

Minutes board meeting SSG, Bergen, 7.5.2019

Present: Akmal Safwat, Thomas Baad-Hansen, Lotta Våde, Panos Tsagkozis, Jukka Kanerva, Eva-Mari Olofsson, Hans Kristian Haugland.

1. The minutes from the meeting in January were reviewed and follow-ups on agreements were discussed in parallel.
 - Regarding organizing board work
 - Frequent video/telephone board meetings 4 times/year – **approved**
 - SSG work load and tasks to be delegated between board members with possible involving of the heads of the working groups - **approved**.
 - At least one monthly telephone/video meeting between chairman+ secretary with Eva-Mari. Other board members are welcome to attend – **approved**. To meet last Thursday in the month, 3.30 pm.
 - The board needs to open a near dialogue with the chairmen the working groups may be through meetings or reporting of activities. The format of this and the details of how this initiative was not discussed in details.
 - There is a desire to open a dialogue channel with the members. We could not reach a consensus on how and how frequent. We agreed to start by sending the members a letter describing the new board vision. Akmal is writing this letter now.
 - We also plan to use the website more for communication! Eva-Mari will investigate if we can use the website to communicate and report to the chairman and the board.

The last three bullet points were discussed together.

Akmal sent a letter as an attachment to an e-mail to all members of the SSG at the end of February, describing thoughts and plans for the future work of SSG under the new board.

To improve on the communication within the SSG, we had an exchange of thoughts on how this could be organized.

Use e-mail to communicate with the members and receive response. The possibility of using social media in communication within the SSG was discussed. Closed group on Facebook, the possibility of crowd funding. Next letter to the members to be distributed via social media. There is a need for more research on how we can apply social media for the purposes of the SSG. Lotta, Eva-Mari and Panos will look into this.

- The working groups and plenary meetings:
 - The board felt that the annual working group and plenary meeting are important meeting points for all SSG members. It was decided therefore to continue to hold these meeting in its present form and use them as an opportunity to encourage the participation of young investigators from Nordic countries through planning dedicated sessions for them to present not only results but also unfinished protocols to get feedback and inspirations. We will encourage the participation of basic science scientists with relevant research results - **approved.**

The education role of SSG:

- The education role of SSG will be strengthened through; a focus on education in the annual meeting; workshops/seminars on particular controversial subjects or rare entities and through making a web based archive of the cases we discuss via mail with follow up results (Eva Mari will investigate this possibility). Eventually, some of these cases could be presented and discussed in the annual meeting – **approved.**

The establishment of archives were discussed. The orthopedic surgeons have had informal case-based meetings. Thomas will get in contact with Haldor Haldorson, the head of the orthopedic surgeons committee, looking into the possibility of establishing an orthopedic archive.

Public relations and fund raising – **approved.**

- Lotta, who has worked extensively with «Kuledagene» in Oslo, will participate in the Sarcoma awareness day to be held in Sweden in the near future. Hopefully with considerable transfer of valuable knowledge concerning organizing such events. In Denmark and Finland there are no established formal patient groups. An initiative from SSG on this matter was discussed.

2. Economy

- The economy is still considered to be in a critical condition. However, the recruitment to the SSG XXII-study is improving. So far, 115 patients are in place. SSG will receive a considerable sum of money when the milestone of 150 patients have been recruited, probably by the end of 2019.
- The plenary meeting in Bergen will not give SSG any significant surplus (contracts with sponsors denies us this possibility). The accounting from the meeting will probably be finalized within 2-3 months.

3. Funding activities

- The possibility of alternative funding for the SSG was discussed. Although there are organizations in the Nordic countries that potentially might sponsor activities which SSG is involved in, multinational societies do not seem to be very attractive. Links to possible funding agencies will be placed on the our

website, responsible Akmal. One possible agency to seek contact with is the Joint Committee for the Nordic Medical Research Councils, <https://nos-m.org/>

4. Meeting events

- The Working Group meeting will be held in Malmö, 2.-3. December.
- The next plenary meeting will be held in Finland, most likely in Tampere. The exact date is still to be decided. The board decided that this meeting in the future officially will be named congress (next meeting the 40th SSG congress).
- The board discussed whether the working group meeting and the congress should be combined into one larger meeting, preferably in September biannually.

5. Trials (status of the old) Any new?

- The SSG has received invitation to an EORTC-trial concerned with quality of life aspects for sarcoma patients. Norway will probably participate.
- SSGXXII has reached 115 patients, probably 150 patients by the end of 2019.

6. Education guidelines

- The first initiatives for the SSG initiated travel fund were not successful. Thomas is however working to get new candidates interested. It is important to emphasize that members from all groups within the SSG may apply.
- Akmal presented his thoughts on a new initiative under the possible umbrella of Danish comprehensive cancer centers called Scandinavian Center for bone and soft tissue tumors (SCBST). A more elaborate draft on scope and organization was sent to the other board members shortly after the meeting.

7. Other tasks

- No other tasks were discussed.

8. Next meeting

- Telephone meeting 19. September, 3.00 PM

Hans Kristian Haugland