

SSG Board meeting, November 28, 2010

Attendance: Thor Alvegård, Bodil Bjerkehagen, Otte Brosjö, Mikael Eriksson, Halldor Jonsson, Fredrik Mertens, Ole Steen Nielsen, Eva-Mari Olofsson, Anders Rydholm, Kirsten Sundby Hall, Clement Trovik, Charlotte Våde, Jan Åhlén

1. The minutes from the board meeting in May 31, 2010, were approved.
2. Halldor Jonsson from Reykjavik has been accepted as an Icelandic representative in the SSG board, and was presented.
3. The present situation for the SSG registry was presented by Clement Trovik (CT). Improvements from some centres have been noted, but still there are problems with lacking data from several sites. A meeting has been held in Lund October 6 with representatives from the Danish sarcoma registry to discuss a merge of this registry with SSG registry. Although some technical problems must be solved, there is a positive attitude from both sides. The Danish sarcoma group will shortly have a meeting to take a final decision on this matter. Jan Åhlén reported that for abdominal and visceral sarcomas, Swedish patients will be registered in the web-based so called INCA platform from January 1, 2011.
4. EURAMOS-2 is a potential new study protocol from the EURAMOS intergroup, and Kirsten Sundby Hall (KSH) reported from a new structure for this osteosarcoma consortium. Thus, a strategy group is presently formed where SSG has been offered three representatives. This group will discuss future strategic study objectives for osteosarcoma in large and coordinate the work within EURAMOS. Furthermore, a protocol group is under construction to be directly responsible for next protocol (øEURAMOS-2ö); according to present plans this study will investigate the value of addition of MTP-PE (mifamurtide, Mepact) to standard MAP treatment, but the position of the owner of this drug, the Japanese pharmaceutical company Takeda, is uncertain. (In fact, some days after the board meeting it was known that Takeda will not support such a study since in their opinion the value of the drug is established and EMEA has approved it in Europe). Finally, also a group for transitional biological research will be founded. The question regarding the SSG representatives has been discussed in a smaller telephone meeting recently, and a suggestion from this meeting has been that KSH and Mikael Eriksson (ME) plus a pediatric oncologist could be a reasonable choice for the strategic group; that KSH will be the best candidate for the protocol group; and that Ola Myklebost could be nominated for the translational group. These suggestions were approved by the board but would be decided finally by the plenary meeting on November 29. (The suggestions were confirmed at the plenary meeting, and it was also decided that the third member of the strategy group will be Catherine Rechnitzer, Copenhagen).
5. ME presented a SSG suggestion to GlaxoSmithKline on support for a study on pazopanib in GIST refractory to both imatinib and sunitinib, which GSK now seems to have accepted. Negotiations are on-going, and the study may hopefully start during the spring 2011.
6. KSH reported that an EORTC study on preoperative radiation therapy in retroperitoneal sarcoma will also be open for larger SSG centres. Centres that may fulfil the criteria of performing enough such operations were identified as Oslo, Bergen, Stockholm, Göteborg and Lund. Jan Åhlén will probably take the position to coordinate the SSG participation, but one representative for every site willing to join the study must be appointed. The earlier discussed smaller SSG study on the same question will not be taken further.

7. ME presented shortly the SSG participation in some registry based studies. The LIVESTRONG project investigating the outcome for adolescents and young adults in clinical studies on osteosarcomas and Ewing's sarcomas presented results at CTOS this year with Sigbjørn Smeland as co-author. The study coordinated in Vancouver looking for a relationship between local recurrences of soft tissue sarcomas of the extremities and later metastatic disease is approaching analysis, and the SSG data will be sent to Vancouver within a month from now.
8. Reports from coming doctoral thesis were given and discussed. Asle Hesla at Karolinska Hospital will look on Ewing's sarcomas in the spine and pelvic region. Marie Ahlström in Lund will include a registry based investigation on predictive factors for response at different chemotherapy in metastatic soft tissue sarcomas in her project. Both these projects were accepted, and the use of the SSG registry was approved. The on-going projects by Nina Jebsen and Hege Oma Ohnstad were also briefly mentioned.
9. Publication and authorship rules have been discussed in a working group consisting of Ole Steen Nielsen (chairman), Otte Brosjö, KSH, ME, CT. In a written suggestion it has been made more clear what will be needed for co-authorship. It has also been discussed in what way use of registry data will be approved for retrospective studies and reviews. A working group with national representatives is suggested. The proposals on these matters will be distributed shortly, and any comments must be sent to KSH not later than January 31, 2011.
10. A suggestion on modifications of the SSG statutes was presented. In this suggestion it is stated that the members of the subcommittees must elect their chairman for five years with permission of re-election. The period is now out for the following chairmen: KSH, Sigbjørn Smeland, CT, Jan Åhlén, Anders Bergenfelz, Bodil Bjerkehaugen. The committees must start the discussion on potential shift of chairman now, and the process must be finalized before the working group meeting in November 2011.
11. A simplified routine for application of membership in SSG has been worked out by KSH, ME and the SSG secretariat after earlier discussions, e.g., during the plenary meeting in Oslo 2009 and the working group meeting in November 2009. According to this new procedure, potential new members will get a "Members page" by Eva-Mari Olofsson, and this will be completed with name, address, speciality and a short description of kind of work/interest in relation to sarcoma. After the application has been approved, the new member will be included in the member's registry at www.ssg-org.net. The present member's page will be overseen before May 2011 to exclude members which will not be judged as presently active or interested in SSG matters.
12. Thor Alvegård gave a short report from the work at the SSG secretariat.
13. KSH presented dates for up-coming meetings: The SSG plenary meeting will take place 4th-6th May 2011 at Malmö Börs and accommodation will be offered at nearby situated Comfort Hotel. May 4 a satellite meeting on "The biology of mesenchymal tumours" will be arranged. The same day there will be meetings for the board and for the central registry. Registration deadline is March 31 and registration fee is 3100 SEK. The deadline for abstracts is February 15. The next EMSOS meeting will be held in Gent, Belgium, May 18-20, 2011; abstract deadline February 20 and registration deadline March 31. The SSG working group meeting next year will be held at DGI Byen, Copenhagen, November 28-29, with board meeting the day before (November 27). The next plenary meeting will then be organized in Helsinki in May 2013.

14. The SSG economy was shortly presented. The funding sources are mainly Amgen, The Swedish Cancer Fund, Novartis, different donations. The economical situation is stable. Response on a new application to the Nordic Cancer Union is awaited. (This application was denied some days after the meeting). It was decided that the fee for the working group meetings will be kept at 1600 SEK.

15. Otte Brosjö suggested an update of SSGs website, after preliminary contact with a designcompany in Stockholm. After discussion, a maximum cost of 25000 SEK was accepted

Lund 21, 2010

*Mikael Eriksson
Secretary*

*Kirsten Sundby Hall
Chairman*

*Otte Brosjö
Chairman*

*Anders Rydholm
Vice secretary*