Multicenter-Study

„Clear-Cell-Sarcoma of Soft-Tissue (Clear-Ce-Sa)“ –
initiated by „Arbeitskreis „Tumoren des Haltungs- und Bewegungsapparates“ of the
German orthopaedic Society (DGOOC) in cooperation with the
European Musculoskeletal Tumor Society (EMSOS)

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Time period: Include only patients with an initial diagnosis of a
clearcell-sarcoma between
January 1st 1990- December 31st 2012
and with a follow-up period of up to June 30th 2015

DEADLINE for contribution: September 30th , 2015

IF YOU HAVE ANY QUESTIONS OR COMMENTS:

PLEASE DO NOT HESITATE TO CONTACT ME

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Institution: Country:
Institution identification (will be done by the study centre)

Patients identification:
Initials (Surname, First name): Date of Birth (day,day,month,month,year,year)

Male/Female,

Ethnic origin: known / unknown,
if possible specify your answer
European, Asian, Hispanic, Jewish, Armenian, Afro-American, other:

Symptoms:
- Pain
- Swelling
- Limited range of motion
- Neurological deficit
- Restriction of blood circulation
- 

Initial diagnosis: when / how:
- Date
- By MRI
- By incisional biopsy with suspicion of Clearcell-Sa.
- Histology after excisional biopsy with no suspicion of Clearcell-Sa.
- Others
- By Accident (unplanned)

Duration of symptoms (months/years):
Tumor localization:

- Upper extremity (Region):
  - Shoulder
  - Upper arm
  - Elbow
  - lower arm
  - Hand

- Lower extremity: (Region)
  - Hip joint / Buttocks
  - Thigh
  - Knee joint
  - Lower leg
  - Foot

- Trunk: (Region)
  - Neck
  - Thorax
  - Abdomen
  - Pelvic ring

Initial stage (MSTS (Enneking)-classification):

- I A/B
- II A/B
- III: distant Metastases:
  Localization of mets:
  Number of mets.
Involvement of lymph nodes: yes / no / unknown

- Lymph-node mapping (search for sentinel lymph-node) yes / no
- Localization:
- Lymph-node resection: yes / no: , if yes: result

Grading:
G 1, G 2, G3 ,
Other (please grading specify system):

Previous surgery (same localization)
Reasons for surgery: When? (Date)

With any histopathological analysis yes / no:
- Result of pathological examination: probably diagnosis of melanoma?

Other diseases incl. tumors:
Particular history of melanoma?
(Because differentiation of Clear-Ce-Sa was difficult or even impossible in former times)

Referential pathological analysis including differentiation from melanoma by:
Institution,
Method
Result
Therapy:

Neo-adjuvant (= preop.) therapy: yes / no

Chemotherapy:
- Protocol yes / no
- Which protocol?
- Other substances without protocol:
  - Isolated limb-perfusion (substances):

Radiotherapy: yes / no
- Dose: _______Gy fractionated
- Type of application: percutaneously, Brachytherapy
- Other modalities: e.g. Cyber-knife

Other therapy:
- Lymphnode resection yes / no if yes: result

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Surgical therapy: yes / no

Resection: Margins of resection (please state Enneking-MSTS-Classification)
- radical
- wide
- marginal
- intralesional
OR (TNM-classification): R0, R1, R2
Reconstruction/Amputation:
- Megaprosthesis: which type
- Rotationplasty: Type:
- Amputation: localization
- Disarticulation: localization
- Hemipelvectomy
- Partial pelvic replacement
- Compartment resection: localization
- Plastic-reconstructive surgery: local flap, free flap kind:
- Other:

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Adjuvant (postop.) therapy:

Chemotherapy: yes / no
- Protocol yes / no
- Which protocol?
- Other substances without protocol:

- Isolated limb-perfusion (substances):

Radiotherapy: yes / no
- Dose: ________Gy fractionated
- Type of application: percutaneously, Brachytherapy
- Other modalities: e.g. Cyber-knife
Other therapy (if any): yes / no

- Lymphnode resection yes / no if yes : result

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**Current status of patient:**

**Dead of Disease (DOD)**

- Duration of survival after initial diagnosis: years, month:
- Cause of death:
- Metastasis where ?: number of mets:
- Recurrence ? when ? (duration after initial diagnosis):

**No evidence of disease (NED)**

- Current duration of survival:

**Alive with disease (AWD): duration of survival**

- Metastasis: yes / no
  - when? (period after initial diagnosis):
  - where ?:
  - number of mets.?:
- Recurrence: yes / no
  - when ? (period after initial diagnosis):
Stable disease (SD): time of survival
- Metastasis: yes / no
  - when?: (period after initial diagnosis):
  - where?:
  - number of mets.?:
- Recurrence: yes / no
  - when?: (period after initial tumor therapy for Clear-Ce-Sa)

Progressive disease (PG): duration of survival:
- Metastasis: yes / no
  - when?: years/months after initial diagnosis
  - where?:
  - number of mets.?:
- Recurrence: yes/no
  - when?: (period after initial diagnosis):

Lost to follow up (LTFU):

Dead of unrelated disease (DUD) (period of survival ? years, months:
Cause of death:
Recurrence: yes / no

Modality of detection of recurrences:

Clinical symptoms?:

At follow-up?:

Duration of the detection of recurrence after initial diagnosis: years months:

Therapy for recurrence: yes / no

- Surgery: yes / no
  - kind of surgery?:
  - margins:

- Chemotherapy: yes / no
  Substances?: Protocol?:
  Application:
    - neoadjuvant (before surgery for recurrence).
    - adjuvant (before surgery for recurrence).

- Radiotherapy: yes / no
  - Dosis: _____Gy fractionated
    - neoadjuvant (before surgery for recurrence):
    - adjuvant (before surgery for recurrence):
      - Type of application: percutaneously, Brachytherapy

- Other therapy: yes / no
  Type?:
  - Lymphnode resection yes / no if yes: result
**Success of therapy for recurrence (duration after begin of therapy for recurrence)**

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<tr>
<th>DOD</th>
<th>NED</th>
<th>AWD</th>
<th>SD</th>
<th>PG</th>
<th>LTFU</th>
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**Metastases: yes / no**

- Modality of detection of recurrences:
- Clinical symptoms? :
- At follow-up?:
- Duration of the detection of recurrence after initial diagnosis: years months:
- Localization of mets:
- Number of mets?:

**Therapy for metastases: yes / no**

- **Surgery: yes / no**
  - kind of surgery? :
  - margins:

- **Chemotherapy: yes / no**
  - Substances? Protocol?:
  - Application:
    - neoadjuvant (before surgery for recurrence).
    - adjuvant (before surgery for recurrence).

- **Radiotherapy: yes / no**
  - Dosis: ______Gy fractionated
    - neoadjuvant (before surgery for recurrence):
    - adjuvant (before surgery for recurrence):
    - Type of application: percutaneously, Brachytherapy
- Other therapy: yes / no

Type? :

Success of therapy for metastasis (duration after begin of therapy for metastasis)

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Course after therapy for recurrence or metastasis:

Second metastasis? Yes No
When?
Where?
Treatment?

Second recurrence? Yes No
When?
Where?
Treatment?
Others

Further comments:
Any further recurrences or mets

Thank You for Your contribution

After deadline I will evaluate the data of this multi-center follow-up and prepare a paper for publication including all contributing hospitals/institutions and mention all contributing colleagues. Thus, you should give me the usual information about the particular person who should be named as Co-author.

Co-author:
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