Report Orthopedic Working Group

Evaluation of photochemical internalization for treatment of sarcomas ï a possible new treatment modality? *Ole-Jacob Norum, DNR Oslo*

> *The concept is based on the ability of red light to facilitate uptake of Bleomycin trough the cell wall when the cell wall is primed by a substance sensitive to light. There seems to be penetration of light at least to a depth of 3 cm and the process could be effective as local treatment of superficial but poorly circumscribed sarcomas or as adjuvant therapy to surgery in such situations. The concept was described as experimental and more studies at phase I level are needed. Possible study designs were discussed.*

Ewing sarcoma of the axial skeleton. Changing therapy preferences? *Asle Hesla/Otte Brosjö, KS*

> *There is a growing acceptance of tumor size as an especially important risk factor in pelvic/sacral localized Ewing sarcoma. Some centers have suggested that as benefit of surgery compared to radiotherapy is uncertain, and functional side-effects are far more serious, small tumors should be treated with radiotherapy alone when surgery would imply loss of the hip joint. Based on data from the SSG central register, Asle Hesla has noted a better prognosis for small sacral tumors compared with pelvic ones. This was so even if pelvic tumors had much more surgery. A thesis project on these questions is in preparation.*

Disappearing Spine. A diagnostic and therapeutic Challenge. *Björn Gunterberg, Sahlgrenska*

> *An overview of this rare and peculiar disease was given. The reasons for the disappearance are unknown and a neoplastic process does not seem to be involved. No therapeutic measures are effective, but orthopedic reconstructive surgery might be necessary.*

Hereditary neoplasia in Orthopaedic Oncology. Could specific follow-up procedures of patients at risk influence prognosis? Discussion. *Fredrick Vult von Steyern, Lund*

> *Most centers informed patients at risk of their condition and that change of symptoms from a known neurofibroma or exostosis should lead to contact with the tumor center. Both MRI and scint screening were in use.*

Isolated limb perfusion in Gothenburg *Peter Berg, Sahlgrenska*

> *The method was used against selected large sarcomas and subsequent surgery was more effective. More than 50 patients had been operated.*

Between the talks, many cases (12 from Iceland!) were displayed and discussed in detail.

Fredrik Vult von Steyern, Lund was approved as the next chairman of the orthopedic working group.

Report from the SSG central register coordinator meeting.

All coordinators were separately called for the meeting as decisions concerning institutions that is not reporting regularly or consistently were announced.

It was decided that 351 records with missing histology, not supplemented after inquiry, and 337 records with missing hospital should be deleted.

One or more basic variables missing:

	2008	2010	
Oslo	635	449	
KS	323	92	
Göteborg	317	339	
Lund	236	168	
Helsinki	191	191	
Trondheim	121	121	
Umeå	79	135	
Tampere	32	38	
Linköping	19	25	
Bergen	19	8	
Åbo	39	39	
Total	1958 / 9142	1779/11030	

The improvements since 2008 were noted and further measures to supplement the records were planned.

The data survey showed that Gothenburg and Umeå had made extraordinary efforts to complete their data sets.

Seven institutions can now be assumed to have reported consistently during the last 20 years. They can prove that they are following their patients according to SSG central register guide lines and most report more than 75% of patients with complete follow-up at any time.

Helsinki, Tampere, Åbo, Trondheim, Tromsø and Ullevål have not been reporting for several years and have not responded to register inquiry. In addition some of the institutions have not been reporting consistently in the past, giving rise to concerns about bias in the selection of patients chosen for report. At present the registry can not recommend the use of data from these institutions in studies based on data from the register only. Data from these institutions will therefore be placed in a ñquarantineò department of the register and no longer be included in register overviews. Their records will neither be checked for missing data nor inconsistencies during test runs and the coordinators will not be notified during inquiries.

There is information that some institutions may commence reporting again in connection with specific studies. This will be welcomed and an institution could easily be re-entered into the register proper when data are completed.

One more round of inquires will be done before the final ñquarantineò placement.

The register now contains reliable, close to population based, data on about 10.000 patients. This might be enough patients to answer most demographic and epidemiological questions that could be asked in a retrospective register study.

It is important however, that the register continue to get population based data on all sarcomas in order to fulfill the ambition to survey the quality of sarcoma treatment in the Nordic countries.

Not all tumor entities will need equal intense survey, however. In order to increase compliance, and reduce the workload of coordinators it was decided to discontinue the registration of:

Atypical lipomatous tumor/Liposarcoma grade I of the extremities and trunk wall

Aggressive fibromatosis

It was also agreed to discontinue the use of ñReason for deathò [DEATH4] as key variable as we were informed that the information contained in this variable could be supplied by statistical methods during analyses.

The Danish sarcoma group announced that they will join the SSG register. Transfer of data from Demark will be done as soon as technical challenges are solved.

Clement Trovik Dec 2010