



Sarcoma  
Patients  
EuroNet

*Together We Can Make A Difference  
For Those Affected By Sarcomas!*

8<sup>th</sup> SPAEN Annual Conference  
for Organisations  
Representing Patients with  
Sarcomas, GIST or  
Desmoid-Tumours

3<sup>rd</sup> – 4<sup>th</sup> February 2018  
Milan/Italy

CONFERENCE REPORT





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We are looking forward to continuing these partnerships on our way to making a difference for those affected by sarcomas!

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## The 8<sup>th</sup> SPAEN Annual Conference – A truly international event in close cooperation with global sarcoma experts

On the 3<sup>rd</sup> and 4<sup>th</sup> of February 2018, the 8<sup>th</sup> SPAEN Annual Conference was held in Milan, Italy. For the first time, it took place within the framework of the ESMO Sarcoma & GIST Symposium 2018.

The **ESMO Sarcoma & GIST Symposium** is an excellent congress for international networking and collaboration, featuring discussions with the key opinion leaders in these rare tumours. The aim of the symposium is to bring the translational researchers and clinicians together for an integrated approach for better patient outcomes.

Combining the patient advocates meeting with the experts' congress has been of great value and brought a lot of synergies for both parties.

### Growing interest in the sarcoma community

In the last years a growing number of participants demonstrated the increasing interest in the sarcoma field. In 2016, approximately 70 participants from over 25 countries joined the three-day SPAEN meeting. The 2018 conference attracted around 80 participants from all over the world: patient advocates, leading sarcoma experts and representatives of the healthcare industry. It was the first truly international meeting after the decision to make SPAEN an international organisation in 2016.

### Broad range of topics, one common goal

For the sarcoma patient community, the SPAEN conference is a valuable platform to learn about advances and challenges in the treatment of

sarcomas, GIST and desmoids and to share experience and best practice. This year's conference was again a balanced symbiosis of medical content, advocacy topics and capacity building sessions, with a lot of highlights ranging from quality of life, to country-specific organisation of sarcoma care, challenges for young and very young sarcoma patients or change management and information and public relations, to mention just a few.

At the SPAEN Annual Conference, patient advocates from the international sarcoma, GIST and desmoid patient community come together, interact with top sarcoma experts, have access to state-of-the-art medical and scientific information and exchange best practice in patient advocacy and capacity building among each other.

But what makes this meeting so special: There is always a common sense between patient advocates, sarcoma experts and the industry that together in a joint effort research in sarcomas can be completed more quickly and new treatments can be introduced faster. There is always a high level of commitment of every participant, irrespective of being a patient advocate, a clinical expert or an industry representative, to take part in "Changing the World" and doing all that they can to achieve our common belief and objective:

**Together We Can Make A Difference for Those Affected By Sarcomas!**

*Participants at the 8<sup>th</sup> SPAEN Annual Conference 2018 in Milan, Italy represented countries from all over Europe and beyond.*



# Buongiorno e Benvenuti – a very warm welcome to Milan!

*“Our role and our mission as patient organizations is to change. First, the lives of individual patients by giving them advice and information, but second, the situation for patients in the healthcare system and the hospitals.”*

Markus Wartenberg, SPAEN co-chair, Germany

Markus Wartenberg, Germany, on behalf of the SPAEN Board, and Barbara Tamagni, Italy, on behalf of the Italian Sarcoma and GIST Patient Groups officially opened the 8<sup>th</sup> Annual SPAEN conference in Milan - for the first time within the framework of the ESMO Sarcoma & GIST Conference 2018 - with a very warm welcome thanking all participants who have decided to attend the meeting this year.

*“To bring knowledge and the right information to the patient – this is our mission.”*

Barbara Tamagni, Italy



Markus Wartenberg (top) and Barbara Tamagni, Italy

## Taking a look back: Achievements in GIST during the last 15 years

In a first session titled **“Overview: 15 years of Research and Treatment in GIST”** important achievements in the treatment of GIST have been highlighted. A very well-known GIST expert from the USA, **George Demetri**, demonstrated where the GIST research journey has led us and what we have learned from GIST for other subtypes of sarcomas.

Especially the development of the tyrosine kinase inhibitor (TKI) imatinib, formerly called STI571, targeting KIT as well as the introduction of other next-generation TKIs approved for GIST such as sunitinib and regorafenib have been outstanding in this disease and have dramatically changed the prognosis of our patients. “In the 1990ies, science gave us new tools to discover things: We were able to study the DNA very closely. And sometimes, you get super-lucky: We found out that a mutation in GIST led to a strange protein – an anti-death signal, which turns the cell into a GIST.” The enthusiasm about the concept of targeted therapies in GIST is still outstanding, even now, so many years after the first patient was treated with imatinib in the advanced setting. “It’s amazing: I have patients on imatinib for nearly 19 years now”, says Demetri. “But the number of those patients is too small – there’s still a lot of work to do.”



### What we learned:

- Especially the tyrosine kinase inhibitor (TKI) imatinib and the other next-generation TKIs have dramatically changed the prognosis of GIST patients.
- However, the number of patients profiting from those drugs is too small – more work needs to be done.

*“Compared to the 1970ies, the respect for patients is astronomically bigger now. For me, patients and doctors has always been a partnership.”*

George Demetri, USA

# Quality of Life for sarcoma patients



Quality of Life (QoL) and Patient Reported Outcome measures (PRO / PROM) are becoming more and more important topics also for sarcoma patients. **Roger Wilson**, UK, described the importance to capture data on quality of life from the patient’s perspective. Unfortunately, until now QoL is far away from being fully integrated into research and clinical trials especially in sarcoma. As an example, we do not have specific QoL tools for sarcoma patients. “The concept of QoL is not in the mind of clinical research yet”, says Roger Wilson. However, this is currently being improved and QoL and PRO is moving much more into the focus of sarcoma research.

*“Quality of life is under-researched and quality of assessment is poor”*

*Roger Wilson, SPAEN Honorary President, UK*



The work of the QoL Group at the European Organisation for Research and Treatment of Cancer (EORTC) was presented by **Francesca Martinelli**, Belgium. Meanwhile, the QoL Group has more than 350 active members implementing QoL measures in cancer clinical trials. The development of questionnaires such as the EORTC QLQ-C30 is one major effort of this group. More recently, disease specific modules and questionnaires are being developed for certain tumour types.

Going exactly into this direction, **Olga Husson**, UK, presented the project “Incorporating the patient voice into sarcoma research: How can we assess quality of life in this heterogeneous group of patients?” The assessment of the patients’ perspective can add important information on cancer treatments in sarcoma. Thus, the broad aim of this project is to raise standards of QoL measurement in sarcoma patients and to develop sarcoma specific modules, items or questionnaires. This project has been endorsed by the EORTC Soft Tissue and Bone Sarcoma Group (STBSG) as well as by the EORTC QoL Group. “In the sarcoma world we have a lot to win regarding health-related QoL (HRQoL)”, emphasizres Olga Husson.

*“In a generic QoL questionnaire, sarcoma-specific side effects, which can affect the daily functioning of the patient, are not included. Health-related QoL (HRQoL) should be assessed as specific as possible.”*

*Olga Husson, UK*



The development of Sarcoma Assessment Measure (SAM), a UK specific project focusing on the assessment of quality of life terms in sarcoma patients, was lively presented by **Rachel Taylor**, UK. “Do patients with sarcoma have the same issues as patients with other cancers?”, she asked at the beginning of the session. Rachel and team came up with an answer during their work, stating that sarcoma patients have different experiences compared to those with other cancer types. In the following discussion it was clearly consented that patients and patient advocacy groups can play an essential role in this process: they can support by sharing their experiences and working in close collaboration together with the doctors and researchers.

“Why is it so important to incorporate PROMs in clinical practice? It can make processes, outcome and satisfaction with care better. Reporting those PROs improves perception of care, enhances communication and reduces psychological distress”, summarizes Rachel Taylor.



## Quality of Life in sarcomas

- QoL is not yet integrated into research and clinical trials in sarcoma
- The EORTC Quality of Life Group is currently developing disease-specific modules and questionnaires
- Sarcoma needs to be assessed specifically as sarcoma is a very heterogeneous disease and patients have different experiences from other cancer patients

# GIST

## Focus on GIST and sarcoma – parallel sessions

In two parallel educational sessions, well-known sarcoma experts talked about current aspects and questions, new agents and clinical trials in the treatment of sarcomas and GIST. We'd like to thank the following who provided their expert input: Prof. Jonathan Fletcher, Prof. Olivier Mir, Sam Hackett, Prof. Ian Judson, Prof. Johnathan Trent, Prof. Sylvie Bonvalot and Prof. Bernd Kasper.

The GIST breakout session started with *three GIST workshops* on the following topics:

- 1) Brainstorming on “New Horizons GIST” topics for 2018,
- 2) The GIST patient pathway: main challenges and decisions where help is needed,
- 3) GIST Research: What are the most important challenges and open questions to improve research.

The individual group work was followed by presentations and discussions on the workshop results.



What are the most pressing challenges in GIST?  
What are the most relevant decisions GIST patients have to take during their journey?  
Where is help and support needed?  
What are the open questions in GIST research?  
Those questions and more were discussed by patients, experts and industry partners during the GIST roundtable sessions.



## Discoveries and successes in GIST basic research

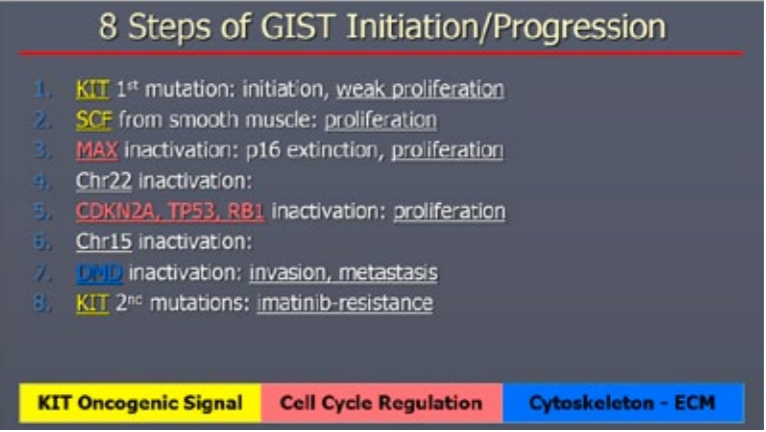
What happens within a cell when it develops from a normal cell to a microGIST to a metastatic imatinib-resistant GIST? This question was answered by **Jonathan Fletcher**, USA, when he walked the audience through the defining eight steps that have been discovered recently. He clearly displayed how the cell and its mutations evolve: whereas the first steps on the way – mutation or inactivation of certain genes – trigger proliferation, the last steps lead to tumour cell invasion, the development of metastasis and resistance towards imatinib.

“However, we don’t know yet if these discoveries will change the diagnostic process or the treatment”, says Jonathan Fletcher.



### Latest developments in GIST basic research

- GIST cells can evolve with time from microGISTs to metastatic imatinib-resistant GIST
- Reasons for this development are mutations or inactivations of certain genes (does not happen in every microGIST)
- It is yet unclear if these findings will change diagnosis or treatment of GIST



## Trials in GIST – an update

In terms of systemic treatment options, after a long period of time in which only two registered drugs – imatinib and sunitinib – were available in Europe for the treatment of GIST patients in the metastatic and/or advanced situation, regorafenib had been approved as 3<sup>rd</sup> line treatment for advanced, metastatic GIST patients after imatinib and sunitinib failure. “However, beyond imatinib, highly effective therapies are missing”, says **Olivier Mir**, France. Response rate and length of progression-free survival decreases with every line of treatment. Furthermore, currently approved agents are ineffective against a specific mutation called PDGFR $\alpha$  D842V. But new agents are on the way:

Avapritinib (formerly known as BLU-285) is a potent and selective inhibitor of PDGFR $\alpha$  D842V and KIT Exon 17 mutants which play a key role in GIST. Recently published data show great potential of the drug. Therefore, the study program for Avapritinib will be expanded: The currently ongoing phase I trial will add another cohort and a phase III trial vs. regorafenib as well as an expanded access program will be opened mid of 2018.

Another promising compound is DCC-2618. It is currently being tested in patients with advanced GIST in a phase III clinical trial. DCC-2618 is an orally administered kinase switch control inhibitor blocking certain kinase enzymes such as KIT and PDGFR $\alpha$ . “It shows encouraging disease control in heavily pre-treated GIST patients”, says Oliver Mir.

Other tyrosine kinase inhibitors currently evaluated in advanced GIST comprise cabozantinib, crenolanib, ponatinib and masitinib.



The audience listens closely to latest developments in treatment and research of GIST.

The sarcoma breakout session started with a closer look at genetics in sarcoma, touched the importance of the nurse in the management of sarcoma and closed with an update in research, latest studies and treatment innovations.



## Sarcomas

### The International Sarcoma Kindred Study (ISKS): The role of genetics in sarcoma

Genetic factors seem to be important in sarcomas. To find out more about them, the International Sarcoma Kindred Study (ISKS) has been set up. Principal investigator in the UK, **Ian Judson**, walked the audience through the basics of genetics in sarcomas – a precondition to understand what is being done in the ISKS. The study identifies, validates and quantifies genetic risk in patients with adult-onset sarcoma. It comprises an international database and blood and tumour samples are collected in order to be used as a resource for research. It’s the ultimate aim to develop clinically useful, population-based criteria for stratifying genetic or hereditary risk for sarcomas. Identifying those at increased risk may lead to early detection, more effective treatment and better survival. “We’ve found that the younger you are when you get cancer, the more likely it is that you have an inherited predisposition”, says Ian Judson. “But there are more questions investigated: We are looking for more information on the full extent of inherited predisposition, what genes and how many of them are going to give us potential new targets.”



### The International Sarcoma Kindred Study (ISKS)

- The International Sarcoma Kindred Study has been set up to find out more about genetic factors in adult-onset sarcomas
- An international database as well as a repository of blood and tissue samples are used as a resource for researchers
- It aims at stratifying genetic and hereditary risk in order to detect the disease earlier, treat more effectively and improve survival

# The role of nurses in the management of sarcomas

The importance of nurses in the multidisciplinary management of sarcoma patients from the UK perspective was highlighted by **Sam Hackett**, UK, specialist sarcoma nurse from Sarcoma UK. The specialist sarcoma nurse plays a key role in coordinating the patient’s pathway and acts as advocate for the patient in situations where he/she is not necessarily present. Moreover, the sarcoma nurse supports the patient and the family throughout the sarcoma pathway. Sarcoma UK has even installed a Sarcoma Support Hotline giving advice to patients and families on the phone. Sam Hackett presented statistics and feedback about this highly successful project, but also displayed the importance of speaking to someone knowledgeable about sarcomas with time to listen and to help.

“The sarcoma nurse is the key person – they stay with a patient throughout the whole treatment.”

Sam Hackett, UK



**Olivier Mir**, France followed, giving the French perspective, with a presentation about a new sarcoma nursing trial (CAPRI study) which evaluates the role of coordinating nurses in patients being treated with approved oral agents. The trial is currently ongoing.

Sarcoma specialist nurses coordinate the patient’s pathway and act as patient advocate where necessary  
They support the patient and family throughout the whole sarcoma pathway



# Potential innovations for future treatment of sarcomas

The role of the immune system in cancer has been one of the most discussed topics in cancer care during the last years. What new developments have arisen for sarcomas were subject of the talks of Jonathan Trent, USA and Sylvie Bonvalot, France.

“We can currently apply five pillars of cancer care to sarcoma”, explains **Jonathan Trent**, USA at the beginning of his presentation: Surgery and radiation are still the main modalities used for management of localized sarcomas. Chemotherapy has a central role in sarcoma management – in the neoadjuvant and adjuvant settings for high risk sarcomas, or for palliation of metastatic disease. The future seems to be precision therapy and immunotherapy.



Normally, the immune system is able to recognize and destroy faulty cells. In cancer, however, several things during this multi-step process can go wrong or can be influenced by cancer cells to prevent the immune system from destroying them. Basically, immunotherapy supports the immune system to become active once more.

In the past, vaccines proved not be very effective in sarcoma. Today, we look at specific biomarkers to be targeted or at checkpoint inhibitors such as PD-1 and CTLA-4. “And there will be a lot more going on in the future”, says Jonathan Trent. This includes CAR-T-cell therapy, oncolytic viruses to infect tumour cells, novel immunomodulating drugs, precision immunotherapy and combinations. These approaches are currently tested in a small number of patients. Jonathan Trent highlighted some of them:

- In synovial sarcoma, a genetically engineered T-cell (NY-ESO-1c259T) can recognize the antigen NY-ESO which is expressed only on the tumour. “It is a complicated and expensive process”, says Jonathan Trent. “However, 43% of the patients that met the eligibility criteria to enter the study benefited from this.”
- CAR (Chimeric Antigen Receptor)-T-Cell therapy – a patient’s T-cell is taken out of the body, modified in the laboratory and then put into the patient again – seems to be promising: A phase I study was conducted in osteosarcomas which expressed the antigen HER2. The treatment induced a number of partial responses and stabilized diseases. This kind of therapy is approved in the USA for the treatment of lymphoma.



- Checkpoint inhibitors can help the immune system to function again and to recognize and destroy cancer cells. There are several different compounds approved for other cancers, but not for sarcoma at the moment. However, if a sarcoma or GIST patient has a proven unstable genome (“micro-satellite instability”), the agent pembrolizumab is an approved option in the US. Studies with this kind of agents are ongoing in soft tissue sarcoma and bone cancer – some activity has been shown so far.
- Combination therapies seem to be more active: a study with nivolumab/ipilimumab versus nivolumab alone induced more complete and partial responses in advanced sarcomas with the combination therapy. Further combinations are being tested, such as immunotherapy plus chemotherapy, radiotherapy or targeted therapies. As another example, Jonathan Trent showed the effect of a combination of pembrolizumab and axitinib in alveolar soft part sarcoma (ASPS).

*“Immunotherapy is one of the most exciting things currently going on in sarcoma management and it will hopefully allow us to help more patients.”*

Jonathan Trent, USA



**Sylvie Bonvalot**, France, also introduced a very novel way of treatment which is currently tested in clinical trials: Nanoparticle therapy. “Despite new treatment options on the way, there remains a high unmet medical need, as many patients do not adequately respond to available therapies”, says Sylvie Bonvalot. Especially radiation therapy is still a major pillar in sarcoma management. However, its efficacy is limited by toxicity on healthy tissue and outcomes in terms of tumour shrinkage are unsatisfying.

Nanoparticle therapy has the potential to improve the outcomes of radiotherapy. As a so called “radioenhancer”, it maximizes the absorption of the X-rays in the tumour – this means, it physically destroys cancer cells by increasing the dose around the nanoparticles by 9 and thus causes more damage in the tumour. Nanoparticles are injected directly into the tumour the day before radiotherapy.

Phase I data have been promising. Therefore, the therapy is currently tested in a phase III trial in soft tissue sarcoma. Results are expected during the Annual Conference of the European Society of Medical Oncology (ESMO) in September 2018.

*“We have to improve the results of radiotherapy.”*

Sylvie Bonvalot, France

#### Potential innovations in sarcoma treatment

- Even though there are several options for the treatment of sarcomas, novel therapies are needed to improve outcomes
- Innovative approaches are currently being tested and show promising results in sarcomas
- Among them are immunotherapies, genetically engineered T-cells, CAR-T cells or nanoparticle therapy to enhance results in radiotherapy (excerpt)

## Clinical trials in sarcomas

What is happening in the sarcoma trial landscape? This question was answered by **Bernd Kasper**, Germany. “Regarding systemic therapy options, the treatment armamentarium for soft tissue sarcoma patients has been enriched in the last years”, says Bernd Kasper. The anti-angiogenic compound and multi-tyrosine kinase inhibitor pazopanib was approved in 2012 for certain subtypes of soft tissue sarcomas excluding liposarcomas. Trabectedin, which has been licenced in Europe already in 2007, again demonstrated sustained activity in a large phase III study comparing trabectedin versus dacarbazine (DTIC) in soft tissue sarcoma. This led to global registration by the FDA in October 2015 for the treatment of patients with leiomyosarcomas and liposarcomas. The phase III trial of eribulin showed an overall survival benefit compared to DTIC in pretreated patients with advanced leiomyosarcomas or adipocytic sarcomas. As there was a clear benefit for the liposarcoma subgroup, eribulin was approved for this subtype in Europe and USA at the beginning of 2016. Olaratumab, a fully human anti-PDGFR $\alpha$  monoclonal antibody, has been tested in a phase II trial in combination with Doxorubicin in first line treatment. Olaratumab is the first agent added to Doxorubicin to improve overall survival in advanced/metastatic soft tissue sarcoma patients in a randomized setting. A conditional market authorization has been granted for olaratumab in 2016; meanwhile it is available in many European countries for first line treatment of doxorubicin naïve patients with advanced/metastatic soft tissue sarcoma. A phase III trial is ongoing, results are expected in 2019/2020.

“The concept of targeted therapies which was initiated in GIST at the beginning of the third millennium has also opened new horizons in the field of soft tissue sarcomas”, summarizes Bernd Kasper. “A better biological and cytogenetic dismemberment of sarcomas in general turns each histological subtype into a potential target for new therapeutic approaches.”

#### Clinical trials in sarcoma

- The treatment armamentarium for soft tissue sarcoma patients has been enriched during the last years with the approvals of trabectedin, pazopanib, eribulin and olaratumab
- A better understanding of sarcomas turns each histological subtype into a potential target for new therapeutic approaches



*“We’ve learned and we cannot stop to emphasize that patients suffering from these rare diseases should be treated in one of the specialized sarcoma units or networks of excellence.”*

Bernd Kasper, Germany

# How is sarcoma/GIST research and expert care organised?

Based on the already published initiative of the “Sarcoma Policy Checklist” ([www.sarcoma-patients.eu/en/sarcoma-reports2/policy-checklist](http://www.sarcoma-patients.eu/en/sarcoma-reports2/policy-checklist)) country profiles have been presented to demonstrate how sarcoma & GIST research and expert care are organised in different European countries:



**France, Olivier Mir**

- Since 2009, a network of 26 reference multidisciplinary centres aiming to improve the quality of care for sarcoma patients in France was granted by the French National Cancer Institute (Netsarc.org)
- All contribute to clinical trials, 24 contribute to translational and/or preclinical research
- NETSARC is associated to a pathology review network (RREPS) and a bone sarcoma network (RESOS)
- The outcome of the patients discussed in these 26 NETSARC multidisciplinary tumour board (NMTB) is presented



**UK, Robin Jones**

- Consultation exercise lead to publication of guidance in 2006 covering early referral, diagnosis, centralisation of care and all aspects of multidisciplinary management
- NICE IOG: Key Recommendations
- All sarcoma patients must be managed by a sarcoma multidisciplinary team (MDT). The MDT needs to comprise all diagnostic and treatment disciplines
  - Designated Diagnostic Centres
  - Provisional sarcoma diagnosis must be reviewed by specialist sarcoma pathologist
  - Treatment Centre must manage ≥ 100 new cases of soft tissue sarcoma a year, 50 for bone sarcomas
  - Sarcoma operations must be done by appropriately experienced surgeons



**Germany, Bernd Kasper**

*Sarcoma centres of reference:*

- Several high-volume centres are treating sarcoma patients
- No formal accreditation system for sarcoma centres yet, formal certification process for STS centres is currently being developed by the German Cancer Society (DKG) & OnkoZert

*Multidisciplinary teams (MDT) and care pathways:*

- Composition of a sarcoma MDT is not yet specified in guidelines, organisation of care into MDTs varies across centres
- Treatment by specialised sarcoma MDTs will be a fundamental criterion for the accreditation process of national sarcoma reference centres

*Research:*

- There is no national sarcoma registry covering all sarcomas yet, but local efforts are trying to change this
- Several national research study groups focus on developing clinical guidelines, implementing and conducting clinical trials, providing training and collaborating with international sarcoma research groups



**Italy, Alessandro Gronchi**

- In October 2002, the Italian Sarcoma Group was formally established. Members: 70 centres (16 National Institutes, 13 Universities, 41 Hospitals)
  - 10 centres support clinical research
  - 5 support translational/basic research
  - 3 support industry-led studies requiring translational research
- There is no Italian registry for sarcomas, but there are at least 2 large institutional prospectively maintained databases
- What is the accepted definition of referral in Italy?
  - N. of treated patients/year: 100 STS/ GIST; 50 bone tumours
  - N. of surgical procedures/surgeon: 40
  - % pts with pre-op diagnosis: >80%
  - % pts discussed at MDT: >90%
  - % pts with proper pre-op assessment: >80%
  - % pts with positive resection margin at primary surgery: <15%
  - % pts treated with pre-op multimodality approach: >20%
  - Local control and overall survival at 5 years



**The Netherlands, Hans Gelderblom**

- 6 sarcoma centres (incl. 1 for children)
- Netherlands Cancer Registry since 1989
  - GIST registry (since January 2009, data -Sept 2016)
- Conclusion:**
- Bone tumours well centralised
  - GIST reasonably well centralised
  - STS need to be better centralised

Key conclusions on the European level have been drawn that sarcoma patients still report some of the poorest experiences of care among cancer patients. Thus, sarcoma presents a key opportunity to improve care for an important family of rare cancers. Access to appropriate information, clinical trials, specialist care and effective treatments is a major concern in all European countries. Solutions require cross-sectoral collaboration at the EU and national level together with all stakeholders (regulators, pricing and reimbursement agencies, health care professionals and patient organisations).

## Sarcoma subtypes in children, teens and young adults

The topic of sarcoma treatment in children, adolescents and young adults (AYA) has been addressed in a special session on Sunday morning. Finding new treatments and improving outcomes for young cancer patients is often an international task. One important consortium for Ewing sarcoma is the Euro Ewing Consortium (EEC, [www.euroewing.eu](http://www.euroewing.eu)), an EU-funded project with partners from around Europe also including patient representatives from SPAEN.

But what are the most common sarcoma subtypes in children and young adults? **Uta Dirksen**, Germany, answered this during her presentation: Osteosarcoma, Ewing sarcoma and rhabdomyosarcoma.



*“The outcome for children, adolescents and young adults with cancer has markedly improved after the implementation of chemotherapeutic agents as systemic treatment. However, sarcoma belong to the subtypes where approximately 30 % of the patients suffer from a relapse. Relapse, especially metastatic relapse in sarcoma is very difficult to treat.”*

*Uta Dirksen, Germany*

**Osteosarcoma** is the most frequent malignant bone tumour in children, adolescents and young adults. Median age at diagnosis is 15 years with a second peak between 60 and 80 years. The tumours occur mainly in the extremities. 20 % of all patients have metastases at time of diagnosis. Therapy modalities are usually surgery and pre- and post-operative chemotherapy.

**Ewing sarcoma** is a rare and highly malignant tumour that grows in the bones and – in rare cases – in the soft tissue. About 3 in one million patients under the age of 15 and only 2,4 in one million above the age of 15 are affected by Ewing sarcoma in the Caucasian population. It affects more males than females. Median age at diagnosis is 14. Especially in older patients, more soft tissue sarcomas can be seen. Main locations are pelvis, chest wall and femur. 20 % of the patients have metastases at diagnosis. Treatment is usually pre-operative chemotherapy, surgery, radiotherapy and chemotherapy again.

**Rhabdomyosarcoma (RMS)** is a malignant tumour that can develop in almost any part of the body. It is very rare and uncommon in adults. Embryonal RMS occurs in very young children whereas alveolar rhabdomyosarcoma affects older children. Alveolar rhabdomyosarcoma can have a tumour-specific translocation, which is usually associated with a poorer outcome. Therapy comprises surgery or chemotherapy upfront, local therapy, chemotherapy maintenance. Risk depends on location and stage of tumour, patient age and translocation.

“A major issue for young cancer patients are late effects”, says Uta Dirksen. Chemotherapy can affect the heart, kidneys, hormones, body shape and it might also lead to chronic fatigue – even many years after the end of treatment. This is especially problematic in young patients: They have to start their lives after treatment – finishing school, starting their studies and jobs. “This is another reason why have to find better treatments for those patients.”



An interview was lead with Sami Sandakly, a sarcoma patient being diagnosed at the age of 13, together with his mother Angelika to lively demonstrate the different perspectives from the patient's as well as the parents' point of view.

*“When I heard the diagnosis, my major concern was to keep my hair. I didn't realise what was happening to me.”*

*Sami*



*“Friends at school didn't know how to react. They didn't understand cancer and that there are different types. They were scared to asked questions.”*

*Sami*

*“For me, the main issue was how to get organised with my daily life – work and family.”*

*Angelika*



*“When Sami was diagnosed at the age of 13 he was a child. When he finished treatment with just 14, he had grown up: A child had become an adult. It was difficult to see that he had gone through things an adult doesn't think about.”*

*Angelika*

**Winette van der Graaf**, UK/The Netherlands concluded with a summarizing description of the challenges for patients, parents and medical experts in this specific age group. Professionally, she spoke as a medical oncologist caring for young adults; however, she also gave a very personal point of view as a mother of a paediatric cancer survivor.

The definition of AYA – Adolescents and Young Adults – with cancer is not quite clear. It ranges from the age of 15-18 to 35-39. In this age group, sarcoma only accounts for approx. 5 % of all cancers in males, and 3 % in females.

“The group of young adults with cancer is often “lost” between paediatric cancer care and adult cancer care. The latter often focuses on older patients where cancer occurs more often”, says Winette van der Graaf. Common issues in the age group of AYA comprise delays and difficulties in diagnosis, lack of centralisation, difficulties in access to new drugs and treatment modalities, low access to clinical trials and low participation in trials as well as lack of peer groups. But there’s more than therapy and drugs: They also face age-specific issues such as sports/mobility, fertility, sexuality, nutrition and late effects and have a lot of questions that arise in follow-up care about school, education, insurances, building homes and starting or raising a family. “It is important that we raise awareness of the AYA cancer patients and address their specific issues and needs”, says Winette van der Graaf.



*“One thing we can learn from paediatric oncologists is that they have already looked at late effects of treatment: They set up guidelines on what to screen depending on the kind of treatment that was applied, but they also installed late effect clinics and give out lifestyle advises.”*

Winette van der Graaf, UK/The Netherlands

### Sarcoma subtypes in children, teens and young adults

- Most common sarcoma subtypes in children and young adults are osteosarcoma, Ewing sarcoma and rhabdomyosarcoma
- A major issue for young cancer patients are late effects of treatment on heart, kidneys, hormones, body shape or leading to chronic fatigue
- Adolescents and young adults (AYA) with cancer are often “lost” between paediatric and adult cancer care, which mainly focuses on older patients
- AYA patients face age-specific needs and issues ranging from school/education to sports, fertility and sexuality, starting or supporting families and building homes

## Information and Public Relations: How to communicate our messages effectively

**Simon Crompton**, UK, writer, editor and communication consultant, showed “How to communicate your messages effectively”. He demonstrated communication tools which can be used for information and public relations within a patient organisation. Firstly, you have to make clear who am I talking to? What do other people want to know or learn from you? Common techniques comprise visual tools, simplifying, hand gestures, making it personal and interesting, drawing, zooming in/out, etc. As one fundamental tool you should be targeting information at the listener!

*“An effort has to be made to work out who you are talking to and what they will understand. To truly deliver your message, it is most important to tune in to the person you want to target.”*

Simon Crompton, UK



## The development of patient associations: When changes become necessary

Important factors of “change management” in the development of a patient association or organisation have been presented by **Kathy Redmond**, Italy. Every organisation needs changes. There are drivers (need to bring in new people with new skills, loss of people, see successful change in other organisations, funds, new opportunities) and inhibitors (founder’s syndrome, fear of change, comfort with status quo, ego) of change and the different responses to change within an organisation always have to be taken into account. Changes pose challenges, but changes are fundamental for the long-term success and stability of your organisation, summarizes Kathy Redmond.



*“Change is a process, it’s not a one-off-thing. It should be a planned process with a clear rationale for it.”*

Kathy Redmond, Italy

# Understanding the role of pathologists as “pilots” for the treatment of sarcomas

The following educational session focused on “Understanding the role of pathologists as “pilots” for the treatment of sarcomas” presented by **Paolo Dei Tos**, Italy. “Approximately 30 % of all diagnoses are inaccurate”, says Paolo Dei Tos. But it has to be done correctly, because the pathological diagnosis is the rationale of clinical decision making and offers information on prognosis and possible response.

Paolo Dei Tos walked the audience through the most important steps in pathology: Always check clinical presentation, take a look at the slides (H&E morphology), then create differential diagnosis and use modern techniques such as immunohistochemistry and molecular genetics to further define and confirm a diagnosis.

In sarcomas there are translocations, mutations, more copies of one gene and epigenetic changes. “It is crucial that we know how to use the information that come from genetics”, explains Paolo Dei Tos.

Next Generation Sequencing is a rather novel method to sequence tumour tissue for mutations. According to Paolo Dei Tos, it is not the solution, but a new technique. But it can broaden understanding: It can help validate current classifications, identify new (more solid) diagnostic markers and new tumour entities, better understand sarcoma pathobiology and identify new potential targets.

“Accurate classification is the key step for appropriate clinical decision making”, emphasizes Paolo Dei Tos. “And more and more treatments may be histotype-oriented. So accurate histotyping is a pre-requisite for effective cytotoxic or targeted systemic treatment.”



**The role of pathologists in sarcoma management**

- Pathological diagnosis is the rationale of clinical decision making and offers information on prognosis and possible response
- Next Generation Sequencing, a novel method of genetic sequencing, helps to broaden understanding of the nature of sarcomas
- Accurate histotyping is a pre-requisite for effective treatment as more treatments may be histotype-oriented in the future



# Sarcoma/GIST and fertility

Cancer and its treatment can sometimes affect the ability to have children. **Christine Rousset-Jablonski**, France, explained how sarcoma treatment can affect fertility and the possibility of becoming pregnant and what can be done to preserve fertility. “With the improvement of therapies, the lifespan of cancer patients and survivors becomes longer and quality of life becomes more important. Fertility and the possibility to become pregnant play a major role in quality of life of cancer patients and survivors.” Most concerned are childhood cancer survivors and adolescents and young adults treated for cancer.

According to Christine Rousset-Jablonski, therapeutic choices by patients can be influenced by the question of fertility. Especially alkylating agents and radiation therapy of the pelvic and the whole body reduce the likelihood to become pregnant.

Different kinds of diseases with different treatment regimens in sarcoma lead to different recommendations: In bone cancer, toxicity of treatment is the most important factor. In these cases, fertility preservation before treatment is recommended. In soft tissue sarcoma, toxicity of treatment is also a topic, but less so because of different dosing schemes of the therapies. But due to longer treatments in different subtypes, childbearing might be delayed, which causes problems for women. This is also an issue for GIST with its long-term treatments. The question of fertility preservation should be asked before start of treatment. However, preservation of semen or oocytes should be preferred as toxicity of treatments is not that high and the risk and effort of preserving tissue (ovarian, testicular) is higher. The situation in desmoids is similar to that in GIST: Delaying childbearing can become an issue.

“One problem is that we only have very few data. So international registries on the short- and long-term outcomes of fertility preservation techniques should be installed”, underscored Christine Rousset-Jablonski.



*“Patients need to be informed about the consequences of treatment on fertility. Fertility preservation should always be part of the discussion with patients in childbearing age.”*

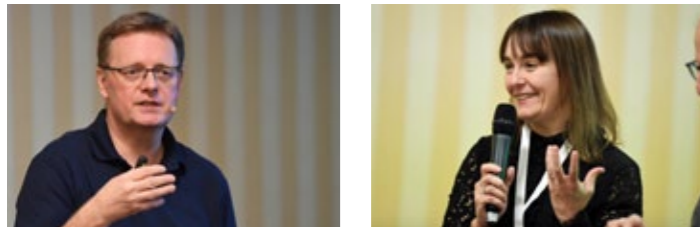
*Christine Rousset-Jablonski, France*

**Sarcoma/GIST and fertility**

- Fertility plays a major role in quality of life of cancer patients and survivors
- Fertility and fertility preservation should be discussed with all patients in childbearing age
- Especially alkylating agents and radiation therapy of the pelvic and the whole body reduce the likelihood to become pregnant
- The choice of fertility preservation methods depends on the type of disease and therapy and the length of treatment

# The past, the present and the future of SPAEN: the Annual General Meeting

The last session of the second conference day was the Annual General Assembly 2016/2017 of the SPAEN Association. On behalf of the SPAEN Board **Markus Wartenberg** and **Estelle Lecointe-Artzner** gave an overview of all activities SPAEN is involved in such as patient engagement in clinical research and projects of collaborations with experts and industry. SPAEN is an international association, legally registered under German law. The network of currently 40 patient groups collaborates closely with international societies, networks and organizations such as ESMO, EORTC, EMSOS, CTOS, SARC, World Sarcoma Network, EMA and Rare Cancers Europe. SPAEN also seeks exchange and close collaboration with currently 20 international cancer patient advocacy networks representing other cancer types.



There is an ongoing and improving collaboration with ESMO (e.g. participating in the process of establishing the Clinical Practice Guidelines), EORTC (e.g. involvement in the EORTC training course “Understanding Cancer Clinical Research”, providing involvement in future sarcoma trials as well as communication of trial progress and results), the European CanCer Organisation (ECCO), EUROSARC and the European Reference Network (ERN) dedicated to rare adult solid tumours (EURACAN). Upcoming challenges SPAEN is facing are helping to establish where the centres of excellence in each country in Europe are and to build up a network structure, to identify where additional expert centres are needed and where new support organisations can be created.

The current aims of SPAEN comprise securing the financial structure of SPAEN, meeting the growing demands and workload of the Board and strengthening important relations with different partners. The financial cooperation with the pharmaceutical industry is structured as a “corporate membership” comprising a lot of interactions such as the discussion and review of patient materials, early involvement and discussion with new companies, participation in advisory boards, and early advice in the design and setup of clinical trials.

The “SPAEN Board of Directors” is a voluntary body of currently seven elected members who jointly run the organization with the support of part-time professionals, freelancers and two elected financial auditors. Board members are elected by the Annual General Assembly for the duration of four years. This year, the terms of Estelle Lecointe-Artzner, Markus Wartenberg, Kai Pilgermann and Christina Baumgarten ended. All of them were unanimously re-elected. Both Estelle and Markus have been confirmed as co-chairs of the board. The board of directors also happily welcomes two newly elected/appointed members to the board: Annika Laakso from Finland and Sami Sandakly from France.

Elected board members are (February 2018, left to right):



Nikhil Guhagarkar, India, Kai Pilgermann, Germany (Financial Director), Markus Wartenberg, Germany (Chair), Christina Baumgarten, Germany, Gerard van Oortmerssen, The Netherlands, Estelle Lecointe-Artzner, France (Chair) and Roger Wilson, UK (Honorary President). Missing here: Annika Laakso, Finland

The elected board of directors has the right to appoint up to seven persons to support them in their tasks. In 2016, the Board appointed Jesica Garcia, Spain, and Ferdinand Mwangura, Kenya († 28.2.2018), as observers to the board as well as Bernd Kasper, Germany, medical oncologist and current Secretary of the EORTC Soft Tissue and Bone Sarcoma Group (STBSG). This year, the board appointed Sami Sandakly from France.



Annika Laakso, Finland, newly elected board member



Sami Sandakly, France, newly appointed board member

The meeting ended with closing remarks and a big thank you to the presenters and the “corporate members” by the SPAEN Board.

SPAEN would especially like to thank the following pharmaceutical companies for their support with unrestricted grants: Bayer, Lilly, Novartis, Pfizer and PharmaMar as well as the new “research partners” Blueprint Medicines and Deciphera.

SPAEN is looking forward to continuing these partnerships on the way of achieving its vision: **Together We Can Make A Difference for Those Affected By Sarcomas!**

“We are very much looking forward to continuing our work with established and new members of the board.”

Markus Wartenberg, SPAEN co-chair, Germany

# Advocacy in Action Award 2017

Patient advocacy ensures that people are heard, take action and ultimately improve situations, achieve changes or help to fulfil unmet medical needs. We decided that it is time to shout out about how important patient advocacy in sarcomas is – for patients, caregivers, healthcare professionals or anyone interested in sarcomas. We therefore created the “Advocacy in Action Award”. In 2017, it was announced for the first time. The winning projects were awarded during the 8<sup>th</sup> SPAEN Annual Conference 2018.

We are very happy to have received submissions of outstanding projects and initiatives for our SPAEN Advocacy in Action Award 2017.

The best projects were chosen by a jury of eight members consisting of patient advocates and experts.



## Those projects are:

Some very special thanks also go to the jury for taking the time to read and evaluate the project submissions: **Dr. Alessandro Gronchi, Dr. Rick Haas, Dr. Robin Jones and Professor Bernd Kasper** representing the experts' perspective and **Lindsey Bennister, Kamil Dolecki, Nikhil Guhagarkar and Kai Pilgermann** on behalf of the patient advocates.



**Friends of Max, India:** Together We Share and Learn - Ongoing life-long relationship management of GIST patients & caregivers



*Excited audience waiting for the announcement of the winners of the SPAEN Advocacy in Action Award 2017 by Estelle Lecointe-Artzner and Kai Pilgermann*



**Polish Sarcoma Patients Association, Poland:** ONCORUN - Together for health!



**Associazione Paola, Italy:**  
1. Paper on sarcoma/rare cancer health policies,  
2. Sarcoma meeting for healthcare professionals and policy makers,  
3. Funding Ewing sarcoma research (travel scholarship 2017/2018),  
4. Lobbying in order to relax the rules for the “compassionate use” in rare cancers

More information about the winning projects can be found on our website [www.sarcoma-patients.eu](http://www.sarcoma-patients.eu).

# Social Media Wall

**WinetteVanDerGraaf**  
@Winette\_vdGraaf

Following

Thanks @sarcomapathents for all your hard work as European Sarcoma patients advocates. Your work is outstanding! It was a privilege to speak about the specific issues young sarcoma patients are faced with, and how to address them.

**SPAEN @sarcomapathents**  
Today is World Cancer Day! SPAEN is meeting today for our Annual Conference, making the motto "We can, I can" come to life....

12:46 PM · 4 Feb 2018

2 Retweets 9 Likes



**Eugenie Younger** @dreugeniley · Feb 3  
Broadening horizons in sarcoma treatment #SPAEN18 @JTrentMDPhD @sarcomapathents





**Roger Wilson CBE** @Amoscar · Feb 3  
@DrSarcoma gives first talk at #SPAEN18 Gives a personal history of being a doctor and how he got excited by oncology. Superb communicator. @sarcomapathents



**george demetri** @DrSarcoma · 19h  
Replying to @sarcomapathents  
Thanks to #SPAEN18 for helping to bring the world together and make it a better place for us all!



**Gistonline.it** @Barbaratamagni2 · Feb 4  
#SPAEN18 professionalism and interpersonal communications. Empathy is an integral aspect of Spae. We learned from the best





**GIST Support UK** · 5 Februar · 0  
This weekend our trustees Jayne and David were at the Sarcoma Patients EuroNet (SPAEN) conference in Milan discussing research, treatment, and patient advocacy.  
#GIST and #Sarcoma ESMO - European Society for Medical Oncology



**The Life Raft Group** · 6 Februar · 0

Life Raft Groups Program Operations Senior Director, Sara Rothschild, is representing us at the SPAEN (Sarcoma Patients EuroNet) and ESMO (European Society of Medical Oncology) GIST and Sarcoma Symposium in Milan, Italy. This combined meeting affords our organization the opportunity to network and learn from the foremost experts in GIST and Sarcomas and with other global advocacy organizations.



**Suomen Syöpäpotilaat ry** · 23 Feb · 0

SSP:n edustaja Annika Laakso valittiin helmikuussa Sarcoma Patients EuroNet -järjestön hallitukseen. Onnittelut Annikal! Matkoon ja Annikan matkaporssi SPAENin vuosikokouksesta sekä ESMO Sarcoma & GIST -tapahtumasta löytyy ohjelmaa linkistä. Übersetzung anzeigen



SSP:n edustaja Annika Laakso valittiin Sarcoma Patients EuroNet -järjestön hallitukseen - Suomen Syöpäpotilaat





**INFO SARCOMES** @infosarcomes · Following

#SPAEN18 : Sami & Angelika talking about the impact of #AYA #sarcoma on family life #cancer



9:51 AM · 4 Feb 2018



**Rachel Taylor** @ctandrrmt · 21h  
Nothing like a group photo to prove you've "worked" all weekend. Some work is better than others! Thank you @sarcomapathents for inviting me to your annual conference, very inspiring

**SPAEN @sarcomapathents**  
Today is World Cancer Day! SPAEN is meeting today for our Annual Conference, making the motto "We can, I can" come to life....



**WinetteVanDerGraaf** @Winette\_vdGraaf · Feb 3  
Quality of Life is hugely understudied in soft tissue #sarcoma. We should approach it from patients perspectives with sarcomas at different locations, this time not laying most emphasis on the different histologies. Interesting session #SPAEN18 @OlgaHusson @ctandrrmt @EORTC\_QLG



**Rachel Taylor** @ctandrrmt · Feb 3  
Inspiring talk from @DrSarcoma #SPAEN18 reduce regulation to facilitate trials in rare cancers



**Jon Trent, MD, PhD** @JTrentMDPhD · 21h  
Inspiring to be a part of @sarcomapathents #SPAEN18 for #sarcoma and #GIST2018 on @WorldCancerDay #WeCanICan with @DrSarcoma Ian Judson @royalmarsdenNHS @Winette\_vdGraaf @myESMO @spaen

**SPAEN @sarcomapathents**  
Today is World Cancer Day! SPAEN is meeting today for our Annual Conference, making the motto "We can, I can" come to life....

**ZIC @ZachPharmD** · Feb 3  
Dr. Jonathan Fletcher walking through what's new in the biological understanding of GIST #SPAEN18



**Bone Cancer Research Trust** · 4 Februar · 0  
Today for #WorldCancerDay we are at the 8th Sarcoma Patients EuroNet (SPAEN) Conference and we are taking a closer look at Sarcoma subtypes, namely osteosarcoma and Ewing sarcoma, which predominantly affect children and young adults as well as discussing Sarcoma treatment and fertility.





# Feedback

*“It was a pleasure to come and share our thoughts with you. The level of engagement was high, it was a great audience and a very good cause – very pleased that I was able to contribute. Very best wishes for the future.”*

*Ian Judson, UK*



*“Thank you for inviting me to speak. It was such an amazing atmosphere, so great to go to a conference which such passion.”*

*Sam Hackett, UK*



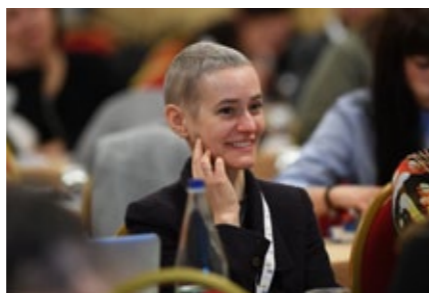
*“It was a fabulous opportunity to work toward our common goal. Let’s do keep “Changing The World”!”*

*Jonathan Trent, USA*



*“It was really terrific to work with the SPAEN group and share our complementary sets of expertise. Keep on doing all the wonderful work for patients and for our collaborative shared practices of patients, caregivers and sarcoma experts.”*

*George Demetri, USA*



*“It was a pleasure.... wishing SPAEN every continued success in your essential life-saving work.”*

*Jonathan Fletcher, USA*

*“What a great event - well done!”*

*Simon Crompton, UK*



*“An absolute pleasure to work with you all.”*

*Robin Jones, UK*

# Feedback

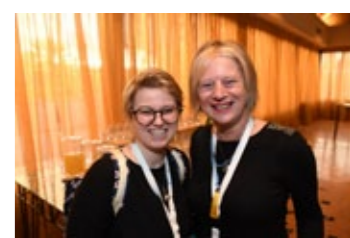
*“It was a great meeting  
and very well organized.  
Thanks for all of your hard work.”*

*Sara Rothschild, USA*



*“The presence of  
SPAEN has certainly  
been an added value  
to the meeting.”*

*Paolo Dei Tos, Italy*



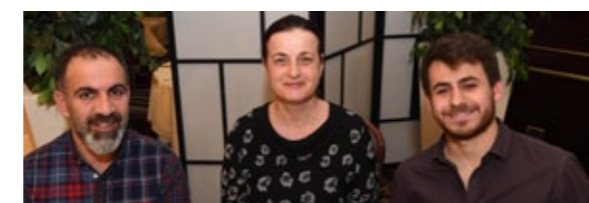
*“I would like to thank you for  
organizing this conference and  
enabling me to participate.  
It was an impressive program  
with a clear structure, mostly  
excellent speakers and the  
combination with ESMO was  
extremely valuable.”*

*Carline Kooy, The Netherlands*



*“Thanks for the warm hospitality and  
the precious conference.  
One of the most important benefits in  
the participation was the opportunity to  
communicate with colleagues and  
doctors from other countries.”*

*Barbara Tamagni, Italy*





Sarcoma  
Patients  
EuroNet

*Together We Can Make A Difference For Those Affected By Sarcomas!*



8<sup>th</sup> SPAEN Annual Conference  
for Organisations  
Representing Patients with  
Sarcomas, GIST or Desmoid-Tumours

3<sup>rd</sup> – 4<sup>th</sup> February 2018  
Milan/Italy



ESMO  
SARCOMA AND GIST  
SYMPOSIUM

5<sup>th</sup> – 7<sup>th</sup> February 2018  
Milan/Italy

## SPAEN at the EMSO Sarcoma and GIST Symposium

Participants of the SPAEN Conference were also welcome to attend the ESMO sarcoma & GIST symposium. Additionally, SPAEN also had a chance to address and discuss some of the concerns and thoughts from patient advocates' perspective during the experts' conference. The **"SPAEN Roundtable Session"** was held on Wednesday, February 7, at 15:30 pm. Roger Wilson and Paolo Casali hosted the session.



**Nikhil Guhagarkar**, India, board member of SPAEN spoke about the challenges patients with GIST and sarcoma face in India. With India being such a big and diverse country with a high density of inhabitants, challenges range from socio cultural to economic factors, to access to treatment, government support or insurance issues. "In premier oncological centres, almost a thousand cancer patients are treated every day", says Nikhil Guhagarkar. "And we can see more and more basic research being done in those centres." It is important to integrate learning between continents and explore how to have a meaningful exchange of information and knowledge. "The way forward is to pull in expertise and resources from all over the world to help each other understand and treat the disease."



**Kathrin Schuster**, Germany, communication manager at SPAEN spoke about why and how we should improve recruitment for clinical trials as a joint action between patient advocates and experts. As one of the most common challenges of randomized controlled trials are problems with recruitment, it is essential for patient advocates and experts to collaborate. Patient advocates face a number of challenges when they want to lobby for and inform about clinical trials: receiving information about trials, language issues (consistency, medical language), myths and misconceptions among patients and limited resources. Patient advocates should educate and inform about studies, point patients in the right direction and give early-on input to clinical studies. And experts should do their bit by providing up-to-date and (if available) lay information to patient groups, but also by designing studies that are really relevant to the patients and involve patient advocates early on in the design of the trial. "Together we could bring innovative and novel medication faster into clinical practice and to the patients", says Kathrin Schuster.

**Roger Wilson**, UK, co-founder and honorary president of SPAEN, highlighted the five challenges in sarcoma management from a patients' perspective that must be faced together with the experts. He started with the question "Why do so many promising drugs not work in sarcoma?" and – taking a step back - asked "Do we even know the questions that we need to ask?"

The young adults comprise a big group within the sarcoma patient community, but do we know and address the needs of those patients? "We could take the lead in improving care and support for this patient group in cancer", says Roger Wilson.

Another and essential topic not only for patients or experts, but also and especially for regulatory bodies is the definition of value for the patient. In a world where drugs become increasingly expensive and healthcare expenses challenge countries, defining value is a social and political need. "Assessment of and research about Quality of Life is essential. We need to complement objectively and subjectively gathered information to assess value of treatments."

Furthermore, a more strategic approach to set sarcoma clinical and research priorities is needed: How far can drug research take us? Do we need to look at other aspects such as innovation in radiotherapy surgery, making use of artificial intelligence?

As a last, but one of the most important aspects, Roger Wilson touched on "late diagnosis of many sarcoma patients": How can we convince healthcare systems of the value to patients for being seen as early as possible in expert centers? "We can help more patients survive longer with a better quality of life if they are diagnosed earlier than by any other means", summarizes Roger Wilson.



# About Sarcoma Patients EuroNet (SPAEN)



## Together We Can Make A Difference For Those Affected By Sarcomas!

Sarcoma Patients EuroNet (SPAEN), the International Network of Sarcoma, GIST and Desmoid Patient Advocacy Groups was founded in April 2009.

The organisation was born from a strong desire among various national patient groups to network, cooperate and share materials, knowledge and experiences.

Acting in partnership with clinical sarcoma experts, scientific researchers, pharmaceutical industry and other stakeholders, SPAEN is working to support sarcoma research and to improve the diagnosis, treatment and care of sarcoma patients through improving information and support and by increasing the visibility of sarcoma with policymakers and the public.

SPAEN is an international association, legally registered under German law. The network of currently 40 patient groups collaborates closely with international societies, networks or organisations such as ESMO, EORTC, EMSOS, CTOS, SARC, World Sarcoma Network, EMA or Rare Cancers Europe.

SPAEN also seeks exchange and close collaboration with currently 20 international cancer patient advocacy networks representing other cancer diagnoses.



## Sarcoma Patients EuroNet

### Our Objectives

- 1 To identify problems, challenges, access issues and unmet medical needs in sarcomas. To find solutions and improve the situation by collaborating with leading sarcoma experts, researchers, industry and other relevant international stakeholders/initiatives in an outcome-oriented way.
- 2 Sarcoma patients need timely and accurate diagnosis and need to be treated according to guidelines; ideally as early as possible in multidisciplinary sarcoma expert centres. SPAEN advocates and supports the implementation of these structures and international collaboration between these centres.
- 3 Clinical research, studies and generating evidence/data are essential parts in the process of developing better and innovative treatment solutions. SPAEN aims to be involved as early as possible in clinical trials, to improve patients' access to studies and to support meaningful research – following the specific needs of rare cancer patients.
- 4 Sarcoma patients and their relatives need a strong “International Sarcoma Patient Voice” and strong “National Patient Support Opportunities”. That’s why SPAEN cares for their members (national patient organisations) and encourages the creation of new ones.

### Our Vision

All sarcoma patients have access to:

- timely and correct diagnosis,
- information about their specific sarcoma subtype,
- treatment and care in specialised centres and
- innovative treatment options including clinical trials.

### Our Core Values

- Focused on the needs of the PAGs (patient advocacy groups) and the patients/caregivers
- Willingness to advocate
- High quality of information/education/training - correct, up-to-date, understandable, independent
- Cooperative and professional
- Ethical, transparent, behave with integrity
- Innovative spirit

# About The People Who Stand Behind SPAEN

An organisation is only as strong as its people: those within the organisation and those who work externally to support the organisation.

## Member Groups / Organisations

SPAEN welcomes every national Sarcoma, GIST or Desmoid Patient Group as full member. Full members are entitled to vote at the Annual General Meeting.

SPAEN also invites individuals who are interested in starting sarcoma, GIST or desmoid support groups in their own countries as well as professionals and consumers who want to be an integral part of this network, to become supporters of SPAEN. All members are part of a united international sarcoma community where we all have a better chance to make our voices heard.

## The elected SPAEN Board of Directors 2018:



Estelle Lecointe-Artzner, Chair (FR)



Markus Wartenberg, Chair (DE)



Kai Pilgermann, Financial Director (DE)



Gérard van Oortmerssen, Board Member (NL)



Annika Laakso, Board Member (FI)



Christina Baumgarten, Board Member (DE)



Nikhil Guhagarkar, Board Member (IND)



Roger Wilson, Honorary President (UK)

## Board of Directors

The “SPAEN Board of Directors” is a voluntary body of currently seven elected members who jointly run the organisation with the support of a part-time professionals, freelancers and two elected financial auditors. Board members are elected by the Annual General Assembly for the duration of four years.

The elected board of directors has the right to appoint up to 7 persons to support them in their tasks. The Board appointed Jessica Garcia, Spain/UK and Ferdinand Mwangura, Kenya († 28.2.2018) in 2016 and Sami Sandakly, France in 2018 as observers to the Board as well as Professor Bernd Kasper, medical oncologist and secretary of the EORTC Soft Tissue and Bone Sarcoma Group.

## Medical Advisory Board

Sarcoma Patients EuroNet has established a Medical Advisory Board with a high level of scientific expertise. Currently the following 14 experts are appointed as members of the SPAEN Medical Advisory Board:

Prof. Dr. Jean Yves Blay (Chair)	France/Lyon
Prof. Dr. Javier Martin Broto	Spain/Sevilla
Prof. Dr. Paolo Casali	Italy/Milano
Prof. Dr. Jean Michel Coindre	France/Bordeaux
Prof. Dr. Mikael Eriksson	Sweden/Lund
Craig Gerrand	UK/London
Dr. Alessandro Gronchi	Italy/Milano
Prof. Dr. Peter Hohenberger	Germany/Mannheim
Dr. Robin Jones	UK/London
Prof. Dr. Bernd Kasper	Germany/Mannheim
PD Dr. Peter Reichardt	Germany/Berlin
Prof. Dr. Piotr Rutkowski	Poland/Warsaw
Dr. Beatrice Seddon	UK/London
Prof. Dr. Winette van der Graaf	UK/London
Dr. Rick Haas	Netherlands/Amsterdam

## Appointed Board Members



Ferdinand Mwangura, Kenya († 28.2.2018)



Jessica Garcia, Spain/UK



Professor Bernd Kasper, Germany



Sami Sandakly, France



Sarcoma  
Patients  
EuroNet

## Corporate Membership / Supporters

SPAEN invites companies and individuals to become Corporate Partners/Supporters with an annual unrestricted grant. Corporate Members/Supporters include commercial companies organisations that would like to demonstrate their willingness to establish a long-term relationship with the association and an active commitment to sarcoma patients by supporting SPAEN. Therefore, SPAEN has developed a policy on commercial funding which provides a set of principles that will be used to guide SPAEN’s decisions. For further information please see: [www.sarcoma-patients.eu](http://www.sarcoma-patients.eu)

## SPAEN Administration Office



Michaela Geissler, Administration Office and Event Manager (DE)



Kathrin Schuster, Communication Manager (DE)



**Sarcoma  
Patients  
EuroNet**

**The International Network  
of Sarcoma, GIST and Desmoid  
Patient Advocacy Groups.**

**[www.sarcoma-patients.eu](http://www.sarcoma-patients.eu)**

#### **SPAEN Administration Office**

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SPAEN Registered Address –  
under German law –  
in Friedberg/Germany -  
registration-no. VR 2609  
Registered office/legal entity:  
Sarcoma Patients EuroNet e.V.  
Untergasse 36  
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Rare Cancers Europe (RCE)  
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