



**Sarcoma
Patients
EuroNet**

Conference Report

**6th SPAEN Annual Conference
for Organizations
Representing Patients
with Sarcomas, GIST or Desmoid-Tumours**

**November 19th – 21st, 2015
Dolce Hotel Chantilly/Paris (France)**

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



We would like to thank the following funders who have supported the 6th SPAEN Conference with an unrestricted educational grant: Bayer, Merck, Novartis, Pfizer, PharmaMar and Takeda. The funding is not related to any of the objectives of SPAEN or any of the objectives/content of the 6th SPAEN Conference in Chantilly, FR.

The idea, conception, planning, preparation, realization, management and the summary of the 6th SPAEN Annual Conference is the responsibility of the SPAEN Board without any influence from the sponsors/funders.

SPAEN is an independent European network of patient advocacy groups. It does not represent the commercial interests of any organisation. SPAEN's funding policy is based on our "Code of Practice".

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



Sarcoma
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Introduction

Sarcoma Patients EuroNet Association (SPAEN), the European Network of GIST, sarcoma and desmoid patient advocacy groups, was founded in April 2009 with the aim of bringing together information services, patient support and advocacy organisations for the benefit of sarcoma patients across the whole of Europe. Acting in partnership with clinical experts, scientific researchers, industry and other stakeholders, SPAEN is working to improve the treatment and care of sarcoma patients in Europe through improving information and support, and by raising the profile of sarcoma with policymakers and the public.

Eleven organisations initiated the foundation of SPAEN on the 6th of April 2009 in Bad Nauheim, Germany. Membership is open to patient groups working with sarcoma patients across Europe. By the end of 2015, SPAEN has 26 full members and further 8 associate members. SPAEN is a European association, legally registered under German law with short term goals and long term ambitions. It is supporting the growing pressure for better treatment of rare cancers through initiatives and groups such as Rare Cancers Europe, EUROSARC, ESMO and EORTC. Sarcoma Patients EuroNet e.V. / Association is supported by leading European sarcoma experts and expert groups as well as

the pan-European collaboration of sarcoma specialized researchers and medical experts. SPAEN has also established a Medical Advisory Board including 14 leading sarcoma experts from several nationalities covering all relevant disciplines.

From November, the 19th until the 21st 2015 the 6th SPAEN Annual Conference for member organisations and those seeking membership was held in Chantilly/Paris, France. The SPAEN Annual Conference was again very well attended with approximately 70 participants from more than 12 countries covering patient advocates, medical experts and researchers as well as the health industry. For the sarcoma patient community the SPAEN conference is always a valuable platform with an opportunity to learn about advances and challenges in the treatment of sarcomas, GIST and desmoids and to share experience and best practice.

Participants at the 6th SPAEN Annual Conference 2015 in Chantilly, France represented countries from all over Europe and beyond.

Among the topics this year were:

- From research to clinic: What does “personalized” medicine mean in sarcomas?
- Research spotlights: Trends and challenges in (rare) cancer research and understanding immune-oncology
- Improving our cancer research knowledge: Learning more about “evidence”
- Workshops on important patient advocacy issues such as “Awareness in sarcomas” and “Reality and challenges of sarcoma treatment in Eastern Europe”
- Parallel tracks for GIST, sarcomas and desmoid tumours with medical updates on current treatment options and ongoing clinical trials
- Sharing best practice sessions including patient driven research and crowdsourcing of patient data for GIST research
- Capacity Building: Risk management for Patient Advocacy Groups

The three day conference focused on research and treatment, advocacy and capacity building. Leading European sarcoma experts and additional speakers from other areas of expertise such as immunology, pathology or radiology joined the meeting to present the latest medical news, to

answer questions and to be available for discussions. It seems most notable that in 2015 a great number of patient delegates, medical experts and healthcare industry deciding to join SPAEN in Chantilly - despite the terroristic attacks taking place in Paris a few days before the start of the conference – and thus demonstrating their maintaining and strong interest in this disease group and in this association.

During the conference there was 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 was also 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 contributing their share to make a difference for the benefit of sarcoma patients. The upcoming challenges SPAEN is facing are establishing centers of excellence in each country in Europe, identifying where expert centers are needed and making sure that patients with these rare tumours are treated at those experienced and specialized centers and networks of excellence.



Day 1 – Thursday, November 19th, 2015



Markus Wartenberg



Geogre Moreau



Janet Shipley

Markus Wartenberg, Germany, Chair of the SPAEN Board and George Moreau, France, on behalf of the French Sarcoma Patient Advocacy Groups officially opened the 6th Annual SPAEN conference in Chantilly outside of Paris with a very warm welcome thanking all participants who decided to attend the conference in spite of the terrible attacks in Paris.

In a first “Research Spotlights” session Janet Shipley, UK, addressed trends and challenges in (rare) cancer research and Sylvie Rusakiewicz, France, gave an overview on understanding the immune system and how immune therapies work in oncology. The whole topic of immunotherapy has become very popular in the recent years especially due to its success in treating patients with malignant melanoma. Immunotherapy, also called immuno-oncology (IO) therapy is a novel way to treat cancer by activating the immune

system in the hope that it will attack the tumour. As an example Rusakiewicz described the mode of action of the tyrosine kinase inhibitor imatinib in GIST patients and could demonstrate that imatinib exhibits anti-cancer effects via immunomodulation in addition to its well known direct effect on GIST cancer cells via inhibition of the KIT gene. Moreover, the idea of combining imatinib plus immunomodulatory drugs may help to overcome situations where imatinib alone is not effective such as in wildtype GIST. However, data on this treatment strategy in GIST and sarcomas are very early and preliminary and it will certainly take a few more years before these strategies will really enter into the clinic.



Sylvie Rusakiewicz





Anette Duensing, USA

Anette Duensing, Pittsburgh, USA, opened the session “From Research to Clinic” with a vivid talk about the topic “What does “personalized medicine” currently mean in GIST, sarcomas and desmoids?” The idea of personalized or precision oncology can be elegantly summarized by “Tailoring the right therapy to the right patient at the right time”. As cancer can be understood as a disease of the DNA, exploring mutations and changes in the genetic material plays a major role in finding therapeutic targets. In her description she first covered the question “What are known targets in GIST, desmoid tumors and different sarcoma subtypes?” such as KIT mutations in GIST, beta-catenin mutations in desmoid tumours, and many sarcoma subtypes have very specific genetic abnormalities. Answering the question “What are the current techniques and procedures used by pathologists and researchers?” she presented conventional staining methods, immunohistochemistry and fluorescence in situ hybridization (FISH). “How does mutational analysis works?” - polymerase chain reaction (PCR) methods and next generation sequencing



Markus Wartenberg, Das Lebenshaus Germany and SPAEN Chair of the Board

(NGS) are used for performing mutational analysis and whole genome sequencing and, more recently, circulating tumour DNA in the patients’ peripheral blood is evaluated for the analysis of GIST mutations.

Finally, Markus Wartenberg stressed the importance of having information about the mutational status in GIST patients and pointed out that as of today performing these analysis is far away from being a standard diagnostic procedure and that there are great differences in the different European countries as well as in the USA. The main question “What can Patient Advocacy Groups do to support and improve the actual rate of patients receiving mutational analysis?” will certainly be discussed at the next New Horizons GIST meeting held in Barcelona in May 2016 because information about the mutational status can be helpful in guiding treatment decision making.

Participants not only discussed with medical experts, but also...



Sean Swarner, USA

The last session of the day was performed by Sean Swarner, Denver, USA, giving a “Motivational Lecture” titled “Keep climbing! How I beat cancer and reached the top of the world”. With only one functioning lung, a prognosis of fourteen days to live, and being in a medically-induced coma for a year, Sean Swarner was the first cancer survivor to stand on top of the world, the Mount Everest. He was diagnosed with two deadly, different, and unrelated forms of cancer, once at the age of thirteen and a second at the age of sixteen. After an incredibly poor prognosis, Sean astounded the medical community when he survived both diseases. He realized that after defeating cancer twice, no challenge would ever be too great, no peak too high. Sean proved his theory when he crested the peak of Mount Everest. As the first cancer survivor to do so, Sean decided to continue climbing and has since topped the highest peaks in Africa, Europe, South America, Australia, Antarctica, and North America, thus completing the “7-Summits”. As Sean continues to defy the odds, test his own endurance and inspire and motivate people around the world, he



shares his message of healing, hope, and triumph with cancer patients worldwide. Sean also serves as a source of inspiration as the founder of the non-profit organization, The CancerClimber Association, as author of the book “Keep Climbing” and as a motivational speaker to corporations, universities and other organizations around the globe. The participants felt enthusiastic about that highly motivating and personal talk.

... enjoyed the sessions.



Day 1 – Thursday, November 19th, 2015 – Internal Dinner



What is awareness?



For the first time at a SPAEN meeting, parallel working groups on important patient advocacy issues were initiated: one on the topic of “Awareness in sarcomas” and “Campaigning for Awareness” (Sarah McDonald and Claire Kelleher from Sarcoma UK) and another on “Sarcoma treatment reality and challenges in Eastern Europe” with a description of the current status quo (Michael Sayers and Markus Wartenberg). To further work on that topic and reach out for possible solutions to improve the situation in Eastern Europe, a round table meeting is planned for 2016. The individual group work was followed by presentations and discussions on the workshop results. Participants evaluated these workshops as highly stimulating and very fruitful in helping the groups in developing concrete strategies and programs within the different countries and patient advocacy groups.

Known sarcoma experts presented in parallel educational sessions about current aspects and questions, about new agents and clinical trials in the treatment of sarcomas, GIST and desmoid tumours. Therefore, we thank the following who provided their expert input (some in more than one session): Prof. Sebastian Bauer, Dr. Sarah Dumont, Prof. Bernd Kasper, Dr. Dario Callegaro, Prof. Anette Duensing, Prof. Isabelle Ray-Coquard, Dr. Rick Haas, Dr. Bas Hassan, Dr. Aisha Mia and Dr. Pramod Rao.



Claire Kelleher (left) and Sarah McDonald, Sarcoma UK



Piotr Fonrobert, Polish GIST group, in the Eastern Europe discussion group

GIST

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, the next promising candidate showing activity in this patient population is clearly regorafenib which has been approved by FDA and EMA as 3rd line treatment for advanced, metastatic GIST patients after imatinib and sunitinib failure. The phase III study leading to approval of regorafenib was the GRID trial which met its primary endpoint of improvement in progression-free survival (PFS). The median PFS was 4.8 months in the regorafenib arm versus 0.9 months in the placebo arm. The most common drug-related side effects included hand-foot skin reaction, hypertension, diarrhea, fatigue, oral mucositis, alopecia, anorexia, rash, nausea and constipation. Important topics that affect prognosis and survival in GIST as well as possible long-term side effects have been presented and discussed with the aim in mind to get the best out of the administered therapy. An update from SPAEN's Task Force on generic imatinib in the CML community and the possible consequences for the GIST patient community has been presented. The enthusiasm about the concept of targeted therapies in GIST is still outstanding even now, more than fifteen years after the first patient was treated with imatinib in the advanced setting. Therefore, spotlights on the actual GIST research and current and upcoming clinical trials have been discussed. Other tyrosine kinase inhibitors being currently tested in advanced GIST comprise masitinib, pazopanib and ponatinib. Localized treatment options being used in patients with progressive and advanced disease have been demonstrated such as surgery, radiofrequency ablation (RFA) and selective internal radiotherapy (SIRT). New strategies and protocols for the diagnosis and treatment of GIST patients within the MITIGATE consortium (www.mitigate-project.eu) were also presented. In this project there is a clear focus on the development of minimally invasive personalized treatment options using techniques such as microwave ablation, SIRT and irreversible electroporation. The MITIGATE project being co-funded from the European Commission will have a major, positive impact on the health of GIST patients and improve the available standard of care.



Sebastian Bauer, Germany



Bernd Kasper, Germany



Sarah Dumont, France

Sarcomas

Initially, a focus has been set on two different subtypes of soft tissue sarcomas this year: gynaecological sarcomas and retroperitoneal sarcomas were presented in a "sarcoma portrait". The last milestone enriching the treatment armamentarium for soft tissue sarcoma patients was the approval of the anti-angiogenic compound pazopanib in USA, Europe and Japan for certain subtypes of soft tissue sarcomas excluding liposarcomas. Pazopanib has been tested in a large EORTC phase III trial (PALETTE) demonstrating a significant advantage regarding PFS prolongation of about three months in favour of pazopanib versus placebo. Therefore, pazopanib has been included in the treatment armamentarium of soft tissue sarcomas in 2012 - five years after the approval of trabectedin in 2007. Regarding trabectedin, a large phase III study in the USA comparing trabectedin versus Dacarbazine (DTIC) again stressed the sustained activity of trabectedin in soft tissue sarcoma patients. Even though the primary endpoint, overall survival, was not reached in this study, the results have been sufficient for global registration of trabectedin by the FDA in October 2015 for the treatment of patients with leiomyosarcomas and liposarcomas. This year, new promising candidates for the treatment of advanced and / or metastatic soft tissue sarcomas are emerging such as Eribulin and Olaratumab. The phase III trial of Eribulin presented at this year's ASCO Meeting in Chicago met its primary endpoint of an overall survival benefit of two months (13.5 versus 11.5 months) in favour of Eribulin compared to DTIC in pretreated patients with advanced leiomyosarcomas or adipocytic sarcomas. Olaratumab, a fully human anti-PDGFR α monoclonal antibody, has been tested in a phase II trial in combination with Doxorubicin; results were also presented at ASCO this year. Olaratumab is the first agent added to Doxorubicin to improve overall survival (25.0 versus 14.7 months) in advanced / metastatic soft tissue sarcoma patients in a randomized setting. Short profiles and results of these important international clinical trials in soft tissue sarcomas were presented. New radiotherapy techniques in sarcomas have been illustrated and discussed. Again, it was pointed out that patients suffering from these rare diseases should preferably be treated in one of the specialized sarcoma units or networks of excellence. The concept of targeted therapies which was initiated in GIST at the beginning of the third millennium has obviously also opened new horizons in the field of soft tissue sarcomas. A better biological and cytogenetic dismemberment of sarcomas in general turns each histological subtype into a potential target for new therapeutic approaches which will bear fruit in the upcoming years. Generally spoken, there is a decline of conventional chemotherapy and a rise of new targeted therapeutics. Aisha Miah, London, UK, concluded the day with a discussion about the right handling of possibly removable lung metastases in sarcomas. A controversial discussion as, stated

Miah, there's no right way, but a variety of options ranging from surveillance, to metastasectomy, radiofrequency ablation, stereotactic radiotherapy and systemic therapy as a neo-adjuvant strategy. To date, the decision needs to be taken individually and depends on disease free interval, histological subtype and true oligometastatic disease. However, more data is required to establish criteria for the use of the different treatment modalities as well as to collect evidence to determine impact on survival.



Rick Haas, The Netherlands



Isabelle Ray-Coquard, France



Aisha Miah, UK

Desmoid Tumours

There was a focus on the diagnosis and treatment of this extremely rare and difficult to treat (but non-malignant) subtype of soft tissue sarcomas. The educational on desmoid tumours focused on diagnostic and treatment aspects such as pathology and mutational analysis, general management strategies of desmoid tumour patients as well as radiotherapy and cryoablation. Especially the importance of performing the mutational status has been stressed as it is not only helpful in establishing the diagnosis but can also have prognostic potential and may give advice in guiding treatment decisions. Last year, an initiative has been taken by SPAEN together with medical experts to organise a round table meeting to discuss aspects and unmet needs of desmoid tumour management. The round table meeting took place May 8th, 2014 in Frankfurt, Germany, bringing together about twenty patients and patient representatives with medical experts from the EORTC Soft Tissue and Bone Sarcoma Group (STBSG) from altogether six European countries. During this meeting, a European consensus approach has been initialized, and on the basis of this meeting a position paper has been coordinated and written by Bernd Kasper, Mannheim, Germany. Within this paper a treatment algorithm has been proposed. Meanwhile, the manuscript has been published in the European Journal of Cancer as a combined SPAEN and EORTC / STBSG initiative based on patients' and patient advocates' and professionals' expertise. This initiative and paper have been presented at the Desmoid Tumor Research Foundation (DTRF) Annual Patient Meeting in Philadelphia, USA, on October 17th, 2015. The following day an international research workshop was organized by the DTRF; a short report from this meeting has been included in the SPAEN program and was presented by Christina Baumgarten from sos desmoid, Germany, and Bernd Kasper. One interesting new treatment strategy in desmoids is Notch signaling. PF-03084014 from Pfizer is an oral reversible gamma-secretase inhibitor. Gamma-secretase cleaves intracellular Notch resulting in Notch signaling. A phase II study of PF-03084014 has been conducted in patients with progressive, symptomatic desmoid tumours that had progressed following at least one line of therapy and one partial response (6 %) was shown and 16 out of 17 patients (94 %) demonstrated stable disease. Hence, PF-03084014 seems active with a manageable side effect profile. Another interesting project launched by the DTRF is a patient reported outcome (PRO) development study in desmoid tumour patients which has been briefly presented. Regarding other current clinical trials in desmoid tumour patients two developments have to be mentioned: Sorafenib is tested in a phase III, randomized, double-blind, placebo-controlled setting in the USA. A randomized trial evaluating pazopanib versus chemotherapy with methotrexate plus vinblastine is ongoing within the French Sarcoma Group. In general, efforts are needed to make

imatinib and other tyrosine kinase inhibitors accessible for advanced desmoid tumour patients in countries where these drugs are not reimbursed.



Dario Callegaro, Team Alessandro Gronchi, Italy



Christina Baumgarten, sos desmoid Germany, SPAEN Board member, moderating the Desmoid track



Anette Duensing, USA



Pramod Rao, France



Roger Wilson, Sarcoma UK, SPAEN Honorary President moderating the Sarcoma track



Estelle Lecointe, Ensemble contre le GIST / Sarcomes France, SPAEN Chair of the Board and ...



... Markus Wartenberg moderating the GIST track



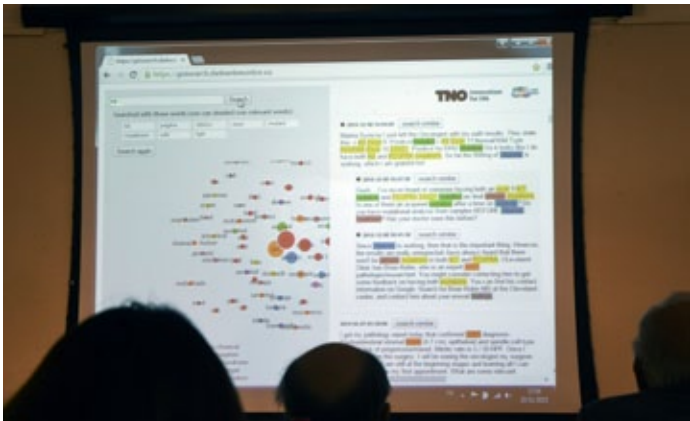
Rick Haas, The Netherlands

Day 2 – Friday, November 20th, 2015

In a “Sharing Best Practice” session the Sarcoma UK research experience was presented by Sarah McDonald from Sarcoma UK. The question if it is possible to “crowdsource” patient data and experiences for GIST research through a Patient Advocacy Group was presented by Gerard van Oortmerssen from the Contactgroep GIST, The Netherlands. The idea of this project is to go through patient discussion forums such as on Facebook and extract valuable information by using search engines for specific words or phrases connected to GIST and, hence, collect and analyze valuable information from the patient’s perspective. These interactive “Sharing Best Practice” sessions are always very welcome among the participants as own experiences can be exchanged and new initiatives can be launched between the different patient organizations.



The day ended with a warm tribute to Hans Keulen who sadly passed away October 29th, 2015 due to the consequences of chordoma, a rare type of bone cancer that affects the bone of the skull and spine. Hans dedicated the last years of his life to the Chordoma Foundation, to improve the lives of patients and to stimulate research for the treatment of this disease. He did all that with a great passion and drive and was a fantastic patient advocate and also a great representative of the European sarcoma patient community. Therefore, SPAEN dedicated this 6th Annual SPAEN Conference to Hans Keulen.



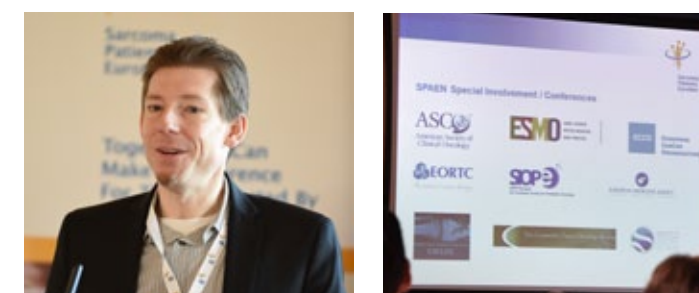
Day 2 – Friday, November 20th, 2015 – External Dinner



Day 3 – Saturday, November 21st, 2015

The third conference day started with the general assembly 2015/2016 of the SPAEN association. Markus Wartenberg on behalf of the SPAEN Board gave an overview of all the activities SPAEN is involved in such as patient engagement in clinical research and certain projects of collaborations with experts and industry. Currently, SPAEN is one out of 18 established Cancer Patient Advocacy Networks with 26 full members and eight associate members being more and more involved in different advisory boards and steering committees. There is an improving collaboration with ESMO (e.g. participating in the process of establishing the clinical practice guidelines, better integration of patient advocacy groups), EORTC (e.g. involvement in the EORTC training course "Understanding Cancer Clinical Research", providing involvement and information support in future sarcoma trials, communication of trial progress and results), Rare Cancers Europe (e.g. working on the methodology of clinical trials in rare diseases), the World Sarcoma Network, EUROSARC and the EURO EWING consortium.

Upcoming challenges SPAEN is facing are establishing where the centers of excellence in each country in Europe are and building up a network structure, identifying criteria and a kind of branding for European sarcoma centers of excellence, identifying where additional expert centers are needed and where new support organisations can be created. Further challenges include discussing the management of treatment side effects of oral targeted therapies and addressing problems of reimbursement, the strategic planning of the financial basis and personal resources of SPAEN in the near future. A mentoring and support project has been initiated together with the Sarcoma and GIST Patient Advocacy Groups in India; representatives of the Indian sarcoma and GIST patient community were also present at this year's SPAEN meeting. Special task forces and round tables for adherence and therapy side effect management, wildtype and paediatric GIST patients, for handling the generic imatinib and for the management of sporadic desmoid tumour patients have already been initiated or successfully completed. The financial cooperation with the pharmaceutical industry is structured as a sustaining partnership 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. All these activities of SPAEN can be appropriately summarized in SPAEN's slogan "Together we can make a difference for those affected by sarcomas!"



In a “Capacity Building” session Markus Wartenberg, Germany, addressed the topic of risk-management for Patient Advocacy Groups. Areas of risk for PAGs can be personal/patient data, online security, information quality, office space, staff/employees/freelancer, finance/funding, legal liability, knowledge transfer, copyright. Finally, an educational aimed to improve our cancer research knowledge: Learning more about “evidence” was presented by Amélie Anot, France: What does evidence mean? What are the different types and levels of evidence? How can we collect or generate evidence? Why is real world evidence becoming more and more important? In the second part PACE was presented by Samuel Thomas from Rose Li & Associates, USA. PACE, a Lilly Oncology initiative, stands for “Patient Access to Cancer Care Excellence”. PACE is a global initiative with the aim to encourage public policies and health care decisions that speed the development of new medicines, promote rapid learning from patient experiences, and assure that cancer treatment and care responds to the needs and qualities of individual patients. PACE is dedicated to encouraging the policy decisions that support the continuation of medical innovation and ensure patient access to the most effective cancer treatments. More information about this interesting initiative can be found on the website <https://pacenetwork.com>

The meeting ended with a short summary, closing remarks and a big thank you to the presenters and the “sustaining partners” by the SPAEN Board. SPAEN would especially like to thank the following research companies which supported the SPAEN Annual Conference 2015 with an unrestricted grant: Bayer HealthCare, Merck, Novartis, Pfizer, PharmaMar and Takeda.

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!”

Written and approved by:
Prof. Dr. med. Bernd Kasper,
University of Heidelberg,
Mannheim University Medical Center,
Interdisciplinary Tumour Center,
Sarcoma Unit Germany



Amélie Anot, France



Samuel Thomas, USA

DAY 1 – THURSDAY November 19, 2015

12:00	LIGHT LUNCH – (60 minutes)
13:00 – 13:30	OFFICIAL START OF THE CONFERENCE Welcome to Paris/Chantilly – on behalf of the SPAEN Board and the French Sarcoma Patient Groups <i>Estelle Lecointe (FR) - George Moreau (FR)</i>
13:30 - 14:30	FROM RESEARCH TO CLINIC <i>Moderator: Markus Wartenberg</i> What does “Personalized Medicine” currently mean in GIST/Sarcomas/Desmoids? What are known targets in the different subtypes? What are the current techniques/procedures used by pathologists? How does Mutational Analysis work? <i>Anette Duensing (USA)</i>
14:30 - 15:30	Discussion & Brainstorming: Status/Practice Mutational Analysis in different countries? What can Patient Groups do to support/improve the rate of patients receiving Mutational Analysis? <i>Markus Wartenberg (DE), SPAEN</i>
15:30 – 16:00	TEA / COFFEE BREAK (30 minutes)
16:00 - 16:45	RESEARCH SPOTLIGHTS <i>Moderator: Estelle Lecointe</i> Trends and challenges in (rare) cancer research? <i>Janet Shipley (UK)</i>
16:45 - 17:30	Understanding the Immune-System and how Immuno-Therapies (Immune-Oncology) work? <i>Silvie Rusakiewicz (FR)</i>
17:30 – 19:00	MOTIVATIONAL LECTURE Keep Climbing! How I Beat Cancer an Reached the Top of the World... Presentation & Questions <i>Sean Swarner (USA)</i>
BREAK BEFORE DINNER (30 minutes)	
19:30 - 22:00	Get Together (Hotel)

Conference Programme

DAY 2 – FRIDAY November 20, 2015

PARALLEL WORKING GROUPS ON IMPORTANT PATIENT ADVOCACY ISSUES			
8:30 – 10:00	Room: Van Gogh Sarcoma treatment reality/challenges in Eastern Europe: Status quo and ideas/solutions to improve the situation... <i>Chair: Michael Sayers, SPAEN Reporter: Markus Wartenberg, SPAEN</i>		Room: Albatros What means “Awareness in Sarcomas”? Campaigning for Awareness? Do we have examples? What would be the main / common objectives and how could we achieve them with joined activities in Europe and in the different countries? <i>Chair: Sarah McDonald & Claire Kelleher (Sarcoma UK) Reporter: Estelle Lecointe, SPAEN</i>
10:00 – 10:30	Presentation and discussion of workshops results		
10:30 – 11:00	TEA / COFFEE BREAK (30 minutes)		
	PARALLEL TRACKS FOR GIST, SARCOMA AND DESMOIDS		
	GIST TRACK Room: Albatros	SARCOMA TRACK Room: Van Gogh	DESMOID TRACK Room: Vermeer
11:00 – 11:45	Important topics that affect prognosis/survival in GIST... <i>Sebastian Bauer</i>	Sarcoma Portrait: Gynaecological Sarcomas <i>Isabelle Ray-Coquard</i>	Pathology <i>Anette Duensing</i>
11:45 – 12:30	Long-term side effects: What do we know? What do we need to know? <i>Sarah Dumont</i>	Sarcoma Portrait: Retroperitoneal Sarcomas (incl. High Vol. Centers) <i>Dario Callegaro</i>	Results of the mutational analysis of the GISG-01 study <i>Bernd Kasper</i>
12:30 – 14:00	LIGHT LUNCH and NETWORKING (90 minutes)		
14:00 – 14:25	Upcoming soon: Generic Imatinib for CML with impact also on GIST: Let’s discuss status and potential actions... <i>Markus Wartenberg</i>	New radiotherapy techniques in Sarcomas... <i>Rick Haas</i>	Report from the international research workshop <i>Bernd Kasper Christina Baumgarten</i>
14:25 – 14:45	New strategies and protocols for diagnosis and treatment of GIST: the MITIGATE project <i>Bernd Kasper</i>	4 short profiles of different international trials in Sarcomas: LINES, MEMOS, Lilly-trial and STRASS <i>Bas Hassan</i>	Cryoablation <i>Pramod Rao</i>
14:45 - 15:30	Localized treatment options under progression: Surgery, RFA, SIRT, etc. <i>Dario Callegaro</i>		
15:30 – 16:00	TEA / COFFEE BREAK (30 minutes)		

16:00 – 17:15	<p>Update on the research-journey in GIST:</p> <p>Basic research <i>Anette Duensing</i></p> <p>Clinical Trials <i>Sebastian Bauer</i></p>	<p>Lung Metast.: Making the right treatment choices. Collecting our questions to a route map for patients... <i>Aisha Miah</i></p>	<p>Radiotherapy in Desmoids <i>Rick Haas</i></p> <p>Surgery in Desmoids <i>Dario Callegaro</i></p> <p>Discussion <i>Dario Callegaro</i> <i>Bernd Kasper</i></p>
17:15 – 18:00	<p>SHARING BEST PRACTICE</p> <p>1. The Sarcoma UK Research Experience <i>Sarah McDonald, Sarcoma UK</i></p> <p>2. Crowdsourcing of patient data/experiences for GIST research? <i>Gerard van Oortmerssen, Contactgroep GIST NL</i></p>		
18:00 – 18:15	<p>Tribute to Hans Keulen</p>		
19:15	<p>Bus-Transfer & External Dinner</p>		
			
<p>DAY 3 – SATURDAY November 21, 2015</p>			
08:30 – 10:30	<p>Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2015/2016 All Conference Participants are welcome! (Voting Rights for SPAEN Members only...) This session has an official invitation / agenda</p>		
10:30 – 11:00	<p>TEA / COFFEE BREAK (30 minutes)</p>		
11:00 – 12:00	<p>CAPACITY BUILDING Risk-Management for Patient Advocacy Groups <i>Markus Wartenberg SPAEN</i></p>		
12:00 – 12:45	<p>SHORT LUNCH (45 minutes)</p>		
12:45 – 14:45	<p>EDUCATIONAL: IMPROVING OUR CANCER RESEARCH KNOWLEDGE Learning more about “EVIDENCE”</p> <ul style="list-style-type: none">- What does evidence mean?- Different “types/level” of evidence?- How to collect/generate evidence?- Why is “Real World Evidence” becoming more and more important? <p><i>Amélie Anota</i></p> <p>Lilly PACE: CII Continuous innovation indicator – a novel tool to measure progress in cancer treatments <i>Samuel Thomas, www.roseliassociates.com for Lilly</i></p>		
14:45 – 15:00	<p>Closing Remarks – End of Meeting <i>SPAEN Board</i></p>		



Estelle Lecointe



Markus Wartenberg



*Roger Wilson,
Honorary President
Sarcoma UK*



Kai Pilgermann



Christina Baumgarten



Michael Sayers



Ornella Gonzato



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

Sarcoma Patients EuroNet (SPAEN), the European Network of Sarcoma, GIST and Desmoid Patient Advocacy Groups was founded in April 2009. The organisation was born from a very 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 in Europe through improving information and support and by increasing the visibility of sarcoma with policymakers and the public.

SPAEN is a European association, legally registered under German law. The network of currently 32 patient groups across Europe 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 18 international cancer patient advocacy networks representing other cancer diagnoses.

Our Vision:

All Sarcoma patients in Europe 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 Objectives:

- Focused on the needs of the PAGs (patient advocacy groups) and the patients/caregiver
- 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

Our Core Values:

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 pan-European collaboration between these centres.
3. Clinical research, studies and generating evidence/data are essential parts of the process of developing better and innovative treatment solutions. SPAEN aims to be involved as early as possible in clinical trials, to try to improve patient's 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 “European Sarcoma Patient Voice” and strong “National Patient Support Opportunities”. That's why SPAEN cares for our members (national patient organisations) and encourages the creation of new ones.

Medical Advisory Board

Sarcoma Patients EuroNet has established a Medical Advisory Board with a high level of scientific expertise. The objectives of the Medical Advisory Board is to support SPAENin:

- gaining legitimacy within the European and International community of experts involved in Sarcoma, GIST and desmoid tumours;
- ensuring patient representation in and integration to major scientific committees and groups of experts at national and European levels.



The following 14 experts are appointed as members of the SPAEN Medical Advisory Board

Name	Field	Country/City	Expert-Group
Prof. Dr. Jean Yves Blay (Chair)	Oncology	France/Lyon	GSF GETO
Prof. Dr. Javier Martin Broto	Oncology	Spain/Palma	GEIS
Prof. Paolo Casali	Oncology	Italy/Milano	ISG
Prof. Dr. Jean Michel Coindre	Pathology	France/Bordeaux	GSF GETO
Prof. Dr. Mikael Eriksson	Oncology	Sweden/Lund	SSG
Prof. Dr. Robert Grimer	Surgery	UK/Birmingham	BSG
Dr. Alessandro Gronchi	Surgery	Italy/Milano	ISG
Prof. Dr. Peter Hohenberger	Surgery	Germany/Mannheim	GISG/KO.SAR
Prof. Dr. Ian Judson	Oncology	UK/London	BSG
PD Dr. Peter Reichardt	Oncology	Germany/Berlin	GISG
Prof. Dr. Piotr Rutkowski	Surgery	Poland/Warsaw	POLSG
Dr. Beatrice Seddon	Oncology	UK/London	BSG
Prof. Winette van der Graaf	Oncology	Netherlands/Nijmegen	EORTC STBSG
Dr. R.L.M. Haas	Radiotherapy	Netherlands/Amsterdam	EORTC STBSG

SPAEN Member Organisations



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SPAEN Full Members

1. Austria: GIST Support Austria
2. Bulgaria: GIST Alliance for Patients Bulgaria
3. Finland: Finnish GIST Patient Network
4. France: A.F.P.G. "Ensemble contre le GIST"
5. France: Info Sarcomes
6. France: SOS Desmoide France
7. Germany: Das Lebenshaus e.V./House of Life
8. Germany: SOS Desmoids
9. Italy: A.I.G. Associazione Italiana GIST
11. Italy: Le Ali Onlus
12. Italy: Luogo di incontro per scambiarsi informazioni sul tumori Desmoide o Fibromatosi aggressiva
13. Italy: Associazione Paola per i Tumori Muscoloscheletrici. Onlus
14. Macedonia: Patient Advocate from Macedonia
15. Netherlands: Contactgroep GIST
16. Netherlands: Stichting Sarcoma Nederlands
17. Netherlands: Chordoma Foundation Europe
18. Norway: Sarkomer
19. Poland: Stow. Pomocy Chorym Na GIST
20. Poland: Stow. Pomocy Chorym Na Miesaki "Sarcoma"
21. Romania: HomeCare Association
22. Spain: Sarcoma Patients Spanish Association/Asociación Española de Afectados por Sarcoma (AEAS)
23. Sweden: Sarkom Sverige
24. Switzerland: GIST Gruppe Schweiz
25. Switzerland: swiss sarcoma
26. UK: GIST Support UK
27. UK: Bone Cancer Research Trust
28. UK: Guy Francis Bone Cancer Research Fund
29. UK: Sarcoma UK
30. USA: The National LeioMyoSarcoma Foundation

SPAEN Associate Members

1. Curacao: Synovial Sarcoma Research Foundation
2. India: Friends of Max (GIST) – Max Foundation
3. India: Spandan – Sarcoma Patient Support Group India
4. Israel: Israeli GIST patient organisation
5. Turkey: Genç Birikim Derneği Youth Accumulation Association
6. USA: GSI – GIST Support International
7. USA: Sarcoma Alliance



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Contact

Sarcoma Patients EuroNet e.V./Assoc.
SPAEN Administration Office

Mrs. Michaela Geissler
Am Rothenanger 1B
D-85521 Riemerling, Germany
Tel.: + 49 89 62836807
Fax: + 49 89 62836808
Email: info@sarcoma-patients.eu
Web: www.sarcoma-patients.eu

Mrs. Kathrin Schuster
Prielstr. 6
86911 Dießen am Ammersee
Mobil +49 (0)162- 97 68 717

Email: info@sarcoma-patients.eu
Web: www.sarcoma-patients.eu

SPAEN is registered as an association
under German law in Friedberg/Germany -
Registration-No. VR 2609

Registered office/legal venue:
Sarcoma Patients EuroNet e.V./Assoc.
Untergasse 36
61200 Wölfersheim/Germany