

Summary from the” 7th Working Group Meeting of the Scandinavian Sarcoma Group for Nurses and Physiotherapists” 3 - 4 February, 2014

Place: World Trade Center, Malmö, Sweden.

Present:

- From Norway: Charlott Våde, Synnøve Granlien, Aina Hollekim Lekven, Merethe Lia Johansen, Lisbet Høiland and Anne-Lise Salbu.
- From Sweden: Annica Petterson, Linda Stridh, Svetlana Mårtensson and Kajsa Källberg.
- From Denmark: Lise Ingeman Petersen, Regina Uhre Hansen, Hanna Maria Fuglø and Astrid Østergaard Mortensen.

Introduction by: Hanna Maria Fuglø.

Monday 3 February, 2014 at 13:00-18:00 p.m.

Opening speech by Lotta about a clearer objective for “Scandinavian Sarcoma Group for Nurses and Physiotherapists” and being active in different projects. How to seek financial support in “Scandinavian Sarcoma Group for Nurses and Physiotherapists”? Synnøve Granlien gives a short talk about visions and that development is a continuous process and about co-operation and interest.

Status from Norway:

Both Oslo and Bergen have held ”Den store kule dagen”.

Oslo: Many patients and relatives are participating (about 250) in the events. This is the fourth year ”Den store kuledagen” is arranged in Oslo which have given more experience in arranging this initiative. Theme nights are arranged once a year for employees. There have been 160 participants from different fan groups. Last theme night content: Mom, dad and sister spoke about the loss of a brother/son and a priest spoke about how to use your self without burning out. Seriousness and laughter. The Patient association was participating and had a stand. Theme night was sponsored with about 40.000 kr.

Physiotherapist students: Merete has taught physiotherapist students at school for 6 hours about cancer, and one of those hours about sarcoma. Merethe wish it will be a permanent part of the education.

Nurse students: Lotta has educated nurse students at nursing school about sarcomas.

Bergen: There has been "Den store kuledagen" in September 2013. Around 70-90 participated. Among other did a former patient talked about his experience.

Trondheim: Merethe has been in Trondheim and informed the staff on how "Den store kuledagen" is being held in Oslo.

Status from Sweden:

Lund: The first sarcoma day in Lund is planned for march 2015. Lotta has been there and informed the staff on how "Den store kule dagen" is held in Oslo.

Stockholm: There have been a "Den store knöldagen" in Stockholm in 2013.

Status from Denmark:

The "Danish Forum for Nurses, Radiografer, Fysioterapeuter og Ergoterapeuter" was established in Denmark the 8/1-2014. The purpose of the forum is: Networking, exchange of experience, collecting knowledge and arranging meetings with professional substance. In the steering group the following professional groups are represented: nurses, physiotherapist and occupational therapists. There are employees from Aarhus University hospital, Odense University hospital, Herlev hospital and Rigshospitalet.

Current plans:

There are plans for arranging a day with professional content for the members the second Wednesday in January 2015 at Rigshospitalet in Copenhagen and to create a WEB page for the group.

Status from Finland:

Unfortunately there are no representatives from Finland in the steering committee. Synnøve has contacted a Finnish physiotherapist and it is agreed that Synnøve will send these minutes to the physiotherapist.

Steering committee:

A speech about expectations to the members in the steering committee and the purpose of the forum is:

- Co-operation between countries.
- Inspire other nurses and physiotherapists who work with sarcoma patients.
- Collect new knowledge and be inspired.
- Become better at giving feed-back at mail to each other.
- Meetings can possibly also be held via SKYPE or similar ways. Arrangement: Hanna will go through the possibilities/finances. We aim to gather once a year this way before next annual meeting in Stockholm in May 2015. A meeting can be held at a conference room near Kastrup Airport in Denmark as an alternative.

There was a discussion about finances and who is responsible for sponsors in each country.

Denmark: Agreement: Lise, Regina and Astrid take responsibility for applying for financial support.

Norway: Agreement: Synnøve has experience in applying for financial support and will send her material to Lise, Regina and Astrid. If sponsors want to hold an oration it shall be arranged with Lotta.

Sweden: No agreement about who is responsible for sponsors in Sweden. Agreement: Synnøve will contact Helen Lersedal about where to get sponsors.

Finances:

Anne-Lise tells about the finances in "Scandinavian Sarcoma Group for Nurses and Physiotherapists". The company "Smart-Fish" who participated in the congress in Helsinki, Finland in October 2013 has still not paid the agreed amount.

As an example its possible to seek financial support to cover travel, conference charges and work meetings.

Project expenses: We will speak about funds to seek. Agreement: Hanna will search for funds which support projects across countries.

Agreement: As regards payment to lectures at the conference in May 2015, Lotta will contact SSG and find a solution.

WEB page:

Merethe and Lotta are responsible for the web page. Material or amendments should be send to them. The web page is primarily ment for employees only.

New material for the website. Its agreed that Hanna:

- Elaborates information concerning "Danish Sarcoma Forum for nurses, radiographers, physiotherapists and occupational therapists"
- Send links: "*Pakkeforløb for sarkomer i knogle og bløddede, Kræftplan III*", "*Forløbsprogram for rehabilitering og palliation i forbindelse med kræft*" and "*Opfølgningsprogram for sarkomer i knogle og bløddede*" when the program is accepted. Also a link to "*Lifestyle and sickness*" from Rigshospitalet intranet.

Facebook:

Lise asks if a facebook group for steering committee should be established. Pros and cons are being discussed and it is decided not to establish one.

Scandinavian Sarcoma Group – annual meeting, Stockholm, May 2015:

Physiotherapist day:

Experience tells that there are only a few physio – and occupational therapists that participate in the annual meeting for ”Scandinavian Sarcoma Group for Nurses and Physiotherapists”. It’s discussed how to attract these and it is decided to arrange an entire day focusing only upon physio – and occupational therapists and do so on the first day (Wednesday) from 10 am. – 6 pm. Thursday and Friday will be held together with nurses.

Physiotherapists who work in the municipality and rehabilitation centers could also be interested in participating and not only the ones who work at the hospitals. In the Norwegian national trade union for physiotherapist the physiotherapists are also registered under oncology/palliation. Agreement: steering committee from Denmark and Sweden are requested to ascertain how the physio- and occupational therapists are registered and attempt to liaise. Report back to Merethe at mail: merej@ous-hf.no before 2 April 2014.

Arrangement of work concerning SSG-annual meeting:

- There is a local committee in Stockholm: Helen Leredal and Lilian Smedberg.
- Branch coordinator: Lotta, Merethe and Helen Leredal.

1) Subject proposal for physiotherapists:

- Youth and motivation.
- Exercise and cancer. Body and cancer. Agreement: Merethe contacts Morten Queist, Physiotherapist from Denmark.

2) Subject proposal for nurses: (three themes are needed).

- Sexuality.
- G.I.S.T. retroperitoneal/abdominal and gynaecological sarcomas.
- Young/adults with sarcomas.

- Treatment at the dentist. Agreement: Regina contacts the dentist.

Agreement: Lotta asks Helen if there are any speakers in Sweden to contact.

3) Subject proposal collaborating with doctors:

- Rehabilitation by Lise Bjerrum, cancer rehabilitation nurse, Rigshospitalet. Agreement: Hanna takes contact.
- R.E.S.P.E.C.T. by Hanne Bækgård Larsen.

Professional contribution

- "Status of rehabilitation for patients with bone- and soft tissue sarcoma", by Hanna Maria Fuglø and Lise Ingeman Petersen, Rigshospitalet. Rigshospitalets preparations to rehabilitation. A follow up program on bone – and soft tissue sarcomas is expected to be accepted and implemented by spring 2014.
- "Patient Progress" by Astrid Ø. Mortensen and Regina Uhre Hansen, Herlev Hospital will be left out because of structure rearrangement in the ward.
- "Nursing Consultations for Sarcoma Patients - Out Patient Department OUS- Radiumhospitalet – is this the future" by Synnøve Granlien. The Norwegian Nurse Association is in favor of nurse appointments. The doctor visits the patient at the nurse appointment. Assignment examples: phone contact, conversation before and after doctor appointment, wound changes, clinical controls (example: superficial sarcoma) about 1½ hour is set aside for each visit.
- "How to maintain motivation for treatment for a young adult with osteosarcoma – a case" by Lotta Våde, Radiumhospitalet. Many small things that together give a solution.
- "Physiotherapy to sarcoma patients in a palliative setting", by Merethe Lia Johansen, Radiumhospitalet. Patients needs. Not taking hope from the patients. Never talk about: when you get well, never promise anything, never speak about "in 10 years".

- ”Challenges in the collaboration with the patient and relatives – a patient case” by Lisbet Høiland. A young boy (teenager) who places the agenda and the mother (divorced) supporting him. The mother’s way to handle / (lack of) care for the younger sibling.

Tuesday 4 february, 2014 at 09:00 am. – 12:30 pm.

As chairman of our working group Lotta is making a summary from the meeting with the chairmen in the other working groups in the SSG setting that were held Thursday afternoon the 3 of February 2014.

Synnøve and Lotta: Members from Denmark in the steering committee are invited to attend in ”Den store kuledagen” which is held in Oslo the 5-6 September 2014 (Friday and Saturday) . The aim is to get inspiration and preparation to possibly arrange a similar day in Denmark in 2015. The Norwegian patient union for sarcoma patients is a result of ”Den store kuledagen”.

Synnøve or Lotta will send material regarding ”Den store kuledagen” to one of the Danish members of the steering committee.

Common projects across borders:

It is decided to write the committees name on ”Scandinavian Sarcoma Group for Nurses and Physiotherapists” material from common projects, and in addition the logo ”Kulemanden” will be placed in the different countries flags.

Patient information (agreement on division):

- Osteogenic sarcomas (work in progress): Synnøve and Lotta
- Desmoid fibromatosis: Lise and Hanna.
- G.I.S.T: Regina and Astrid.

Web site adress for sarcoma patients:

It's agreed that Hanna and Lise will make a flyer and a book mark with relevant web sites.

Members of the steering committee can also suggest relevant webpages, Example:

- www.sarcoma-patients.eu (SPAEN: European society for sarcoma patients)
- www.sarkom.no

Purpose with "Scandinavian Sarcoma Group for Nurses and Physiotherapists":

Go through the purpose with "Scandinavian Sarcoma Group for Nurses and Physiotherapists":

Common forum with the doctors:

Lotta make a summary from the meeting as chairman of our working party