

## ***SSG Board meeting, December 2, 2012***

*Place: First SSG meeting to be held at World Trade Center, Malmö*

Attendance: Thor Alvegård, Carl Blomqvist, Otte Brosjö, Øyvind Bruland, Jacob Engellau, Mikael Eriksson, Halldór Jónsson Jr, Anders Krarup-Hansen, Fredrik Mertens, Eva-Mari Olofsson, Pehr Rissler, Anders Rydholm, Mikael Skorpil, Kirsten Sundby Hall, Clement Trovik, Fredrik Vult von Steyern, Charlotta Våde, Jan Åhlén (+ invited for point 3: Olga Zaikova, Emelie Styring)

Excuse: Anders Bergenfelz, Paula Lindholm, Bodil Bjerkehagen

1. ***The Minutes*** from the last board meeting in Copenhagen November 27 2011 were approved without further comments.
2. ***Short reports from the different subcommittees including research projects***
  - a) *Pathology/tumor biology* (PR, FM): The main focus of the pathology subcommittee presently is to closely consider the increased use of the three-graded so called French grading system in parallel with, and in the future may be substituting, the four-graded scale. Some completing review may be appropriate. Further, there are plans to create a net-based “data-bank” with visible slides of rare or difficult cases, mainly such that have been reviewed also by second opinion at non-Nordic sites. A new meeting by the review group is planned in Gothenburg in connection with the EMSOS meeting May 29-31, 2013. Review of SSG XX will continue.
  - b) *Orthopedics* (FVvS): No special activities to report. It was noted, however, that the orthopedic net for discussion on problematic cases has been less used this year, the reason not quite clear. Thus, not even potential candidates for “Group B” in the adjuvant trial SSG XX have been discussed before decision regarding risk of intralesional margin at primary surgery. The subcommittee will discuss this issue further.
  - c) *Oncology – radiotherapy* (JE, ØB): No specific new activities to report. ØB described the seemingly promising results regarding local control and lack of late toxicity in the Oslo patients in SSG XX, and proposed a potential interim analysis in this respect. No decision was taken.
  - d) *Nurses and physiotherapists* (CV): A successful sarcoma day was arranged in Stockholm this autumn. In Oslo, the “Sarcoma Awareness Day” (“Den Store Kuledagen”) was arranged for the third year. Some Swedish participants from Lund participated and plan to bring the idea to Sweden. Furthermore, the subcommittee deals presently on written patient information and how to improve them.
  - e) *Retroperitoneal and visceral sarcomas* (JÅ): The implementation of the INCA platform for registration of retroperitoneal/visceral sarcomas to the SSG Registry in Sweden was delayed but has now started in Stockholm and will be used also at

other sites shortly. Participation in the EORTC randomized trial on preoperative radiotherapy in retroperitoneal sarcomas has been much delayed, mostly depending on EORTC bureaucracy, but will probably soon start to enroll patients in Oslo, Stockholm and Copenhagen.

f) *Imaging (MS)*: No new activities to report.

g) *Oncology – medical treatment (KSH, ME)*: Several on-going, planned and/or considered projects were briefly described (some of them being further described during the working group meeting):

- SSG XX is enrolling fairly well, now in total 143 patients (of 158 planned) are registered. Enrollment will probably be finalized during 2013.
- Discussions on-going with the Italian sarcoma group to join an on-going adjuvant trial comparing standard neo-adjuvant chemotherapy in STS with histiotype-based therapy; may potentially start when SSG XX is fully enrolled. Further discussions will continue in the subcommittees.
- A new trial in advanced GIST is suggested by Heikki Joensuu and the Australasian sarcoma group comparing standard imatinib in first line with a schedule using changing periods of imatinib and regorafenib (a new promising tyrosinkinase inhibitor in GIST). SSG is wished as the sponsor and administrative group for the project. A meeting will be held in January, and preliminary the SSG secretariat has been positive provided economical funding and early influence in logistics and technical set-up.
- A long time discussed phase II trial on the use of Multiferon in fibromatosis (desmoid tumors) has now lead to the involvement of an Oslo-based CRO company, Smerud Medical Research International AS, and an application for EU funding (Eurostar) has been submitted; decision awaited later this month. SSG will thus consider to cooperate with Smerud and the Swedish company SOBI, owning and producing Multiferon.
- EURAMOS-1 for osteosarcoma is approaching analysis with expected results for “good responders” in March 2013 and for “poor responders” possibly in September 2013. KSH, ME and Catherine Rechner are actively participating in “EURAMOS Strategy Group” with participants from the four groups cooperating in EURAMOS-1 and some other European groups (Spain, Italy, France) to inform each other on on-going projects, hopefully leading to a new joint study in the future. The concept of randomized adding of zoledronic acid to chemotherapy is investigated by the French sarcoma group, and other groups may be welcome, which will be simplified by a planned amendment allowing any standard chemotherapy, e.g., MAP. This could have been a possibility for SSG, but probably not the best way to go, at least not yet knowing the results from EURAMOS-1.
- The Swedish company Isofol has developed an active metabolite to leucovorin (Modufolin) with a potential improvement for the rescue after high dose Methotrexate in osteosarcoma, and wish to involve SSG centers for a pilot project; discussions on-going.

- SSG is participating in an on-going European giant EU application process for various studies in Ewing's sarcoma. Probably would studies on new drugs be of most interest for SSG. KSH will, together with Lars Hjort, participate in a meeting regarding these possibilities shortly.
- EURELOS is a project discussed since some years together with the German COSS and the Italian sarcoma group, and has the aim to collect data on different treatment results for recurring osteosarcoma. The problem is the work needed for applications and organization of SSG participation, yet not solved.
- The Italian sarcoma group, through Stefano Ferrari, has proposed a follow-up study with collection of data on Ewing patients treated in our earlier common protocols, discussions on-going.

3. ***Annual report of SSG Central Register data***

After a certain discussion during the autumn regarding how, where and when register data may be presented, a suggestion for a first "annual report" was presented by Olga Zaikova and Emelie Styring, with a revised draft distributed at the meeting. This report dealt with the two years 2008 and 2009, and consisted of tables and diagrams showing e.g., reported cases by country, histology, localization and malignancy grade. Furthermore, referral status and used treatment modalities were described, including also surgical margins. The suggested report did not include any treatment results or follow-up, however, and no data for single institutions. The discussion that followed the presentation found the report mainly useful as a preliminary start. However, there are still errors that must be corrected and a new draft must be awaited. Remarks regarding such errors should be sent to Olga Zaikova and/or Emelie Styring. It was also proposed that it must be remarked more clearly throughout the report that the data only represents reported cases (and not population-based), and that there obviously are many lacking cases. For the future several aspects were discussed, for example whether the report should separate those institutions which have more or less population-based data from others, and when and how it may be acceptable to also include treatment results, especially at the institutional level. It was stressed that we must know that central register data which will be made available for others, e.g., by the website or other official reporting, must be correct. At this stage only descriptive data are planned to be published, not treatment results which will require a tremendous process with heavy statistical analysis and quality assurance. The SSG board will prove content and statistical analysis in the annual report before publishing. There will probably be a continuous discussion with modifications and adaptations over following years, and no definite decisions may be taken at this time point.

4. ***Status and update of members list in each country*** was briefly discussed. Eva-Mari Olofsson, with support by Emelie Styring, has now revised most member list data from Norway, Sweden and Finland. Anders Krarup-Hansen will assist with the update of Danish members.
5. ***Patients advocacy groups*** may be new useful partners to strengthen sarcoma care and research throughout the SSG area, with the first one founded a year ago in Norway, "Sarkomer" ([www.sarkomer.no](http://www.sarkomer.no)). It was shortly discussed whether and how such groups may be formally associated to SSG. Primarily, it was decided that such

advocacy groups will be invited to our plenary meeting, but not to the working group meetings.

6. **Status at the SSG secretariat in Lund** was described by Thor Alvegård, and a new organization in Sweden was described, where the old Oncological centers now are being replaced by so called “Regional Cancer Center, RCC”, one in each of the six Swedish health care regions. The SSG secretariat, which actually moved to new locations within the office of the RCC South (“RCC Syd”) two days ago, will be a part of the new organization. No big differences in the possibilities for SSG to continue its work may be foreseen for the moment. Thor Alvegård, being the treasurer of SSG, also gave a report on the economy, which is mainly based on industrial grants (Amgen), support from the Swedish Cancer Fund and support from the Norwegian “Nasjonal Kompetansetjeneste for sarkomer”, but also to a lesser degree from donations. The economic situation is stable, but we must also in the future charge the members for participation at the working group meetings.
7. **SSG board:** The mandate period of 5 years for Kirsten Sundby Hall as chairman and Mikael Eriksson as secretary will end during 2013. Both are willing to a further period, but others might be interested, and decision making was postponed until the plenary meeting October 2013. (Later during the working group meeting the subcommittees made some new elections. Thus, in the oncology-radiotherapy committee Nina Jebsen replaces Øyvind Bruland; as chairman for the SSG Central register Henrik Bauer replaces Clement Trovik; as additional chairman beside Jan Åhlén in the retroperitoneal/visceral committee Toto Hølmebakk was elected to replace Anders Bergenfelz).
8. **36<sup>th</sup> SSG Plenary meeting in Helsinki, October 8-11, 2013** was briefly discussed. The program is finalized with an OK from all invited speakers. The economy for the meeting is secured by the support from several sponsors. Carl Blomqvist informed about the social activities with a concert planned the first night and a gala dinner the second. Deadline for abstracts for the meeting is May 31, 2013. The next board meeting will be held in connection with the meeting, at October 8, 17.00-19.00.
9. **Upcoming meetings** of interest were briefly mentioned. Thus, the next meeting of EMSOS will be arranged in Gothenburg, May 29-31, 2013. SSG has had some input on the program, and some SSG members will speak at the meeting. The 19<sup>th</sup> SSG Working committee meeting will be held in Malmö (same venue as the present meeting) in February 2-4, 2014.
10. **The project “Treatment of bone sarcoma in Scandinavia through 25 years, experience from the SSG Central register** was presented by Olga Zaikova. She wanted an opinion from the board regarding whether this report could be acceptable in its present form as an abstract for the ESMO meeting (described above) in spite of being rather premature with many lacking data. The board encouraged Olga to go on with the work on this report, but found a presentation with available data to early and incomplete for a presentation already at EMSOS.

Mikael Eriksson

Secretary

Kirsten Sundby Hall

Chairman

Anders Rydholm

Vice secretary

Otte Brosjö

Chairman