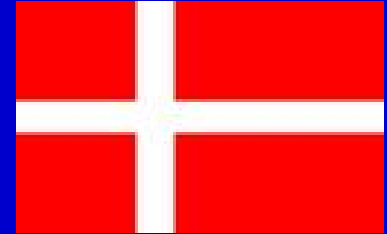


Could you give a few “key facts” on SCI in DK?

Denmark: 5.5 mill.



Incidence (estimates):

Traumatic SCI: 50-70/year

Non-traumatic: 80-100/year
(including spina bifida ↓)

Prevalence (estimate): 3000

National Board of Health in Denmark

Individuals with spinal cord lesions to be treated in one of two centres and for very specialised topics in one centre only:

Based on Report from 1994 on:

Organisation of Treatment and Control of Para- and Tetraplegics

This is recently confirmed by the Speciality Planning for Denmark in September 2010

National Board of Health

Individuals with spinal cord lesions (SCL) in Denmark to be treated in two centres only for:

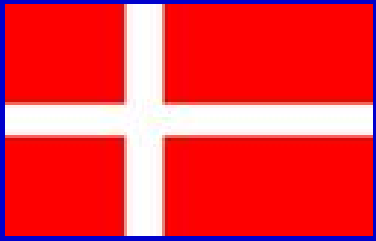
- Acute Orthopaedic/Neurosurgery
- Lifelong treatment and rehabilitation
- Urinary tract problems related to the SCL
- Gastrointestinal problems related to the SCL
- Plastic surgical treatment for pressure ulcers
- Obstetric challenges (birth)
- Respiratory support – including home ventilation
- Children with spinal cord lesions

National Board of Health

Individuals with spinal cord lesions to be treated in one centre only for:

Implantation of phrenic nerve stimulator (diaphragmatic pacer)

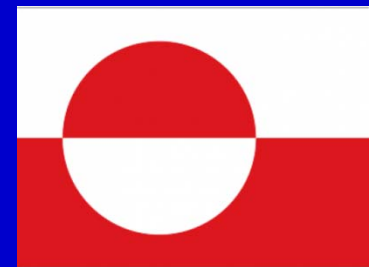
Upper extremity surgery for tetraplegics



DENMARK

Treatment, rehabilitation and life-long follow-up for Spinal Cord Lesioned individuals are centralised to two centres in Denmark:

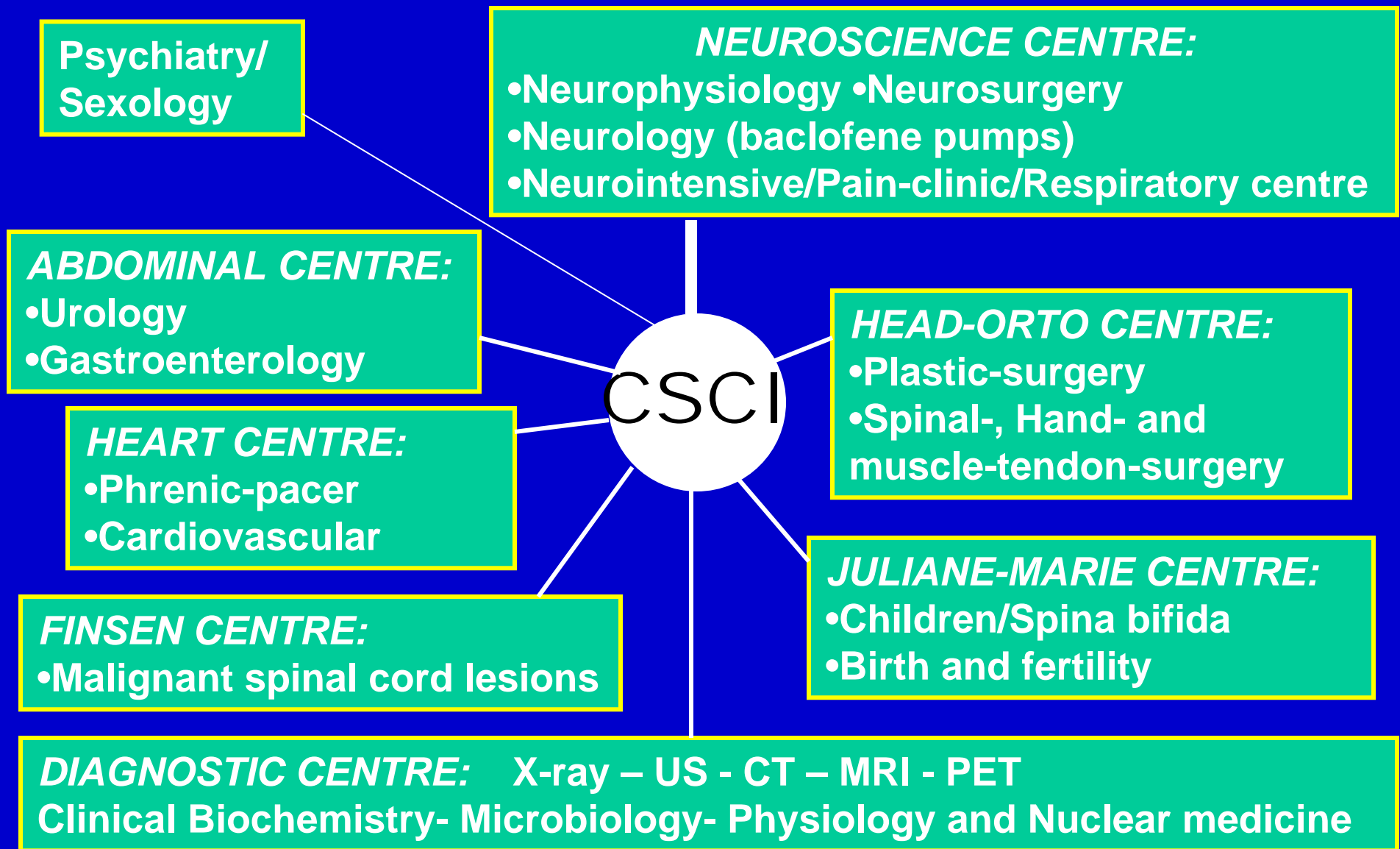
- Århus/Viborg for West-Denmark
- Rigshospitalet Copenhagen/Hornbæk for East-Denmark, the Faroe Island and Greenland





Clinic for Spinal Cord Injuries, NeuroScience Centre, Rigshospitalet, and University of Copenhagen, Denmark

Organization of treatment and rehabilitation and follow-up of spinal cord injuries at Rigshospitalet

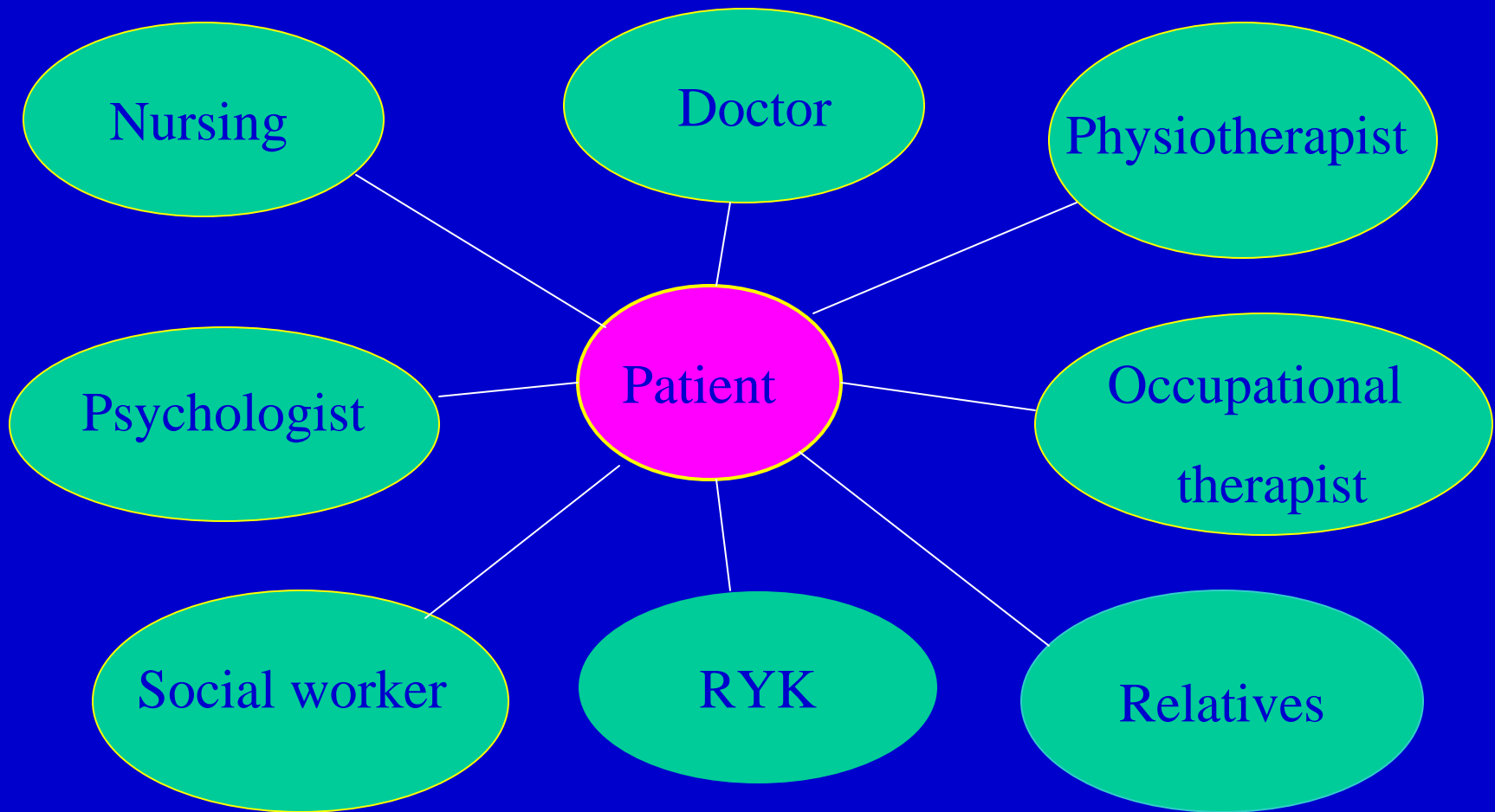


Clinic for Spinal Cord Injuries, NeuroScience Centre, Rigshospitalet, and University of Copenhagen, Denmark

In your role as head of the Clinic for Spinal Cord Injuries at the Copenhagen University Hospital can you describe your contact with the Danish SCI consumer organization?

CONTINUOUS
NEARLY DAILY

MULTIDISCIPLINARY COOPERATION



Contacts related directly to the Patients in the Clinic

- General education programme for patients and relatives
- Sexology groups
- Mentor arrangements
- Visit to homes with new patients
- Special events in the hospital arranged by the consumer organisation (e.g. Johnny Walker)
- Hornbæk group
- Information material/web-site/magazine

Contacts related to the Hospital

- The consumer organisation educate the personnel
- Yearly meetings in the hospital
- Personnel write about the clinic in the Magazine, and take part in Q and A
- Directly involvement with innovations in the clinic, e.g. conference structure (interviews)
- Personnel representative in the board of directors in the consumer organisation
- Informal contacts / dialogue

Contacts related Political institutions / Public

- Overlooking changes which may hamper the situation for the SCI consumers
- Writing to these institutions and put pressure when appropriate
- Establishing a professorship in SCI
- Research projects
 - Activated macrophages
- Seeking advise when writing

You are active in both NoSCoS and ISCoS – what contact/collaboration do you have with consumer groups in Scandinavia, Europe and elsewhere? Can you give some examples?

- General cooperation and communication about anything when relevant, e.g.
 - Finland consumers – regarding centralisation
- Introducing Organisations in New countries
 - Baltic countries – cooperation
 - Albania – consumers initiated the development

- Research projects
 - Nordic: Women sexuality
 - European: Back to Work
 - International: Participation and QoL Data Set
- Lecturing
 - European Spinal Cord Injury Federation
 - Croatian Paraplegic and Tetraplegic Association, Umag, Croatia.

Should SCI consumer organizations be doing more to support their members/SCI professionals? If so, what would you suggest?

If possible: Global SCI consumer organisation

Find a cooperation platform between the professionals (ISCoS) and the consumers to enhance the possibility for influence regarding all aspects which may be for the benefit of SCI consumers

Help in centralization of the treatment, rehabilitation and follow-up

Constructive critical support to improve all aspects of the prevention, management and research in the field of SCI