

SSG Board meeting, November 27, 2011

Attendance: Thor Alvegård, Bodil Bjerkehagen, Carl Blomquist, Otte Brosjö, Øyvind Bruland, Jacob Engellau, Mikael Eriksson, Halldor Jonsson, Fredrik Mertens, Eva-Mari Olofsson, Anders Rydholm, Mikael Skorpil, Kirsten Sundby Hall, Clement Trovik, Fredrik Vult von Steyern, Charlotte Våde, Jan Åhlén.

Excuse: Anders Krarup-Hansen, Paula Lindholm, Ole Steen Nielsen

1. ***The Minutes*** from the last board meeting in Malmö May 4 2011 were approved, but Thor Alvegård corrected a small mistake regarding the time period for the on-going support from the Swedish Cancer Fund (§10); the present grant is guaranteed until 2012, not 2013. A new application must be made in the spring 2012. Another mistake was that Ole Steen Nielsen was missing in the list of attendance.
2. ***It was announced*** that Ole Steen Nielsen is leaving the board as he also will leave the sarcoma center in Aarhus to become Vice Dean for Research at the Faculty of Health at Aarhus University.. He is replaced by Anders Krarup-Hansen from Copenhagen who will be vice chairman. Both OSN and AKH had planned to participate in the board meeting, but both were unfortunately ill and could not participate.
3. ***EURAMOS-2*** protocol work was presented by Kirsten Sundby Hall, who with regret told that the COG scientific committee recently denied to support the proposed phase III-study comparing the standard regimen MAP with or without the addition of zoledronic acid (Zometa). Presently, alternative approaches are discussed within the EURAMOS strategy group, e.g., a phase II multi-stage multi-arm strategy comparing different experimental treatment options and closing the arms that do not show any signal of potential efficacy. A strategy group meeting is planned in London in early spring. Regarding the earlier study option, mifamurtid, it was concluded that the EURAMOS group position is that this drug needs to be tested in a new clinical trial since present data is not sufficient. SSG fully adhere to this view.
4. ***Short reports were given from the different subcommittees*** (which now all have their specific links prepared to use at the SSG home page):
 - a) ***Medical oncology/Radiotherapy*** (KSH, ME, ØB) : SSG XX is on-going and recruiting fairly good. SSG XXI (PAGIST) is under preparation in the five Nordic countries with start planned in January 2012. EURAMOS-1 is in continuous follow-up phase; first results may be expected next year. EURAMOS-2 – see above! Regarding Ewing, the protocol ISG/SSG III is still used as standard treatment for localized disease. The results from ISG/SSG IV (metastatic Ewing) have been analyzed, will be published soon, and may influence our treatment strategy in the future until we have a new study protocol. The Swedish pediatricians will now formerly join the new version of the Euro-E.W.I.N.G.-protocol; applications are under preparation. The radiotherapy subcommittee has not been very active during the last year, but aim to build a collaborative network for discussions within SSG in difficult situations. TA announced an invitation to

SSG to give a speech on radiotherapy in soft tissue sarcoma in Bologna at the EMSOS 25-jubilee meeting, and JE accepted to give this lecture.

- b) *Visceral & retroperitoneal (JÅ)*: The registration on the INCA-platform is now starting in Sweden for abdominal cases; data to be registered includes both all needed data for SSG Central register (which will be transformed to this register at the SSG secretariat), and some additional quality parameters, especially on lead times. Both Stockholm and Oslo will be participating in the EORTC randomized study on preoperative radiotherapy for retroperitoneal sarcomas, possible start will be in January 2012.
 - c) *Nurses & physiotherapists (LV)*: A new web page is under preparation. In Norway, a second awareness day for lumps and bumps (“Store kuledagen”) has been arranged with a very good response, and at this occasion a patient society for sarcomas was founded. The awareness day was described by a poster at CTOS in Chicago.
 - d) *Morphology/Tumor Biology (BB, FM)*: The reference group meets usually twice every year, last time in Turku (Åbo), next time in March 2012 in Krakow. From now on, the costs for these meetings are expected to be shared, with the home institutions to pay the travel ticket and SSG to pay for hotel and other costs at the site. The meetings concentrate on protocol patients and specific research projects. Some subjects that recently have been discussed include MPNST and myxofibrosarcoma. The up-coming year, a review will also be done on the patients included in the ISG/SSG II osteosarcoma study. If and when time allows, a new report from the work in this group may be prepared for publication. For tumor biology, no specific activity was reported. At the next plenary meeting in Helsinki, there will not be a specific biology meeting, but hopefully biology lectures integrated in the normal program.
 - e) *Imaging (MS)*: At this working group meeting, the imaging group plan to concentrate on difficult and interesting cases, which have been distributed already (without any diagnosis). Various new techniques will also be discussed. A specific project is dealing with intraarticular sarcomas.
 - f) *Orthopedic surgery (FVvS)*: The group had a very comprehensive program at this meeting, partly together with the imaging group. New imaging techniques may influence the guidelines for remittance of lumps in the future.
 - g) *Central register (CT)*: An intense activity among coordinators has now made the register for all orthopedic cases almost complete! For abdominal sarcomas, there is still much missing data.
5. ***The metastases register*** was shortly discussed. Since this had been closed, and its focus not has been sarcomas, the SSG board now finds that no more SSG activity will be spent on this register. Potential follow-up will thus be organized outside SSG, and this may be further discussed in the orthopedic surgery subcommittee.
6. ***Next plenary meeting*** will be held in Helsinki in October 9-11, 2013, at Hotel Scandic Crown. CB will lead the program committee together with KSH, also consisting of the other chairman (OB), the secretary (ME), JE for the radiotherapy aspects, and from Finland Jukka Kanerva, Maija Tarkkanen, Aarne Kivioja, Tom Böhling, Sakari

Knuutila and Erkki Tukiainen. Furthermore, LV asked CB to try to organize a nurse/physiotherapy group to be involved in the preparations of the program for that group. A common session for both groups will also be planned. The main structure in principle with program and speakers should be finalized in late spring 2012. One subject for the meeting, that has already been decided upon, is the similarities and differences between children/adolescence and adult sarcomas related to biology and treatment. Lee Helman at NCI has already been asked and accepted to give a lecture on rhabdomyosarcoma and Ewings sarcoma. Other subjects and potential lecturers were discussed. Marco Manfrini, an orthopedic surgeon at the Rizzoli Institute in Bologna, specialized in bone sarcomas in children, may be an option. JE suggested that proton therapy could be a subject, since this modality will be available in Uppsala in 2013, and it will probably be of most value for children. A possible lecturer could be Kristina Nilsson in Uppsala. A possible subject could also be the role of mifamurtide in osteosarcoma with e.g., Stefan Bielack as lecturer.

7. **Other meetings** were discussed. A new board meeting could be needed, e.g., in April 2012, but no final decision on this was taken. The next working group meeting will be held in Malmö at World Trade Center/Park Inn Hotel in 2-4 December 2012. The change of venue from Copenhagen is motivated by the higher cost in Denmark (2363 SEK per person in Malmö, 3980 SEK at DGI Byen in Copenhagen). As usual, a board meeting will be organized at 5 pm, Sunday December 2. The next working group meeting will not be held in late 2013 because of the change in time of the plenary meeting from May to October (due to the EMSOS meeting in Gothenburg in May 2013). Instead, a working group meeting will be organized in early 2014, preliminary February 2-4. As a potential site for the next plenary meeting in 2015, TA suggested Stockholm.
8. **The subcommittees** must elect their chairmen every 5 year according to the statutes, reminded KSH. Accordingly, the time has come to elect (or reelect) the chairmen for the Visceral and Retroperitoneal Group, the Central Register, as well as the Radiotherapy section of the Medical Oncology Group. Each of these subcommittees should start discussing potential candidates during this meeting. Election decisions will be finally ratified at the working group meeting in December 2012. The subcommittees are therefore encouraged to have thorough discussions during the next year.
9. **The status of the SSG secretariat** was reported by TA. The creation of a so called Regional Cancer Center (RCC) in Southern Sweden may lead to a re-localization of the Oncologic Center, and thus also of the SSG secretariat. At the secretariat, a clinical trial group is responsible for the daily running of SSG studies under the SSG board. Monitoring of the SSG studies is now “outsourced” to the company CROAK AB, where the staff is very knowledgeable with SSG and their studies since before. In May 2012, it will be time to apply for a new three year period of support from the Swedish Cancer Fund. Mikael Eriksson will write the application in cooperation with Thor Alvegård and the SSG chairmen. Hopefully, we will also have further support from Amgen.
10. **Thesis projects within SSG** were briefly reported. Nina Jebesen will probably finalize her thesis on radiotherapy in soft tissue sarcoma including the SSG XIII study during

the next year. Asle Hesla has changed his direction from Ewings sarcoma towards soft tissue sarcoma, and his thesis will not be based on the SSG register or studies. Marie Ahlström is in her early phase with the project concerning different aspects of chemotherapy in soft tissue sarcoma, including the on-going SSG XX study.

11. Members of SSG are somewhat uncertain today because of lacking update of the membership register. The need to review and up-date this register is obvious. It was decided that this will be done per country, either by one member per site reviewing and inquiring all names of the list from that place confirming work place, e-mail addresses etc, or by one representative of each discipline (medical oncologist, pathologist etc) reviewing all members of their discipline in the country. Potential new members will have to require a simple membership application form from Eva-Mari Olofsson at the SSG secretariat.

Lund 2011-12-05

Mikael Eriksson

Secretary

Anders Rydholm

Vice secretary

Kirsten Sundby Hall

Chairman

Otte Brosjö

Chairman