

Work meeting of "Scandinavian Sarcoma Group for Nurses and Physiotherapists" in World Trade Center, Malmö, Sweden, 5th – 6th of December 2016

Referent: Hanna Maria Fuglø

Present from the leading group

Norway: Synnøve Granlien; Lisbeth Utne Høiland; Stine Næss; Charlott (Lotta) Marie Våde; Aina Lekven; Merethe Lia Johanson and Anne-Lise Salbu.

Sweden: Annica Petterson and Linda Stridh.

Denmark: Lise Ingeman Petersen and Hanna Maria Fuglø.

Other participants present: Marit Eversen, from Norway.

Absent from the leading group:

Denmark: Astrid Mortensen and Marie Petersen.

Sweden: Käjsa Källberg.

Monday 5th of December 2016 13.30 – 1800 o'clock

Chair work

Find out who are willing to continue in "*Scandinavia Sarcoma Group for Nurses and Physiotherapists*" after the next meeting in September 2017.

Find out how the future of "*Scandinavia Sarcoma Group for Nurses and Physiotherapists*" should be.

There was a voting in the SSG chair where Lotta whom was the representative of the nurses and physiotherapist unfortunately did not get chosen. Next voting will be in two years. In the meantime, the future of "*Scandinavia Sarcoma Group for Nurses and Physiotherapists*" should be considered with demands and wishes to an improved teamwork with the doctors as key concepts.

Important:

Henceforth will our work meetings be open for everyone who wish to join, contrary to previously where the work meeting only was available for members of the leading group.

Henceforward shall only members of SSG be entitled to vote. Enrolment forms are available on the SSG homepage.

Economy:

Anne-Lise Salbu the treasurer will go through the account of “*Scandinavia Sarcoma Group for Nurses and Physiotherapists*”.

The price of two rented promises of the congress in Stockholm Maj 2015 was 59.593 SEK and not noted in the summary of the work meeting in December 2015 since that price (34.965 DKK) was noted without value-added-tax.

SSG-for Nurses and Physiotherapists congress in Aarhus 20-22 of September 2017:

The congress is postponed from 9-11th of may 2017 to 20-22nd of September 2017. The schedule of Wednesday consisting of work-shops are in place. The last two appointments on the program of Thursday and Friday will be arranged. Simultaneously will the contact to the last two speakers be appointed.

Synnøve Granlien has been chairwoman of the working group concerning planning of the congress which should be hold in Aarhus 2017. Due to massive burden of labour at her work, Synnøve have wanted to pass on this task to Lotta Våde, whom became responsible of this task in autumn 2016.

Lise and Hanna will write 10-year anniversary book and therefore request pictures and experiences from other participants.

To delegate the message of the congress:

- Making flyers as advertisement for our congress which should look like the ones of the Lisbon congress.
- Establish contact persons on the various sarcoma centre in Scandinavia. 4 in Norway (Bergen, Oslo, Tromsø and Trondheim), 5 in Sweden (Goteborg, Lund, Stockholm, Linkjølbing and Umeå) and 2 in Denmark (Aarhus and Copenhagen/Herlev).
- Contact to islandic and finish nurses is desired. Lotta will be responsible for initiating the contact.

Status from Norway

Bergen: Anne-Lise Salbu and Lisbeth Utne Høiland are working on a sarcoma book targeted too patients. Standardized discharge conversations.

Oslo: Stine Næss participated in a working group which produced guidelines for adolescents with cancer in hospital valid for the Oslo University hospital.

Lotta Våde, Stine Næss and Merethe Lia Johansen has been involved in organizing “Den store kuledagen” for patients and relatives, which was held in this autumn. 250 people participated.

A sarcoma day for personnel has been arranged.

A meeting between 15 – 20 finished treated patients has been held.

A movie has been made regarding sarcoma. As of right now there is Norwegian and English subtitles which also can be translated to Danish and Swedish.

Lotta Våde and Stine Næss was in the working group which arranged nursing day in CTOS, Lisbon, Portugal. There were ca 50 participants.

There have been a sarcoma day in Trondheim which Lotta and Stine has participated in together with two American nurses from M.D. Anderson, Houston Texas.

Two American nurses from M.D. Anderson, Houston, Texas has been on a study visit in Oslo

Merethe Lia Johanson has taught on Norway’s School of physical training (Idrætshøjskole) regarding knee prosthesis Merethe has arranged physiotherapist sessions for SSG. Nurses and physiotherapists congress in September 2017.

Kysthospitalet: Aina Lekven has arranged sarcoma weeks for patients. It has been held a week x 2.

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Status from Sweden

Lund: Linda Stridh have participated in having a sarcoma day for patients. 160 patients participated.

Umeå: Annica Petterson participated in nurse day in CTOS, Lisbon, Portugal in November 2016. At the department which she work at there have been a reorganization where there now work three contact nurses to the sarcoma patients. A patient day for sarcoma patients are being arranged.

Status from Denmark

Copenhagen: Lise Ingemann Petersen and Hanna Maria Fuglø have spent a lot of time together with nurse Birthe Hedegård from Aarhus arranged the next “*Scandinavian Sarcoma Group for Nurses and Physiotherapists*” congress. There have also been spend a lot of time seeking sponsorship.

”*Scandinavian Sarcoma Group for Nurses and Physiotherapists*” bookmark has been made and handed out to patients which are giving a malign diagnosis.

Danish Sarcoma group arranges an annual meeting for personnel the second Wednesday in January each year. Some of the program is joined for doctors, nurses and physiotherapists. The annual meetings should be held sequentially at Aarhus, Herlev and Copenhagen and be arranged by the personnel at the hospital. Last annual meeting was in Aarhus and the next will be at Herlev Hospital (suggested themes are chemotherapy and radiation therapy to the sarcoma patients.)

Professional program:

- No SarC – A national study of gene mutations in sarcomas. S Næss, Oslo.
- Standardised care process for subcutaneous and musculo-skeletal sarcoma in Sweden. A Petterson, Umeå.
- Life with neurofibromatosis – transforming to malignant disease. S Granlien, Oslo.
- Report from ”Sarkomdagen” in Lund September 24, 2016. E-M Olofsson, Lund.
- Follow-up of the closest relatives to the patient who has died. L Utne Høiland, Bergen.
- Physical activity and cancer. M Lia Johansen, Oslo.
- Patients with soft tissue sarcoma and quality of life. H M Fuglø, Copenhagen.

6th of December 2016 0900 -1100 o'clock

Lise Petersen talks about a new Danish book for patients concerning amputation which is free and can be downloaded through “*Amputationsforeningen i Danmark*”. It has been agreed that the link to the web page will be placed on the webpage of “*Scandinavian Sarcoma Group for Nurses and Physiotherapists*”. Lise will send the link to Lotta.

Marit Eversen and Aina Lekven talks about a patient case from the rehabilitation centre - Kysthospitalet where they employed.

Web page

The webpage will continue in its present form. Lotta Våde and Merethe Lia Johanson are web masters.

Future projects

CTOS – the nursing day on Maui, Hawaii 8th – 11th of November 2017. Lotta Våde, Stine Næss and to nurses from M.D. Anderson of Houston, Texas are arrangers. The theme are radiation treatment and young people with sarcomas. There is a budget for hiring a guest speaker. Presentations should last 20-30 minutes.

Lotta has made material for patients regarding: Osteosarcoma, Ewing-sarcoma go GIST-tumours. This material is available using apps. Novartis are responsible for lay-out and graphics and can be used for translation to other languages. (Please note that there is a “Children cancer” app available in Sweden which can be used with great success.)

The use of rotation plastic is paused. The use have giving great outcome for earlier users.

Study visits:

Merethe Lia Johanson would like to visit different departments in Scandinavia.

Two nurses from Radium hospital in Oslo have been staying in Bologna, Italy for one week at a time over the last three years.

Two nurses from Radium hospital in Oslo have visited M.D. Anderson, Houston, Texas for one week in the child sarcoma department. A permanent agreement is trying to be made. Lotta Våde and Stine Næss will travel in may 2017 to M.D. Anderson, Houston to make a program for study visit and course which also can give points.

Important notice: Radium hospital in Oslo, Karolinska in Stockholm and Rigshospitalet in Copenhagen are all sister hospitals to M.D. Anderson in Houston, Texas.

”Store Kule dagen” in Denmark?

It has been discussed whether or not “Store Kule Dagen” should be held in Denmark. Lotta Våde and Stine Næss would like to be persons of resources. Lise Petersen and Hanna Fuglør would bring up the subject at the DSG meeting the 11 of January 2017.

Joint meeting with the doctors:

Lotta Våde, head of chair in our leading group, will present the summary from our work meeting.