



Helsedirektoratet

Norwegian Directorate of Health

Rehabilitation and Rare disorders Department

Definition of rarity

- Medical conditions (diagnoses/syndromes) that affect less than 100 known cases per million inhabitants (<500 at a national level).
- About 30.000 persons with rare disorders in Norway
- To get services from a Centre of Expertise:
 - Congenital
 - Complex/compound dysfunctions
 - A need for multidisciplinary and coordinated services

Our department's tasks

- Provide an overview of the incidence of congenital and rare disorders
- Provide an overview of the living conditions of the concerned groups
- Keep the Ministry of Health updated about developments and suggest reallocation of means between Centres of Expertise (16 centres for about 320 disorders)
- Advice users, family members and service providers
- Co-operate with the Centres of Expertise on common measures to use resources in an optimal way

Channels of information

- <http://www.helsedir/sjelden>
- www.rarelink.no (nordic collection of links to qualified information)
- "*En sjelden guide* (A rare guide)", which contains an overview of services for about 320 diagnoses/ groups
- Several official documents, directives, regulations, acts etc.

- Help-line **+47 800 41 710**
 - Free information about rare disorders
 - Requests from users, family members and professionals

2008-2010: Report to identify in a five years perspective which Centres of Expertise are needed and where within the specialist health care services they should be placed.

Directive on hearing these days.

Norwegian Centres of Expertise

National Centres of Expertise for rare disorders (quote from “a rare guide”):

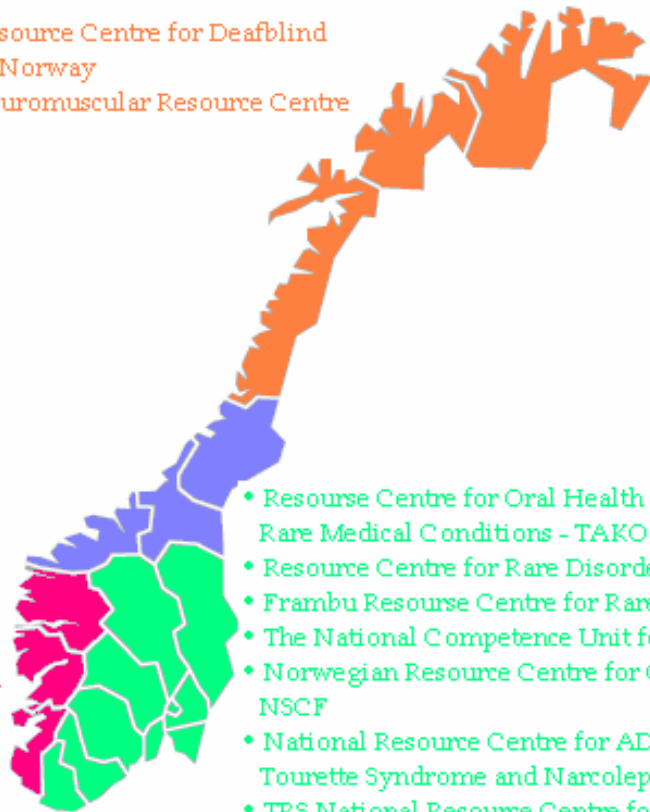
*“In Norway we have several national resource centres for rare conditions (... ..)
... to ensure that persons with rare conditions are given the same opportunity for treatment and assistance as everyone else. Secondly, they are expected to meet the need for support, which will not be met by standard procedures. This may be specialized information, consultations, medical and pedagogical studies, preventive and diagnostic treatment and the possibility to get in touch with other persons with the same/similar condition.”*

- Financed by earmarked grants through the state budget
- Total of ~320 diagnoses, distributed as clusters
- 16 different centres, 6 of these for dual sensory impairment.
- “To live with...” perspective (life-long)

NORWEGIAN CENTRES of EXPERTISE

- **Centre of Expertise for Oral Health in Rare Medical Conditions - TAKO**
TAKO-senteret, N-0456 Oslo. Website: www.tako.no
- **Centre for Rare Disorders – SSD (~50 conditions incl. craniofacial, bleeding, ectodermal dysplasia, huntington, +++)**
Senter for sjeldne diagnoser, Rikshospitalet, N-0027 Oslo. Website: www.sjeldnediagnoser.no/
- **Frambu Centre for rare disorders (>60 conditions; microdeletions, progrediating, chromosomal, some metabolic, +++)**
Sandbakkveien 18, N-1404 Siggerud. Website: www.frambu.no
- **The National Unit for Autism**
Rikshospitalet, Oslo. Website: <http://www.autismeenheten.no>
- **National Centre for Cystic Fibrosis – NSCF**
NSCF, Ullevaal universitetssykehus, N-0407 Oslo Website: www.ullevaal.no/nscf
- **National Neuromuscular Centre - NMK**
Nevromuskulært kompetansesenter, PO Box 46, N-9038 Tromsø. Website: www.unn.no/nmk
- **National Resource Centre for AD/HD, Tourette Syndrome and Narcolepsy - NK**
Ullevaal universitetssykehus, N-0407 Oslo. Website: www.nasjkomp.no
- **Norwegian Porphyria Centre – NAPOS**
Website: www.napos.no
- **Resource Centre for Rare Disorders – TRS (OI, spina bifida, Marfan, Ehler Danlos, Short stature, Limb deficiency, AMC)**
TRS, Steinveien 3, N-1450 Nesoddtangen Website: www.sunnaas.no/trs
- **Centre of expertise on rare epileptic disorders (Tuberous Sclerosis, Landau Kleffner, Sturge Weber, Aicardi)**
Website: www.rikshospitalet.no
- **The National Resource System for Deafblind People**
(coordinating unit + 6 national and regional centres)

- Regional Resource Centre for Deafblind in Northern Norway
- National Neuromuscular Resource Centre - NMMK



- Norwegian Porphyria Resource Centre - NAPOS
- Regional Resource Centre for Deafblind in Western Norway

- Resource Centre for Oral Health for Rare Medical Conditions - TAKO
- Resource Centre for Rare Disorders - SSD
- Frambu Resource Centre for Rare Disorders
- The National Competence Unit for Autism
- Norwegian Resource Centre for Cystic Fibrosis - NSCF
- National Resource Centre for AD/HD, Tourette Syndrome and Narcolepsy - NK
- TRS National Resource Centre for Rare Disorders
- Tuberous Sclerosis Resource Centre - TS-KS
- Regional Resource Centre for Deafblind at Skådalen Competence centre
- Regional Resource Centre for Deafblind at Andebu Centre for deafblind
- Eikholt National Resource Centre for Deafblind
- Huseby Resource Centre for persons with visual impairments

Challenge:
What about the 14.000 without a Centre of Expertise??