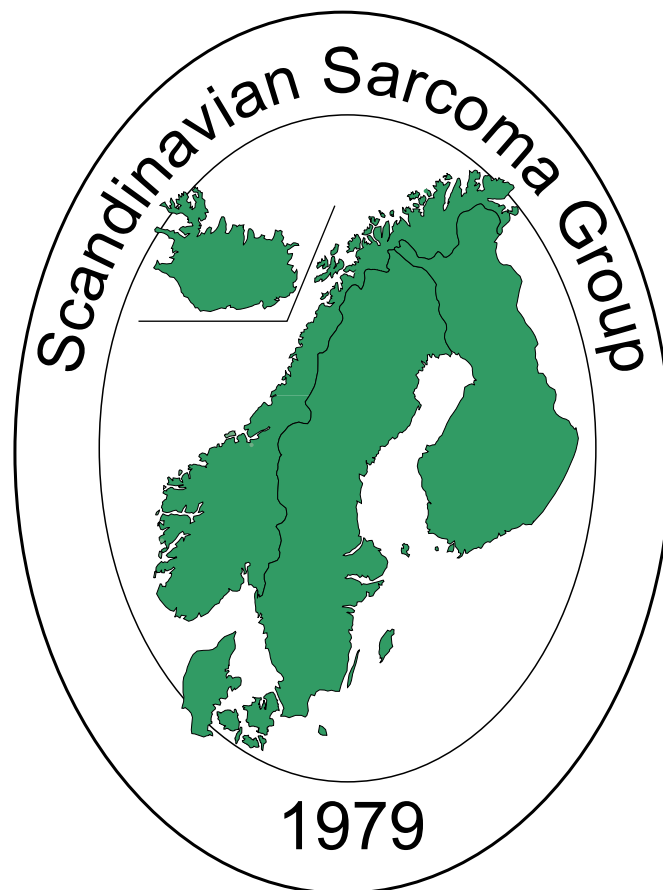


Scandinavian Sarcoma Group and  
Oncologic Center, Lund, Sweden

## SSG XVI

**Centralized registration of patients with  
surgically treated skeletal metastases**



*Started in April 2000  
Modified April 2002*

Scandinavian Sarcoma Group  
&  
Oncologic Center  
Lund, Sweden

## **Centralized registration of patients with surgically treated skeletal metastases**

### **SSG XVI**

A Scandinavian, regional, multicentric, prospective study for evaluation of treatment results and prognostic factors in patients with surgically treated skeletal non-spinal metastases by a central registration.

#### **Revision 26.06.02 for addendum to guidelines.**

In case of more than one surgically treated metastasis in the same operation you must decide which one of the metastasis is the clinically most important. The most important bone metastasis is registered in *the operation form* (in the database this operation will appear as number 1). The most important bone metastasis is not necessarily the largest bone metastasis. The operation of the other bone metastasis is registered on a separate *operation form* (in the database this will appear as operation number two)

In case of bone metastasis to both bones of a joint only the clinically most important bone metastasis is registered.

Complications or reoperations after total joint replacement or hemiprosthesis must refer to the registered operation independently of which of the bones caused the failure. However, if e.g. an intertrochanteric bone metastasis treated with a nail progress to acetabulum a new complete set of forms are needed.

On the follow up forms you must indicate which operated bone you refer to ( e.g. right femur). Only complications after first operation in each bone is registered.

Clinically follow up is registered only 6 weeks, 6 month and one year after the first operated bone.

Started in April 2000  
Modified April 2002

**Internet version**

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## Introduction and background

Skeletal metastasis is a dreaded complication in malignant disease. These metastases *per se* are seldom responsible for cancer mortality but often dramatically affect quality of life by causing pain, pathologic fracture, hypercalcemia, anemia and paraparesis. The precise incidence is unknown. It has been estimated that half of all patients with malignant disease will acquire metastases and half of these will arise in the skeleton. This is an increasing clinical problem in countries with an increasing proportion of elderly and with increasing survival times after cancer diagnosis.

During recent years, more attention has been directed towards improved palliative care for cancer patients with skeletal metastases. Radiotherapy remains the mainstay for painful skeletal metastases, but treatment with hormone therapy, chemotherapy and bisphosphonates are also important treatment modalities. The application of surgical treatment for pathologic fracture has increased dramatically.

There are no prospective randomized studies of surgical treatment for pathologic fracture. Current treatment is based on retrospective analyses of single institution experience. The reported series comprise heterogeneous patient populations regarding types of primary cancer, extent of the metastatic disease, and location of the lesions. Furthermore, some patients are treated for complete fracture while others will have prophylactic stabilization for what is considered an impending fracture.

The aim of surgical treatment is to achieve immediate restoration of function while alleviating pain. The surgeon must take into consideration that pathologic fractures often will not heal and that bone destruction may proceed. There remains uncertainty whether to choose osteosynthetic devices or endoprotheses in pathologic fractures of the humerus and the femur. Estimation of the risk for fracture through a bone destruction and indications for prophylactic surgical treatment remain unclear. The role of post-operative radiotherapy needs to be defined as radiation decreases the risk of local tumor progression but increases bone-healing complications.

The Scandinavian Sarcoma Group has since 1986 a well functioning registry of patients with primary skeletal and soft-tissue sarcomas in the Scandinavian countries as well as in Finland. With the aim to improve the surgical treatment of cancer patients with pathologic fractures the Skeletal Metastasis Group, a subgroup of the Surgery Group started the Skeletal Metastasis Registry in 1999. The aim was to create a database including all patients surgically treated at the involved sarcoma centers. Further aims of the registry are to provide a scientific basis for treatment recommendations and to provide participating departments a tool for quality assessment as measured in terms of reoperation rate, operation mortality and operation frequency of impending fractures. Criteria for inclusion consist of patients surgically treated for skeletal metastases excluding the spine. Presently 7 orthopedic oncology centers representing 4 countries is participating and the yearly accretion rate is approximately 120 patients.

## Organization

### The SSG skeletal metastasis group

*Johnny Keller* (chairman of the skeletal metastasis register)

Dept of Ortopedic Surgery  
Aarhus University Hospital  
8000 ÅRHUS C  
Denmark

*Peter Bergh*

Dept of Ortopedic Surgery  
Sahlgren University Hospital  
413 45 GOTHENBURG  
Sweden

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0407 OSLO  
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Dept of Ortopedic Surgery  
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0310 OSLO  
Norway

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Dept of Ortopedic Surgery  
Haukeland University Hospital  
NO-5021 BERGEN  
Norway

### The following Tumor Centers have to the date of 1<sup>st</sup> March 2002 provided data to the Skeletal Metastasis Registry

Dept of Ortopedic Surgery  
Aarhus University Hospital  
Aarhus

Dept of Ortopedic Surgery  
Sahlgren University Hospital  
Gothenburg

Dept of Ortopedic Surgery  
University Hospital  
Tampere

Dept of Ortopedic Surgery  
Ullevål Hospital  
Oslo

Dept of Ortopedic Surgery  
Karolinska University Hospital  
Stockholm

Dept of Ortopedic Surgery  
Lund University Hospital  
Lund

Dept of Ortopedic Surgery  
The Norwegian Radium Hospital  
Oslo

Dept of Ortopedic Surgery  
Haukeland University Hospital  
Bergen

*Printing and distribution of the final protocol will be arranged by the Oncologic Center in Lund.*

*The SSG XVI protocol will be activated of April 1, 2002*

*Lund March 31, 2002*

## Guidelines for completion of forms

Some patients need surgical treatment for more than one pathological fracture. In these cases a new set of forms has to be completed and each operated fracture is considered as a “new patient”. A failed reconstruction of a pathological fracture that necessitates surgical treatment is considered as a reoperation. In this case only a follow-up form has to be completed.

### A. Primary form

#### *Diagnosis date*

Date of diagnosis of the primary tumor. If in doubt, use the middle of the year or the month (e.g first of July, 15<sup>th</sup> of March).

#### *Radiotherapy*

Data concerning date and dose are not compulsory.

#### *Haemoglobin at referral*

Haemoglobin in millimol/l or gram/l.

#### *Pain and function*

Refers to the time period before operation. In case of a diaphyseal fracture, the time period of interest is just before the fracture.

#### *Status at referral (in case of fracture: just before the fracture)*

If the fracture had occurred 1 month or more before referral, the Karnofsky performance should be evaluated at referral.

#### *Tokuhashi score*

Unless all 5 questions can be answered, the total Tokuhashi score may not be completed.

#### *Karnofsky score*

From the above Karnofsky performance.

#### *Total number of skeletal metastasis*

The patients must have a bone scan in case of less than 4 known metastases, *otherwise the question can not be answered.*

#### *Organ/pulmonary metastasis*

Ultrasound or CT of the abdomen as well as a chest x-ray are mandatory, *otherwise the question can not be answered.*

#### *Primary tumor*

There is no demand of investigating the primary tumor.

## **B. Operation form**

### *Bone*

The operatively treated bone.

### *Localization in the operated bone: site of fracture or major destruction*

Only one localization may be chosen. This question may be neglected in pelvic fractures.

### *Localization in the operated bone: addition or minor destruction in this part*

Several locations can be chosen.

*Operation method:* reconstruction nail is considered a type of intramedullary nail with connecting hip screws.

*Operative strategy “surgical margin”:* a cemented prosthesis should be registered as “curettage & cement”.

## **C. Follow up form**

Should be completed preferably at 6 weeks, at 6 months and at 12 months after 1st surgery or in case of reoperation or death.

### *Cytology and histology report numbers*

Not compulsory.

### *Karnofsky performance*

Should be the last time period (the last 1 or 2 weeks).

## **Publication**

Rules for publication corresponds with those of the Scandinavian Sarcoma Registry.

Ideas for publication (including authors, possible magazines and presentation in meetings) are discussed in the skeletal metastasis group at the meetings or by e-mail. The skeletal metastasis group decides publications.

The Scandinavian Sarcoma Group Experience must be included in the title of papers and abstracts  
All departments with included patients must be mentioned in the paper.

At submission the paper must be sent to the publication ombudsman of SSG and the chairman of the skeletal metastasis group. The authors are responsible for the papers.

Centralized registration of patients with surgically treated skeletal metastases. **SSG XVI**

Name (first & family name)  
Date of birth (day, month, year)

**PRIMARY FORM** (complete *before* operation) **1**

Send to: SSG secretariat  
Regional Tumour Registry  
Lund University Hospital  
SE-221 85 LUND  
Sweden

Hospital and department

Doctor

Sex

Male  Female

Date of diagnosis Day | | | | | Month | | | | | Year | | | | |

Date of first bone metastasis Day | | | | | Month | | | | | Year | | | | |

Primary tumor

Breast  Lung  Prostate  Kidney  Uterus  Myeloma

Lymphoma  Unknown  Other, specify;

Has the op. met. been previously radiated?

No  Yes  Not known

Date: Day | | | | | Month | | | | | Year | | | | | (date and dose, not compulsory)  
Dose: | | | | | Gy × | | | | | days

Hgb at referral: (not compulsory) | | | | | mmol/l | | | | | g/l

**Pain & function: At operation or just before fracture**

Pain from destruction site?

No  Load related  Pain at rest  Load related and pain at rest  Not known

If pain, for how many days before op? | | | | | days  Not known

Pain

No  Light  Moderate  Strong  Severe  Not known

Analgesics

No  Peripheral/light  Opioids  Not known

Mobility

Walking without crutches  Walking with crutches  Wheel chair  Confined to bed  Not known

**STATUS at referral** (in case of fracture: just before the fracture)

**Karnofsky performance\***

Able to carry out normal activities - **good**  100%  90%  80%

Unable to work, able to self care - **moderate**  70%  60%  50%

Unable to care for himself - **poor**  40%  30%  20%  10%

**Tokuhashi score:** (Not compulsory)

Karnofsky score

poor = 0, moderate = 1, good = 2

Total number of skeletal met

≥4 = 0, 2-3 = 1, 1 = 2, not known (bone scintigraphy if less than 4) = 3

Pulmonary / abdominal metastasis (chest x-ray and CT or ultrasound of abdomen)

not removable = 0, removable = 1, no metastasis = 2, not known = 3

Primary tumor

lung, liver, pancreas = 0, kidney, breast, prostate, uterus, other, unknown = 1, thyroidea, lymphoma, myeloma = 2

Fracture

present = 0, urgent = 2

Score

3-5 = expected survival less than 7 months, 0-2 = less than 3 months

**\*Karnofsky performance**

Able to carry out normal activities - **good**  
no limitations no complaints 100%  
no limitations minor symptoms 90%  
no limitations some symptoms 80%

Unable to work, able to self care - **moderate**  
care for himself 70%  
require occasional assistance 60%  
considerable assist. frequent care 50%

Unable to care for himself - **poor**  
disabled. Require special care 40%  
very sick, hospitalisation, active support 20%  
severely disabled, hospitalisation 20%  
moribund 10%

Centralized registration of patients with surgically treated skeletal metastases. **SSG XVI**  
**OPERATION** (complete *after* operation) **2**

Name (first & family name)  
 Date of birth (day, month, year)

Send to: SSG secretariat  
 Regional Tumour Registry  
 Lund University Hospital  
 SE-221 85 LUND  
 Sweden

Hospital and department Doctor

Date of operation Day Month Year

Cytology #/i.d. Histology/PAD #/i.d.  
 (not compulsory) (not compulsory)

**Bone**

Femur  Humerus  Tibia  Pelvis  Scapula  Other, specify: .....

**Localisation in the operated bone**

Site of fracture or major destruction, if applicable: <input type="checkbox"/> proximal (In femur: caput/collum) <input type="checkbox"/> intertrochanteric (femur) <input type="checkbox"/> subtrochanteric (femur) <input type="checkbox"/> diaphysis <input type="checkbox"/> distal	Additional or minor destruction: <input type="checkbox"/> proximal (In femur: caput/collum) <input type="checkbox"/> intertrochanteric (femur) <input type="checkbox"/> subtrochanteric (femur) <input type="checkbox"/> diaphysis <input type="checkbox"/> distal <input type="checkbox"/> acetabulum
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**Side**

Right  Left

**Main indication of surgery**

Complete fracture  impending fracture  pain  Other, specify: .....

**Operation method**

glide screw plate  
 plate  
 reconstruction nail  
 intramedullary nail  
 hemiprosthesis  
 prosthesis, total joint replacement  
 prosthesis & acetabular reconstruction  
 tumor prosthesis  
 hip screws  
 allograft  
 other, specify: .....

**Operative strategy "surgical margin"**

curettage + cement  
 curettage only  
 stabilisation without tumor removal,  
 excision with wide margins  
 other

Centralized registration of patients with surgically treated skeletal metastases. **SSG XVI**  
**FOLLOW-UP** (complete at 6 weeks, 6 and 12 months after surgery or in case of reoperation or death) **3**

Name (first & family name)  
 Date of birth (day, month, year)

Send to: SSG secretariat  
 Regional Tumour Registry  
 Lund University Hospital  
 SE-221 85 LUND, Sweden

Hospital and department

Doctor

**Follow-up**

Date of follow-up			Time after 1 <sup>st</sup> surgery		
Day	Month	Year	<input type="checkbox"/> 6 weeks	<input type="checkbox"/> 6 months	<input type="checkbox"/> 12 months
<b>Karnofsky performance*</b>					
Able to carry out normal activities - <b>good</b>			<input type="checkbox"/> 100%	<input type="checkbox"/> 90%	<input type="checkbox"/> 80%
Unable to work, able to self care - <b>moderate</b>			<input type="checkbox"/> 70%	<input type="checkbox"/> 60%	<input type="checkbox"/> 50%
Unable to care for himself - <b>poor</b>			<input type="checkbox"/> 40%	<input type="checkbox"/> 30%	<input type="checkbox"/> 20% <input type="checkbox"/> 10%
Pain from operated site					
<input type="checkbox"/> No	<input type="checkbox"/> Light	<input type="checkbox"/> Moderate	<input type="checkbox"/> Strong	<input type="checkbox"/> Severe	<input type="checkbox"/> Not known
Analgesics					
<input type="checkbox"/> No	<input type="checkbox"/> Peripheral/light	<input type="checkbox"/> Opioids	<input type="checkbox"/> Not known		
Mobility					
<input type="checkbox"/> Walking without crutches	<input type="checkbox"/> Walking with crutches	<input type="checkbox"/> Wheel chair	<input type="checkbox"/> Confined to bed	<input type="checkbox"/> Not known	

**Complications after 1<sup>st</sup> surgery**

Date	Day	Month	Year	<input type="checkbox"/> wound infection
				<input type="checkbox"/> deep infection
				<input type="checkbox"/> prosthetic dislocation
				<input type="checkbox"/> nerve injury
				<input type="checkbox"/> systemic
				<input type="checkbox"/> other, specify; .....

**Reoperation: Bone** ..... **Side** .....

Date	Day	Month	Year	<b>Surgical method</b>	<b>Reason</b>
				<input type="checkbox"/> glide screw plate	<input type="checkbox"/> non-union
				<input type="checkbox"/> plate	<input type="checkbox"/> local tumor progression
				<input type="checkbox"/> reconstruction nail	<input type="checkbox"/> stress fracture of bone
				<input type="checkbox"/> intramedullary nail	<input type="checkbox"/> immediate failure (within 6 weeks)
				<input type="checkbox"/> hemiprosthesis	<input type="checkbox"/> technical error
				<input type="checkbox"/> prosthesis, total hip replacement	<input type="checkbox"/> other, specify; .....
				<input type="checkbox"/> prosthesis & acetabular reconstruction	
				<input type="checkbox"/> tumor prosthesis	
				<input type="checkbox"/> hip screws	
				<input type="checkbox"/> allograft	
				<input type="checkbox"/> other, specify; .....	

**Death**

Date	Day	Month	Year	Reason
				<input type="checkbox"/> Due to cancer <input type="checkbox"/> Other reason

**\*Karnofsky performance**

Able to carry out normal activities - <b>good</b>	Unable to work, able to self care - <b>moderate</b>	Unable to care for himself - <b>poor</b>
no limitations no complaints 100%	care for himself 70%	disabled. Require special care 40%
no limitations minor symptoms 90%	require occasional assistance 60%	very sick, hospitalisation, active support 30%
no limitations some symptoms 80%	considerable assist. frequent care 50%	severely disabled, hospitalisation 20%
		moribund 10%