

A summary from the work meeting in "SSG-for Nurses and Physiotherapists" in World Trade Center, Jungmansgatan 12, Malmö, Sweden January 22, 2018

Meeting room: WTC "New York" at 13:30 -19

Present: Charlott (Lotta) Maria Våde, chairman (Oslo), Astrid Mortensen, vice chairman (Herlev), Anne-Lise Salbu, treasurer (Bergen), Hanna Maria Fuglø, secretary (Copenhagen), Lise Ingeman Petersen (Copenhagen), Annica Petterson (Umeå), Lisbeth Utne Høiland (Bergen) and Stine Næss (Oslo).

Unable to attend: Merethe Lia Johansen (Oslo), Hilde Bøgseth (Oslo) and Emilie Frisk (Stockholm).

Annual report for "SSG-for Nurses and Physiotherapists" from 2016-2017

Lotta initiates the meeting by going through the annual report for "SSG-for Nurses and Physiotherapists" from 2016-2017. The annual report will be available at "SSG for Nurses and Physiotherapists" website.

There is a status from Norway, Denmark and Sweden where the members from each country elaborate on the country's input for the annual report.

Information and agreements which cannot be found in the annual report from 2016-2017

Oslo, Norway, "Store Kule dagen": Lotta informs that when patients and relatives is participating in "Store Kule dagen" it is registered as ambulant consultation at "Center for leaning and mastering"

Denmark: It's settled that Hanna will call the rehabilitation nurse Lise Bjerrum Thisted, Rigshospitalet regarding possible education of patients with sarcomas. Hanna will also contact Professor, chief of medicine Michael Mørk Petersen regarding a procedure for contacting in the Danish Sarcoma Registry.

The upcoming work-meeting for "SSG-for Nurses and Physiotherapists" in 2018

The upcoming work meeting is hosted the 12/03 – 12/04 2018 in Malmö, Sweden.

Accountancy

Anne-Lise, treasurer, informs about economy in *"SSG-for Nurses and Physiotherapists"*. There are approximately 50.000 NKR surpluses.

Fees for congress participation are discussed. It's mentioned that the fees were higher in Aarhus, Denmark than the fees at Maui, Hawaii. There is a large focus on the fees for the congress in Bergen, May 2019.

It's also very expensive to participate in the work-meeting.

Planning of the 40th anniversary congress 05/08- 05/10 2019 in Bergen, Norway.

The upcoming congress will be hosted in Bergen the 05/08- 05/10 2019. The congress will be the 40th anniversary party for SSG. Anne-Lise, Lisbet, Stine and Lotta are in the workgroup that is responsible for organizing the congress. Anne-Lise informs about the planning of the program.

Following three themes for the congress is agreed upon:

- Rehabilitation. Brain-storm: sequelae. Lecturer Christoffer Johansen, Professor, chief of medicine, Rigshospitalet.
- Wound. Brain-storm: insufficient healing of surgical wound, case and pressure chamber.
- Alternative treatment and sarcoma patients: Brain-storm: Cannabis. Lecturer Anita Lunde. In addition lecturer from MD Anderson, Houston, Texas.

WEB master and website.

Lotta doesn't want to continue as WEB master. A post she has had since 2009. Hanna will take over the post as WEB master.

Projects

Norway: The Norwegian patient associations for sarcoma patients are making an app regarding the different sarcoma illness categories.

Denmark: There is a motivation in Denmark to hold Store Kuledag in 2019. To make this succeed it will take more people to help raise the event.

Combined Nordic project. Hanna wishes to make a book for adult sarcoma patients and their relatives from a patient perspective. Similar books exist for patients with pelvic cancer, lung cancer and breast cancer. Hanna is project manager: Hanna, Astrid, Lise, Anne-Lise, Lisbeth, Annica, Stine

and Lotta agree to the proposition. The resulting ideas of a brain-storm can be sent to Hanna. There is a talk about where possible funding for the project could come from.

Rotation plastic (?)

Lotta wants to get the rotation plastic group started again. Annica wants to join the group. There is a wish from Denmark to have Danish patients invited to a possible gathering.

Agenda:

- *"Sarcoma knows no borders, neither should Nursing and Supplement Care"*, Stine Næss and Charlott Maria Våde, Oslo, Norway.
- *"The male cancer patient and communication"*, Astrid Østergaard Mortensen, Herlev, Denmark.
- *"From conference to reality"*, Lise Ingeman Petersen and Hanna Maria Fuglø, Copenhagen, Denmark.
- *"Mentorship program for patients treated for sarcoma"*, Charlott Maria Våde, Oslo, Norway.
- *"Meeting point for children and young adults, during and after treatment"*, Hilde Bøgseth, Oslo, Norway. **REMOVED.**
- *"Conversation before discharge from hospital"*, Lisbeth Utne Høiland, Bergen, Norway.
- *"Amputations and physiotherapy"*, Merethe Lia Johansen, Oslo, Norway. **REMOVED.**
- *"Evaluation of the distress thermometer as a tool for the need for cancer rehabilitation"*, Annica Petterson, Umeå, Sweden.

Reporter: Hanna Maria Fuglø, 01/22-2018