

SSG board meeting 2009-11-22, Copenhagen

Present: Thor Alvegård, Øyvind Bruland, Jacob Engellau, Mikael Eriksson, Fredrik Mertens, Eva-Mari Olofsson, Anders Rydholm, Mikael Skorpil, Sigbjørn Smeland, Kirsten Sundby Hall, Charlott Marie Våde, Jan Åhlén

Excused: Otte Brosjö, Clement Trovik, Tom Böhling, Paula Lindholm, Rikard Wedin, Anders Bergenfelz

1. On-going research projects

- a) “Does local recurrence of soft tissue sarcoma predict disease-specific mortality in STS?” This is an invitation from Dept of Orthopedics, University of British Columbia, Vancouver, with the purpose to collect data from different sarcoma registries around the world regarding primary diagnosis of STS in extremities, treatment, later local recurrences and later metastatic disease. The question to be answered is whether a local recurrence is an independent risk factor for later metastatic disease and thus risk for disease-specific mortality. The study has been approved by the Ethical board in Southern Sweden, and we are discussing how to collect missing data in the Central Registry, either by letters to the respective clinics or by having some person travelling around to collect data. Clement Trovik is responsible for the SSG participation. Mikael Eriksson has done the application to the Ethical board, and is discussing with Elisabeth Johansson at the SSG secretariat and with the oncology colleague Marie Ahlström in Lund whether they together may at least start the work by looking at available data and start listing missing data. In parallel, a mail contact is on-going with the main investigator, dr Paul Clarkson in Vancouver, who prefer to have some even immature data sent soon to check quality and magnitude of the SSG material. This question will be discussed further when Clement Trovik is back from temporary work mission abroad.
- b) LIVESTRONG Young Adult Alliance/Ewing sarcoma workshop. This is a collaborative effort by two cooperating study consortia related to different factors influencing prognosis in mainly adolescents and young adults (15-30 years), an age group with a potential less pronounced improvement of prognosis for many malignant tumours during the last decades according to registry acquired data. The two projects have been merged to one study protocol for the SSG participation. Sigbjørn Smeland is the main investigator and has written this SSG protocol based on diverse documents from the two study consortia, and Mikael Eriksson has written an application to the Ethical Board in Southern Sweden, not yet answered. The purpose is to collect a lot of data from study data bases from the so far presented studies on osteosarcoma and Ewings sarcoma within SSG to be merged with data from similar studies from other groups. The exact work task in the study (what?, when? by whom?) is not yet decided; we are awaiting the response from the Ethics Board before further decisions.
- c) The epidemiology and prognosis of chondrosarcomas. This is a project run by colleagues Frihagen/Walløe at Ullevål in Oslo. The researchers have got rather few responses regarding missing data in the central registry after an inquiry via the SSG secretariat, but still the project seems to be proceeding towards publications. Sparse information about the project was available at the meeting.
- d) Parosteal osteosarcoma – risk factors for local recurrence. Olga Zaikova in Oslo is collecting data on this entity from the registry and has found 14 cases from Norway, 26 from Sweden and 2 from Finland. The purpose is to merge data with a somewhat bigger material from Birmingham. At the meeting, it was argued by Fredrik Mertens that genetics could be of interest in these patients, and he will contact Olga Zaikova about this.
- e) SSG XX. It was decided to support a suggestion of letting SSG XX be a part of the planned dissertation work by Marie Ahlström, oncologist in Lund under supervision by Mikael Eriksson.

- f) Thoracal chondrosarcoma. It was reported that Henrik Bauer gave a presentation at CTOS this year from the up-coming dissertation by Björn Wide. The project is not a regular SSG project since only Swedish patients derived from the Swedish Cancer Registry have been included. However, the diagnoses have been confirmed by the review pathology group of SSG, and SSG should therefore be mentioned in publications and presentations.
- g) Lung metastases after treatment of osteosarcoma. This is a new SSG-project as a part of the dissertation work by Hege Oma Ohnstad. A large cohort of patients treated within the protocols SSG II, SSG VIII or SSG XIV will be investigated with respect to occurrence of lung metastases, survival and prognostic factors. In the discussion, the importance of imaging was stressed, and it was recommended that an experienced radiologist would be involved in the work.
- h) Question from CONTICANET about potential availability of biological material from SSG to be sent for studies on osteosarcoma in children. Since we already have a similar collaboration with EUROBONET it was decided to deny the request from CONTICANET. Furthermore, there are some indications of a present collaboration between these two networks.
- i) An invitation to collaborate has been received from Sharon A Savage, NCI, regarding the project "Genome-wide association study of osteogenic sarcoma". Ola Myklebost is reported to be interested in the project, and at the meeting also Fredrik Mertens declared his interest. The board declared a positive attitude but stressed that this project ought to be approved by EUROBONET.
- j) The pharmaceutical company Sanofi-Aventis has asked for a potential access to the SSG central registry to be able to learn about clinical practice in the handling of sarcomas today, obviously to use for their developmental strategy even if the specific purpose is not stated. After some debate it was decided that we would refuse such an open request, but that they may specify any specific project, and if so, we could discuss the matter again. The chairman (KSH) will reply to the company.
- k) Sigbjørn Smeland raised the question whether it would be allowed and technically feasible to send the data from the central registry back to e.g., the cancer registries in the other countries. This would then allow any researcher within the SSG to get access to registry data locally which in turn could make application to the Ethical boards/committees in any country possible for registry-based studies. KSH promised to make an inquiry with the Norwegian Cancer Registry.

2. Status at the SSG secretariat and the economical situation

Thor Alvegård reported about the activities at the secretariat in general and what the different persons involved with SSG are doing specifically. He also gave advice to visit our homepage for more information. TA also briefly presented the situation for the economy. In spite of being an expensive meeting, the economy related to the plenary meeting in Oslo in May is balanced, everything is paid. Regarding potential future income TA reported to have made a new application from the NCU for 2010, where we earlier have received 40,000 Euro yearly for some time. In April next year, a new application to the Swedish Cancer Fund for a new 3-year period (2011-13) will be sent, and hopefully we will get further support at the same magnitude as now (100,000 Swedish Crowns yearly). Amgen has been supporting SSG with 350,000 Swedish Crowns yearly the last years, and a new discussion with them will take place soon, hopefully with a similar support in the future. Novartis is supporting the adjuvant GIST protocol (SSG XVIII) with large amounts (the study is very expensive to run), and we have been promised 1.2 million Swedish Crowns to be paid soon, and probably we will have 3 millions more in the near future, out of which 2 millions will be paid to the Oncology Centre in Lund as compensation for staff time used.

3. Potential future cooperation with the Italian Sarcoma Group

A planned report from a recent “brain-storm”-meeting in Bologna was not given because of lack in time, but reports of some study proposals was announced for the up-coming Working Groups Meeting.

4. Membership in SSG

A discussion about whether we also in the future will claim CV and reference list from applicants for membership in SSG was postponed to next board meeting in May 2010 because of lack of time.

5. Meetings

Next SSG Working Groups meeting was announced to November 28-30, 2010.

A board meeting was decided to be held in Copenhagen May 31, 2010.

The next plenary meeting (SSG 35th meeting) will be arranged in Malmö, May 4-6, 2011, and the venue is inspected and booked. As to the program, it was decided to arrange a seminar about lung metastases.

6. Elections to the board

The mandate period has run out fro Paula Lindholm and Tom Böhling. PL has been asked and accepted a re-election for five more years and this was approved by the board. Tom Böhling, however, has rejected a re-election because of lack of time, and must then be substituted. The board discussed the idea to try to elect some Danish colleague to strengthen the cooperation with this country. Some names were thereby mentioned, and members of the board will have discussions with potential candidates before a decision. This position in the board will therefore be vacant for some time. Thereafter, the chairman ended the meeting since no other matters were raised.

Addendum

One week later it became clear that Ole Steen Nielsen accepted an invitation (decided at the board meeting) to be one of two vice-chairmen in SSG.

Mikael Eriksson
Secretary

Kirsten Sundby Hall
Chairman