

Report from the SSG central register coordinators meeting

All listed coordinators were specifically called for the meeting.

They include:

Alvegård Thor, Lund
Bauer Henrik, Stockholm
Bergh Peter, Gothenburg
Vult von Steyern Fredrik, Lund
Åhlén Jan, Stockholm
Blomqvist Calle, Helsinki
Kivioja Aarne, Helsinki
Eriksson Sigvard, Gothenburg
Erlanson Martin, Umeå
Hall Kirsten Sundby, Oslo
Hesla Asle, Stockholm
Holmberg-Jørgensen Peter, Aarhus
Isaksen Vidar, Tromsø
Johansson Ingela, Umeå

Jonssón Haldor Jr, Reykjavik
Kalén Anders, Linköping
Knobel Heidi, Trondheim
Laitinen Minna, Tampere
Lausten Gunnar, Copenhagen
Lindholm Paula, Åbo
Löfvenberg Rickard, Umeå
Olofsson Eva-Mari, Lund
Rydholm Anders, Lund
Smeland Eivind, Tromsø
Styring Emelie, Lund
Trovik Clement, Bergen
Zaikova Olga, Oslo

A draft version of the annual accrual report has been made by Olga Zaikova, Oslo and Emelie Styring, Lund. The report was presented, and it was agreed to continue the work based on similar amount of detail, and based on two years of accrual, the most recent year being 2009 in 2012.

There was a discussion on whether to present the annual report based on institutions or based on groups of institutions from each country. We found a general interest in presenting data based on individual institutions, both concerning accrual data and for treatment results. No formal decision has been made however; as there was interest in awaiting the experience of the large national Swedish and Norwegian arthroplasty registers. Due to government regulation, these registers are in the process of releasing comparative institutional treatment/result data to the public. Jonas Ranstam, a Lund based statistician, central to the arthroplasty process has agreed to summarize these experiences at the next working committee meeting in February 2014.

A decision is also pending on whether the annual report will be the only way of communicating data from the central register, outside scientific publications. A decision on this will greatly influence the scope and detail of the report and of the production process.

Two scientific projects have been approved for data release by the publication committee:

- **A study of epidemiology and outcome in chondrosarcoma**

Joachim Thorkildsen, M.B.C.h.B, dep. of orthopaedic surgery, Dr Olga Zaikova (MD, PhD) Dr Ole Jacob Norum (MD, PhD) professor Øyvind Bruland (MD, PhD), Norwegian Radium Hospital, Oslo University Hospital.

- **Soft tissue sarcoma in adolescents and young adults in Scandinavia**
Karin Papworth, MD, PhD, Senior Consultant Oncology, Beatrice Melin, Professor, Senior Consultant Oncology, Martin Erlanson, MD, PhD, Senior Consultant Oncology, Björn Tavelin, Statistician

Two further projects was approved for data release at the coordinators meeting:

- **Unplanned excision of *upper extremity* soft tissue sarcoma. Increased risk of local recurrence and poor outcome? A cohort study of patients from SSG register.** Toni-Karri Pakarinen, MD, PhD Minna Laitinen, MD, PhD Tampere University
- Extended validation of a prognostication system previously validated on 350 Patients from the Southern Sweden database and published:

[Br J Cancer](#). 2012 Mar 13;106(6):1076-82. doi: 10.1038/bjc.2012.48.Epub 2012 Feb 21.

A web-based prognostic tool for extremity and trunk wall soft tissue sarcomas and its external validation.

[Sampo M](#), [Tarkkanen M](#), [Tukiainen E](#), [Popov P](#), [Gustafson P](#), [Lundin M](#), [Böhling T](#), [Blomqvist C](#), [Lundin J](#)

It was decided to postpone the deadline for entering data eligible for the planned report on STS until May 1. 2013:

The Scandinavian Sarcoma group Central register.

6000 patients after 25 years of monitoring referral and treatment in Orthopaedic Soft Tissue Sarcoma.

Clement S. Trovik, Henrik C.F. Bauer, Kirsten Sundby Hall, Fredrik Vult von Steyern, Sigvart Eriksson, Ingela Johansson, Calle Blomqvist, Minna Laitinen, Anders Kalén, Haldór Jónsson, Elisabeth Johansson and Thor A. Alvegård.

It was also decided to expand the number of authors to an oncologist + an orthopaedic surgeon from each institution.

A similar 25 years of experience-project concerning about 2500 bone sarcomas in the Register was planned, and prime responsibility for this was accepted by the chondrosarcoma study group in Oslo, represented by Olga Zaikova.

Work on defining the variables in the Danish sarcoma register according to the values in the SSG register are progressing and data transfers are expected during 2013.

In 2012 inquiries concerning inconsistent data in the register were planned, but have not been concluded. Work will proceed in 2013 according to principles decided a year ago.

Professor Henrik Bauer, Karolinska Hospital, Stockholm was unanimously elected as chairman of the Central register.