

# Making progress in National Plans: Comparison of different approaches In Denmark, Germany and the UK



**Lene Jensen**  
**CEO, Rare Disorders Denmark**  
**on behalf of the**  
**EURORDIS-EUROPLAN Advisors**



# This presentation

1. A short portrait of the three countries
2. **WHEN** will a Plan or Strategy be ready?
3. **HOW** did the process get started and how is the Plan prepared? Patient involvement?
4. **WHAT** do we expect to be the result and what will be next?
5. Best piece of advice and lessons learned –  
Conclusions

# National Plans and Strategies – the EU background

- **2008: Consultation and Communication from the European Commission: “Rare Diseases: Europe's challenges”**
- **2009: Recommendation from the EU Health Ministers: “An action in the field of rare diseases”**
- **2010-2012: EUROPLAN project I**
- **2013: Deadline for National Plans according to the Recommendation**
- **2013 – 2015: EUROPLAN project II**
- **Furthermore: The work of EUCERD, including recommendations**

# Ad. 1: A short portrait – Rare Disease Patient Organizations

- **DK:**

- Rare Disease Denmark, RDD: A patient organization with 47 member societies
- Plus 15 – 20 other small rare disease patient societies

- **UK:**

- Genetic Alliance UK, a non-profit patient charity with over 150 member organizations
- Rare Disease UK, RDUK: A multi stakeholder alliance of over 140 patients organizations and other stakeholders
- Specialized Healthcare Alliance, SHCA

- **Germany:**

- The German National Alliance for Chronic Rare Diseases, ACHSE: 117 member Organizations
- The Alliance of all Patient Organizations, BAG SELBSTHILFE is also an important player in the National Plan process.

# Ad. 1: A short portrait

- **Welfare systems – a complex issue**

- DK: Centralized, universal system, financed by general taxation
- UK: Decentralized universal system financed by general taxation. Health services are the responsibility of each of the nations of the UK (England, Northern Ireland, Scotland and Wales).
- Germany: Decentralized, federal structure of health care system, financed by State taxation, public and private insurance (mostly public)

# Ad. 1: A short portrait – The purpose of this presentation

- **The purpose of this presentation is to illustrate, that**
  - The Recommendation from the EU Health Ministers has played and still plays an important role in the process towards National Plans or Strategies in three, different countries
  - The approach has not been quite the same, but the characteristics of the result is quite similar
  - Patients has been and are key players
- **All three countries:**
  - No Plan and no dedicated funds for rare diseases in general
  - A process is going on right now

## **Ad. 2: WHEN will a plan or strategy be ready?**

- **DK: A National Strategy will be ready this Autumn, 2013**
- **UK: A National Plan is due to be published at the end of 2013**
- **Germany: A National Strategy will be ready in June**
- **Summa: The Plans or Strategies for the three countries will be ready this year. But implementation and resources – and results – depends on the willingness of all parties concerned to actively pursue the suggested matters and find the necessary resources – more about this later...**

## **Ad. 3: HOW did the process get started and how is the Plan prepared? - DK**

- **2001: Important special report with a number of recommendations, two highly specialized rare disease treatment centres**
- **2007 → 2010: Comprehensive plan for establishing Centres of Expertise and more**
- **2010: National Conference within the EUROPLAN Project**
- **2011: RDD-advocacy for the need for a national plan and structure for RDD working with our base**
- **2012: At the end of 2011 a Working Group within the National Board of Health was formed, first meeting in 2012, broad Stakeholder Representation**
- **2013: Autumn: Strategy to be finished and handed over to the political level**



## **Ad. 3: HOW did the process get started and how is the Plan prepared? - UK**

- **2008: The creation of RDUK – a multi stakeholder group campaigning for a strategic plan for rare diseases in the UK**
- **2009. RDUK established five working groups to help develop a vision for a UK rare disease strategy**
- **2010: Specialised Healthcare Alliance (SHCA) hosted SCHA Conference on Delivering Quality in Specialised Care**
- **2010: EUROPLAN conference to examine proposals for a National Plan – outcome: A RDUK-report entitled “Improving Lives, Optimizing Resources: A vision for the UK Rare Disease Strategy**
- **2011: Presentation of the vision the House of Commons**
- **2011: All four health departments across the UK have signaled their willingness to take on board RDUK’s recommendations in developing a strategy**
- **2011: SHCA-report Leaving No One Behind: Delivering High Quality, Efficient Care for People with Rare and Complex Conditions**

## **Ad. 3: HOW did the process get started and how is the Plan prepared? – UK II**

- **2012: A consultation document on the development of a National Plan prepared by the four Health departments in the UK was published on Rare Disease Day 2012. Over 350 responses**
- **2013: On Rare Disease Day, the relevant Minister announced a Rare Disease Stakeholder Forum would be established to bring together key people from the rare disease community along with policy makers to discuss and formulate the Governments Rare Disease Plan, including RDUK**
- **End of 2013: The final plan is due to be published**

## **Ad. 3: HOW did the process get started and how is the Plan prepared? – Germany**

- **2009: An in-depth evaluation of the situation of patients affected by rare diseases in Germany was published by the Federal Ministry of Health – a study from the perspective of various actors, including patient organizations**
- **2010: The Federal Ministry of Health initiated a national action league for people with rare diseases – NAMSE (Nationales Aktionsbündnis für Menschen mit Selteten Erkrankungen) – a coordination and communication platform comprising all key bodies and organizations. NAMSE is coordinated in a joint effort by the Ministry of Health, The Ministry of Education and ACHSE.**
- **2013: Finalizing the process with a German National Action Plan → a Strategy to be presented in June / July**

## Ad. 3: Common experience and slightly different approaches:

- **Common experience:**

- The Recommendation provides the framework
- The Patients has propelled the process

- **Slightly different approaches:**

- In DK, patients has worked together with other stakeholders and the Authorities around EUROPLAN, leading to the formation of a working group within the NBH
- In the UK, patients and other stakeholders has created RDUK and the Authorities has become active later on in the process
- In Germany, patients has lobbied for the creation of a special body, and the Authorities has established NAMSE, which is coordinated in a joint effort by the Ministry of Health, The Ministry of Education and ACHSE.

## **Ad. 3: Patient involvement, summa**

- **In all three countries, the process has been going on for years and has been propelled by patients and their organizations.**
- **The patients cooperate closely with other stakeholders – in Germany through NAMSE, in the UK through RDUK and in Denmark, the EUROPLAN Conference 2010 was a driver to a closer cooperation with health care professionals and authorities.**
- **When it comes to the formulation of the Plan or Strategy, patients have also been close to “the table”**

# Ad. 4: WHAT do we expect to be the result ?

- **Concrete results? A question very hard to answer!**
- **Problems identified**
  - Need to reach diagnosis and access treatment and services in a timely manner
  - Need for better coordination in many ways (from childhood to adulthood, treatment, services, research and more)
  - Need for more knowledge and information
  - The conditions for patient education and other empowerment tools should improve
  - And many more...
- **Worries**
  - Having an excellent report and no action – no budget
  - Having too weak a structure for governance, implementation and evaluation of the Plan or Strategy
  - Having too few resources to keep up the good work of patient organizations in the process to come

## **Ad. 4: WHAT will be next?**

- **DK: A National Strategy will be ready this Autumn, 2013. Then it is handed over to the politicians and RDD will change our lobby-gear**
- **UK: A National Plan is due to be published at the end of 2013 – not clear what happens after that**
- **Germany: A National Strategy will be ready in June 2013, to be presented to the Minister of Health. Some measures has time frames, but not clear what happens after the presentation**

# Ad. 4: WHAT do we expect to be the result?

- **In common:**
  - It is not clear, what happens, when the Plan or Strategy is finished
  - No dedicated budget
  - Too weak a model for managing, monitoring and evaluation
- **The setting – a success:**
  - Policy focus drawn to the area of rare diseases → the profile of rare disease is raised
  - New partnerships has been made → the patients are not alone
- **But the success of the plan will depend on the willingness of all parties concerned to actively pursue the suggested matters and of the government to provide money where necessary**



# Ad. 5: Best piece of advice and lessons learned – Conclusions

- **Process:**

- Work together with others
- Make partners with the civil servants in the relevant Ministry
- Work closely with your base

- **Contents:**

- Start thinking and talking about managing, monitoring and evaluation of the plan as soon as you can.
- Not very concrete? Remains to be seen! But the doubt itself underlines the need for cooperation and inspiration across borders, identifying key common issues:
  - Key: Essential measures
  - Common: Across countries

**MUCH MORE ABOUT THIS IN THE NEXT PRESENTATION!**

# For further information

- Rare Disorders Denmark, Lene Jensen:  
[lj@sjældnediagnoser.dk](mailto:lj@sjældnediagnoser.dk), +45 3314 0010
- Genetic Alliance UK, Melissa Hiller:  
[melissa@geneticalliance.org.uk](mailto:melissa@geneticalliance.org.uk), +44 20 7704 3141
- ACHSE, Mirjam Mann:  
[Mirjam.Mann@achse-online.de](mailto:Mirjam.Mann@achse-online.de), +49 30 33007080

**Thank you!**