

## **SSG Working group meeting Dec 2-4, 2012, Malmø Report from “Nurses & physiotherapists Group”**

### **Drinking restrictions for patients with Osteogen sarcoma receiving high dose Methotrexate (12g/m<sup>2</sup>)**

*L. Våde, Oslo*

A group from OUS - The Norwegian Radiumhospital has used Evidence-Based Practice to conclude on this issue. After a systematic search of literature this is the drinking restrictions recommended:

Oral intake:

Day 1. 600 ml (our 1-24)

Day 2. 1000 ml (our 24-48)

Day 3. 1000 ml (our 48-72)

Delayed secretion of MTX: No restrictions of oral intake

For more information about this work:



### **Treatment procedures for sarcoma patients**

*A. Lekven, Stavern*

SiV – Rehabilitation department, Kysthospitalet has during 2012 started to draw up treatment routines for rehabilitation for patients who has been treated for sarcomas. This work will be a quality assurance of the rehabilitation for those patients.

You can read more about Kysthospitalet here:

<http://www.sykehuset-vestfold.no/pasient/behandlinger/rehabilitering/rehabiliteringstilbud/kreftsykdommer/Sider/sarkom-rehabilitering-etter-behandling.aspx>

### **Activity week for patients with sarcomas**

*A. Lekven, Stavern*

In June 2012 SiV – Rehabilitation department, Kysthospitalet arranged an activity week for patients who were treated for sarcomas. Seven people participated. During this week the patients tried out new type of activities as, climbing and bicycling with protheses. They also had focus on conversation and supporting each other by sharing experiences. The activity week was a success and will be arranged again in 2013.

[http://www.sykehuset-vestfold.no/SiteCollectionDocuments/Brosjyrer/Brosjyre\\_Sarkom\\_05.pdf](http://www.sykehuset-vestfold.no/SiteCollectionDocuments/Brosjyrer/Brosjyre_Sarkom_05.pdf)

### **The start of ”Sarkomer”- a Norwegian patient organization**

*S. Granlien, Oslo*

Sarkomer was founded 1st October 2011. Sarkomer is a Norwegian patient organization for both current and former sarcoma patients and those in close relations with sarcoma patients.

Sarkomer is an organization that will contribute to;

1. The publishing and spreading of information about symptoms of sarcomas and to contribute to earlier accurate diagnosis and earlier start of treatment of sarcoma patients
2. The advocacy of patient rights and welfare of sarcoma patients
3. Former sarcoma patients helping sarcoma patients in coping with the disease

The organizations main goal and vision is therefore to raise awareness of sarcomas

You can read more about the organization here: [www.sarkomer.no](http://www.sarkomer.no)

### **Sarcoma awareness day – Norway**

*S. Granlien, Oslo*

Background: Frustration over meeting many patients with recently discovered sarcoma with a long time of symptoms and metastasis at the time of diagnosis. Lack of knowledge about sarcoma among G.P. and other healthcare professionals. Honouring sarcoma survivors and their relatives and organize a meeting together with the patient association, Sarkomer.

Purpose: Increased attention on sarcomas for health care personal and if possible decrease time from appointment with G.P. to diagnosis and start of treatment. Organize a possibility for sarcoma patient to meet, learn from and support each other.

Results: 120 G.P s, physiotherapists, nurses and other health care professionals participated at the conference of Sarcoma Awareness in Oslo 2012 and 60 persons participated at the same conference in Stavern this year.

250 sarcoma survivors and their relatives joined the evening event in Oslo, about 60 persons joined the event in Stavern.

Hopefully there will be arranged a Sarcoma awareness day in Sweden in 2013. The next Sarcoma awareness day in Norway, will be hold in Bergen in April 2013.

### **Exercising for patients with sarcomas**

*M. Lia Johansen, Oslo*

A lot of research shows that exercising prevent cancer, lately we also learned that exercising during treatment of cancer can increase survival and prevent recurrence. There is no research in this field of patients with sarcomas but there is no reason to believe that this group of patients is different than other cancer diagnoses.

The results from research shows us that we have to give the patients possibilities to exercise during treatment. In OUS - The Norwegian Radiumhospital M. Lia Johansen has organized a fitness room close to the ward for sarcoma patients. This fitness room is financed by private sponsors.

### **The 36th SSG Plenary meeting in Helsinki, October 9-11th**

*L. Våde, Oslo*

The program for Helsinki was looked over, a few small changes were made. The program is almost all set.