



**Sarcoma
Patients
EuroNet**

“The Sarcoma 101 Training Course:” An intensive 24 hour introductory course to Soft Tissue Sarcomas & Bone Sarcomas

Learning Objective

All course members will have improved their understanding of the diagnostic and treatment pathways faced by sarcoma patients and will have developed their ability to respond to questions from patients about sarcoma and their individual treatment pathways.

Target Audience

- Patient Group Representatives / Patient Advocates (also GIST-Reps. - who want to learn more about Sarcomas)
- Young doctors or nurses – who are newly interested in Sarcomas
- Representatives of pharma companies, medical societies, networks – who are newly interested in Sarcomas

Prior Understanding

- Some experience of offering support to patients
- Desire to extend that experience
- Good understanding of English and ability to converse
- Have read the “SPAEN Sarcoma Pathways Policy Paper”

Faculty Members

SPAEN Board Members / Leadership Team,
Surgeon, Pathologist, 2 Oncologists, Nurse

Suggested Dates/Location

Friday 27 & Saturday 28 October 2017

(Five sessions plus dinner in 24 hours - from 14:00 to 14:00)

in Frankfurt/Main - Germany

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PROGRAMME / TIMETABLE (DRAFT)

DAY 1 – Friday - October 27, 2017

Session 1 – 14:00 to 16:00 – Introduction (90 Min. lecture + 30 Min. case presentation)

Tutors: Patient expert, surgeon, oncologist

- What are sarcomas?
Why do they appear? What causes them? Who gets them?
How can we prevent them? Can we screen for them?
- What are the 'red flag' symptoms?
How are they diagnosed? What can go wrong in diagnosis? Who should diagnose them?
- Importance of specialists/experts (sarcoma expert centres) in sarcoma.
- Overview of the expert diagnostic process. Clinical examination, imaging, biopsy.
Role of radiologist (imaging), pathologist, second opinions networks...
- How is this information presented to patients.
- Prognostically important information: location, size, stage *** grade, histology.
The first three come from examination and imaging. Second two from pathology.
- 30 Min.: Introduce six cases/profiles which are going to re-appear during the course: (suggestions) – e.g.:

<i>16 yr old with arm osteosarcoma</i>	<i>28 yr old with alveolar rhabdomyosarcoma</i>
<i>35 yr old male with clear cell sarcoma</i>	<i>52 yr old with retroperitoneal liposarcoma</i>
<i>58 yr old lady with gynae leiomyosarcoma</i>	<i>70 yr old with leg tumour sarcoma NOS</i>

Consider how you would handle a telephone call from each of them given only the information from them you have here. Discuss over dinner.

Dinner talk: Nurse who runs a helpline - about talking to patients

Coffee Break – 16:00 to 16:30 (30 Min.)

Session 2: 16:30 to 18:00 – Pathology, diagnosis, staging (90 Min.)

Tutors: Patient expert and pathologist

- What the pathologist actually does.
- Value of genetic analysis.
- Finalising diagnosis – confirming sarcoma or other, grade and histology.
- Consideration of our cases/profiles – what the sarcoma is, how it behaves.
- Incidence of different sub-types.
- Short description of other common sub-types, bearing in mind incidence, patient age etc.
- Consider the six cases/profiles. What prognostic understanding of each of them do you have.
How would you tell them what you know and understand, would you suggest they talk more to their doctors etc.

Break before Dinner: 18:00 – 19:30 (90 Min.)

Internal Dinner 19:30 – 21:30

- Dinner talk: Nurse who runs a helpline - about talking to patients



DAY 2 – Saturday - October 28, 2017

Session 3: 08:00 to 10:00 – Treatment Opportunities (120 Min.)

Tutors: Patient expert, surgeon, oncologist

- How decisions are made in multi-disciplinary meeting.
- Creating and communicating a treatment plan.
- Primary treatment is surgery – with/without radiotherapy before/after, chemotherapy in bone tumours, endoprostheses, mutilating surgery.
Special care with retroperitoneal sarcoma. STRASS study.
- Role of chemotherapy in STS. Some adjuvant value. Curative in some paediatric.
Otherwise mostly palliative.
- Rehabilitation – bring in our nursing specialist
- Diagnosis with lung metastases. Treatment options – surgery, RFA, SABR
Chemo regimens – why they differ. Therapies beside classic chemo:
Trabectedin, Pazopanib, Eribulin, Olaratumab
What to expect from first-line, second-line etc. Note fall-off of take-up between lines.
- Handling end of treatment discussions.
- Consider what issues might arise with our six cases/profiles.
What information or support might they need.

Coffee Break – 10:00 to 10:30 (30 Min.)

Session 4: 10:30 to 12:00 – Special cases & Special procedures (90 Min.)

Tutors: Everyone in faculty team

Disease issues:	Paediatric tumours behave differently for same histology Teenage – Ewings sarcoma, DSRCT, ASPS GIST, Desmoids, Chordomas are very special diseases Gynae sarcomas referred in for oncology care
Treatment issues:	Specialist surgery – ILP, endoprosthetics, reconstructive, thoracic Radiology – RFA for lung metastases New radiotherapy techniques Proton beam therapy Other technologies – HIFU Sarcomas: A role for immune-therapies? Sarcoma specialist nurses Planned rehabilitation

30 Min.: Short Lunch Break: Quick pick of your lunch / build your own sandwich...



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(Lunch-)Session 5: 12:30 to 14:00 – Networking & Expert-Patient-Engagement (90 Min.)

Tutors: Everyone in faculty team

Sharing Best Practice – Plenary Bursts (10 Min. each = 50 Min.):

Examples, how the Sarcoma Community (Experts & Patients) are organised in:

- United Kingdom Roger
- France Estelle
- Germany Markus
- Netherlands Gerard
- Poland Kamil

Sarcoma Initiative/Networks/Projects on the intl. level: (30 Min.):

- Guidelines (ESMO/NCCN) & Position Papers
- Societies: EORTC-STBSG – EMSOS – SARC – World Sarcoma Network
- Conferences 2018: ESMO GIST & Sarcomas – EMSOS – CTOS
- EU funded Projects: The basis: Conticanet – EuroSarc – EuroEwingConsortium
- Rare Cancer Initiatives: Rare Cancers Europe – Joint Action For Rare Cancers (JARC),
ERNs European Reference Networks >>> EURACAN

Closing Remarks & Farewell (10 Min.)