

**Minutes SSG board meeting at Clarion Hotel, Kastrup Airport, Copenhagen, 2019-01-11  
(12.00 - 16.30)**

**Participants:**

Akmal Safwat (chairman)

Panos Tsagkozis (treasurer)

Hans Kristian Haugland

Eva-Mari Olofsson (SSG secretariat and secretary for the meeting)

**Excused:** Thomas Baad Hansen (scientific secretary), Lotta Våde and Jukka Kanerva.

**Invited to session II from the former board:** Kirsten Sundby Hall, Mikael Eriksson and Fredrik Mertens.

**Session I – Organizing future board work**

The new board gathered to discuss how to organize future tasks for SSG and among the board members. Akmal presented his thoughts and questions and all the points were discussed.

A summary of the points discussed and the decisions made is presented below. All to be re-discussed further at our upcoming meetings:

**1) Regarding organizing board work**

We agreed on:

- Frequent video/telephone board meetings 4 times/year (see dates at the end)
- SSG work load and tasks to be delegated between board members with possible involving of the heads of the working groups.
- At least one monthly telephone/video meeting between chairman+ secretary with Eva-Mari. Other board members are welcome to attend.
- The board need 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.

**2) Regarding our future vision and plans**

The board discussed the following points:

- a) 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.

b) 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.

c) Clinical research and trials:

- We would like to invite all members with interest in clinical research to come with ideas. A first step could be to focus on phase II studies with interesting translational element. The board task could be to :
  - Help in preparation of the protocol (if needed)
  - Advertise and seek possible international collaborators in other groups SARC, EORTC etc.
  - Help find funding agents and give letter of support
  - Help contacting pharma if needed
- We need to make it clear for members that protocols initiated by the board members will be run and controlled by the investigators and that our role will only be supportive.
- It was suggested to form a “clinical trials strategy group” that will hopefully come up with more concrete ideas about how to make SSG an attractive base for your trials.
- The registry is of extreme importance and can be the base for registry based- studies. Akmal expressed a wish that a priority of this board should be to aim at a complete and merged registry and help the registry group get all needed funds to overcome obstacles.

d) Public relations and fund raising

- The board discussed that it is important to focus on creating an SSG “public image” through the web page, social media and connection with patient organizations as this will help in raising funds for SSG scientific activities.
- The board discussed forming a particular group for fund raising activities (Lotta, Eva Mari and Panos).
- We need to seek:
  - Funds to support specific research projects and/or trials
  - Funds to support the organization

- Before embarking on fund raising activities we need to have:
  - A list of possible funding agents (that is to be updated regularly)
  - A system to remind us when a deadline is approaching)
  - A person responsible in each country + Eva Marie
  - A detailed SSG CV/portfolio presentation to be used in applications for funds (Eva Mari)
  - A short one-page brochure/poster SSG presentation to be used in public events seeking for public support (Eva Mari)

At the end of the meeting a “Task and time table” was created (see table at the end of the text).

<u>Task</u>	<u>Responsible persons</u>	<u>Time table for progress report</u>
<u>Clinical trial strategy group</u>	<u>Akmal, Jukka, Thomas</u>	<u>Next board meeting</u>
<u>Website/Archiving tasks for the board</u>	<u>Eva-Mari, Panos, Lotta</u>	<u>Next board meeting</u>
<u>Social media</u>	<u>Eva-Mari, Panos, Lotta</u>	<u>Next board meeting</u>
<u>Patient organization / Sarcoma awareness day</u>	<u>Eva-Mari, Panos, Lotta</u>	<u>Next board meeting</u>
<u>A list of possible funding agents</u>	<u>Panos, Akmal, Hans Kristian, Jukka, Eva-Mari</u>	<u>Next board meeting</u>
<u>A detailed SSG CV/portfolio</u>	<u>Mikael &amp; Kirsten?</u>	<u>Next board meeting</u>
<u>A short one page brochure/poster SSG</u>	<u>Hans Kristian</u>	<u>Next board meeting</u>
<u>Website/Archiving cases</u>	<u>Akmal, Eva-Mari, Panos</u>	<u>Next board meeting</u>

## **Session II – Report from the former SSG board members**

### **Treasurer tasks (Fredrik Mertens)**

Fredrik gave a short presentation of the economy within SSG. The main and, also the basic problem, is that SSG doesn't have a steady income and that the study office is not fully funded. It basically runs with money from sponsored clinical trials, and the money mainly comes from Novartis for running the SSG XXII study.

SSG receive payments from Novartis (SSG XXII) according to a schedule with milestones, mainly based on recruitment of patients for the said study. However, we have recently been able to negotiate month-to-month regular payments based on "running costs".

Nevertheless, we might experience a deficit in our account during the year. According to the department at the University Hospital in Lund where SSG is formally organized, it is OK to have a deficit since we know that money is coming.

An amendment will soon be written by Mikael in the SSG XXII study to increase the enrolment in the study. Mikael will also discuss with Novartis about changing the payment schedule.

Oslo (Nasjonal kompetansetjeneste for sarkom) support SSG yearly (mainly to arrange and perform the pathology/review meetings twice/year). We have had until last year regular grants from the Swedish Cancer Foundation (Cancerfonden) but we will apply again next year. We can also apply money from (Barncancerfonden, Nordisk Cancer Union). We have got money (220 000 NOK) from NOS-M (The Joint Committee of the Nordic Medical Research Councils), Fredrik Mertens will be responsible for this project in the future.

### **Clinical trials**

Mikael made the presentation of the different studies and the support to them. He also gave advice and support for running of new and future trials, see attached his PP-presentation.

Mikael will still be involved in the studies and Fredrik will be responsible for the new project (NOS-M).

### **Collaboration work/contacts**

International collaboration become more important every day. It is therefore of great significance for SSG to continue the participation in the big organizations (EMSOS, ASCO, ESMO sarcoma faculty, CTOS) and be present at the various meetings by presenting what is going on in SSG. SSG is still a highly respected organization internationally.

The possibility of SARC collaboration has been raised and they are positive and we will contact them again. ISG and GEIS are also interesting collaborators.

EORTC have a big and heavily bureaucratic organization, where the voice of a small organization like ours might be difficult to be heard.

## **Next and upcoming meetings (dates suggestions)**

We suggest following dates in 2019:

<b>Date</b>	<b>Time</b>
July 12	16.30 (TC)
October 11	16.30 (TC)
December 1	17.00 (in connection with the next WGM in Malmö)