

Summary from” Working Group Meeting of the Scandinavian Sarcoma Group for Nurses and Physiotherapists” 30th of November – 1st of December 2015

Location: World Trade Center, Malmö, Sweden.

Present from the leading group:

- Norway: Charlotta Våde, Synnøve Granlien, Stine Næss, Aina Hollekim Lekven, Merethe Lia Johansen and Anne-Lise Salbu.
- Sweden: Annica Petterson, Linda Stridh and Kajsa Källberg.
- Denmark: Lise Ingeman Petersen and Hanna Maria Fuglø.

Other:

- Sweden: Linn Rosell, Pia Johansson, Jessica Sindal and Ann-Clara Esbjørnsson.

Absent from the leading group:

Lisbet Utne Høiland, Norway, Astrid Mortensen and Maria Petersen, Denmark.

Reporter: Hanna Maria Fuglø.

Monday 30th of November 2015 1-6 pm

Status from Norway:

- The ”1 st symposium – Sarcoma Nurses Group” meeting is arranged at ” *The Connective Tissue Oncology Society*” (CTOS)-congress 6th of November 2015 in Salt Lake City, U.S.A.
- Lotta Våde and Stine Næss were on a four day study visit at MD Anderson Hospital, Houston in August 2015
- Two meetings regarding patients with rotation plasty and their relatives were hold in Oslo in 2015. The meetings were at 12-14th of June 2015 with participants from Norway and Sweden and again in relation with”*Den Store Kuledagen*” 12th of September 2015 with participants from Norway, Sweden and Denmark. A Danish doctor and physiotherapist and a Swedish physiotherapist also attended the later meeting.

- *”Den Store Kuledagen”*: Is an educational day for personnel and an educational day for patients and their relatives. The day is arranged by *”Sarkomforum for sykepleie og fysioterapi”* in Oslo.
- Theme evening for personnel was hosted in Oslo and the invitation applied to the whole of Norway.
- Course for ca. 15-20 patients twice a year in Oslo.

Status from Sweden:

- A physiotherapist from Lund and two physiotherapists from Stockholm have had a study visit to Oslo.

Status from Denmark:

- *”Dansk Sarkom Gruppe for sygeplejersker, fysioterapeuter, ergoterapeuter og radiografer”* hosted 14th January 2015 a day with professional content which was arranged by personnel from Rigshospitalet. One presentation was together with the doctors in *”Dansk Sarkom Gruppe”*. The next sarcoma meeting is planned to be held at 13th of January 2016 in Aarhus, which will be arranged by personnel from Aarhus.
- A private Facebook-group, *”Dansk Sarkom Gruppe”*, is established for the use of relevant personnel.
- National Board of Health: *”Opfølgningsprogram for sarkomer”* is published February 2015 and Hanna Maria Fuglø and Birthe Hedegaard have been present in the work group.

Status from Finland:

Unfortunately no representatives from the Finnish leading group were present. Synnøve Granlien has tried to investigate the Finnish status, but has unfortunately received no feedback.

Leading group:

Expectations to the members of the leading group are being discussed:

- Objectives of responsibility.

- Distribution of the objectives. Being a member of the leading group is not necessary to be a part of a working group.

Objectives of responsibility:

The economy is discussed and all participants are being responsible in the appealing of sponsor money. All agree to this matter but more information on how this is achieved is needed. Lotta Våde will reply on this matter later.

Economy:

The sky high price of the last congress in Stockholm 2015 and the need to look at the economy of the next congress in Aarhus 2017 is being discussed. Many abstained to participate because of the vast price. The possibility of a one day participation is mentioned. In general the need of a cheaper congress centre and lower hotel prices which can be chosen from the congress package.

Treasure Anne-Lise Salbu scrutinizes the economy in "*Scandinavian Sarcoma Group for Nurses and Physiotherapists*".

Even though a congressional fee of 5.250 DKK/ per person was paid and extra bill of 34.965 DKK for the rent of the two rooms in the last congress in May 2015 in Stockholm has been received. In addition to this did our own association pay for our own lectures (12 persons).

Lotta reminds the meeting of the possibility of appealing to get travel expenses, congressional fee and working meetings refunded by the association: "*Scandinavian Sarcoma Group for Nurses and Physiotherapists*".

Congress "*Scandinavian Sarcoma Group for Nurses and Physiotherapists*" Aarhus 9-11th of May 2017:

Work arrangement regarding the annual "Scandinavian Sarcoma Group for Nurses and Physiotherapists" meeting.

Working group for "*Scandinavian Sarcoma Group for Nurses and Physiotherapists*": Käjsa Källberg chair of the group and vice chair of the group Synnøve Granlien are the coordinators.

Representatives from Denmark: Hanna and Lise

Everybody in the leading group are responsible for getting lectures and making a good program. The members are also responsible for the work towards having lectures from Denmark, Norway, Sweden and at least one lecture from outside of Scandinavia.

Main responsibility for the program

- Nurse: Kajsa Källberg. *Following additionen and changes per 12/09-15: Due to Kajsa Källbergs absent Synnøve Granlien will take over the task.*
- Physiotherapist: Merethe Lia Johanson.

Congress day settings:

- Tuesday 9/5 2017: Nurse and physiotherapist together.
- Wednesday 10/05-17: ½ a day for physiotherapists and ½ a day for nurses and ½ united day together.
- Thursday 11/5-17: Doctors, nurses and physiotherapists together. We need three lectures. Chief phsycician Johnny Keller Aarhus is the chair of the working group.

The physiotherapist wants to keep a separate program for half a day due to good experience from the Stockholm congress.

Subject proposals for physiotherapist:

- Radiation therapy:

Subject proposals for nurses:

- Radiation therapy (ex. late side effects, skinproblems)
- Cancer support functions.

Radiation therapy:

Astrid Mortensen has suggested two speakers from radiation therapy department on Herlev Hospital. Hanna and Lise will be in contact with Astrid.

Cancer support function:

- The doctors want to have different work shops on the 8th of May. Birthe Hedegaard has suggested a visit to Heimdal could be suitable on this day.
- Birthe Hedegaard has suggested a conversation with a cancer patient and relatives. Hanna and Lise will contact Birthe.
- Hanna and Lise suggest the "Navigator project" which the anti-cancer NGO "Kræftens Bekæmpelse" has made.

By contacting the lectures

- A 20 minute lecture on English
- Short abstract on English
- The travel fees and one night at a hotel will be paid for.
- The lectures cannot be paid for

Professional presentations

- *"Experiences from my observation days in Oslo University Hospital"* L. Stridh, Lund.
- *"Mapping and advice patients in rehabilitation how to find new goals"* A. Lekven, Stavarn.
- *"Sarcoma patients' and health personnel's perspectives on the processing of individual genetic research information: An etical, legal, health economics and anthropological study (NoSarC – ELSA). S. Granlien, Oslo.*
- *"Brochure by patients with fibromatose"* H. Fuglø og L. Petersen, Copenhagen. **Cancelled.**
- *"Report from nurse education day"* at CTOS 6th of November 2015 L.Våde, Oslo.
- *"Rehabilitation after ortopedic cancer surgery" – a pilot project"* M. Lia Johansen, Oslo.

Tuesday the 1st of December 2015 at 09:00 -11:00 am

WEB-site:

Lotta and Merethe are WEB-masters. Lotta scrutinize the website: www.ssg-nurses-physiotherapists.org. It was discussed what has to change to make the website more user friendly and usable also whether the front page should be changed to look similar to this website: www.sarkomforum.no

The bookmark which Hanna and Lise are preparing for printing can hopefully make the website more wellknown. The bookmark can be distributed to personnel, patients and relatives. One person from the leading group in each country will be responsible for the distribution of the bookmarks to the different sarcoma centres. The logo on the bookmark should not be "Kulemanden" as agreed at the last work meeting, but the SSG logo.

Projects:

Nurse meeting at CTOS

- In the future the nurse meeting at CTOS congress will be in "*Scandinavian Sarcoma Group for Nurses and Physiotherapist*" auspices.
- The chosen in the working group are: Lotta Våde, Stine Næss, Anne-Lise Salbu, Norway and Annica Petterson, Sweden.
- At the last meeting the 6th of November 2015 in Salt Lake City, U.S.A there were 39 participants. Next congress will be in November 2016 in Lisbon, Portugal and in November 2017 in Maui, Hawaii.

Patient information:

Lotta and Stine have started this work.

Fibromatosis: Hanna and Lise have started the fibromatose (patient guidance) but the treatment is being changed therefore further work on the fibromatose will wait.

G.I.S.T.: Astrid Mortensen has sent some information to Lotta Våde.

Rotation plasty: In the future the meeting regarding rotation plasty project will be in "Scandinavian Sarcoma Group for Nurses and Physiotherapists" auspices. There have been 6-8 patients present beside their relatives. Last time 14/9-2015 there were participants from Norway, Sweden and Denmark. The different ages where from age 10 to age 27. Most of them where around age 20-27 years.

The chosen in the working group are: Lotta Våde and Merethe Lia Johanson, Norway. Kajsa Källberg and Annica Petterson, Sweden. There is a desire to get a representative from Denmark in the working group. Hanna and Lise take the assignment to find someone possible interested.

Next work meeting is the 5th - 6th of December in Malmö, Sweden.

Next congress is at 9th – 11th of May 2017 in Aarhus, Denmark.

Because of the **10 year anniversary** of "Scandinavian Sarcoma Group for Nurses and Physiotherapists" which was found in 2007 Bergen, Norway Hanna and Lise want to make a "Anniversary Magazine". Everybody is more than welcome to send pictures and fun memories from the past years.

Joint forum with doctors:

As head of chair in our leading group Lotta made a summary from the work meeting.