

***The 34th Meeting of the Scandinavian Sarcoma Group – 30 Years Jubilee.
May 6-8th, 2009***

The Scandinavian Sarcoma Group was founded in 1979, and the 34th plenary meeting held in Oslo May 6-8th was organized to specifically celebrate the 30 years anniversary. In total, 216 delegates visited this meeting, among them several foreign guests. Number of participants from the various countries: Sweden: 80, Norway: 84, Denmark: 25, Finland: 11, France:2, Netherland:1, Germany:3, Iceland:1, Italy:4, Spain: 1, Switzerland:1, England: 1, USA: 8. The excellent venue for the meeting was selected to be Hotel Opera in the centre close to the railway station. Furthermore, the extraordinary neighbour, the new Oslo opera, was the site for the main cultural event at the second night of the conference, the opera “Carmen” by Bizet.

The scientific program was enlightened by many international “sarcoma stars” representing different disciplines and interests within the sarcoma field. In the following, a short summary of the subjects dealt with is presented.

The scientific program consisted of 56 oral presentations and 15 posters. The abstracts can be found on the homepage of SSG www.ssg-org.net.

Already early in the morning a special symposium, “The Pathology of Sarcoma”, was started. Several items regarding basic sarcoma research, e.g., sarcoma progenitor cells, mesenchymal stem cells, cytogenetics, oncogenes, p53, receptor tyrosine kinases, biomarkers and inflammation, were presented by experts from the Nordic countries, Italy and Switzerland.

In parallel, meetings were held with the SSG board (see below) and the SSG central register, see separate protocol attached.

In the late afternoon, the 34th meeting was officially opened by the SSG chairmen, and this was followed by a minisymposium on the use of trabectedin in the treatment of soft tissue sarcoma; a lecture given by dr Jean-Yves Blay from Lyon.

The main conference dinner at the Hotel Opera closed the day with a nice folk music performance by Karl Seglem and his band.

Thursday May 7th

The day was saturated with interesting lectures, many of them by international experts. Thus, D. Vanel from Bologna discussed conventional and functional imaging, H. Jürgens from Münster presented his view of current standard and future aspects of Ewings sarcoma, P. Hogendoorn educated the audience on chondromatous tumors, A.K. Raymond from Houston describe the pathologist’s perspective on osteosarcoma, and P. Picci from Bologna presented a demographic study of 1500 osteosarcoma patients. Different aspects on treatment were delivered by R. Schwarz from Hamburg regarding radiotherapy, S. Patel from Houston on chemotherapy, and A. Abadu from Birmingham on endoprosthetic replacement in children. A. Gilsenan presented characteristics of patients in a US osteosarcoma surveillance study.

The day also included many interesting presentations from the Scandinavian delegates. Thus, resection of the spine for primary tumours was discussed by B. Gunterberg. The SSG experiences on bone sarcomas in general and of the intergroup study EURAMOS-1 in

particular was supplied by S. Smeland, and the experiences in soft tissue sarcoma by K. Sundby Hall. Short presentations of SSG thesis, concluded and ongoing, were given by J. Engellau, K. Engström, K Svarvar, N. Jebsen, and B. Widhe. Some well presented free papers ended the scientific program of the day: B. Bjerkehagen discussed prognosis of radiation-induced sarcoma, P. Lindholm increased our knowledge on PET in musculoskeletal tumours, and finally, M. Kolberg presented new prognostic markers for MPNST.

Friday May 8th

The morning started with a session on visceral and retroperitoneal sarcomas, and J. Åhlén presented the new SSG recommendations for the diagnosis and treatment of these tumours (SSG XVII, version 2). The international GIST expert H. Joensuu from Helsinki clearly discussed the scope of adjuvant treatment in this disease. This was followed by a free paper session including presentations on GIST in a neonate (Å. Jakobson), aspects on hyperthermia in ILP (L.E. Podleska from Essen), fruit drinks and methotrexate elimination (K. Sundby Hall), P53/HDM2 interaction in synovial sarcoma (B. Brodin), and gene expressions profiles of MPNST and neurofibroma (T.H. Ågesen). A poster session, effectively run by Ø. Bruland, included 15 posters on very different topics, and ended the morning session of the last day. Three of the posters received prizes. 1. prize: Danielsen SA et al. Methylation of RASSF1A-a prognostic biomarker in NF1-patients with Malignant Peripheral Nerve Sheath Tumors. 2. prize: Sampo MM et al. A web-based prognostic tool for extremity and trunk wall soft tissue sarcomas and its external validation. 3. prize: Sellevold S et al. Saddle prosthesis after resection of periacetabular tumors.

After lunch we had a joint session with the nurses and physiotherapists, and this was started by G. Ottaviani from Milan, who with a dynamic powerpoint-show discussed late events in osteosarcoma survivors. A presentation on the same topic was given by L.H. Aksnes who presented data from her recently defended thesis on health status in bone sarcoma survivors. L. Våde presented interesting data from a Scandinavian survey on practical procedures when giving high-dose methotrexate; further exchange of knowledge and perhaps also common standards seem highly appropriate. Two papers from Stockholm ended the session; P. Pergert discussed transcultural caring relationships, and M. af Sandeberg delivered a lecture on health-related QoL during childhood cancer treatment.

The last session, only for SSG members, discussed organizational questions under the heading “SSG matters”, see comments in the SSG board protocol.

The successful meeting was closed with the hope to meet again in two years for the 35th meeting which will be organized in Malmö, Sweden, in May 2011.

SSG Board Meeting May 6th, 2009

1. SSG organization

A revision of the organization of SSG has been prepared and was discussed during the meeting, whereby the following changes were decided.

As earlier announced, Thor Alvegård is at this meeting resigning from his long chairmanship, and Kirsten Sundby Hall, who already for some period had been additional chairman will now take this responsibility completely. The other chairman, Henrik Bauer, has recently also declared his decision to leave this post, and to his successor Otte Brosjö was today elected.

A new position as treasurer was decided, and Thor Alvegård accepted to take this position for 1-2 years.

A new resource group (named "Clinical Trials" on the home page) was founded with position at the SSG secretariat in Lund and with the task to assist the SSG investigators regarding performance of our trials, e.g., with matters concerning eligibility, protocol issues, CRFs, data quality and other questions. This group consists of Jeanette Ceberg (coordinator/monitor), Maria Rejmyr Davis (data manager) and Mikael Eriksson (trial physician).

The data management group, also at the SSG secretariat, will consist of Maria Reymyr Davis, Elisabeth Johansson (responsible for the Central Register), and Thomas Högberg, head of the Oncologic Centre of Southern Sweden, where the SSG secretariat is situated. As new statistician at the SSG secretariat Karolina Carlsson has been appointed.

In the program committee Henrik Bauer and Thor Alvegård were replaced by Otte Brosjö and Mikael Eriksson; the other members still being Kirsten Sundby Hall and Anders Rydholm.

The epidemiology section was removed from the central organization, but remains as a subcommittee.

Furthermore, it was decided to remove "members" and only keep chairmen for all subcommittees (with few exceptions described below). The reason for this is that the activity and participation of different members varies over time, and it could well be questioned why not other interested SSG participants are on this list. Thus, the chairmen, one or two per group, are responsible to gather and stimulate as many interested participants as possible for the subcommittees meetings, but no other will be mentioned specifically. However, the Central Register subcommittee will have specified "coordinators" at all SSG centres besides of the chairman (see attached list!). Another exception is the recently founded subcommittee for nurses and physiotherapists, which has an elected board with two chairmen, treasurer, secretary and other board members.

The specific situation of some subcommittees was discussed. The Morphology subcommittee is renamed as "Morphology/Tumor biology" with two chairmen, Bodil Bjerkehagen and Fredrik Mertens. The Imaging subcommittee has a vacancy as chairman which will be discussed in the near future with a final decision at the working group meeting in Copenhagen in November this year. The Radiotherapy subcommittee will have two chairmen, Øyvind Bruland and Jacob Engellau. The subcommittee for skeletal metastases was declared to be

temporary for the purpose of the on-going project which will probably end within a couple of years.

New honorary members of SSG at this Jubilee meeting in Oslo were Gunnar Sæter and Anna Elisabeth Stenwig. Furthermore, Thor Alvegård was appointed as the first honorary chairman in the history of SSG (which was not disclosed until the Jubilee dinner later the same day).

2. Upcoming SSG meetings

The working group meeting this year will be held at DGI-Byen in Copenhagen 23-24. November, with an early start at Monday morning (arrival Sunday night recommended).

The chairmen of the subcommittees must submit proposals for subjects to be discussed before September 15 to Kirsten Sundby Hall (k.s.hall@radiumhospitalet.no)

Next “Plenary meeting” will be organized in Malmö in 2011, May 4-6th or May 11-13th, and it is planned that we may have 120 physicians and 80 nurses/physiotherapists participating.

3. Economy

The economy of SSG is based on different income sources. A sponsor support from Amgen of 350,000 SEK has been received the last years (earlier somewhat more). From the Nordic Cancer Union (NCU) we receive a yearly support, this year 40,000 Euro; a new application must be made in September for next year. The Swedish Cancer Fund is supporting with, for the present period, 100,000 SEK yearly, approved until 2010. A new application must be done next spring. The on-going adjuvant GIST-trial, SSG XVIII, is supported by Novartis with 250,000 SEK yearly for the coming five years, but this grant is not covering any other costs than the performance of this trial.

The money is approximately used for the SSG secretariat (1/3), to organize the meetings (1/3) and for smaller subcommittee meetings, travels etc (1/3).

Possible future income sources were discussed, as other potential funds. It was suggested to put a fee on the participation in the yearly working group meeting, e.g., 1500 SEK. A membership fee was not regarded as a good solution.

4. Publication

The Acta Orthopædica supplement with SSG review papers recently published and the thesis by Liv Hege Aksnes : “Health in long term survivors of bone sarcoma” have been distributed to all participants at the present SSG Jubilee meeting.

5. Research projects

Five projects have been proposed:

a) The University of British Columbia has invited SSG, through Clement Trovik, to participate in a meta-analysis with data from major sarcoma groups/centres on the question “Does local recurrence of soft-tissue sarcoma predict disease-specific mortality?” The board showed a positive attitude to this project, but a protocol is awaited before a final decision on

participation may be made. A committee consisting of Clement Trovik, Henrik Bauer and Kirsten Sundby Hall will consider the proposal closely and decide for SSG.

b) SSG has also been invited to participate in a study under the umbrella of LIVESTRONG Young Adult Alliance, a large project being launched by NCI and Lance Armstrong Foundation in the USA. The study is a global meta-analysis of bone sarcoma studies to examine patient, tumor and treatment related factors uniquely important for outcome in adolescents and young adults. Data will be drawn from the SSG registry on patients treated for bone sarcomas within the SSG study projects during the years. The participation of SSG has already been decided, and Sigbjørn Smeland will be principal investigator for SSG. He has written a specific study protocol, and on the base of that Mikael Eriksson will now write an application to the Ethical board of southern Sweden, where the registry is placed.

c) The chondrosarcoma project by Anders Walløe and Frede Frihagen at Ullevål University Hospital in Oslo has proceeded very slowly because of poor data collection result. A part of the project is, however, presented at this meeting concerning “The epidemiology and prognosis of chondrosarcomas in the axial skeleton”. The future for the project is uncertain in its current form.

d) Olga Zaikova at Radiumhospitalet has, during her stay in Birmingham recently, investigated risk factors for local recurrence and death in parosteal osteosarcoma in a material of 63 patients collected at the Royal Orthopaedics Hospital database during the last 30 years. Now, Olga will merge these data with similar data from patients with this diagnosis in the SSG registry. Even if members of the board declared this diagnosis to be a very limited problem, the suggestion by Olga was accepted.

e) The planned project to suggest a follow-up to handle long-term side effects in patients treated for bone sarcomas was also discussed briefly, mainly to suggest further members of the committee. There are enough Norwegian members, among them Liv Hege Aksnes, but only one so far from Sweden, Lars Hjorth. Henrik Bauer was proposed and accepted this appointment. Katarina Engström was also suggested.

6. Closure

The board meeting was thereafter declared closed, and it was decided that the result would be presented and further discussed at the plenary meeting “SSG matters” on May 8th.

Further discussion/decisions at the plenary meeting

Kirsten Sundby Hall presented the decisions from the board, and they were largely approved by the plenary meeting. Some specific further decisions were taken:

a) Veli Söderlund declared that it has been decided within the imaging subcommittee that Mikael Skorpil will be the new chairman for this group.

b) Catherine Rechnitzer expressed an interest in the project on a long-term follow up program for bone sarcoma patients, and she was approved as a member of that group. The other members are: Liv Hege Aksnes, Heidi Knobel, Heidi Glosli, Lars Hjorth and Henrik Bauer. Katarina Engström will also be asked. A first draft from the group will be presented at the up-coming working group meeting in Copenhagen in November.

c) It was decided that the up-coming working group meeting in Copenhagen November 23-24th also this year will include a session for the retroperitoneal/intraabdominal sarcomas, and that this will be on November 24th, after lunch.

d) The possibility of the board to decide a participation fee for the yearly working group meeting, e.g. 1500 SEK, was approved.

d) The next plenary meeting will be arranged in Malmö 2011, May 4-6th or May 11-13th.

e) The next board meeting will be held Sunday November 22 (later decided to be held from 17-19.30) this year in Copenhagen. **SSG members are invited to send matters for discussion to Kirsten Sundby Hall or Otte Brosjö before November 1th.**

Mikael Eriksson
Secretary

Kirsten Sundby Hall
Chairman

Thor Alvegård
Chairman (resigning)

Henrik Bauer
Chairman (resigning)

Otte Brosjö
Chairman (elected)

Paula Lindholm, Tom Böhling
Vice chairmen

Anders Rydholm
Vice secretary