



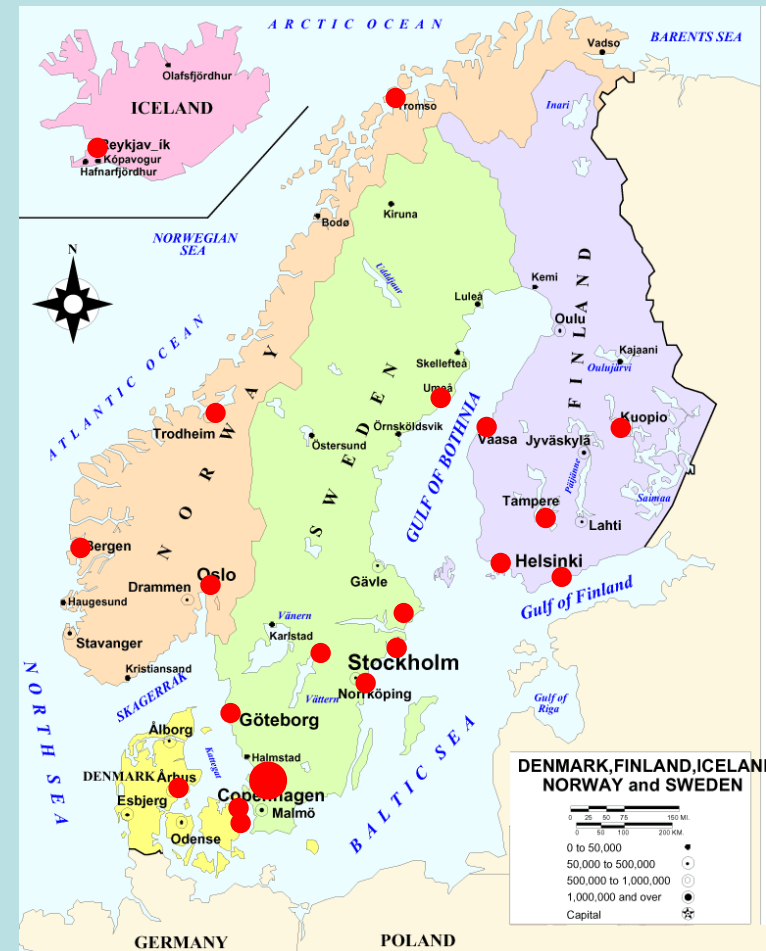
# **The Scandinavian Sarcoma Group organisation of osteosarcoma studies**

**Sigbjørn Smeland**



# SSG structure

- Multidisciplinary society of **nine** specialties to cover most aspects of sarcomas
- 21 tumor centers in the five Nordic countries
- Data center at the Regional Tumor Registry, Lund, Sweden





# Scandinavian Sarcoma Group

## Main purposes

1. Clinical trials and research projects
2. Treatment Guidelines
3. Information and education
4. SSG Registry; centralized register of all sarcoma patients in Scandinavia



# Decision making process SSG board

## **SSS Board**

- 16 board members  
(KS Hall, O Brosjö)
- Bone-sarcoma subcommittee  
(S Smeland)
  
- Two annual board meetings
- Need before decision confirmation in national tumor groups (i.e. pediatric society etc)

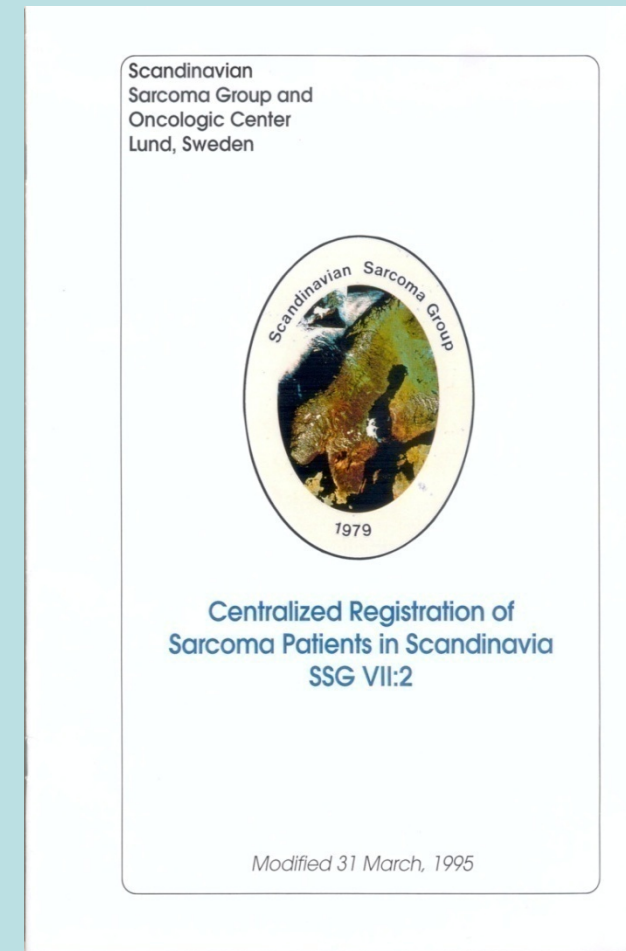
## **Funding**

- Data center funding  
(common infrastructure)
  - University hospital
  - Pharmaceutical companies
  - Nordic cancer union
- National funding
  - University hospitals
  - External sources
- Pr study funding
  - University hospitals
  - National-wise Research councils (EURAMOS-1)
  - Other external sources



# SSG Registry 1986 -

- 9/10 off all sarcoma patients in Sweden and Norway are reported to the registry
- Approx 350 pts/year; 250 Soft-tissue and 100 Bone Sarcomas
- Merging data with the national cancer registries ~ 100 % long term follow-up possible
  - Monitor care pattern
  - In depth analyses for quality assurance
  - Basis for research projects



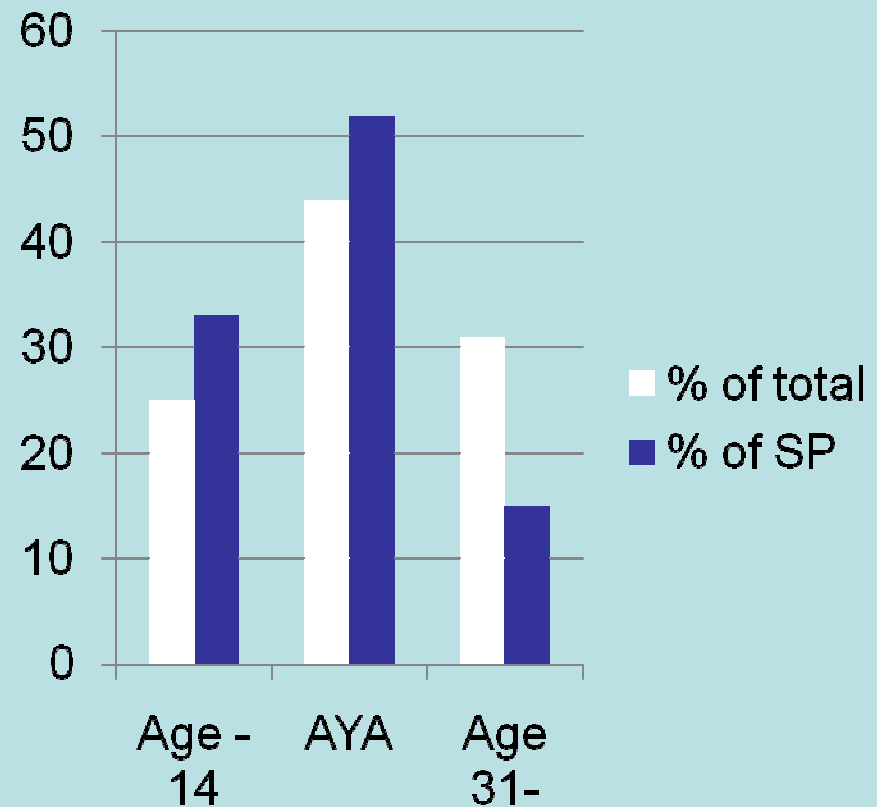


# SSG Registry: Osteosarcoma patients

Age distribution:

All and study patients

- 708 OS pts registered; 1986-2008
- 58 % study patients
- 73 % age < 41 years
- 49 % classical



AYA: adolescents and young adults, age 15-30



# SSG osteosarcoma studies

Study	n	annual recruitment	
SSG II	97	14	classical
SSG VIII	113	14	classical
ISG/SSG 1	57	16	classical
SSG XIV	63	16	classical
Euroboss	36	6	All > 41
Euramos*	89	18	All $\leq$ 40

\* Includes Denmark



# SSG

1. Multidisciplinary sarcoma group include all five Nordic countries~25 mill people
2. Estimated annual recruitment for osteosarcoma studies < 40y: 15-20 pts/year
3. Government paid health care system (include drugs, insurance).
4. Studies need extra funding as for EURAMOS-1
5. Marketing license for drugs follows main Europe (EMA)  
– compassionate use of MTP for relapsed patients. In Norway MTP will not be paid by the health care system.