Rare Disorders Denmark

National Plan / Strategy in Denmark

Lene Jensen, CEO

Basis

- No Danish National Plan or Strategy involving all sectors exists, but
  - Important special report 2001
  - Two highly specialised rare disease treatment centres covering 200 diagnosis
  - Comprehensive plan for establishing Centres of Expertise and more
- No dedicated funds for rare diseases

Status for national Strategy

- A working group within the National Board of Health was formed in 2011, first meeting 2012
- The working group has a broad representation of stakeholders, including patient representatives
- The task is to draw a National Strategy on the basis of the 2001-report and the EU-Reco
- A concensus Strategy is expected to be ready autumn 2013 after app. 10 meetings in main working group. Here after: Political process
- The Draft is written by the NBH, but contributions are welcome

How did we get there?:

- 2010: EUROPLAN I-Conference
- 2011: Formulation and dissemination of a booklet about the need for a National Plan
- 2012: Rare Disease Day Conference
- 2012 + 2013: Working within the working group
- 2014: EUROPLAN II Conference and change of lobby gear

How we conduct our mandate

- Rare Disorders Denmark: Board of representatives, Board of Directors, secretariat
- From 2011: Internal working group, NASTRA
- From ult. 2011: Corps of Health- and Social policy Representatives
- Bonding with experts….
- Ambition: To involve all rare patient societies – not fulfilled completely

Patient involvement

- The process has been propelled by patients – argumentation: The same opportunities as all other citizens
- The formality: The working group: 9 civil servants from relevant authorities, 7 health care professionals/scientists, 3 patient representatives (2 from RDD, 1 from PKU), NBH as secretariat
- The reality: All the speaking time we need, good possibilities to influence the agenda

Milestones and expectations

- Gradual milestone: Getting acceptance of the need to create a national plan
- Formal milestone: Meeting with the minister of health
- Expectations:
  - To identify the problems
  - To solve some of them
  - To have started an ongoing process
  - But worried about ressources, follow up and management, evaluation and more

Identifying the problems

- Untimely diagnosis
- From childhood to adulthood
- Lack of coordination in many ways
- Not enough knowledge, especially in the system for social support
- Too little information for professionals and for rare Citizens
- The conditions for patient education and other empowerment tools could be better

Solving some of the problems

- A more clear and well described procedure for Centres of Expertise and other centres – dynamic mechanism? Better ressources for CoE´s?
- Better coordination – but enough?
- More and better information for professionals and for rare Citizens
- Better possibilities for education of patients / rare families and other empowerment tools – but how?

We are worried about

- Having an excellent report but no action (been there, done that!) – no extra ressources
- Too weak a structure for governance and evaluation of the Strategy
- Too few ressources, power and skills in RDD and in our member societies to push for the implementation of the plan and to prepare for the next one

A piece of advice…

- EUROPLAN Conference – the preparation is as important as the Conference itself
- Make partners and make up…. But watch over your integrity and prepare to get back in opposition!
- Be skilled! Involve all good forces

May the force(s) be with you!

Contact

For further information:

- Lene Jensen, e-mail: lj@sjaeldnediagnoser.dk