SSG board meeting 2010-05-31, Hotel Hilton, Kastrup Airport, Copenhagen

Present: Thor Alvegård, Bodil Bjerkehagen, Otte Brosjö, Mikael Eriksson, Odd Monge, Eva-Mari Olofsson, Anders Rydholm, Mikael Skorpil, Sigbjørn Smeland, Ole Steen Nielsen, Kirsten Sundby Hall, Clement Trovik, Charlott Marie Våde, Jan Åhlén

1. Board representation from Iceland

The Icelandic sarcoma physicians have expressed a wish to participate in the SSG board, and it has been decided to invite one representative from this country. Kirsten SH has now received a mail with the information that Halldór Jónsson is appointed. Unfortunately, he was not able to participate atinin the meeting today. His name will be included on the SSG webside.

2. Protocol proposal: Preoperative radiotherapy in non-metastatic retroperitoneal sarcomaa, a phase I-II study

As representative and leader of a working group emanating from the SSG working group for abdominal/visceral sarcomas, Odd Monge presented a protocol version (dated 30 April 2010) of the above mentioned clinical study. Whereas at least Bergen, Stockholm, Gothenburg, and Lund have shown an interest forinin the protocol, the abdominal surgeon in Oslo Stephan Stoldt, who unfortunately not has been able to participate at inin the recent meetings in the abdominal/visceral working group, is not willing to participate. According to a letter last week he argues that a new non-randomized study will learn us too little. However, he would accept to participate in the planned randomized EORTC study investigating the same question (i.e., whether preoperative radiotherapy is beneficial for DFS and OS). Kirsten SH has written to the EORTC chairman Peter Hohenberger to ask him about the status for their plans, and furthermore whether SSG could participate even if our centres will not be able to register more than 20 patients per year (which was earlier discussed). There is no reply yet from Hohenberger. Ole Steen Nielssen will follow- up and try to get in contact with Hohenberger.

After a thorough debate the meeting concluded:
1. That a randomized study open for SSG would be preferable, at least if it may be expected to start during this year.
2. Since the EORTC study is uncertain, the planned SSG project is better than nothing, and the working group is encouraged to go on with its planning (even if Oslo would not participate).
3. Some comments on the present version of the protocol has been sent to Odd Monge, and some other issues were raised during the discussion, e.g., that core needle biopsy would be mandatory, so there will be no doubt that it really is a sarcoma; the histological diagnosis may also be useful for potential medical therapy. The working group will make corrections and present a hopefully (almost) final version at the working group meeting in late November.

3. Reports from the working groups

a) Imaging

Mikael Skorpil presented four present projects:

- Review paper with guidelines for remittance to sarcoma centre of tumours fulfilling criteria for lipoma on MRT
- Role of CT/PET for sarcomas is evaluated with comparison with bone scintigraphy; use for evaluation of early response also considered
- Subgroup will look at imaging for abdominal sarcomas

- Potential participation in studies regarding; a) multiple hereditary exostoses; b) lung metastases in osteosarcoma; c) interferon in aggressive fibromatosis

b) Pathology
Bodil Bjerkehagen reported from the last review meeting held recently in Warsaw. Main interest was put upon SSG XX, where the review showed a rather good agreement with local pathologist report. The group is mostly reviewing study patients, but underlines the importance of review also of other difficult cases, e.g., Ewing, where no studies are presently on-going. Interest is also directed towards structured reports, and a modern GIST risk classification (according to the suggestion by Heikki Joensuu). On request from Mikael Eriksson, a problem to get access to slides and specimens from some pathology departments within clinical studies at least in Sweden, was discussed in Warsaw. The problem seems to be derived from earlier experiences of problems to get tissues back to the department after review. A further discussion on this topic lead to a suggestion that the chairman of the pathology group together with SSG chairmen could write a letter to all pathology departments on the matter, either in general or at the start of a new project. No formal decision was taken, however.

c) Surgery and central registry
Clement Trovik briefly mentioned that the orthopaedic surgery group is focusing on indications and margins. He then presented new data from the central registry. In total the registry now includes data on 11,092 patients, half of them orthopaedic soft tissue sarcomas and the rest bone sarcomas and abdominal/visceral sarcomas. Report results have improved quite a lot during the last year, not least from some centres. As a consequence it was suggested to now add Umeå and Linköping on the list of centres from where we have sufficient data to allow use in e.g., the on-going “Vancouver project” (relation of local recurrence and metastases in STS). Present plans include to go through all quality parameters in the registry with the locally responsible persons before the working group meeting in November. Denmark is considering to join the SSG registry, and Jonny Keller will be invited to the next registry meeting.

d) Abdominal/visceral sarcomas
Janne Åhlén reported that Swedish registry data according to the plan will soon be entered into the so called INCA platform for web-based registration. Short discussion about potential consequences for SSG.

e) Nurses and physiotherapists
Lotta Våde reported from a Scandinavian day at EMSOS in Birmingham recently, which became a very fruitful meeting. At October 13 a Swedish sarcoma day for nurses will be arranged. A working group for methotrexate administration is active. The physiotherapists have an emerging activity. Finally, Lotta V reported that the programme for the plenary meeting in Malmö next year is under progress, and will focus on palliation.

f) Oncology
Kirsten SH reported that 78 patients have been registered in the SSG XX adjuvant study. No major problems have occurred.

Mikael E gave an update from the present adjuvant GIST study, SSG XVIII/AIO, where the needed number of events (110) now is awaited to allow the major analysis. The rate of new events has decreased recently, and the analysis may not be possible until late this year. ME

also shortly presented an offer from Novartis to SSG to run a single-arm study on nilotinib adjuvant in GIST, also this time in cooperation with the Germans; Peter Reichardt is suggested to be PI.

Finally, ME also described the early plans of a third-line study of the new tyrosine kinase inhibitor pazopanib in advanced/metastatic GIST refractory to imatinib and sunitinib. ME and KSH had a meeting with the company GSKgsk in Oslo last week, and we have been invited to send a synopsis; their early view was positive. This would also be a SSG sponsored study with free drug and administrative economical support from GSKgsk.

Sigbjørn Smeland reported from EURAMOS-1 where more than 1800 patients now have been registered; probably the inclusion will close late this year when the goal of 1260 randomized patients has been met. Sigbjørn also reported the result of a multi-group planning meeting in London in March this year for the next osteosarcoma protocol, where SSG was represented by five persons. The most probable up-coming project will evaluate both mifamurtide (MTP) and zoledronic acid as additives to the three-drug combination MAP in a multi-arm multi-stage setting. This has been discussed in a special bone sarcoma meeting before the board meeting, where also potential coming studies in Ewing´s sarcoma was discussed (see separate minutes!).

4. Membership in SSG

In the statuetes of SSG it is written that the application for membership in SSG should be accompanied by a CV and publicationincluding list. This seems not to have been practiced strictly, and it was agreed that a simplification is warranted. It was therefore decided that the application in the future only must clearly state the discipline of the applicant, the working place and the role in sarcoma treatment and care. A proposal for application form will be worked out by the secretary (ME).

5. Publication rules

Questions have been raised regarding the publication rules for papers based on the SSG registry, e.g., from Danish representatives when discussing whether Denmark would join the registry in the future. It has been concluded that these rules, as today described in the statues, may be a little vague. A small working group is constituted to come up with a suggestion to the working group meeting in November. Chairman of this group is Ole Steen Nielsen and other members are Kirsten Sundby Hall, Otte Brosjö, Clement Trovik and Mikael Eriksson.

6. Coming meetings

Kisten SH described the programme for the working group meeting in November, and disclosed that we will now charge participants a sum of 1600 SEK. The meeting will have its usual form, starting with the board meeting at Sunday November 28 at 5 PM. During Monday, a general meeting will be followed by group meetings, continuing on Tuesday morning until a summing-up session. Tuesday morning also a meeting by the Central register subcommittee will take place. Tuesday aAfter lunch, the abdominal/visceral sarcoma group meeting will have their meetingtake placetake place (participation in this session only will cost 400 SEK). Venue for the meeting will be DGI-byen in Copenhagen. The chairmen of the subcommittees must send their program to Kirsten Sundby Hall before September 15.

Kirsten also described the programme for the next plenary meeting in Malmö, May 4-6, 2011. Many prominent guests have promised to participate, e.g., Paulo Casali, Dorothe Carrle, Daniel Vanel, Peter Hohenberger, andSimon JardonJordan and Hans Gelderblom. The

registration fee cost for the meeting will be 3100 SEK. and in additionbesides hotel expences will come. plus hotel. The final programme will be available at the SSG homepage during July. There will be a tumor biology symposium on Tuesday . Registration fee for the symposium will be 600 SEK.
Registration will be open on the webside Oct 10th 2010. Abstract deadline February 15th, 20110.

7. Status at the SSG secretariat and the economical situation
Thor Alvegård reported about the activities at the secretariat in Lund, and specifically about the existing small trial group. He also gave an economical report after a brief description on the formal organization of the Oncology Centre in Lund, where the SSG secretariat is situated. Regarding funding, we will have response from the Swedish Cancer Fund for the coming period this autumn. In September, we will send new applications to the Nordic Cancer Union and the Swedish Children Cancer Fund. As earlier we also have some support from industry, mainly from Novartis to run the adjuvant GIST trial. Thor Alvegård also reported that the home page of SSG now is the first page which pop up at a search for "SSG" by Googles.

8. Next board meeting
Nov 28-30th, 2010, DGIYbyens -hotel, Copenhagen

Addition: By googling " skandinavisk sarkomgruppe" SSG`s home page is now the first page which pop up.

See point 6 above!
Lund June 18th, 2010

Mikael Eriksson	Kirsten Sundby Hall	Otte Brosjö
Secretary	Chairman	Chairman

SSG bone sarcoma meeting

Hotel Hilton, Kastrup Airport, Copenhagen, May 31 2010

Attending:
Thor Alvegård, Otte Brosjö, Bodil Bjerkehagen, Mikael Eriksson, Heidi Glosli, Lars Hjorth, Odd Monge, Ole Steen Nielsen, Eva-Mari Olofsson, Catherine Rechnitzer, Mikael Skorpil, Einar Stensvold, Sigbjørn Smeland, Kirsten Sundby Hall, Clement Trovik, Charlott Marie Våde, Jan Åhlén

Ewing´s sarcoma

Kirsten Sundby Hall went through the recent history of Ewing protocols within SSG including the two collaborative studies made together with the Italian Sarcoma Group; ISG/SSG III for localized Ewing and ISG/SSG IV for limited metastatic disease (lung metastases and/or not more than one bone metastasis). ISG/SSG III was closed in December 2007, and has since then been used as standard treatment ; however, the Swedish pediatricians have been treating their patients within the frame of EuroEwing 99 since more than five years, including randomization for high dose therapy in the intermediate risk arm.

Further strategy for Ewing has been discussed at several SSG meetings during later years. At the last working group meeting in Copenhagen in November 2009, it was concluded that neither a new preliminary suggestion from the ISG, nor the present plans from the EuroEwing group, was interesting enough for SSG for the moment, in the light of the time- and cost-consuming work-up that would be needed. For localized disease, a continuing use of ISG/SSG III as standard was recommended (with the exception of the Swedish pediatricians who proceed within EuroEwing). For metastatic disease, it was recommended to choose either the good response arm from ISG/SSG III (without high dose therapy), or the control arm from EuroEwing; VIDE x 6 + VAI x 8.

Evolving results from several studies with antibodies against IGF1-R have been eagerly awaited, but by now it seems that the results of these studies have been rather disappointing.

The question for the present meeting was what to do now? For localized disease, there were three alternatives: a) join the planned Italian study ISG AIEOP EW1 (it may still be possible to influence on the design, according to Thor Alvegård); b) join the successor to EuroEwing 99 called Ewing 2008, a very similar protocol as EuroEwing 99, launched by the Germans mainly for funding reasons; c) not change anything now but continue to use ISG/SSG III design as standard. (For details regarding alternatives a and b, please contact Kirsten Sundby Hall).
After some discussion, it turned out that there were no strong advocates for any of the mentioned protocols, and several question marks were raised related to design. Thus, it was concluded that the recommendation of ISG/SSG III is still valid. However, new information may change this up to the time for the next working group meeting in late November. Lars Hjorth told that EuroEwing organization have discussed a possible randomization of the induction treatment between VIDE and a condensed regimen with treatment given every 14 days (according to an interesting recent US study showing an advantage). The next meeting of that group will be held shortly before next SSG working group meeting, and a very up-dated report may be expected. Kirsten Sundby Hall will tell ISG that we will not decide to participate in their project, at least not now. She will also ask whether the protocol still is possible to influence.

Regarding metastatic disease, there are some promising reports using high dose treatment; the Scandinavian part of ISG/SSG IV is, however, very poorly up-dated with few useful data. An effort to improve this is being made by Sigbjørn Smeland. The meeting today could not give any recommendation for this group of patients.

Bodil Bjerkehagen underlined the importance of further review and reporting for Ewing sarcoma patients also outside formal protocols, and suggestions for the registry forms will be considered.

Osteosarcoma

Sigbjørn Smeland described shortly the past and present SSG osteosarcoma protocols from SSG XIV to the on-going EURAMOS-1. The registration of patients in the latter protocol will probably cease by the end of the year, when the goal of 1260 randomized patients is expected to be fulfilled.

In March this year, an osteosarcoma meeting to discuss further protocols was organized in London, and both the groups participating in EURAMOS-1 and other groups participated. SSG was represented by Sigbjørn Smeland, Kirsten Sundby Hall, Lars Hjorth, Oskar Hagberg and Mikael Eriksson. At that meeting different proposals were presented and discussed. The most likely suggestion made by the European EURAMOS counterparts was a multi-arm multi-stage designed project using standard MAP regimen as control to investigate several options; MAP with mifamurtide (MTP), zoledronic acid, or ifosfamide; or combinations of these additives. Since the Americans have decided to refuse ifosfamide, the most probable suggested project will be a 4-armed study with the following arms: a) MAP only; b) MAP + MTP; c) MAP + zoledronic acid; d) MAP + MTP + zoledronic acid.

The main problem with this design seems to be funding of MTP, since this drug is now approved by EMEA for osteosarcoma (but not by FDA). Since the drug is very expensive, it is hardly possible to use it within a study if the drug costs are not covered. Therefore, there will be discussions with the responsible drug company, Takeda, trying to convince them, that the “osteosarcoma society” is not enough convinced to use the drug without a new confirmatory study. If the study will be started, the participants of the meeting today seemed agreeing that SSG will try to join, but there will nevertheless be matters of financing that must be solved.

Sigbjørn Smeland also described a registration project discussed between ISG, COSS and SSG, EUROLES, with the purpose to register treatment and outcome for relapsed osteosarcoma. A new formal study would claim approvals, and it was suggested that these data may be collected by the registry follow-up. No final decision was taken.

Lund June 18th 2010

Mikael Eriksson	Kirsten Sundby Hall	Otte Brosjö
Secretary	Chairman	Chairman