



Sjældne Diagnoser

EMM 2023

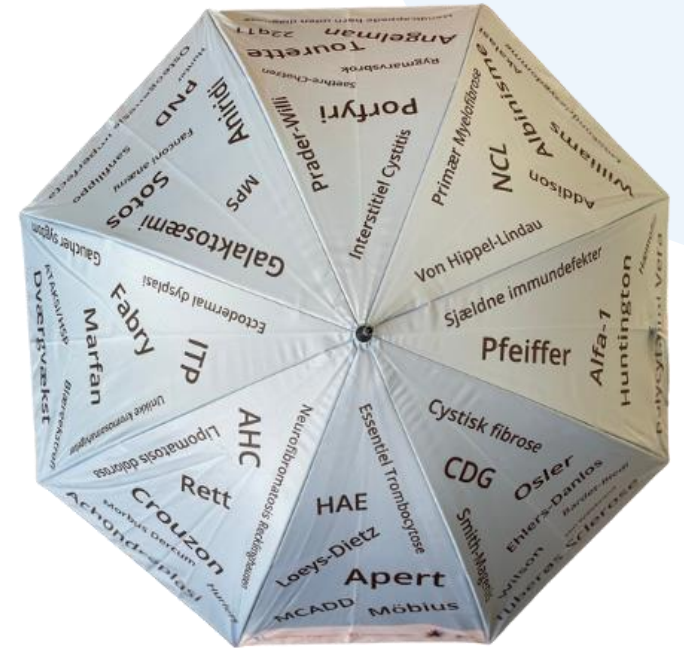
NETWORK SESSION: National actions which had an impact: What has worked in my country?

May 26., 2023,

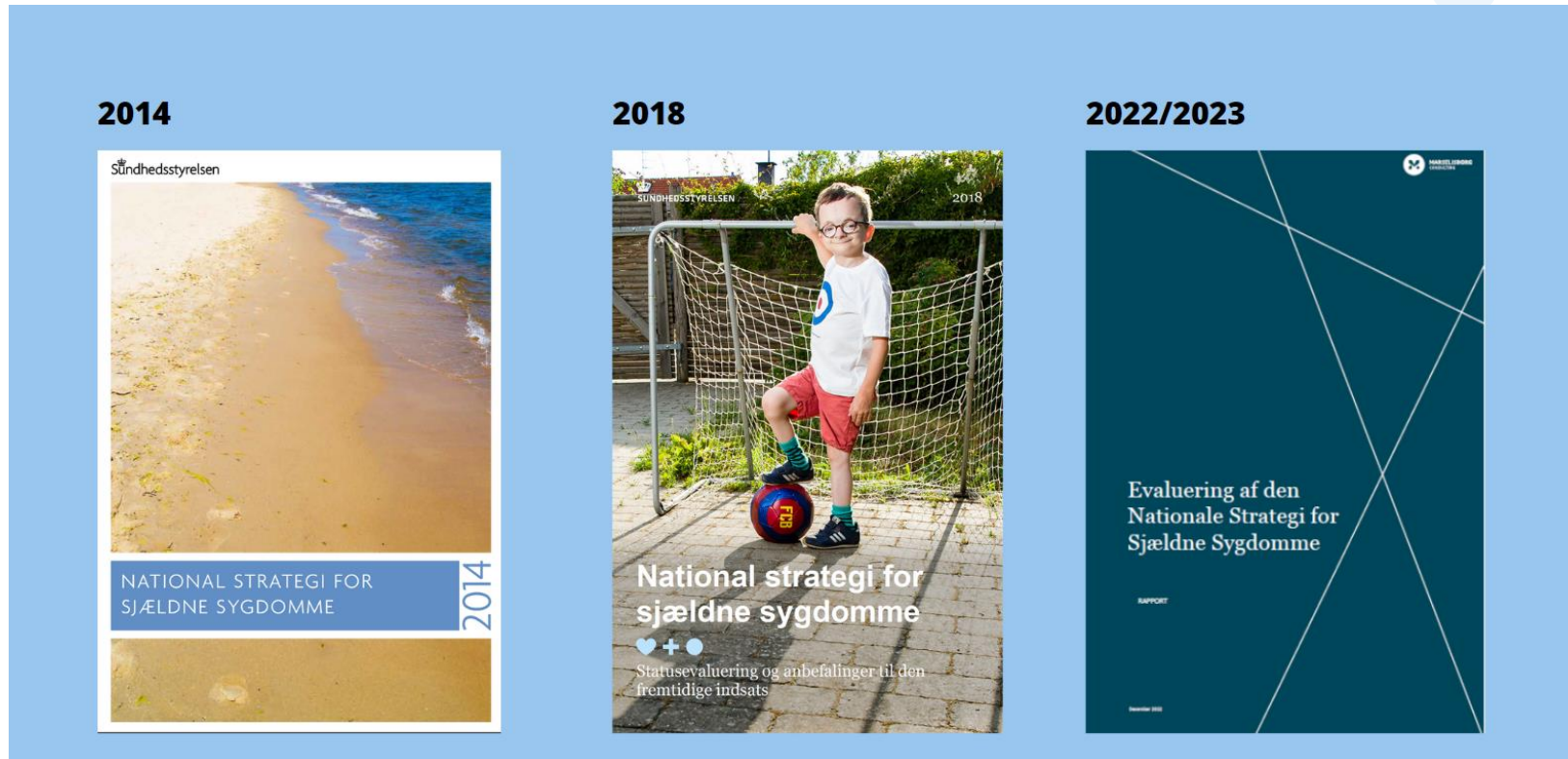
Lene Jensen, CEO Rare Diseases Denmark

RARE DISEASES DENMARK

- NGO for almost 40 years
- Voluntary based organisation with the support of a small, professional secretariat
- 55 member associations + 1 NURD = 12.500 members, 460 different rare diagnosis
- Active members of Danish Patients and EURORDIS
- Tasks:
 - Umbrella for the member associations
 - Platform for all PLWRD:
 - Advocacy
 - Knowledge stakeholder
 - Helpline and more



WHAT HAS WORKED IN MY COUNTRY: THE JOURNEY TOWARDS A NATIONAL STRATEGY



Visit Rare Diseases Denmark's theme site on the Danish national strategy for rare diseases here: <https://sjældnediagnoser.dk/national-strategi/>



THE JOURNEY TOWARDS A DANISH NATIONAL STRATEGY

The launch pad was European:

- 2008: Communication from the European Commission
- 2009: Recommendation from the EU council of Health ministers

EUROPLAN project 2008 – 2015:

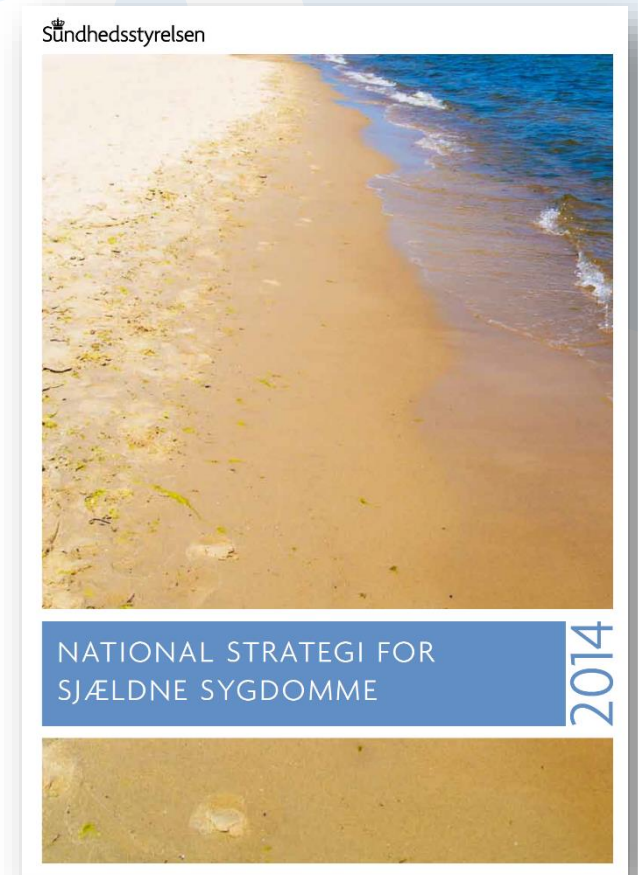
EUROPLAN

European Project for Rare Diseases National Plans Development



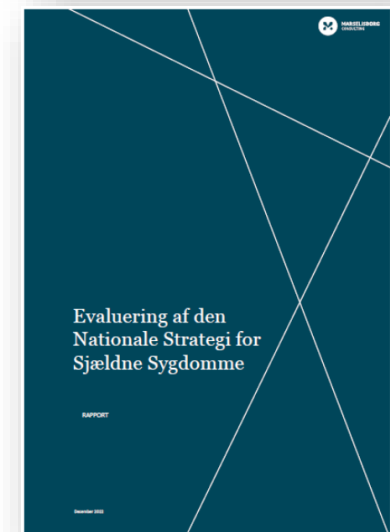
FROM IDEA TO STRATEGY REPORT

- 2010 – 2011: Rare Diseases Denmark advocacy for a Danish national strategy
 - EUROPLAN conference
 - Meetings at the Danish parliament and at governmental level
- 2011: Forming of DHA-working group with stakeholders representing
 - HCPs from relevant scientific societies and centres of rare diseases
 - Authorities from the health and social area – regional and state level
 - Patient representatives: Rare Diseases Denmark and the PKU Association
- 2014: The first Danish national strategy for rare diseases is published
 - Descriptive chapter and 12 themes with app. 100 recommendations
 - No dedicated budget
 - Working group ad hoc



FROM STRATEGY REPORTS TO EVALUATION REPORT

- 2015: EUROPLAN Conference on the Danish national strategy
- 2016: Implementation of recommendation about Helpline
- 2017: Workshop in EUROPLAN format
- 2018: A status report with concentrated recommendations
- 2020: Workshops on empowerment and ERN
- 2022: Satellite workshop under ECRD
- 2022: evaluation of the 2014 + 2018-reports → published February 2023
 - Three evaluation perspectives: Implementation, effect, relevance
 - Working group continues
 - Meeting with Danish Health Agency
 - Meeting with Minister of Health

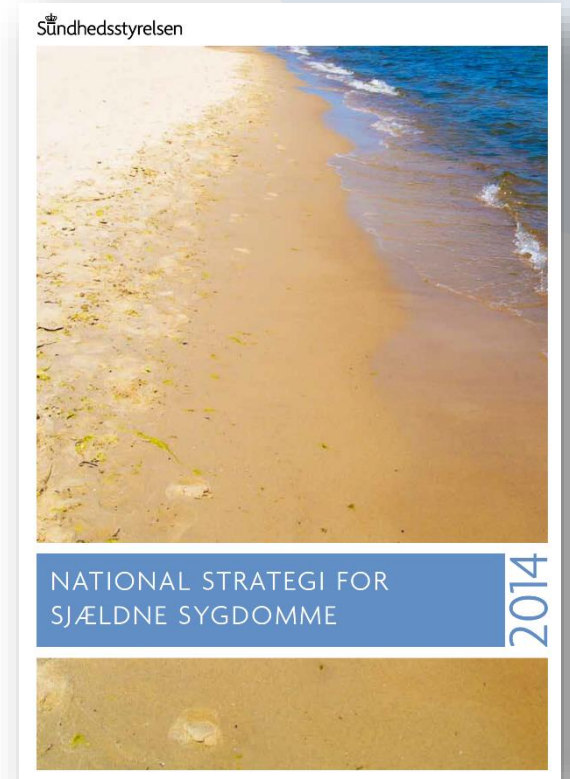


THE ROLE OF PATIENT ASSOCIATIONS I

2014-strategy, recommendation:

- *“Patient associations should be involved in the work regarding the patient group's special problems, e.g. as a hearing party for new legislative proposals with relevance to the area, in relevant working groups etc. set up by public bodies and should be equipped to handle this task*
- *Patient associations can be involved with great advantage in gathering experience, satisfaction surveys, etc.*
- *Support to the commitment and participation of the patient associations”*

**Rare Diseases Denmark:
advocate, knowledge holder and supplier**



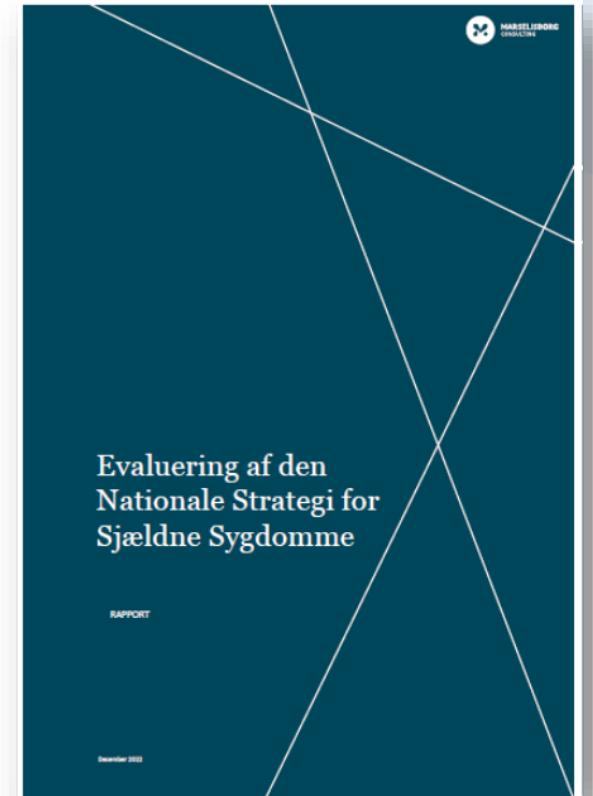
THE ROLE OF PATIENT ASSOCIATIONS II:

2023-evaluation, result:

“The involvement of patient associations is crucial for the quality of efforts and initiatives for people with rare diseases, including the implementation of the recommendations. The associations have a unique knowledge of the patient group's challenges and needs. This knowledge has been essential for the work with the development of interventions and recommendations targeted at people with rare diseases.”

(p. 70)

<https://sst.dk/da/udgivelser/2023/Evaluering-af-den-Nationale-Strategi-for-Sjaeldne-Sygdomme> - including an English summary)



WHAT HAS WORKED IN YOUR COUNTRY?

YOUR BIGGEST SUCCESS IN THE LAST DECADE?



- What did you do?
- What was the result?

YOUR BEST PIECE OF ADVICE? 😊

- What did you learn from the process?

