

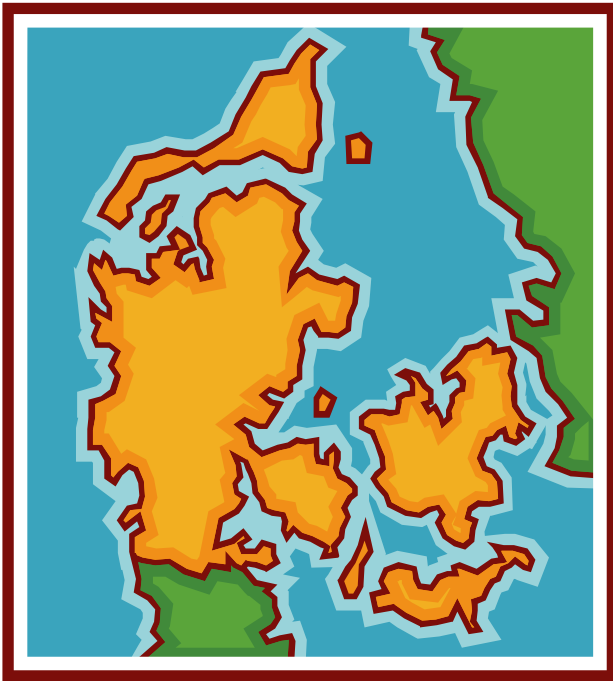


The Danish Center for Rett syndrome

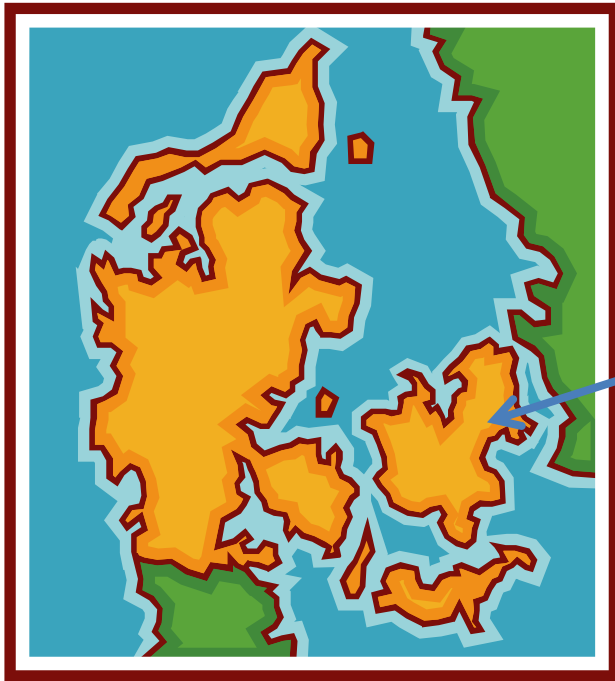
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How there came a Center for Rett Syndrome in Denmark



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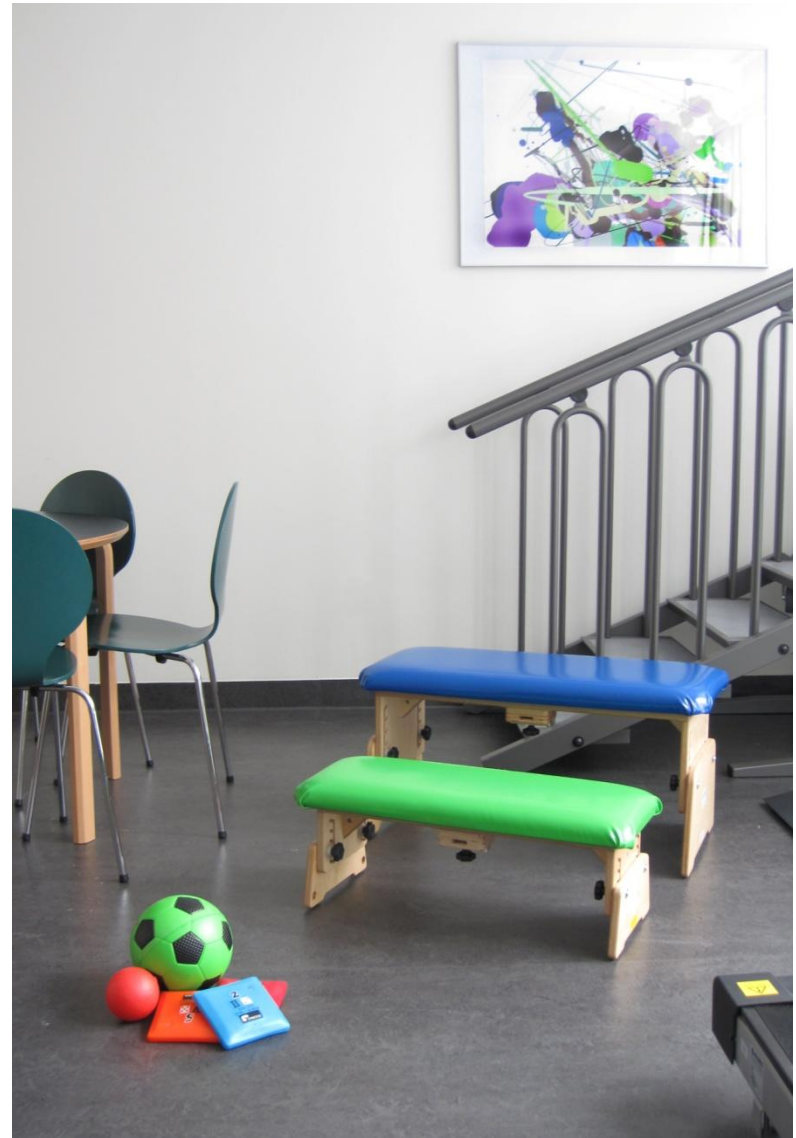
- 1988
Danish Rett syndrome association
- 2007-2010
temporary funding from the state
- 2011-
permanent funding

A multidisciplinary team

- 1 neuropaediatrician
- 2 physiotherapists
 - 1 clinical
 - 1 research
- 1 educational psychological advisor
- 1 socialworker (30%)
- 1 research assistant
- 1 dietician (2 hours a week)
- 1 nurse (20%)
- 1 secretary (50%)



- **The purpose of the center is to improve the overall quality of life for persons with RTT and their families**



How are we organized?

We offer

- clinical follow-up of persons with **RTT in Denmark** on a **livelong basis** as a highly specialized service
- **multidisciplinary** counseling and support to all Danish patients and families
- advice on management of persons with RTT for local health care and social authorities
- **outgoing function** (teaching in RTT and patient-related counseling) to special education centers, daycare centers and living homes for disabled persons
- **education** of families and professionals in cooperation with the **National Family Association for RTT**

107 persons with RTT – September 2014

median 21 - mean 23,7 years

