

SSG Board meeting, October 8, 2013

Attendance: Thor Alvegård, Henrik Bauer, Bodil Bjerkehagen, Otte Brosjö, Jacob Engellau, Mikael Eriksson, Nina Jebsen, Anders Krarup-Hansen, Paula Lindholm, Fredrik Mertens, Eva-Mari Olofsson, Mikael Skorpil, Kirsten Sundby Hall, Fredrik Vult von Steyern, Charlotta Våde, Jan Åhlén

Excuse: Anders Rydholm, Toto Hølmekakk, Halldór Jónsson Jr, Carl Blomqvist

1. ***The Minutes*** from the last board meeting in Malmö December 2, 2012 were approved without further comments.

2. ***Short reports from the different subcommittees including research projects***
 - a) ***Pathology/tumor biology (BB, FM)***: A new review meeting in the pathology group was held in Gothenburg during the spring, where especially the trial patients were reviewed. A revision of pathology for patients in the SSG registry has also started, so far mostly for Oslo patients. The grading system will be further discussed at the up-coming working group meeting in February -14 to discuss whether to keep or not to keep the four-grade scale along with the French three-grade system. KSH pointed out the recently started chondrosarcoma doctoral project as a potentially important task also for the pathology group. TA stressed the importance of a comparison between revised diagnosis in the registry with the patients where no revision has been performed. FVvS marked the importance of implementation of the decided template for pathology response at all SSG sites.
 - b) ***Orthopedics (FVvS)***: No new activities to report. Some contacts between centers regarding patients occur now and then, but it was again noted (as at our last board meeting), that the orthopedic net for discussion on problematic cases has been less used by time, 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 possibility to achieve margins with primary surgery. The subcommittee will discuss this issue further.
 - c) ***Oncology – radiotherapy (JE, NJ)***: No specific new activities to report. It was pointed out that some trials do occur with radiotherapy involved, not only SSG XX (see below on medical treatment!). Thus there is a trial of palliative radiotherapy in late stage GIST for some centers, and the large intergroup EORTC trial on preoperative radiotherapy compared with no such treatment for retroperitoneal sarcomas is about to start (see below on retroperitoneal sarcomas!). The future access to proton therapy, e.g., in Uppsala, is interesting not only for children but also for several tumors in adults, also including selected cases of sarcomas. This deserves further consideration, and will also be presented during the present plenary meeting in Helsinki. JE and NJ have plans for writing SSG guidelines for radiotherapy.

- d) *Nurses and physiotherapists (CV)*: The group is presently focusing on patient information and will propose a written standard information for different sarcoma diagnoses to be translated to the different Nordic languages, which may be modified or completed as needed. In Oslo, the “Sarcoma Awareness Days” (“Den store kule-dagen”) was arranged for the fourth year, and a similar event has also been arranged in Bergen, and, for patients and relatives, also in Stockholm. Similar plans are under way in Lund.
- e) *Retroperitoneal and visceral sarcomas (JÅ)*: Participation in the EORTC randomized trial on preoperative radiotherapy in retroperitoneal sarcomas has been very much delayed for SSG centers, but it is now formally started in Oslo, Århus and Copenhagen, and is expected to be ready for start also in Stockholm soon. So far, no SSG patients have been randomized. There may be need for some revisions of the SSG guidelines for visceral and retroperitoneal sarcomas, and this and other items will be discussed at the working group meeting in February -14.
- f) *Imaging (MS)*: An article for *Läkartidningen* on MRI and fat tumors is under preparation. Otherwise, no new activities to report.
- g) *Central register (HB)*: Two SSG-members are presently and eagerly up-dating the register, Olga Zaikova for bone sarcomas and Emelie Styring for soft tissue sarcomas. It was suggested, and thereafter decided at the meeting, to formally appoint OZ and ES as vice chairmen in the Central register working group. For Swedish patients, it is expected that the INCA platform will be used to enter register data early next year, and this has already started for abdominal and retroperitoneal sarcomas.
- h) *Oncology – medical treatment (KSH, ME)*: Several on-going, planned and/or considered projects were briefly described, among them also some that will never be started:
- SSG XX is enrolling steadily but with a clearly slower pace since some time. In total 143 patients are registered in group A out of 158 needed, and besides that 16 in group B. Enrollment will be finalized during 2014. There are presently no plans for a new adjuvant trial for STS, neither a SSG study nor participation in any intergroup trial. SSG must discuss and decide whether it is reasonable to recommend any adjuvant treatment for routine use when enrollment in SSG XX is closed, and this will be discussed at the working group meeting in February next year.
 - The SSG XXI protocol, “PAGIST”, for third line treatment with pazopanib in advanced GIST is now running in Sweden, Norway, Denmark and Finland, and three German centers have also joined the trial – Berlin, Mannheim and Essen. Furthermore, Iceland is waiting for approval on recently submitted applications. Up to now, 40 out of a planned total of 72 patients are enrolled. The pre-defined interim analysis based on the 22 first included patients did not give any indication to halt the trial in advance.
 - A new adjuvant protocol for GIST together with German groups is suggested, SSG XXII, where the present standard treatment of three years of imatinib for high risk patients will be compared with a prolonged treatment for five years.

This will be achieved by enrolling and randomizing patients who have fulfilled the standard three years to two more years or observation only. Novartis has promised to support the study economically but details in this agreement are still to be discussed.

- A new trial for first line treatment in advanced GIST has been suggested by Heikki Joensuu and the Australasian gastrointestinal tumor group (AGITG) comparing standard imatinib with a schedule using changing periods of imatinib and regorafenib (a new tyrosin kinase inhibitor recently approved for third line treatment in GIST). Recently, also EORTC declared their interest in participation and further discussions between these groups and with the producer of regorafenib, Bayer, are expected within the near future.
- The since long time discussed phase II trial on the use of Multiferon in fibromatosis (desmoid tumors) failed to get EU funding (Eurostar), and the future is uncertain for this project.
- EURAMOS-1, our intergroup protocol for primary treatment of osteosarcoma, has been analyzed for “good responders” during the spring 2013, and there was a non-significant trend for favor of the interferon arm. A problem was that quite many patients refused randomization in this group, and, even more remarkable, many of those who were allocated interferon did not start the treatment. A longer follow-up is needed to elucidate any potential statistically significant endpoints. For “poor responders” the primary analysis is expected in 2014.
- The “EURAMOS Strategy Group” with participants from the four groups cooperating in EURAMOS-1 and some other European groups (Spain, Italy, France) has not yet found any new question to investigate in a coming EURAMOS-2 protocol since earlier efforts with mifamurtid and zoledronic acid failed. A potential study with sorafenib has been discussed but it is now clear that such a study will not be opened.
- 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. In a first stage, a phase I/II trial will soon be opened in Lund and certain Eastern European centers. Later, it may be possible that further development of this drug in a planned phase III trial may involve several SSG centers.
- SSG has been participating in the bureaucratic intergroup/intercenter application process for an EU grant for various studies in Ewing’s sarcoma, and recently this application got a positive outcome, with a substantial amount to SSG for participation in a multiarm/multistage project in relapsing Ewing’s sarcoma, comparing different known and potentially useful chemotherapy regimens in this situation. The trial design also allows later inclusion of other treatment arms, e.g., if new targeted therapies show interesting results in early trials.
- EUROLES is a project for registration of type of treatment and outcome for patients with relapsed osteosarcoma where SSG has promised its collaboration

with the German COSS and the Italian sarcoma group (ISG) since many years, but still only has participated vary limited and only in Norway. The problem has been lack of resources to do the application and organization for this trial. A somewhat facilitated form for collection of data is under development, and SSG will now try to be a more active partner shortly.

3. ***New suggested projects based on the SSG register***

SSG has been approached by two new applications for use of register data:

- a) Application from Henrik Schröder, pediatrik avdelning, Århus. The project aims to compare osteosarcoma in children treated in Denmark with Sweden and Norway to try to identify factors that may explain different outcome between the countries. The board found it necessary to have more data supporting the background than were included in the application, and KSH will contact the applicant for further discussion.
- b) Application from Panagiotis Tsagkozis, Otte Brosjö and Henrik Bauer at the Department of Orthopaedics at Karolinska University Hospital. The project titled “Prognostic factors and optimal follow-up policy for superficial soft tissue sarcomas” was discussed and found well motivated and interesting. The board decided to approve the application.

4. ***Election of chairman and secretary in SSG for 2013 – 2017 and associated matters.***

OB reminded that a postponed election for chairman instead of KSH and secretary instead of ME must be performed at the “SSG matters” meeting at the present plenary event, and that the board should prepare a suggestion. OB had, as an informal election committee, considered possible candidates, but after discussion with KSH and ME, who both accepted a potential suggestion for a new period, he suggested that re-election of KSH as one of two chairmen and of ME as secretary would be the proposal to the members meeting, and the board agreed to this suggestion. (The members meeting the next day decided in accordance with this suggestion, and both were elected for a new period 2013-2017).

In connection to this election ME brought up a suggestion that the principles for representation in the board, and the possibility of a smaller more active working committee within the board should be a matter of discussion for the up-coming working group meeting in February 2014. A related matter is whether a formal election committee should be appointed.

5. ***Upcoming meetings*** were discussed. As earlier decided, it was remembered that next working group meeting will be held in Malmö February 2-4, 2014. Furthermore, a one day meeting in Lund will be planned for the oncologists to discuss on-going trials at December 5, 2014. Next plenary meeting, number 37, will be organized in Stockholm, and probable dates are May 20-22, 2015. Suggested venue is the Waterfront Hotel. This plenary meeting will then be followed by a new working group meeting in Malmö in December 2015. The 38th plenary meeting will be held in Denmark, and the

Danish sarcoma group will suggest venue, either in Copenhagen or in Aarhus. Finally, it was also notified that the two next EMSOS meetings will be organized in Vienna May 21-23, 2014, and in Athens April 29-May 1, 2015.

6. *Status at the SSG secretariat in Lund* was described by TA, and it was thereby noted that SSG now must pay 80% of the salary for our administrative secretary Eva-Mari Olofsson (20% by Skåne Läns Landsting). Even if the economical situation is relatively stable, new funding sources must constantly been looked for. A new application to the Swedish Cancer Fund will be sent during the spring 2014. We will also have to charge a fee for participation at the working group meeting, as we have done the last years.

7. *Next board meeting* will be held Sunday February 2, 2014 (17.00) in Malmö.

Lund 2013-10-20

Mikael Eriksson

Secretary

Kirsten Sundby Hall

Chairman

Otte Brosjö

Chairman