

## Summary from the Working Group Meeting December 5-6, 2022 Malmö

### Nurses and Physiotherapists working group

We started with a board meeting during breakfast on Monday morning:

We decided to wind down the board for nurses and physiotherapist in the future and instead replace it with a working group, like the other professions in SSG have. This decision has to be discussed at an annual meeting and we plan to try having such a meeting next year probably through Teams. More information about this will thus be announced next year.

### Short summary of our presentations on the group meeting, Monday afternoon:

Stine from Radiumhospitalet, Norway, gave us a summary of the presentations they had at the 5th ISNAP meeting on CTOS in Vancouver, 2022.

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Marte Klafstad, Merethe Lia Johansen, Berit Hofset Larsen and 115 others like this

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The first ISNAP meeting was held in Salt Lake City in 2014 and are now an accepted part of the CTOS meeting.

The main purpose of the ISNAP meeting is to share knowledge and to create network and collaboration. As one nurse said at the first ISNAP meeting: “Sarcoma patients often feel alone as they have been affected by a rare disease. Nurses who work with sarcoma patients feel equally alone”.

Kenneth and Synne from Radiumhospitalet, Norway, told us about their project in the A8 ward, Happy Walls. With the help of wallpaper, they have transformed 3 worn out rooms into significantly more hospitable ones.





The 3 rooms are called the Oslo room, the balloon room and the boat room and are for the AYA patients. The AYA patients are the once who has chosen the wallpaper. Happy walls have brought about a big change for a low cost and increased well being for the AYA patients during their stay at the A8 ward.





Hilde from Radiumhospitalet, Norway held a longer version of the presentation she held at the CTOS meeting, There's no place like home. Nobody wants to be at the hospital.

In Radiumhospitalet they have started with home chemotherapy. They have given it to 15 AYA patients in a pilot. The median age was 16 yrs, and the median was 5 cycles per patient. Totally 67 chemotherapy cycles were administered. The chemotherapy regimens given at home were, High-dose Methotrexate, Doxorubicin (48h), Etoposid/Ifosfamid and High-dose Ifosfamid.

Their experiences so far are only positive. The complication rates were low and patients' well-being seems to be improved. A prospective study will start recruitment soon.

Annica from Norrlands Universitetssjukhus, Sweden, talked about the work of developing "my care plan" for bone and soft tissue sarcomas. My care plan contains nationally produced information to patients with sarcomas. The plan follows the patient during investigation, diagnosis, treatment and follow-up. It covers everything from procedures, self-care advice to rehabilitation. The patients can get the care plan both digital and on paper. The digital version is on 1177, which is a national platform for health care in Sweden. The main purpose with a nationally produced care plan is to increase equality and improve the quality of the information we give to our sarcoma patients.

There has been a great lack of good written information for sarcoma patients in Sweden and my care plan will fill this huge gap. A nationally group has recently been formed and is now beginning the work of producing my care plan for abdominal sarcomas as well.

Link to my care plan: [Nationell Min vårdplan skelett- och mjukdelssarkom - RCC \(cancercentrum.se\)](https://cancercentrum.se/nationell-min-vardplan-skelett-och-mjukdelssarkom)

Link to regimbiblioteket: [Skelett- och mjukdelssarkom - RCC Kunskapsbanken \(cancercentrum.se\)](https://cancercentrum.se/skelett-och-mjukdelssarkom-kunskapsbanken)

Merethe from Radiumhospitalet, Norway, showed us her first result from her study MAGUS. *Muscle strength characteristics following megaprosthesis knee reconstruction for bone sarcoma.*

If you want to hear more of these results, contact Merethe Lia Johansen. Data from the study have not yet been published.

We had a very good meeting with good discussions. Many interesting presentations which led to plans for collaboration among us. We had 18 participating nurses and physiotherapists on our meeting. Which is some kind of record for the working group meeting.

Sadly we had no participants from Finland or Iceland and only one from Denmark. This shows that we need support, to get more Scandinavian Sarcoma centers to send nurses and physiotherapists, and not just physicians to these meetings.

In the end of our meeting we also formed a program committee for the SSG Congress in Gothenburg, 2024.

Annica Pettersson

Secretary of the Scandinavian Sarcoma Group Nurses and Physiotherapists