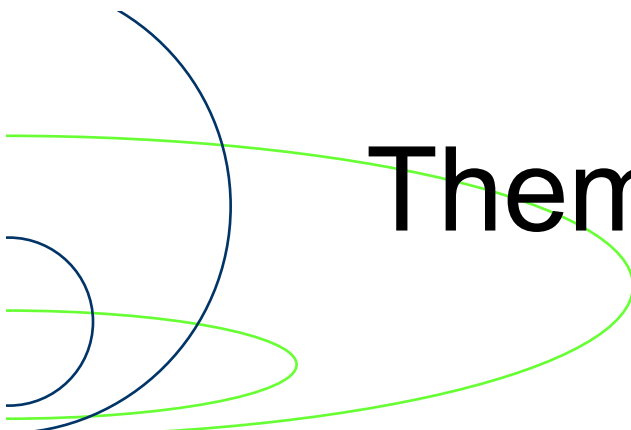


European Conference on Rare diseases, Krakow d. 14. May





Theme 4: Helpes lines, CSH model

- Director Henriette Hutter
- Specialist Consultant
Gunver bording





Centre for Rare diseases and Disabilities (Danisk abbreviation CSH)

A public Danish Centre with
nationwide responsibility for:

- counselling
- Information
- Development projects





CSH is:

- a self-governing body under the Danish Ministry of Social Affairs
- associated with the National board of Board of Social Services.





CSH in ordre:

- create national overview
- document conditions of life
- spread knowledge and create dialog
- to give better possibility for prevent problems





Main TaskS

- web – site www.csh.dk
- open phone and e-mail counselling
- elaboration of rare diasesdescription.
- developepment projects
- teaching





Main tasks continue:

- supprt N`GO`s
- newsletter
- the Danish Contact System.





Target group

- People with rare diseases and their relatives
- Professionals from all sectors in the decentralised system (municipalities and counties).





Content of www.csh.dk

- 260 short descriptions of syndromes, including links
- 40 review articles of disabilities
- Articles of social legislation and general medical information
- 100.000 visitors per year





Prime actors specialised in the field of rare diseases in Denmark.

- 2 clinics for rare diseases in the health care system
- Centre for Rare Diseases and disabilities
- 30 NGO's and 1 umbrella NGO





Contat persons

- Objective: to create network between people with the same rare disease – who has no NGO
- 350 persons are registered (some alone for serveral years)
- Some times basis for creating a user organisation
- Nordic project

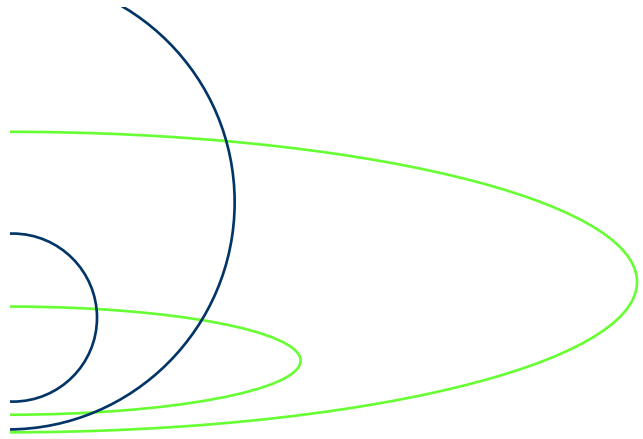




Counselling team

- 2 specialist consultant
- 1 counselling worker
- Medical consultant and legal adviser





Counselling

- About 800 counselling cases a year
- Concerning about 270 different diseases

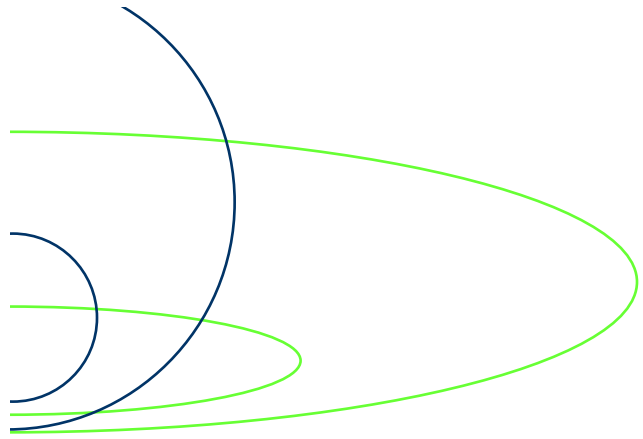




Types of requests:

- information on syndroms
- specific social questions and social questions and social advice
- specifik medical question
- seeking contact with others with the same diagnosis

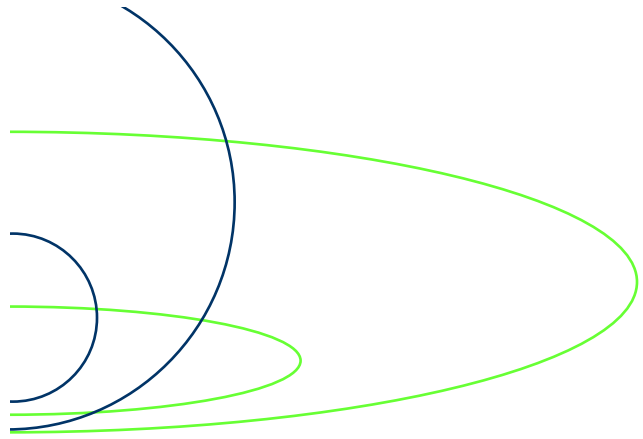




Methods

- primarily a call-in-service-telehpone and e-mail counselling
- selhelp and process-oriented counselling
- guidance
- supporting conversation





principle

- impartial
- no referral
- interdisciplinary
- based on network

