

**Business meeting Central register coordinators
May 6th 2009**

Ref. : Clement Trovik

All coordinators listed below had received an invitation for the meeting and was verified as coordinators and individuals responsible for maintenance of the SSG central register at the sarcoma centres:

Umeå – Martin Erlandson/
Richard Lövenberg/
Ingela Johannson

Stockholm – Henrik Bauer/Jan Åhlén/
Asle Hessla

Lund – Fredrik Vult von Steyern

Linköping – Anders Kalén

Göteborg – Sigvard Eriksson/
Peter Berg

Bergen – Clement Trovik

Oslo – Kirsten Sundby Hall

Tromsø – E. Smeland/Vidar Isaksen

Trondheim – Heidi Knobel

Reykjavik – Halldór Jónsson

Helsinki – Calle Blomqvist

Åbo – Paula Lindholm

Tampere – Minna Laitinen

Århus – Bjarne Hansen

An evaluation of quality of data in the register has been started. This should be based on a set of variables required completed for the patient to be registered or retained in the register.

Variables agreed upon are:

- Hospital
- Age at Diagnosis
- Sex
- Date of Diagnosis
- Referral pattern
- Metastasis at Diagnosis
- Histology = Sarcoma/GCT
- Malignancy grade/MGNA
- Size
- Site
- Location
- Number of operation for primary.
- Oupdate
- Other treatment or protocol number
- Follow-up date. State at follow-up > 1 year since date of diagnosis
- Death date. Reason for death

The register contains at present:

9052 patients with histology 1986- sept. 2008
4583 Soft tissue sarcoma in extremity and trunk wall
2617 Bone sarcoma + Giant cell tumors
1120 Visceral/Retroperitoneal/Head-Neck/
Gynecology/Thoracic organs

An overview proportion of cases with one or more missing key variables
(Total,Extremity,Visceral) was provided:

Oslo	635	355	280
KS	323	275	48
Göteborg	317	311	6
Lund	236	231	5
Helsinki	180	180	0
Umeå	79	72	7
Trondheim	72	48	24
Tampere	32	29	3
Bergen	19	19	0
Linköping	19	17	2
Åbo	18	18	0
Total	1958 / 9142	1582 / 8011	376 / 1131

It was agreed that metastases, diagnosed <30 days after date of diagnosis, should be regarded as present at diagnosis. Patients diseased < 2 years after diagnosis of metastasis should automatically be regarded as dead of disease when the metastases are not surgically removed or the patient is specifically deemed free of metastases in the meantime.

There was a short orientation by Janne Åhlen concerning preparatory work to start Registration of visceral/retroperitoneal sarcomas using the new net-based and secure INCA platform for cancer registration in Sweden.