⇒ **Conclusion of bilateral agreements with border countries** (art 10(3))



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# Thank you.

<http://www.sante.public.lu/publications/maladies-traitements/maladies-rares/maladies-rares-enquete-personnes-atteintes-gdl/maladies-rares-enquete-personnes-atteintes-gdl.pdf>