The TAKO-centre

A success story

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National Resource Centre for Oral Health in Rare Medical conditions
Political signals in all the Nordic Countries

regarding improvement of Knowledge and

Care for persons with Rare Conditions
Finland
University of Helsinki, Dental faculty
Special unit for Rare Diagnoses: 1991

Norway
University of Oslo, Dental faculty, TAKO-centre 1993

Sweden
Mun-H-Center, 1994
Special unit in Jönköping 1994 and
Umeå 2004

Denmark
Centres in Aarhus and Copenhagen from 2003
The TAKO-centre - why?

Persons with rare conditions may have:

- Developmental disturbances of teeth or facial structures
- Chewing swallowing and speech problems
- Dry mouth or other oral effects of drugs
- Defects in ectodermal or connective tissue which may effect oral structures
The TAKO-centre - How?

Dentists, dental hygienists, speech pathologists and physiotherapists collect, systematize and disseminate information on oral health problems in rare conditions.
Target groups

- The dental team
- Other health professionals
- Patients and families
- Politicians and lawmakers
Methods

- Collecting information
- Examination of patients
- Contribution to diagnosis
- Short- and long term treatment plans
- Treatment of complicated cases
- Advice and information to dental teams
- Research
- Post-graduate education programmes
Budget

- NOK 14,6 mill. per year
- 26 persons employed
- Full government financing
Oral motor stimulation for children and adolescents an important activity
Infants

Severely hypotonic, premature or sick infants may not be able to breast feed
The mouth

A sensitive and important organ for

- Food intake
- Communication
- Self esteem (aesthetics)

Oral diseases cause pain!
Infancy

- Orofacial stimulation
- Dietary advice
- Fluorides and tooth cleaning
Pre-school children

Continued orofacial stimulation

Stimulation devices

- whistles
- drinking straws
- palatal plates

Preventing oral diseases
School children

- Maintenance
- Follow up
- Orthodontic/prosthodontic treatment
- Interdisciplinary cooperation
Adults

- Oral rehabilitation
- Maintenance
Important issues

◆ Maintaining good oral health for life
◆ Close cooperation between units giving assistance to persons with disability
◆ Acceptable time-use and cost for the patient
The TAKO-centre specialists in the craniofacial team

◆ Speech pathologist
◆ Paediatric dentist
◆ Physiotherapist
◆ Other dentist specialists
Research activities at the TAKO-centre
Doctorate project on oligodontia and ectodermal dysplasias
Hilde Nordgarden/KS
On Oligodontia, Ectodermal Dysplasias and Salivary Gland Function and Development

Hilde Nordgarden
Thesis 2004
Oligodontia

- Congenital absence of six or more permanent teeth, third molars excluded

- Prevalence of oligodontia in the population was unknown
Ectodermal dysplasias

- Large and heterogenic group of disorders (< 100)
- Developmental disturbances in two or more of the following tissues
  - Hair
  - Teeth
  - Nails
  - Sweat glands
Doctorate project on Williams syndrome
Stefan Axelsson/KS
Variation of the cranial and dental phenotype in Williams syndrome

Stefan Axelsson
Thesis 2005
Doctorate project on Prader Willi syndrome
Rønnaug Sæves/KS
Prader - Willi syndrome (PWS)

- Congenital
- 1:15000
- Both sexes
- Appr. 110 persons in Norway
Joint projects with other institutions on

- Osteogenesis imperfecta
- Duchenne
- APS-type 1
- Velocardiofacial syndrome (DiGeorge, 22q11-deletion)
- Drooling
- Sleep apnea
- Cherubism
- Aagenæs syndrome
- Treacher Collins syndrome
- Rett syndrome
- We started in 1993 with a dentist and a secretary
- 2012: 26 employees. 10 dental specialists, 5 with a doctorate degree. Many publications and more coming