



**Sarcoma
Patients
EuroNet**

Conference Report

**5th SPAEN Annual Conference
for Organizations
Representing Patients
with Sarcomas, GIST or Desmoid-Tumours**

**November, 13th – 15th 2014
The Crown Plaza, Amsterdam, NL**

**A Better Future For Patients
With A Rare Cancer.**

Acknowledgements

We would like to thank the following funders who have supported the 5th SPAEN Conference with an unrestricted educational grant: Bayer, GSK, Novartis, PharmaMar, Pfizer and Takeda. The funding is not related to any of the objectives of SPAEN or any of the objectives/content of the 5th SPAEN Conference in Amsterdam, NL.

The idea, conception, planning, preparation, realisation, management and the summary of the 5th SPAEN Annual Conference, is the responsibility of the SPAEN Board without any influence from the sponsors/funders.

We are looking forward to continuing these open and transparent partnerships with the healthcare industry. This will help us achieve our goal of collaboration with independent sarcoma cancer patient organisations on a European and global level, to improve the lives of sarcoma cancer patients at a national level.





At the request of the Board of Directors, SPAEN received equal grants from these Sustaining Partners.

This funding has no bearing on any of SPAEN's objectives or any of the objectives / content of the SPAEN Annual Conference.

The idea, conception, planning, preparation, realisation, management and report of the SPAEN Conference 2014 were the sole responsibility of SPAEN 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 creating

"A Better Future for Patients with a Rare Cancer!"

Sarcoma Patients EuroNet

Introduction

Sarcoma Patients EuroNet Association (SPAEN), the European Network of GIST, desmoid and sarcoma 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. SPAEN is a European association, legally registered under German law with some 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 13th until the 15th 2014 the 5th SPAEN Annual Conference for member organisations and those seeking membership was held in Amsterdam, The Netherlands. The previous SPAEN annual conferences were very well attended with over 80 participants from more than 15 countries covering patient advocates, medical experts and researchers and the health industry. For the sarcoma patient community the SPAEN conference is 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.

Among the topics of the 2014 SPAEN Conference were:

- Patient involvement in clinical research
- What does it mean to live with a sarcoma?
- Treatment and Care: Diagnostics
- Parallel tracks for GIST, sarcomas and desmoids with medical updates on current treatment options and ongoing clinical trials
- Market place and sharing best practice sessions
- Session on pharma relations: Working with the health-care industry

The three day conference focused on research and treatment, advocacy and capacity building. Leading European sarcoma experts and additional speakers joined the meeting to present the latest medical news, to answer questions and to be available for discussions.

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 where are the centers of excellence in each country in Europe, identifying where expert centers are needed and make sure that the patients with these rare tumours are treated at those experienced and specialized centers and networks of excellence.



Day 1 – Clinical Research





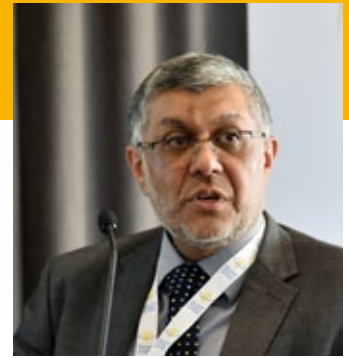
Roger Wilson



Markus Wartenberg



Gerard van van Oortmerssen



Raz Dewji

After the opening of the 5th Annual SPAEN conference by Roger Wilson (SPAEN President, UK) and Markus Wartenberg (SPAEN Board, Germany) and a warm welcome on behalf of the Dutch GIST-Patient Group (Gerard van Oortmerssen, The Netherlands), Raz Dewji from GSK, United Kingdom, opened the part I of the “Clinical Research” session with a vivid description of the drug development process - a highly complicated, long-lasting and cost intensive process. It covers basic chemistry and drug discovery at the early beginning, the preclinical and clinical development phase ending up eventually on the market as an approved medical compound. This process may take 10 to 15 years or even longer and may cost around one billion US dollar. One major step in this process is the clinical testing in human beings within phase I-III clinical trials; however, after approval of the drug the post approval testing in phase IV trials is essential to collect real life data of

newly introduced compounds. Raz Dewji pointed out that the whole process should be a working together within a sustainable partnership including industry, prescribers, regulators, the society and the patients.

Clinical endpoints in sarcoma trials were discussed by Winette van der Graaf, The Netherlands, current chair of the Soft Tissue and Bone Sarcoma Group (STBSG) from the European Organisation for Research and Treatment of Cancer (EORTC). Currently open clinical trials within STBSG are the STRASS study (surgery plus or minus radiotherapy in retroperitoneal sarcomas) and the CREATE trial (crizotinib targeting the ALK pathway in rare subtypes of soft tissue sarcomas such as alveolar soft part sarcomas and clear cell sarcomas). New initiatives of the STBSG include database related projects, bone sarcoma trials, a liposarcoma platform, imaging studies, quality of life evaluations



Day 1 – Clinical Research



and a consensus initiative for desmoid tumour patients in cooperation with SPAEN. She described the advantages and disadvantages of possible endpoints in clinical trials such as the objective response rate, overall survival, progression-free survival or patient related outcome measures. In recent years, especially the progression-free survival turned out to be a valuable endpoint in smaller studies in rare cancer types such as soft tissue sarcomas. Just to give an example for the design of clinical studies in sarcomas, Winette van der Graaf presented retrospective data from an evaluation of the elderly sarcoma population (age > 65 years) in the Netherlands and stressed that roughly half of the patients belong to this patient group, but only 11 % of them were actually treated within clinical trials. The Rare Cancers Europe initiative was briefly presented and it was pointed out that a methodological position paper on recommendations for the design of clinical trials in rare cancers has just been published in the Annals of Oncology addressing the fundamental requirements of clinical trials

in rare tumour subtypes. The ultimate goal of this initiative is to make sure that rare cancer patients, including sarcoma patients, are not discriminated because of the rarity of their diseases and the sarcoma community plays a driving role in this initiative.

In the part II of the "Clinical Research" session Antoine Italiano, France, summarized the last 10 years of studying targeted therapies: what did we learn so far? Imatinib in GIST documented the proof of principle for the activity of targeted therapies in sarcomas. For soft tissue sarcomas, there has been a paradigm shift from conventional chemotherapies to targeted agents such as trabectedin, where a distinct mode of action has been described in the last few years suggesting that trabectedin is a targeted chemotherapy, and more recently pazopanib as a multityrosine kinase inhibitor with anti-angiogenic properties. It is extremely important not to lump together all sarcoma subtypes in one clinical study as we often did in the past years;





Winette van der Graaf



Antoine Italiano



Irene Garcia Bravo



Hans Gelderblom

we have to identify targets and pathways in the different sarcoma subtypes and should design specific histotype driven clinical trials.

The drug approval process in Europe was presented from Irene Garcia Bravo from the European Medicines Agency (EMA) in London, United Kingdom. One of the important aspects she addressed was the question which role do patients and patient organisations play in this process? There is an established framework of interaction with the ultimate goal to involve patient organisations into the EMA activities. Patients and patient organisations are involved in the scientific advice, the benefit / risk evaluations and EMA communications representing the patient's interests and providing a patient's perspective.

In the "Clinical Research" session part III Hans Gelderblom, The Netherlands, and Abigail Evans, United Kingdom, gave feedback from EU research projects where SPAEN is involved such as EUROSARC and the EuroEwing Consortium.

EUROSARC is a research network for bone and soft tissue sarcomas with the aim to perform translational research projects and to initiate academic trials, for example, a number of trials have been initiated evaluating the efficacy of regorafenib in bone and soft tissue sarcomas.

The last interactive session of the day tried to answer the question "What does it really mean to live with a sarcoma, GIST or a desmoid tumour? In four short key note lectures aspects of living with cancer were presented. Andrew Sheppard, United Kingdom, addressed the topic "How does a sarcoma affect young adults?" Jayne Bressington, United Kingdom, spoke about "How to change your diet after stomach surgery?" Roger Wilson, United Kingdom, addressed the topic of palliative care and what to do "If treatment comes to an end?" Pain evaluation and the importance of an adequate pain management in patients with desmoid tumours was presented by George Moreau, France, based on a survey which has been performed by SOS desmoïde in France.



Day 2 – Treatment and Care, parallel tracks for GIST, sarcoma and desmoids and market place sessions





Christina Messiou

The session "Treatment and Care: Diagnostics" started with the important role of pathology in sarcomas presented by Pancras Hogendoorn, The Netherlands. In particular, he gave an update based on the revised 2013 World Health Organisation (WHO) classification for soft tissue and bone sarcomas as a standardized diagnostic terminology. Some major changes of the new version comprise the addition of new entities such as GIST and malignant nerve sheath tumours as well as the incorporation of more detailed cytogenetic and molecular data. Radiological modalities in sarcomas were excellently illustrated by Christina Messiou, United Kingdom. In principle, there are two different imaging modalities: imaging of the morphology and imaging of the function. The routine imaging, of course, is based on morphology using computed tomography and magnetic resonance imaging. Functional imaging is performed mainly using positron emission tomography. Again, it was pointed out that patients should absolutely be referred to specialized and experienced sarcoma centers or networks - also for questions of radiology - not to miss any information or mistreat the patients. Another important task of radiology is the tumour response assessment using classifications such as the Response Evaluation Criteria in Solid Tumors (RECIST) which is based on tumour size only or alternatively the CHOI criteria based on tumour size and tumour density for soft tissue sarcomas (Non-GIST) and GIST.

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. Also very rare types of sarcomas were covered on the agenda. Therefore, we thank the following who provided their expert input (most of them in more than one session): Dr. Ramesh Bulusu, Prof. Bernd Kasper, Prof. Peter Hohenberger, Prof. Jean Yves Blay, Prof. Uta Dirksen, Prof. Alessandro Gronchi, Prof. Sylvie Bonvalot, Dr. Odile Oberlin, Dr. Nick Gough, Dr. Danique van Broekhoven and Nicolette Leijerzapf.



Pancras Hogendoorn



Dr. Ramesh Bulusu

Day 2 – Treatment and Care, parallel tracks for GIST, sarcoma and desmoids and market place sessions

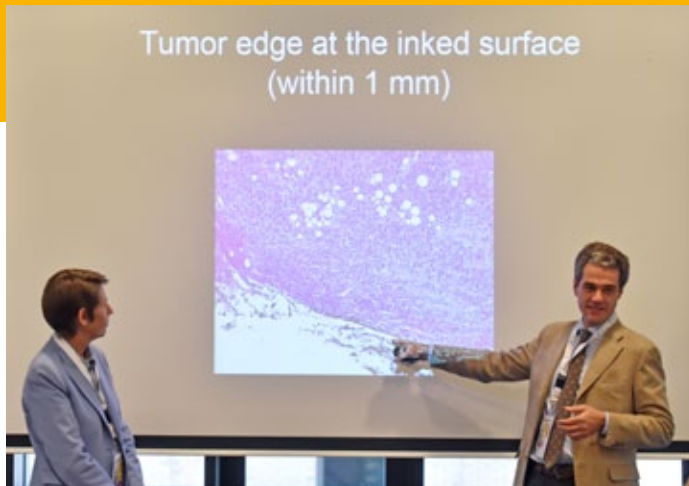
GIST

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 recently been approved by FDA and EMA as 3rd line treatment for advanced, metastatic GIST patients after imatinib and sunitinib failure. The GRID study 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. Evidence and practical experiences as well as the importance of an adequate side effect management regarding treatment with regorafenib in GIST have been presented with the aim in mind to get the best out of your therapy. Health care professionals dealing with Regorafenib should assess patients early and regularly, take prompt action, and educate, advise and manage patients appropriately.



The enthusiasm about GIST and the concept of targeted therapies in this disease is still outstanding even now, fourteen years after the first patient was treated with imatinib in the advanced setting. Therefore, spotlights on the actual GIST research have been discussed such as Non-KIT/PDGFR GIST as well as the role of circulating DNA and liquid biopsies. Local interventions being used in patients with progressive and advanced disease have been demonstrated such as surgery, laser, radiofrequency ablation (RFA) and selective internal radiotherapy (SIRT).





Prof. Sylvie Bonvalot & Dr. Alessandro Gronchi



Prof. Bernd Kasper

Sarcomas

A focus has been set on the treatment of bone sarcomas in children, teenagers and young adults with an introduction into the treatment strategies of osteosarcoma and Ewing sarcoma. Another focus has been set on a certain subtype of soft tissue sarcomas: gynaecological sarcomas. 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) in collaboration with GSK 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. Surgery in sarcomas starting from treating the basic limb tumour, using radiotherapy prior to surgery, the role of adjuvant therapies (radio- or chemotherapy) and using more advanced techniques such as isolated limb perfusion have been illustrated and discussed based on case descriptions. Moreover, the topic of oligo-metastasis in sarcomas - local surgery versus systemic treatment options - has been presented controversially. Again, it was pointed out that patients suffering from these rare diseases should be preferably treated in one of the specialized sarcoma units or networks of excellence. Additionally, new UK research on health related quality of life in advanced sarcoma patients was presented. The concept of targeted therapies which was initiated in GIST at the beginning of the third millennium has obviously 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.



Prof. Peter Hohenberger



Prof. Jean Yves Blay

Day 2 – Treatment and Care, parallel tracks for GIST, sarcoma and desmoids and market place sessions

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 focused on treatment aspects such as surgery including a front-line watch & wait strategy, new pathology aspects and general management strategies of desmoid tumour patients. Pain management and patient related problems in desmoid-type fibromatosis have also been addressed. Last year, an initiative has been taken by SPAEN together with medical experts to organise a round table meeting to discuss needs and aspects of desmoid tumour treatment. The round table meeting took place on the 8th of May 2014 in Frankfurt, Germany, bringing together about twenty patients and patient representatives with medical experts from the EORTC / STBSG from altogether six European countries. During this meeting, a European consensus approach has been initialized, and on the basis of this meeting a consensus paper has been coordinated by Bernd Kasper, Mannheim, Germany. Within this paper a treatment algorithm has been proposed. The manuscript has been discussed and approved during the last STBSG meeting held in Berlin, Germany, during the CTOS meeting. The full paper has already been accepted by the European Journal of Cancer and will be published very soon as a combined SPAEN and EORTC / STBSG initiative based on patients' and patient advocates' and professionals' expertise. Regarding 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. In the case of a positive outcome of this registration trial, sorafenib will certainly change the landscape of systemic treatment options for desmoid tumours. 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.



Prof. Sylvie Bonvalot



Prof. Uta Dirksen



Dr. Alessandro Gronchi



Day 2 – Treatment and Care, parallel tracks for GIST, sarcoma and desmoids and market place sessions

For the second time at a SPAEN conference, an advocacy market place session was performed with four parallel sessions from which delegates could choose three sessions dealing with the following topics: Peer to peer support (Claire Kelleher, Sarcoma UK), How to support scientific research as a patient group (Sarah McDonald, Sarcoma UK), Who cares for the carer (Judith Robinson, GIST Support UK) and Getting the best out of your meetings (David Falconer, GIST Support UK). This format was very well accepted and should be continued in future meetings.



David Falconer with his group on "Getting the best out of your meetings"

Claire Kelleher with her group on "Peer to peer support"





Dr. Danique van Broekhoven



Dr. Odile Oberlin



Sarah McDonald with talking about "How to support scientific research as a patient group"



Dr. Nick Gough



Judith Robinson with the group talking about "Who cares for the carers"



Nicolette Leijerzapf

Day 3 - SPAEN AGM & Sharing best practice



Day 3 - SPAEN AGM & Sharing best practice

The third conference day started with the general assembly 2014/2015 of the SPAEN association. The 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 15 established Cancer Patient Advocacy Networks with 26 full members and six 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 being summarized in a position paper as described above), the World Sarcoma Network and EUROSARC.

Upcoming challenges SPAEN is facing are establishing where the centers of excellence in each country in Europe are and building up a network structure (EU reference network in sarcomas), 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. Special task forces and round tables for adherence and therapy side effect management, wildtype and paediatric GIST patients and desmoid tumour patients have already been successfully initiated or 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.



Day 3 - SPAEN AGM & Sharing best practice

5th SPAEN Annual Conference 2014: Members elected a new Board of Directors.

The association - with currently 32 member organisations - has just held its 5th Annual Conference in Amsterdam with more than 80 delegates from 20 countries including patient advocates, medical experts and researchers and the pharmaceutical industry. For the sarcoma patient community the annual SPAEN conference is a valuable opportunity to learn about advances and challenges in the treatment of Sarcomas (Soft Tissue Sarcomas, GIST, Desmoids, Bone Cancer) and to share experience and best practice. The three day conference focuses on research, state of the art treatment and advocacy. Leading European sarcoma experts and other invited speakers join the meeting to present the latest medical news, to discuss unmet medical needs in sarcomas and to be present for questions and detailed discussions.

During the conference there was general agreement between all involved that by working together research in sarcomas can be completed more quickly and new treatments introduced faster. *"Sarcomas are a heterogeneous group of tumours. Looking to the currently available systemic treatments and the more than 60 different sarcoma subtypes: We definitely need more and better treatment options. We have seen major advances in sarcoma subtypes such as GIST (Gastrointestinal Stromal Tumours). Why shouldn't this be achievable in other sarcoma subtypes? Close collaboration between all stakeholders incl. the patient community is one of the success factors for better and faster research,"* said Estelle Lecointe SPAEN-Board Member and the driving force behind GIST- and Sarcoma patient advocacy in France.

"A major challenge for many patients in the different European countries is to find the medical experts who are really experienced in the diagnosis and treatment of sarcomas - as early as possible" stated Markus Wartenberg SPAEN-Board Member and involved in Sarcoma Patient Advocacy Activities in Germany. Wartenberg added: *"We know that there are significant differences in outcome and prognosis for patients treated in sarcoma centres of excellence com-*

pared to other hospitals with less knowledge, experience and without multidisciplinary teams. We need to refer patients as early as possible into the process of qualified sarcoma management. This is one of the future tasks SPAEN will take on together with our colleagues from the sarcoma expert community."

During this year's Annual Conference, SPAEN also held its Annual General Meeting (AGM) with elections to the SPAEN Board of Directors. The assembly confirmed that the previous Board Members should retain their places on the Board for the next 4 years and elected new members to the Board. The newly established Board will now be jointly chaired by Estelle Lecointe from France and Markus Wartenberg from Germany. Both stated that they would be very honoured and motivated to chair the board and lead SPAEN as an organisation together with a very good team of experienced colleagues for the next four years.

The members of the newly established SPAEN-Board are:

Estelle Lecointe (FR) - Chair of the Board

Responsible for medical development/topics - relations with the Sarcoma Expert Community/Societies/ Networks

Markus Wartenberg (DE) - Chair of the Board

Responsible for organizational development/topics - relations with the Healthcare Industry and other Societies/ Networks

Kai Pilgermann (DE) - Board Member / Financial Director

Lindsey Bennister (UK) - Board Member / Secretary

Christina Baumgarten (DE) - Board Member / Patient Expert for Desmoids

Michael Sayers (UK) - Board Member / Patient Expert for GIST

Ornella Gonzato (IT) - Board Member / Patient Expert for Bone Cancer



Due to personal health issues and the limited ability to travel, former SPAEN President Roger Wilson (UK) was not able to run again for the presidency. But the assembly elected him as the first and only *"SPAEN Past/Honorary President."* In this new role, Roger remains highly committed to supporting the new SPAEN Board with his knowledge and experience.

Day 3 - SPAEN AGM & Sharing best practice

SPAEN's mission is: "Improving the situation of Sarcoma Patients and their relatives in Europe!" This can be only achieved through close collaboration with relevant organisations such as EORTC, EORTS-STBSG, EMSOS, CTOS, ESMO, ECCO, ESSO, SIOP, Rare Cancers Europe, EMA, HTA-bodies, ESO, the Pharma Companies, national sarcoma expert groups, other cancer patient networks and other stakeholders in an outcome-oriented way.



Estelle Lecointe



Markus Wartenberg



Kai Pilgermann



Christina Baumgarten



Michael Sayers



Ornella Gonzato

For the coming years, SPAEN has recognised the following four main general 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 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 their members – the existing national patient organisations and encourages the creation of new ones.

The newly established SPAEN Board of Directors is highly committed to continuing and extending their efforts to move the organisation forward, to give their member organisations the best possible support and to improve the long term situation of sarcoma patients and their relatives in Europe. The first face to face meeting of the new Board is planned for the end of January 2015 to finalize the project- and activity plan for 2015.



Lindsey Bennister

Day 3 - SPAEN AGM & Sharing best practice

In a **“Sharing Best Practice”** session examples of successful partnerships between patients, patient advocates and medical professionals were presented followed by an interactive discussion. Firstly, Hans Keulen, The Netherlands, presented the concept and story of the Chordoma Foundation as an excellent example of patients driving research in rare cancer types. He also underlined the launch of a biobank in the US and Europe as well as the Chordoma Registry as a prospective patient database, one of the main achievements of the Chordoma Foundation. Secondly, successful ideas, projects and initiatives resulting from patient groups and experts relationships were presented with examples from Bulgaria (An update from the GIST Group Bulgaria) and The Netherlands (GIST Contactgroep NL: Extracting medical data from patient discussion forums and social media).

Finally, Markus Wartenberg (SPAEN, Germany) addressed the topic of pharma relations in a special lecture describing ways of working in collaboration with the healthcare industry. (...)

The meeting ended with a short summary, closing remarks and thanks to the presenters and the “sustaining partners” by Roger Wilson and Markus Wartenberg. SPAEN would especially like to thank the following research companies which supported the SPAEN Annual Conference 2014 with an unrestricted grant: Bayer HealthCare, GSK, Novartis, Pfizer, PharmaMar and Takeda. SPAEN is looking forward to continuing these partnerships on the way to creating **“A better future for patients with a rare cancer”**.



Hans Keulen, Chordoma Foundation



Gerard van Oortmerssen



Markus Wartenberg

Conference Programme

DAY 1 – THURSDAY November 13, 2014

12:00	LIGHT LUNCH – (60 minutes)
13:00 – 13:30	OFFICIAL START OF THE CONFERENCE Opening, Welcome, Organizational Issues, Thanks to the Sponsors, etc. <i>Roger Wilson, UK & Markus Wartenberg, DE</i> Welcome on Behalf of the Dutch GIST-Patient Group <i>Gerard van Oortmerssen, GIST Contactgroep NL</i>
13:30 - 14:15	CLINICAL RESEARCH – Part I The Drug Development Process <i>Raz Dewji, GSK, UK</i>
14:15 - 15:00	Clinical Endpoints in Sarcomas <i>Prof. Winette van der Graaf, NL</i>
15:00 – 15:30	TEA / COFFEE BREAK (30 minutes)
15:30 - 16:15	CLINICAL RESEARCH – Part II 10 Years of Studying Targeted Therapies: What did we learn so far? <i>Dr. Antoine Italiano, FR</i>
16:15 - 17:00	Patient Participation in Rare Cancer Research: The Chordoma Foundation as a driving force... <i>Hans Keulen, NL</i>
17:00 – 17:10 17:10 – 17:20	CLINICAL RESEARCH – Part III Feedback from EU Research Project where SPAEN is involved Eurosarc EuroEwing Consortium <i>Dr. Abigail Evans, UK & Prof. Hans Gelderblom, NL</i>
17:20 – 18:00	What does it really mean to live with a Sarcoma, GIST or Desmoid? (4 key note lectures a 10 minutes plus podium discussion) How does a sarcoma affect young adults? <i>Estelle Lecointe, FR</i> How to change your diet after gastric surgery? <i>Jayne Bressington, UK</i> If treatment comes to an end <i>Estelle Lecointe, FR</i> Pain management in desmoids <i>George Moreau, FR</i>
18:00 – 18:30	Podium Discussion
18:30 – 19:30	BREAK BEFORE DINNER (60 minutes)
19:30 - 22:00	Internal Get Together (Manhattan Bar & Restaurant one o one)

Conference Programme

DAY 2 – FRIDAY November 14, 2014

9:00- 9:45	TREATMENT AND CARE: DIAGNOSTICS		
9:45 - 10:30	The Role of Pathology in Sarcomas <i>Prof. Pancras Hogendoorn, NL</i> Radiology Modalities in Sarcomas <i>Dr. Christina Messiou, UK</i>		
10:30 – 11:00	TEA / COFFEE BREAK (30 minutes)		
	PARALLEL TRACKS FOR GIST, SARCOMA AND DESMOIDS		
11:00 – 11:45	GIST TRACK Room: Broadway Chairs: <i>Kai Pilgermann & Markus Wartenberg</i> Overview Wild-Type / Non KIT/PDGFR GIST <i>Dr. Ramesh Bulusu, UK</i>	SARCOMA TRACK Room: Times Chairs: <i>Estelle Lecointe</i> Bone Sarcomas in Children, Teens and Young Adults: Osteosarcoma Ewing Sarcoma <i>Prof. Uta Dirksen, DE,</i>	DESMOID TRACK Room: Square Chairs: <i>Christina Baumgarten & Hilly van der Zande</i> Consensus paper on current treatment of desmoids <i>Prof. Bernd Kasper, DE</i>
11:45 – 12:30	After EMA-Approval: Evidence and Practical Experiences with Regorafenib <i>Prof. Bernd Kasper, DE</i>	STS Sarcomas: Gynaecological Sarcomas <i>Prof. Jean-Yves Blay, FR</i>	Surgery including „watch and wait“ <i>Dr. Alessandro Gronchi, IT</i>
12:30 – 13:30	LIGHT LUNCH (60 min.) Restaurant One O One		
13:30 – 14:15	Local Interventions at Progressive Disease: Surgery, Laser, RFA, Chemo-Embolisation, SIRT & Co. <i>Prof. Peter Hohenberger, DE</i>	Surgery in Sarcomas: - Treating the “Basic Limb Tumour” - Using Radiotherapy prior to Surgery - When to consider Adjuvant Therapy (Radio or Chemo?) - Using more Advanced Techniques such as ILP <i>Dr. Alessandro Gronchi, IT & Prof. Sylvie Bonvalot, FR</i>	New pathology speaker tbd Pain Management in Desmoids <i>Dr. Odile Oberlin, FR & George Moreau, FR</i>
14:15 - 15:00	Circulating DNA, liquid biopsy <i>Dr. Nikolas v. Bubnoff, DE</i>		Patient related problems in Desmoid type fibromatosis - the role of a nurse practitioner <i>Nicolette Leijerzapf, NL</i>
15:00 – 15:30	TEA / COFFEE BREAK (30 minutes)		
15:30 – 17:00	Actual spotlights on GIST Research: <i>Prof. Jean-Yves Blay, FR</i>	Oligo-Metastasis in Sarcomas: Local Surgery vs. Systemic Treatment? <i>Prof. Peter Hohenberger, DE</i> New UK-Research on “Quality of Life” in Advanced Sarcoma <i>Dr. Nicholas Gough, UK</i>	Round Table “Challenges of desmoid patients in different countries”

Conference Programme

DAY 2 – FRIDAY November 14, 2014

17:00 – 18:30

MARKET PLACE SESSIONS

(4 parallel sessions 25 min each + 5 min for change, delegate chooses 3 sessions)

1. Peer to Peer Support

Claire Kelleher, Sarcoma UK

2. How to support scientific research as a patient group

Estelle Lecointe, SPAEN/Info Sarcomes, FR

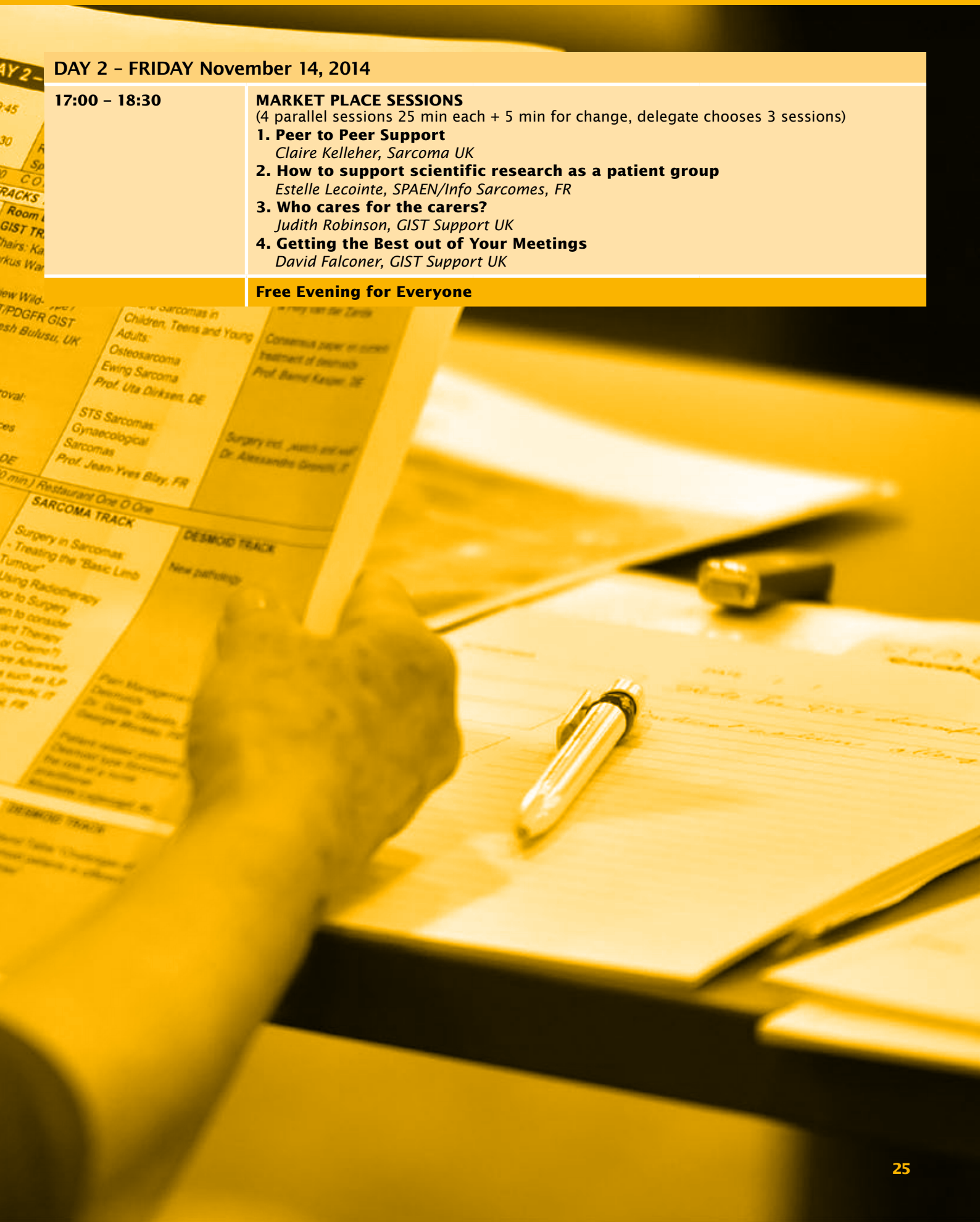
3. Who cares for the carers?

Judith Robinson, GIST Support UK

4. Getting the Best out of Your Meetings

David Falconer, GIST Support UK

Free Evening for Everyone



Conference Programme

DAY 3 – SATURDAY November 15, 2014	
09:00 - 10:30	Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2014/2015 All Delegates are Welcome (Voting Rights for SPAEN Members only)
10:30 - 11:00	TEA / COFFEE BREAK (30 minutes)
11:00 - 12:30	SHARING BEST PRACTICE <ol style="list-style-type: none"> 1. How to Get Your Message Across / How to Influence Health Care Authorities? (20 min) <i>Estelle Lecointe, FR</i> 2. Centers of excellence: What is the ideal profile? (20 min) <i>Markus Wartenberg, DE</i> 3. Successful Ideas/Projects/Initiatives – Resulting from Patient Groups and Experts Relationships (4 x 5 min) <ul style="list-style-type: none"> • Examples from Norway • Yuliana Popova, GIST Group Bulgaria: An update from Bulgaria • Gerard von Oortmerssen, GIST Contactgroep NL: Extracting medical data from patient discussion fora and social media • Hans Keulen, Chordoma Foundation Europe: “The Chordoma Registry has been launched: A short project overview...” “
12:30 - 13:30	LIGHT LUNCH (60 min.) Restaurant One O One
13:30 - 15:00	Pharma Relations: Working with the Healthcare Industry... <i>Markus Wartenberg, DE & Estelle Lecointe, FR</i>
15:00 - 15:15	End of meeting, Summary, Feedback-Forms, Closing Remarks, Thanks to the Presenters & Sponsors
15:15	OFFICIAL END OF THE CONFERENCE
	Optional Session after the Conference:
15:30 - 18:00	Being prepared for the future: <ol style="list-style-type: none"> 1. Identify unmet medical needs in the patient community (45 min) 2. Generics (45 min) 3. What can SPAEN do to support? (45 min) SPAEN Working Group, Voluntary SPAEN Members + Medical Experts <i>Moderator: Markus Wartenberg & Roger Wilson</i>

Participants List

Country	First Name	Second Name	Organisation
Bulgaria	Adelina	Mihailova	GIST Alliance for Patients Bulgaria
Bulgaria	Yuliana	Popova	GIST Alliance for Patients Bulgaria
Finland	Marita	Ritmala-Castren	Finnish GIST Patients Network
France	Estelle	Lecointe	SPAEN
France	Simone	Bacconier	World Sarcoma Network
France	George	Moreau	SOS Desmoïde
France	Odile	Oberlin	SOS Desmoïde/Institute Gustave Roussy
Georgia	Alexander	Chirinashvili	Universal Medical Center Tbilis
Georgia	Elene	Sakvarelidze	Universal Medical Center Tbilis
Germany	Markus	Wartenberg	SPAEN
Germany	Christina	Baumgarten	SPAEN
Germany	Uli	Deck	Photographer
Germany	Kai	Pilgermann	Das Lebenshaus
Germany	Michaela	Geissler	SPAEN
Israel	Gideon	Moshe	ISRAEL GIST ORG
Israel	Avi	Zigdon	ISRAEL GIST ORG
Italy	Vincenzo	Ippolito	Le Ali Onlus and Unit of Orthopedic Oncology, Brescia
Italy	Gabriela	Tedone	AIG Associazione Italiana GIST Onlus
Italy	Elio	Guletta	AIG Associazione Italiana GIST Onlus
Macedonia	Dejan	Krstevski	GIST Patient Group Macedonia
Netherlands	Hilly	van der Zande	
Netherlands	Robert	van der Ploeg	Contactgroep Sarcoma NL.BE
Netherlands	Jasper	Smitt	Contactgroep Sarcoma NL.BE
Netherlands	Hendrik	van Rooijen	Stichting Contactgroep GIST
Netherlands	Hans	Keulen	Chordoma Foundation Europe
Netherlands	Gerard	van Oortmerssen	Contactgroep GIST NL
Norway	Frode	Homb	Sarkomer Norway
Poland	Piotr	Fonrobert	Stowarzyszenie Pomocy Chorym na GIST / GIST Patients Aid Association
Poland	Malgorzata	Krzywicka	Stowarzyszenie Pomocy Chorym na GIST / GIST Patients Aid Association
Poland	Kamil	Dolecki	Stowarzyszenie Pomocy Chorym na Miesaki "SARCOMA"
Romania	Flavia	Boghiu	HomeCare Association
Romania	Simona	Ene	HomeCare Association
Spain	Angeles	Diaz Leon	Sarcoma Patients Spanish Association (AEAS)
Spain	Ana	Velasco	Sarcoma Patients Spanish Association (AEAS)
Switzerland	Audrey	Mahot	GIST Group Switzerland
Switzerland	Franziska	Seeli	Swiss Sarcoma Center
Turky	Salih	Yuce	Youth Acumulation Association

Participants List

Country	First Name	Second Name	Organisation
UK	Michael	Sayers	SPAEN
UK	Roger	Wilson	SPAEN
UK	Andrew	Sheppard	Bone Cancer Research Trust
UK	Anna	Wallace	Living beyond diagnosis
UK	Claire	Kelleher	Sarcoma UK
UK	Jayne	Bressington	GIST Support UK/PAWS-GIST
UK	David	Falconer	GIST Support UK
UK	Sarah	McDonald	Sarcoma UK
UK	Judith	Robinson	GIST Support UK
UK	David	Robinson	GIST Support UK
UK	Jennifer	Houniet	Bone Cancer Research Trust
UK	Abigal	Evans	UCL Cancer Institute/EURO EWING Consortium
Ukraine	Ivan	Zelenskyi	RPX Ukraine Dneptopetrovsk
Ukraine	Larysa	Kutovenko	RPX Ukraine Dneptopetrovsk

European GIST, Desmoid and Sarcoma advocacy and support groups have agreed to form the collaborative association Sarcoma Patients EuroNet. SPAEN was officially founded on the 6th of April 2009 in Bad Nauheim/ Germany. 11 foundation members initiated the foundation of SPAEN and membership is open to patient groups working with sarcoma patients across Europe. SPAEN is an European association – legally registered under German law. The association has some short term goals and some long term ambitions, and is supporting the growing pressure for better treatment of rare cancers being led by groups such as EORTC, ESMO, ECCO, EURORDIS, ECPC and other stakeholders. Acting in partnership with experts, the healthcare industry and other stakeholders, SPAEN will work to improve treatment and care of GIST, Desmoid and sarcoma patients in Europe through improving information and support, and by increasing the visibility of sarcoma with policymakers and the public.

Sarcoma Patients EuroNet e.V./Assoc. is supported by leading “European Sarcoma Experts (Expert Groups)” and the pan-European collaboration of sarcoma specialist researchers and doctors. SPAEN has also initiated a Medical Advisory Board.

Our Vision

All Sarcoma (incl. GIST) Patients in Europe have access

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

Our Mission

Improving the situation of Sarcoma (GIST) Patients and their relatives in Europe. By

- building one strong European Sarcoma Voice,
- cooperating with all relevant European stakeholders in an outcome-oriented way and
- strengthening this European coalition of national Sarcoma-, GIST- and Desmoid Patient Advocacy- and Support Groups.

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 multi-disciplinary 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.



Medical Advisory Board

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 their members – the existing national patient organisations and encourages the creation of new ones.

Our Core Values:

- Focussed 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 Code of Practice

SPAEN welcomes donations, grants and sponsorship to fund certain projects and to allow our network to grow and develop. SPAEN has developed a transparent and robust Code of Practice to guide the relations between patient organisations and the industry (including their representatives and consultants).

Please see “Code of Practice” at www.sarcoma-patients.eu



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

- 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/Sevilla	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. Pjotr 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



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

SPAEN Associate Members

1. Israel: Israeli GIST patient organisation
2. Turkey: Genç Birikim Derneği Youth Accumulation Association (Associate Member)
3. USA: GSI – GIST Support International
4. USA: Sarcoma Alliance
5. USA: The Liddy Shriver Sarcoma Initiative
6. Curacao: Synovial Sarcoma Research Foundation



**Sarcoma
Patients
EuroNet**

Contact

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

Registered office/legal venue:
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Untergasse 36
61200 Wölfersheim/Germany