Sjældne Diagnoser

Welcome to the workshop on European Reference Networks

SUNDHEDSSTYRELSEN

2018

National strategi for sjældne sygdomme

Statusevaluering og anbefalinger til den fremtidige indsats

Birthe Byskov Holm, 28.02.2020

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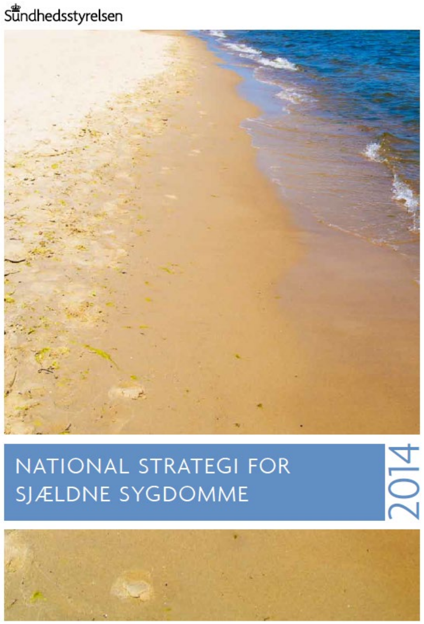
Program

- 13.10 – 13.50: **ERN: What, Why, When?** – and Q &A´s, by ERN & Healthcare advisor Matt Bolz-Johnson, EURORDIS
- 13.50 – 14.10: **Denmark & ERN – Status and foresight**, by Special Advisor Søren Neermark, Danish Health Authority
- 14.10 – 14.45: **Perspectives on future ERN, participation and integration:**
  - 14.10 - 14.25: The Healthcare providers by Dr.med. MPM Per Jørgensen, Rigshospitalet
  - 14.25 – 14.35: The HCPs, by Allan Meldgaard Lund, member of MetabERN
  - 14.35-14.45: The Patients, by Anne-Grethe Lauridsen, Patient Representative in MetabERN
- 14.45 – 15.00: **Coffee break**
- 15.00 – 15.50: **Think tank: How to integrate ERN and the Danish Health Care System – what does it take?** moderated debate

Presentations, additional papers and more on website next week

The Danish national strategy for rare diseases

- 2009: EU Recommendation
- 2011: DHA-Working group
- 2014: National strategy for rare diseases
- 2018: Follow up report on national strategy



Sundhedsstyrelsen

NATIONAL STRATEGI FOR
SJÆLDNE SYGDOMME
2014

SUNDHEDSSTYRELSEN
2018

National strategi for sjældne sygdomme

Statusevaluering og anbefalinger til den fremtidige indsats

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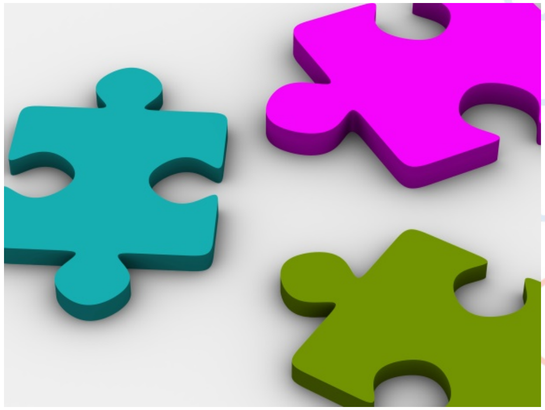
Follow up report 2018 I

- Reco no. 16:
  - The regions should establish a national cooperation concerning Danish participation in international cooperation, including Danish participation in European Reference Networks and Orphanet.



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Follow up report 2018 II

- Reco no. 17:
  - The regions should develop regional networks to support the coordination of the work of the regions between the Danish members of the ERNs including the application process for the hospitals and assist with the communication of relevant information from DHA to the regions.

Follow up report 2018 III

- Reco no. 18: DHA supports the regions and strenghten the Danish participation in ERN in the build-up phase to
  - A) make clear, that hospitals with highly specialized functions are recommended to join the ERNs if such relevant network exists
  - B)support Danish hospitals participation by communicate contacts and information, e.g. information-meetings, when the next Call for members is known.
  - C)participate in the Nordic cooperation among these Nordic Network on Rare Diseases(NNRD) and Nordic cooperation on Highly Specialized Treatment and Clinical Trials when cooperation in relation to ERNs is debated.

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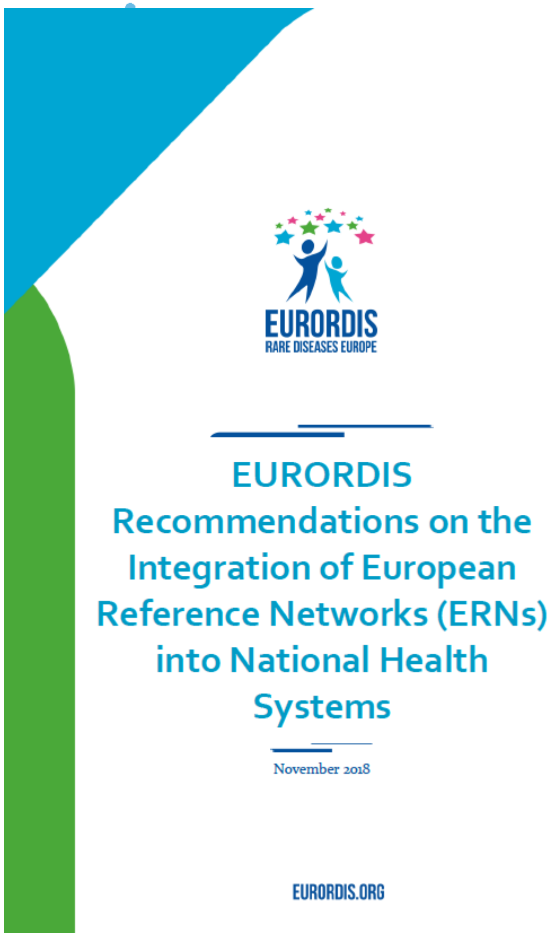
EURORDIS
RARE DISEASES EUROPE

EURORDIS Recommendations on the Integration of European Reference Networks (ERNs) into National Health Systems

November 2018

EURORDIS.ORG

Recommendations

1. [Create a good level of awareness at national level of the ERN model among all key stakeholders]
2. [Ensure political leadership and ownership of the ERN system at national level and generate sound evidence on the value of the ERN model]
3. [Review or adapt national policies on rare or low prevalence and complex conditions to address integration of ERNs into the national health systems]
4. [Member States to set up national networks of rare disease expert centres and the RD patient community to create national networks compatible with the ERN-disease groupings]
5. [Incorporate new Full Members and Affiliated Partners specifically to cover ERNs geographical and/or expertise gaps]
6. [Set up National Coordination Hubs and designate ERNs national focal points]
7. [Streamline the process to endorse healthcare providers that apply for full membership]
8. [Define and validate ERN referral pathway at national level to ensure timely access to ERNs advice and adequate management of case referrals]
9. [Establish a funding mechanism to finance ERNs virtual advice]
10. [Develop a mechanism to recognise and adopt at national level clinical guidelines reviewed or adopted by ERNs]

http://download2.eurordis.org.s3.amazonaws.com/ern/Draft%20Recommendations%20for%20Integration_final.pdf


BREAK

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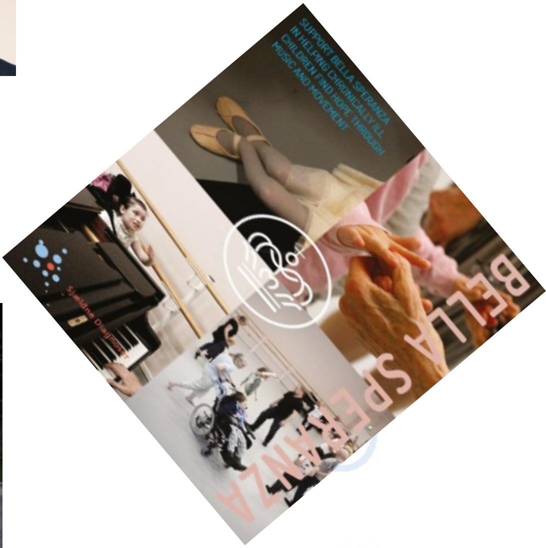
Moderated debate

- Presentations, additional papers and more on website next week

Now, for the reception!

- The reception:
  - Postcard for Politicians

  - Bella Speranza



  - Cook book first edition
  - UNIK Magazine

Thank you for your participation!

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