



**Sarcoma  
Patients  
EuroNet**

## **Conference Report**

**4<sup>th</sup> SPAEN Annual Conference  
for Organizations  
Representing Patients  
with Sarcomas, GIST or Desmoid-Tumours**

**October, 10<sup>th</sup> – 12<sup>th</sup> 2013  
Novotel London Paddington, UK**

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

# Acknowledgements

We would like to thank the following sponsors for supporting the SPAEN Annual Conference 2013 with an unrestricted grant:

Bayer, GSK, MSD/Merck, Novartis, PharmaMar, Pfizer, Takeda



Takeda Pharma



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 2013 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

SPAEN is the Sarcoma Patients EuroNet Association (SPAEN), a network of European GIST, desmoid and sarcoma patient advocacy groups. It 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 increasing the awareness of sarcoma with policymakers and the public.

Eleven organisations initiated the foundation of SPAEN on the 6<sup>th</sup> 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 both short term goals and long term ambitions. It supports the growing pressure for better treatment of rare cancers through initiatives and groups such as RARECARE, RARE CANCERS EUROPE, ESMO and EORTC.

Sarcoma Patients EuroNet e.V./Association 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 consisting of 14 leading sarcoma experts covering all relevant disciplines from several countries.





SPAEN's 4<sup>th</sup> Annual Conference for member organisations and those seeking membership, was held from 10<sup>th</sup> to 12<sup>th</sup> October in London. This year's conference saw a record number of attendees, with over 100 people from 25 countries present. Previous SPAEN Annual Conferences were also very well attended with over 90 participants from more than 20 countries, including patient advocates, medical experts, researchers and representatives of the health industry. SPAEN's annual conference provides a valuable opportunity for the sarcoma patient community to learn about advances and challenges in the treatment of sarcomas/GIST and to share experience and best practice.

Among the topics of the 2013 SPAEN conference were:

- Patient involvement in clinical research
- Adherence and therapy/side effect management
- Reimbursement and access to innovative drugs
- Parallel tracks for GIST, sarcomas and desmoids with medical updates on current treatment options and ongoing clinical trials
- Market place sessions

The three day conference focused on research and treatment, advocacy and capacity building. Leading European sarcoma experts and other speakers joined the meeting to present the latest medical news, to answer questions and to be available for discussions. Last year, the 3<sup>rd</sup> SPAEN conference in Florence, Italy was attended by around 90 participants from 20 countries. Among those attending were patient advocates, medical experts and representatives of the healthcare industry. This year, more than 100 participants from over 25 different countries demonstrated the increasing interest in this group of diseases.

During the conference it became clear that there was general agreement between patient advocates, sarcoma experts and the industry that, by working together, research in sarcomas can be completed more quickly and new treatments introduced faster. There was a high level of commitment on the part of every participant, whether they were there as a patient advocate, a clinical expert or an industry representative, to playing their part in "Changing the World" and doing all that they can to improve the outlook for sarcoma patients.



## Statements of Participants





**Prof. Ian Judson,  
Royal Marsden Hospital,  
London, UK**

I was delighted to attend the SPAEN meeting. It is always refreshing to hear the patients' perspectives regarding the key issues that concern them. The discussions were stimulating and challenging and for me it was valuable to review a

topic about which I thought initially there was little new to say and to realise that this was not the case. In fact there is always something new to learn and the best way is through dialogue, for which SPAEN is a great forum.



**Simon Bacconier,  
Scientific Manager World  
Sarcoma Network, France**

The World Sarcoma Network and SPAEN have a long partnership history of about 6 years now. It is always a pleasure to participate at their annual conference since it is a key sarcoma event.

Actually, SPAEN has been highly professional to organize this type of patient events and invite the top level speakers on a yearly basis. It is a tremendous opportunity to meet patient group representatives as well as committed professional, private and public, and build future collaborative projects. My advice to young sarcoma investigators would be to participate to this opportunity rich top level event as much as possible.



**Sylvie Bonvalot  
Institut Gustave Roussy,  
France**

I was honoured by the invitation of SPAEN. I felt impressed by the high level of knowledge of all the audience. I found the high commitment of patients for both research and treatment amazing. It is a good example for others patient as-

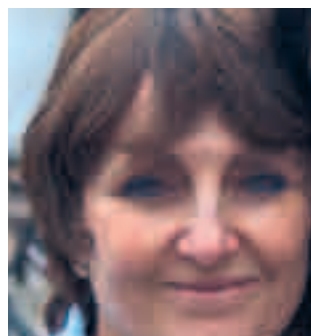
sociations from other fields. I take the opportunity of this statement to thank again for the support of SPAEN concerning "Esurge", a teaching course which shows live surgery and discusses therapeutic strategy for GISTs and sarcomas.



**Mike Francis,  
Guy Francis Bone Cancer  
Research Fund, UK**

Cancer knows no boundaries – so why should national frontiers be a barrier to combatting cancer? For me, this year's SPAEN Conference showed that there is a real willingness amongst patients, carers and healthcare professionals from

throughout Europe, to learn from each others' experiences and to move forward with greater understanding and co-operation. Am eagerly awaiting next year's event!



**Mª Ángeles Díaz León,  
AEAS - Spanish Sarcoma  
Patient Group**

Despite the fact I attended the SPAEN conference for the first time, I felt really comfortable since the atmosphere was quite friendly and welcoming. We have made new friends to be in contact with, from all over Europe. High level and up

to date speeches were given by the experts about the different aspects of sarcoma, including sarcoma trials on new drugs. Also the contributions from the patient associations based on their experiences were very valuable. Worth mentioning is the lecture about patient involvement in trial design, given by Derek Stewart: Thanks for transmitting us the important message to be heard, no matter which obstacles you find. Nice support from Roger, Markus and Michaela - congratulations for your work and effort to organize this conference every year which provides a great deal of valuable information, a treasure for our associations.



**Hilly van der Zande**

Sarcoma.nl started a year ago and this was my first international experience. By meeting other representatives in person, I could share experiences and get a lot of new ideas for the future. The sessions from experts learned me what is needed to run a patient advocacy group. That and all the medical information that was

given, will help me to support the Dutch speaking Sarcoma patients even better. It is great that through SPAEN and other international contacts we will be able to play a part in the search for a successful treatment of Sarcoma.

**Thursday,  
October the 10<sup>th</sup> 2013 –  
Getting the best out of your  
therapy**







*Raz Dewji*



*Roger Wilson*



*Barbara Doré*

After the opening of the 4th Annual SPAEN conference by Roger Wilson (SPAEN President, UK) and Barbara Doré (SPAEN Board Member, UK) Raz Dewji, GlaxoSmithKline (GSK) Oncology Global Medical Affairs, UK, welcomed SPAEN to London and pointed out the value of the “Patients’ Voice” in the process of drug development. In 2010, GSK initiated a special unit for rare diseases, including sarcomas. He stressed the impact of partnerships between industry and patient advocacy groups and introduced GSK’s initiative named “Focus on the Patient”, which was already working on topics such as:

- simplification of informed consent forms and processes,
- participation in treatment adherence initiatives,
- support for the involvement of patients and physicians as well as support for patient advocacy groups.

Raz Dewji summarized the key milestones of the development of the compound pazopanib for advanced soft tissue sarcomas from the initial program start in 1996 until its approval in 2012. One key milestone within this development was, of course, the phase III PALETTE study in close collaboration with the Soft Tissue and Bone Sarcoma Group (STBSG) of the European Organisation for Research and Treatment of Cancer (EORTC)

The importance of the role of the “Patients’ Voice” for UK sarcoma patients had been demonstrated by the intervention of Sarcoma UK and SPAEN, without which, they would have been excluded from the PALETTE trial.



## Thursday, October the 10<sup>th</sup> 2013 – Getting the best out of your therapy

One of the most important issues for the patient advocacy community is the process of reimbursement: to get involved, to make oneself heard and to construct an evidence-based case. Dr. Karen Facey, Health Policy Consultant, UK, gave an update on the process of Health Technology Assessment (HTA) and tried to answer the question as to how patient groups can get involved in the process of access to new therapies. By definition, HTA describes a multidisciplinary process summarizing information about medical, social, economic and ethical issues related to the use of a health technology (including screening, vaccines, medicines and devices) in a systematic and transparent manner. Parameters such as safety, clinical effectiveness, costs and economic evaluation play an important role in this highly complex process. But what are the main findings and insights from a patient's perspective? And how can they be included in the process?

Patients' views and preferences may contribute to HTA principally in two ways: by providing robust evidence and through participation in the analysis and decision processes. Evidence and experiences from patient organisations may include partnerships in research (e.g. early involvement in the design of clinical studies, patient related outcomes), review of helpline questions, surveys and questionnaires, social networking, collecting patient stories and building an evidence base. Participation in the HTA process should take place at every stage of the assessment, because patients can provide unique knowledge. Patients' perspectives are extremely useful and are taken into account. Involvement should result in patient-influenced decision-making, leading to stronger and more robust recommendations. As an example, Eric Low from the patient organisation Myeloma UK presented how they build up their own evidence base for patients with myeloma to demonstrate how patient groups can play an active part in the HTA process. He pointed out that early involvement of





*Karen Facey*



*Eric Low*



*Markus Wartenberg*



*Francesco Pignatti*

patient organisations is critical, inputs from the patient advocacy groups need to be better structured and HTA is only part of the process and not the end.

The second “burning” issue for the patient advocacy community is adherence. In the session, “Getting the best out of your therapy”, it was made clear that adequate therapy and side effect management are fundamental to achieving the maximum benefit for patients from their treatment. A major prerequisite to deriving the maximum benefit from any particular therapy is to adhere to the specified dose of the prescribed agent. However, adherence can be affected by a variety of factors and, of course, one of these factors is side effects. It follows that adequate patient information and side effect management play a fundamental role in ensuring the success of any particular treatment. To address this issue, SPAEN had set up a special “SPAEN Task Force Group” on the subject of therapy and side effect management. In May 2013, patient group leaders from Bulgaria, Germany, the Netherlands and Switzerland held an initial meeting in Berlin, Germany, together with medical experts. Markus Wartenberg gave a status report on this first meeting. Side effects of the oral drugs commonly used in GIST and soft tissue sarcomas such as imatinib, sunitinib, regorafenib and pazopanib had been discussed. The plan

was to produce information booklets in English giving practical information on the prophylaxis and management of these side effects. He opened up the discussion of the subject, inviting advocates to speak about their experience of the problems, and went on to present examples of possible tools to improve adherence.

The authorisation process for new generic drugs in Europe was summarized by Dr. Francesco Pignatti from the European Medicines Agency (EMA), UK. He illustrated this issue by reference to Novartis’ patent for imatinib which was due to end soon. When this happens, it will be possible to manufacture the drug at significantly lower prices. Usually after about 10 years generics can be put on the market. He explained what type of data is needed to authorise a generic; traditional phase I-III studies are usually not necessary for the authorisation of generic products. But it has to be ensured that the active substance of the generic product acts in the same way as the original compound (bioequivalence). On the other hand, it has to be taken into account that, many patients experience psychological insecurity when changing to another drug after sometimes years of taking the original. This plays an especially important role in the case of anticancer therapies such as imatinib.



**Friday,  
October the 11<sup>th</sup> 2013 –  
Treatment Day**





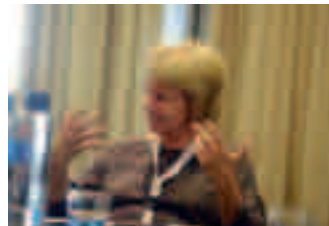


*Elaine Stewart*



*Rachel Brindley*

For the “Early Birds”, two breakfast sessions were held on Friday and Saturday morning with Elaine Stewart and Rachel Brindley from the London Maggie’s Centre covering the topics of “What to do, when treatment comes to an end?” and “Who cares for the carer?”. These gave attendees the opportunity to share their opinions and knowledge in a small group of interested people.



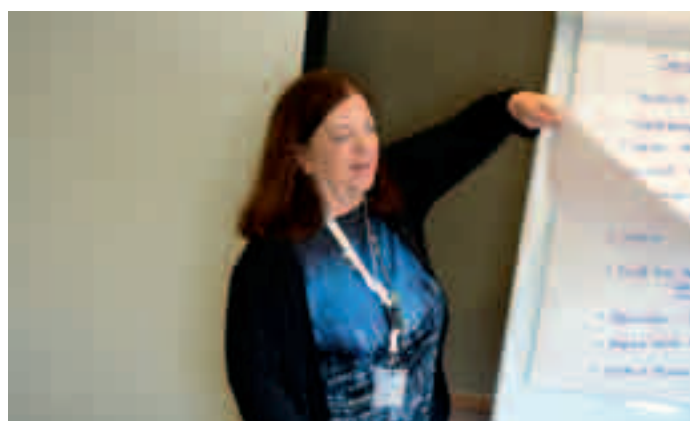
# Friday, October the 11<sup>th</sup> 2013 – Treatment Day

For the first time at a SPAEN conference, an advocacy marketplace session was held with four parallel sessions. Delegates could choose to attend any three of these. The following topics were covered:

- working with the experts (Estelle Lecointe, SPAEN),
- working with the pharmaceutical industry and other funding sources (Markus Wartenberg, SPAEN),
- how to run a patient group meeting (Barbara Doré, SPAEN)
- patient group survey (Roger Wilson and Claire Kelleher, Sarcoma UK).

The advocacy marketplace sessions were highly interactive, non-PowerPoint sessions with brief flipchart/poster presentations and concise, focused discussions. The aim of the sessions was to provide participants with the opportunity to discuss best practice topics with advocates in an informal small group setting. Each session started with a 5 minute flipchart/poster presentation to introduce the topic, after which the workshop leader facilitated questions/discussion/sharing best practice for 20 minutes.

This format was very well received and will certainly feature in future conferences.



*Delegates listening to the presentation of Estelle Lecointe about "Working with the experts".*

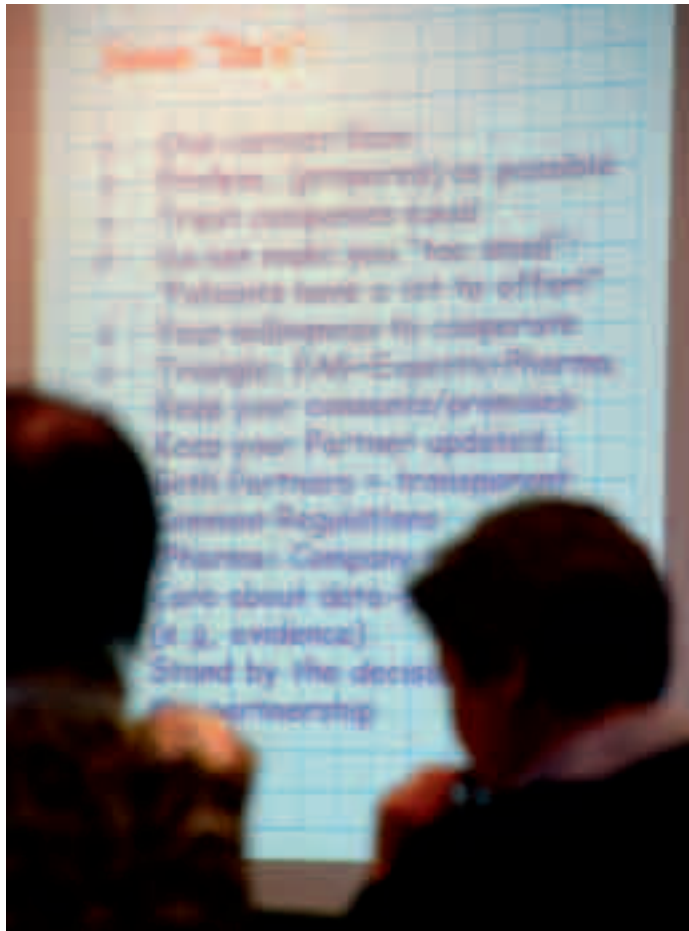




Ian Judson



Marco Fiore



Strategies for the treatment of metastases in sarcoma and GIST patients were discussed from the different perspectives of a medical oncologist (Prof. Ian Judson, UK) and an expert surgeon (Dr. Marco Fiore, Italy). 50 % of soft tissue sarcoma patients will develop metastases in the course of their disease and that has not significantly changed in recent decades. Ian Judson highlighted again that there are many different subtypes of soft tissue sarcomas with heterogenic characteristics and also a different chemo sensitivity.

Beyond first line standard chemotherapy with doxorubicin alone or in combination with ifosfamide, for example, paclitaxel is most useful in angiosarcomas, the combination of gemcitabine and docetaxel in leiomyosarcomas and trabectedin is especially effective in liposarcomas, leiomyosarcomas and synovial sarcomas. Ifosfamide can be administered through prolonged infusion over 14 days with significant activity and less toxicity in undifferentiated liposarcomas. On the other hand, certain soft tissue sarcoma subtypes, such as clear cell sarcomas or alveolar soft part sarcomas, are simply not responsive to chemotherapy. Molecular characteristics such as ALK mutations or CDK4 amplifications may also help to develop targeted therapies in certain sarcoma subtypes (e.g. EORTC CREATE study). From the surgical perspective there is a survival advantage for patients undergoing resection of (pulmonary) metastases compared to no surgical treatment. Prognostic factors playing a role in this context are the number and location of metastases and the extent of the performed resection. Currently, the treatment strategy for each patient is based on an individualized decision made by a multidisciplinary team preferably at a specialized sarcoma centre.



Key issues of the presentations were put down in action charts.



# Friday, October the 11<sup>th</sup> 2013 – Treatment Day

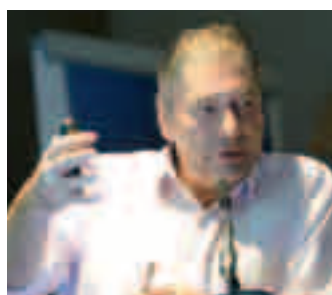
Parallel educational sessions, led by leading sarcoma experts, gave delegates the latest information about developments in treatment, new drugs and clinical trials. The sessions related, respectively, to sarcomas, (including very rare types of sarcoma) GIST and desmoid tumours.

Therefore, we are indebted to the following for their expert input (some in more than one session):

Prof. Ian Judson, PD Dr. Peter Reichardt, Prof. Sylvie Bonvalot, PD Dr. Sebastian Bauer, Prof. Jean Yves Blay, Dr. Beatrice Seddon, Dr. Marco Fiore, Julia Hill, Dr. Rick Haas, Dr. Daniela Segat, and Prof. Bernd Kasper.



*Ian Judson*



*Peter Reichardt*



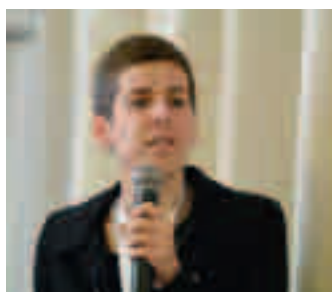
*Sylvie Bonvalot*



*Sebastian Bauer*



*Jean Yves Blay*



*Beatrice Seddon*



*Marco Fiore*



*Julia Hill*



*Rick Haas*



*Daniela Segat*



*Bernd Kasper*



## GIST

Currently, the only two registered drugs in Europe for the treatment of patients with metastatic and advanced GIST are imatinib for first line and sunitinib for second line therapy. The next promising candidate showing activity in this patient population is clearly regorafenib. Last year, results of the phase III GRID trial with regorafenib in advanced GIST patients were presented. 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, diarrhoea, fatigue, oral mucositis, alopecia, anorexia, rash, nausea and constipation. Regorafenib has already been approved by the FDA in the United States and Japan; however, approval in Europe is not expected before mid-2014. Profiles of and clinical practice with the therapies currently used to treat GIST were presented with the aim of showing patients how to get the best out of their therapy.

An interesting trial from South Korea was presented at this year's ASCO dealing with the problem of managing progressive disease by comparing a restart of imatinib versus surveillance in third line therapy and beyond. The study confirmed what we already knew: a restart of imatinib is useful even in patients who had already progressed under imatinib several years previously. Restarting on a KIT inhibitor in the same treatment line slows down tumour progression for some patients continuing their treatment beyond RECIST progression. The discontinuation of any treatment leads to excessively rapid progression. These results validate the 2012 ESMO guidelines which stressed the importance of restarting imatinib after failure of previous therapies. Surgical strategies in GIST were presented. In the context of advanced and metastatic disease, a number of new generation tyrosine kinase inhibitors, such as masitinib and ponatinib are undergoing clinical testing. There are also some new therapeutic strategies on the way.

## Soft Tissue Sarcomas

For soft tissue sarcomas, an update on new and ongoing clinical trials was presented. The last milestone enriching the treatment armamentarium for soft tissue sarcoma patients was the approval of the anti-angiogenic compound pazopanib in the US, Europe and Japan for certain subtypes of soft tissue sarcomas. Pazopanib has been tested in a large EORTC phase III trial (PALETTE) demonstrating a significant advantage regarding PFS (progression free survival) 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. Two interesting aspects regarding the activity of trabectedin were also discussed: The combination of trabectedin plus doxorubicin in previously untreated uterine leiomyosarcomas revealed an objective response rate of 57 % and a tumour control rate of 86 %.

The high chemo sensitivity of uterine leiomyosarcomas to trabectedin and the activity of the combination with doxorubicin in first line therapy may lead to the drug becoming standard treatment in leiomyosarcomas in general. Secondly, a retrospective study of 885 patients treated with trabectedin in France evaluated the possible benefit of maintenance therapy. In this cohort, patients who were still progression-free after six cycles of trabectedin and continued the treatment beyond, did significantly better in terms of PFS and overall survival than those who stopped. Short profiles of certain rare sarcoma subtypes, chordomas and uterine sarcomas, were also presented. During this session the topics of peer review of quality of treatment, access to treatment and the role of centres of excellence were also covered. Again, it was pointed out that patients suffering from these rare diseases should preferably be treated in one of the specialized sarcoma units.



# Friday, October the 11<sup>th</sup> 2013 – Treatment Day

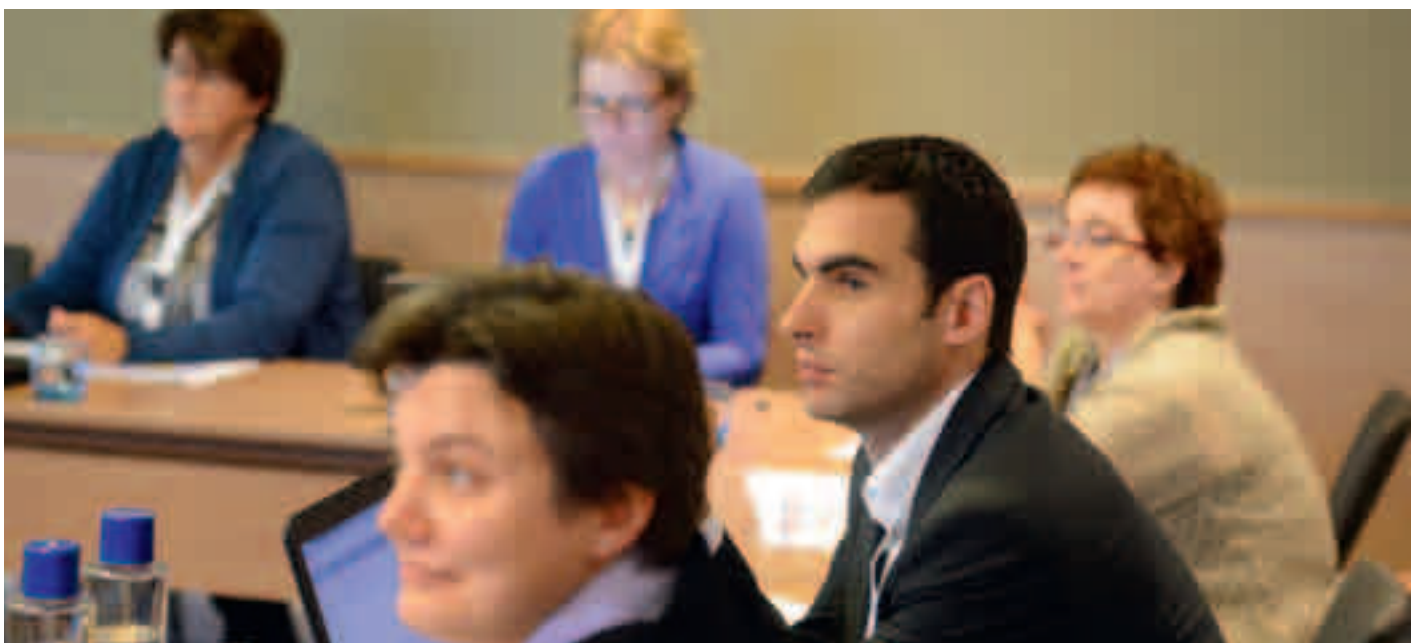
## Desmoid Tumors

There was an initial 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 radiotherapy, general management strategies of desmoids and systemic treatment options. To evaluate the efficacy of radiotherapy for inoperable desmoid tumours, the EORTC Soft Tissue and Bone Sarcoma Group carried out a study assessing moderate dose radiotherapy in desmoid tumour patients not amenable to resection without significant function loss. Patients received radiotherapy for a total of 56 Gy in 28 fractions. This radiation dose seems to be critical in the therapy of desmoids. The non-randomized phase II study enrolled 44 patients between 2001 and 2008 and could demonstrate a favourable result with an 81.5 % local disease control rate at three years after a median follow-up period of 4.8 years with very moderate side effects limited to skin, mucosal membranes and pain. The best overall response during the first three years was: complete response in six patients (13.6 %), partial response in 16 patients (36.4 %), stable disease in 18 patients (40.9 %) and progressive disease only in three patients (6.8 %). After three years, two patients improved to complete response and one patient improved to partial response, demonstrating that continuous regression is seen even after three years. Due to the heterogeneity of desmoid tumours and their often unpredictable clinical course, there is no established standard of care for this disease. Surgery remains the therapeutic mainstay, however, a period of watchful waiting or a front-line conservative approach even in resectable tumours may be the most appropriate method of management in selected asymptomatic patients which

could be demonstrated. In summary, treatment needs to be individualized to optimize local tumour control and the preservation of patients' quality of life. A potential novel marker for desmoid tumours on the cellular level, GSK-3beta, has also been presented. The correlation between diagnosis of a desmoid tumour and pregnancy remains an interesting issue currently being investigated in more detail. Systemic treatment options and upcoming clinical trials for patients with desmoid tumours were discussed such as the ongoing randomized trial of the French Sarcoma Group evaluating the activity of pazopanib versus chemotherapy with methotrexate and vinblastine in 94 adult patients with desmoid tumours (DESMOPAZ). There is a clear unmet medical need for prospective and randomized clinical studies in this rare disease to gain more evidence-based data. However, designing and funding clinical trials in this rare disease remains difficult.



*Rick Haas explaining the key issues of radiooncology during the desmoid session.*



SPAEN maintains numerous partnerships and collaborations crucial for the success of this patient organisation. Prof. Winette van der Graaf, The Netherlands, gave a presentation on the World Sarcoma Network and in particular the work and ambitions of the EORTC Soft Tissue and Bone Sarcoma Group (STBSG) as its current chairman. Currently open clinical trials 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 include database related projects, bone sarcoma trials, a liposarcoma platform, imaging studies and quality of life evaluations. A preclinical consortium of research centres will be implemented as well as a public relations subcommittee to increase the transparency of the group. Prof. Jean Yves Blay, France, briefly presented the structure and goals of EUROSARC as a research network for bone and soft tissue sarcomas with the aim of carrying out translational research projects and of initiating academic trials. The project of a prospective patient database for chordoma patients was presented by Hans Keulen and Sierk Bakker on behalf of the Chordoma Foundation. Moreover, there is a formation of a European consortium for wildtype and paediatric GIST patients which was briefly introduced by Barbara Doré and Jayne Bressington, UK.



Winette van der Graaf



Sierk Bakker

*Delegates listening during the desmoid session.*



**Saturday,  
12<sup>th</sup> October 2013**





The third conference day started with the general assembly 2013/2014 of the SPAEN association. The Board gave an overview of all the activities SPAEN is involved in such as patient involvement in clinical research and certain projects of collaborations with experts and industry. There is an improving collaboration with ESMO (e.g. participating in the process of establishing clinical practice guidelines, better integration of patient advocacy groups), EORTC (e.g. involvement in training courses, providing involvement and information support in future sarcoma trials, communication of trial progress and results, research project on adherence and experiences with oral cancer therapy and side effect management), Rare Cancers Europe (e.g. working on the methodology of clinical trials in rare diseases), the World Sarcoma Network and EUROSARC. Upcoming challenges SPAEN is facing are establishing the location of the centres of excellence in each country in Europe, identifying where expert centres are needed and where new support organisations can be created, discussing the management of treatment side effects of oral targeted therapies and addressing problems of reimbursement. Further challenges also include the strategic planning of the financial basis and personal resources of SPAEN in the near future. Special task forces and roundtables for therapy side effect management, wildtype and paediatric GIST patients and desmoid tumour patients have already been initiated or will take place in early 2014. The financial cooperation with the pharmaceutical industry is structured as a sustaining partnership. After four years of contribution all members of the SPAEN board have been re-elected for another four years; Ornella Gonzato from Italy was elected as an additional board member.



*Markus Wartenberg reporting on the SPAEN activities in 2013*



*SPAEN members casting their votes during the SPAEN General Assembly*



*Ornella Gonzato,  
newly elected  
SPAEN board member  
from Italy.*

Patient involvement in clinical research is one way of maintaining SPAEN's partnerships. Derek Stewart, Associate Director for Involvement at National Institute for Health Research - Clinical Research Network, UK gave an excellent talk on the topic of improving research through involving patients, carers and the public. He introduced the two main aspects of involvement: participation (e.g. in clinical trials) and engagement. He pointed out the value of the patients' and carers' experience. Better research, simpler and more effective systems, clearer access to studies, improved recruitment, open access for results, better patient outcomes and satisfactory experience are the most important goals of this initiative. For example, there is an international clinical trials day on 20th May with lots of activities.

Markus Wartenberg, Germany discussed in more detail practical experiences from the point of view of a patient organisation. Only 6-10 % of cancer patients are participating in clinical trials leading to delays in knowledge and information. The role of patient organisations in the process of engagement in research and clinical trials covers education, communication of available and upcoming clinical trials, making trial issues understandable, supporting recruitment e.g. in rare subtypes, facilitating informed consent forms and processes, incorporating quality of life aspects, dissemination of the results and more and more involvement at the very early stage of designing clinical trials. Networking with other disease groups can also be extremely helpful in this ongoing process.

The basic definitions and tools of strategic planning were presented by Markus Wartenberg, Germany including the "Big Five" of strategic planning: mission, vision, values & beliefs, goals and strategies. He explained the general tools and procedures being used in this process.

Lindsey Bennister from Sarcoma UK shared her practical experiences on the way how these theoretical strategies can be implemented in the daily work of a patient organisation. She demonstrated the importance of strategic planning using the example of Sarcoma UK's project defining goals and the strategy for 2014-2020. Based on their defined values and goals strategic priorities were elucidated and an annual operational/business plan will be worked out to define each year's specific aims and budget.



*Lindsey Bennister, Sarcoma UK, speaking about the importance of strategic planning for patient organisations.*



*Derek Stewart presenting on the value of patient involvement in clinical research.*



*Markus Wartenberg presenting the basic definitions and tools of strategic planning.*

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 2013 with an unrestricted grant: Bayer HealthCare, GSK, MSD/Merck, 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”.

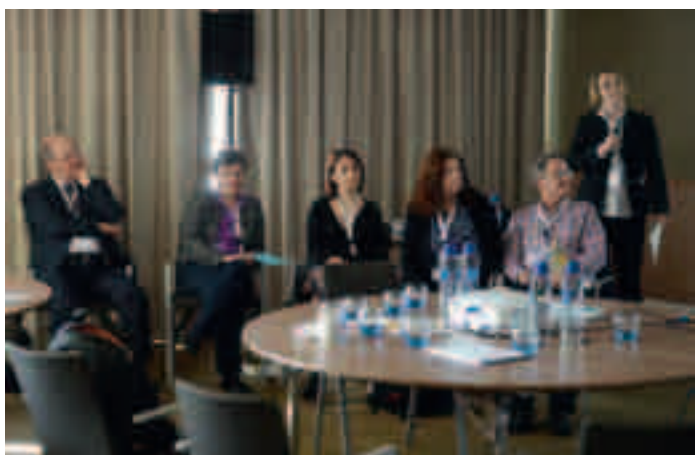
An optional training course for conference delegates on the topic “Understanding Cancer: Biology 1x1 for Patient Advocates” was led by Anette Duensing, pathologist and GIST researcher from the University of Pittsburgh Cancer Institute, USA covering topics such as the healthy cell, definition and characteristics of tumours, reasons for the development of a tumour, mechanisms and pathways of tumour development, development of sarcomas as well as targets and targeted therapies.



*Roger Wilson, SPAEN president, thanking all attendants, presenters and partners.*



*Delegates during the training course “Understanding Cancer: Biology 1x1 for Patient Advocates”.*

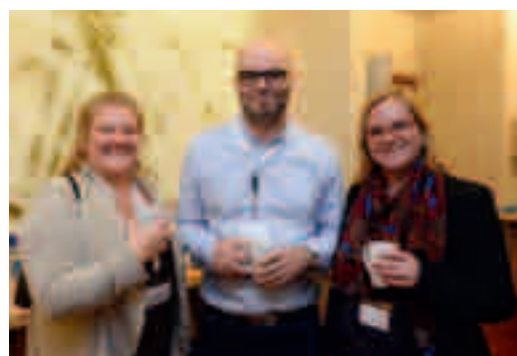
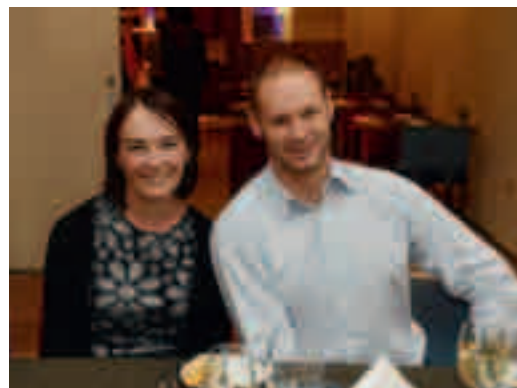


*The SPAEN board of directors during the General Assembly.*

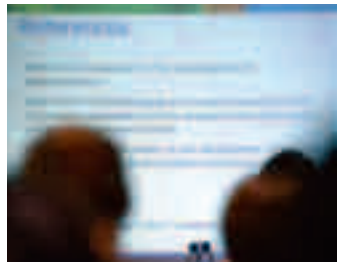




# Impressions



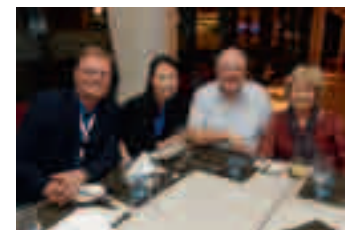
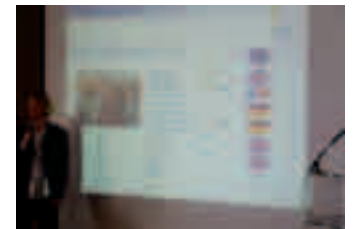




# Impressions







# Conference Program

<b>DAY 1</b>	<b>THURSDAY October 10<sup>th</sup>, 2013</b>
<b>12:30</b>	<b>LIGHT LUNCH</b> in front of main meeting room
<b>13:30</b>	<b>OFFICIAL START OF THE CONFERENCE</b> Main room – "Sheldon Suite"
<b>13:30 - 14:00</b>	<b>Opening, Welcome, Organizational Issues, Thanks to the Sponsors, etc.</b> <i>Roger Wilson, SPAEN, UK and Markus Wartenberg, SPAEN, Germany</i>
<b>14:00 – 14:30</b>	<b>GSK Europe welcomes SPAEN in UK/London</b> <i>Raz Dewji, GlaxoSmithKline Oncology Global Medical Affairs, UK</i>
	<b>GETTING THE BEST OUT OF YOUR THERAPY</b> <i>Chair: Markus Wartenberg, SPAEN</i>
<b>15:15 - 16:00</b>	<b>Status Report from the SPAEN Task Force "Therapy and side effect management" Problems and experience from other advocates - examples of adherence tools?</b> <i>Markus Wartenberg, SPAEN, Germany</i>
<b>14:30 – 15:15</b>	<b>The process of authorisation for new generic drugs</b> <i>Francesco Pignatti, Scientific and Regulatory Management Department, European Medicines Agency, UK</i>
<b>16:00 – 16:30</b>	<b>COFFEE BREAK</b>
	<b>REIMBURSEMENT PROCESS: BEING INVOLVED, BEING LISTENED TO AND BUILDING OWN EVIDENCE</b> <i>Chair: Roger Wilson, SPAEN</i>
<b>16:30 - 17:00</b>	<b>Introduction to Health Technology Assessment (HTA)</b> <b>How can patient groups be involved in the process of access to new therapies?</b> <i>Dr. Karen Facey, Health Policy Consultant, UK</i>
<b>17:00 - 17:30</b>	<b>Build your own evidence base - experiences with NICE in UK</b> <i>Eric Low, Myeloma UK</i>
<b>17:30 - 18:00</b>	<b>Questions &amp; Answers</b>
	<b>BREAK BEFORE DINNER</b>
<b>19:30 - 22:00</b>	<b>Internal Dinner</b> (Novotel Paddington Restaurant)



DAY 2	FRIDAY October 11 <sup>th</sup> , 2013		
7:30 Optional:	Morning Talk - What to do, when treatment comes to an end? (60 Minutes - Sheldon Suite) <i>Elaine Stewart &amp; Rachel Brindley, London Maggie's Centre</i>		
9:00 - 10:30	ADVOCACY MARKET PLACE SESSION (4 parallel sessions, delegates can choose 3 sessions each 25 minutes + 5 min switch) 1. Working with the experts, Estelle Lecointe, SPAEN 2. Working with the pharma and other funding sources, Markus Wartenberg, SPAEN 3. How to run a patient group meeting, Barbara Doré, SPAEN 4. Patient group survey, Roger Wilson & Claire Kelleher, Sarcoma UK		
10:30 – 11:00	COFFEE BREAK		
11:00 - 12:30	STRATEGIES FOR METASTASIS IN SARCOMAS AND GIST <i>Chair: Roger Wilson, SPAEN</i> Perspectives of oncologist and surgeon <i>Ian Judson, The Royal Marsden Hospital, UK</i> <i>Marco Fiore, Istituto Nazionale Tumori Milan, Italy</i>		
12:30 – 13:30	LIGHT LUNCH		
PARALLEL TRACKS FOR GIST, SARCOMAS AND DESMOIDS			
	GIST Track Sheldon Suite <i>Chair: Barbara Doré</i>	Sarcoma Track Room Bishops <i>Chair: Estelle Lecointe</i>	Desmoid Track Room Westbourne <i>Chair: Christina Baumgarten</i>
	Profiles of and clinical practice with the currently approved therapies in GIST: Getting the best out of your therapy	Update on new and ongoing trials <i>Jean Yves Blay, Centre Leon Berard Lyon, France</i>	Radiooncology <i>Rick Haas, The Antoni van Leeuwenhoek Hospital Amsterdam, Netherlands</i>
13:30 – 14:00	Imatinib <i>Ian Judson, The Royal Marsden Hospital, UK</i>	Short profiles of sarcoma subtypes Chordoma <i>Hans Keulen, Chordoma Foundation, NL</i>	Unravelling the desmoid-type fibromatosis tumor at the cellular level: GSK-3beta, a new piece of the puzzle. <i>Daniela Segat, Istituto Malattie Rare "Mauro Baschirotto", Italy</i>
14:00 – 15:00	Sunitinib and Regorafenib <i>PD Dr. Peter Reichardt, HELIOS Klinikum Bad Saarow, Germany</i>	Uterine Sarcoma <i>Beatrice Seddon, UCL Hospital NHS Trust, UK</i>	Brainstorming for a European Round Table on Desmoids in 2014
15:00 – 15:30	COFFEE BREAK		

# Conference Program

DAY 2	FRIDAY October 11 <sup>th</sup> , 2013		
15:30 – 16:15	<b>Surgery of GIST</b> <i>Sylvie Bonvalot, Institut Gustave Roussy, Villejuif, France</i>	<b>The interdisciplinary process of diagnosis</b> <i>Marco Fiore, Istituto Nazionale Tumori Milan, Italy</i>	<b>Update from clinical trials and new clinical trials</b> <i>Prof. Bernd Kasper, Mannheim University Medical Center, Germany</i>
16:15 - 17:00	<b>Clinical trials and innovations in GIST</b> <i>Sebastian Bauer, Universitätsklinikum Essen, Germany</i>	<b>Peer review of quality of treatment, access to treatment and centres of excellence</b> <i>Julia Hill, National Cancer Peer Review, UK</i>	<b>Management of desmoids</b> <i>Sylvie Bonvalot, Institut Gustave Roussy, Villejuif, France</i>
17:00 - 17:20	<b>SPAEN Partnerships and Collaborations</b> <i>Chair: Estelle Lecointe, SPAEN</i>		
17:20 - 17:40	<b>EUROSARC</b> <i>Jean Yves Blay, Lyon, France</i>		
17:40 - 17:50	<b>EORTC and World Sarcoma Network</b> <i>Winette van der Graaf, Chair EORTC STBSG, Netherlands and Estelle Lecointe, SPAEN, France</i>		
17:50 - 18:00	<b>Patient database for chordoma patients</b> <i>Hans Keulen &amp; Sierk Bakker, Chordoma Foundation</i>		
18:00 - 18:30	<b>Formation of a European Consortium for Wild Type and Paediatric GIST</b> <i>Barbara Doré, SPAEN &amp; Jayne Bressington, PAWS/GIST Support UK</i>		
	<b>BREAK BEFORE DINNER</b>		
19:00 – 23:00	<b>Departure to External Dinner</b>		

<b>DAY 3</b>	<b>SATURDAY October 12<sup>th</sup>, 2013</b>
<b>7:30 Optional:</b>	<b>Morning Talk - What to do, when treatment comes to an end?</b> (60 Minutes - Sheldon Suite) <i>Elaine Stewart &amp; Rachel Brindley, London Maggie's Centre</i>
<b>09:00 - 10:30</b>	<b>Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2013/2014</b> <i>All delegates are welcome (voting rights for SPAEN Members only)</i>
<b>10:30 - 11:00</b>	<b>COFFEE BREAK</b>
	<b>PATIENT INVOLVEMENT IN CLINICAL RESEARCH</b> <i>Chair: Markus Wartenberg</i>
<b>11:00 - 11:45</b>	<b>Public involvement in clinical research</b> <i>Derek Stewart, Associate Director for Involvement at National Institute for Health Research - Clinical Research Network, England</i>
<b>11:45 - 12:30</b>	<b>Practical experiences and examples from patient organisations</b> <i>Markus Wartenberg, SPAEN, Germany</i>
<b>12:30 - 13:30</b>	<b>LIGHT LUNCH</b>
<b>13:30 - 15:00</b>	<b>BASICS OF STRATEGIC PLANNING FOR PATIENT GROUPS</b> <b>Lecture:</b> <b>The basics of strategic planning and practical experiences from a patient group</b> <i>Markus Wartenberg, SPAEN, Germany &amp; Lindsey Bennister, Sarcoma UK</i>
<b>15:00 - 15:15</b>	<b>End of meeting, Summary, Feedback-Forms, Closing Remarks, Thanks to the Presenters &amp; Sponsors</b>
<b>15:15</b>	<b>OFFICIAL END OF THE CONFERENCE</b>
<b>15:30 - 19:00</b>	<b>Understanding Cancer: Biology 101 for Patient Advocates"</b> <ul style="list-style-type: none"> <li>• The healthy cell</li> <li>• Definition and characteristics of tumors</li> <li>• Reasons for the development of a tumor</li> <li>• Mechanisms and pathways of tumor development</li> <li>• Development of sarcomas</li> <li>• Targets and targeted therapy</li> </ul> <i>Anette Duensing, M.D., Pathologist and GIST Scientist/Researcher University of Pittsburgh Cancer Institute, USA</i>

# Participants List

1	<b>Abascal Briones</b>	Encarnita	Sarcoma Patients Spanish Association (AEAS)	Spain
2	<b>Asselberg</b>	Jack	Contactgroep GIST Netherlands	Netherlands
3	<b>Bacconier</b>	Simone	World Sarcoma Network	France
4	<b>Bakker</b>	Sierk	Chordoma Foundation Europe	Netherlands
5	<b>Bauer</b>	Sebastian	Universitätsklinikum Essen	Germany
6	<b>Baumgarten</b>	Christina	SPAEN/SOS Desmoids	Germany
7	<b>Bennister</b>	Lindsey	Sarcoma UK	UK
8	<b>Benson</b>	Charlotte	The Royal Marsden Hospital	UK
9	<b>Berezin</b>	Nancy	GIST Support International	US
10	<b>Blay</b>	Jean Yves	Centre Leon Berard Lyon	France
11	<b>Bonvalot</b>	Sylvie	Institut Gustave Roussy	France
12	<b>Breban</b>	Florina	Romanian Rare Cancer Association	Romania
13	<b>Bressington</b>	Jayne	GIST Support UK/PAWS-GIST	UK
14	<b>Castiglione</b>	Federica	Novartis Oncology Region Europe	Italy
15	<b>Deck</b>	Uli	ARTIS-Photographie	Germany
16	<b>Delin</b>	Karen	Sarcoma UK	UK
17	<b>Dewji</b>	Mohamad	GSK	UK
18	<b>Díaz León</b>	Angeles	Sarcoma Patients Spanish Association (AEAS)	Spain
19	<b>Dibabu</b>	Darara	Bayer	UK
20	<b>Decise</b>	Donatella	Novartis Farma S.p.A.	Italy
21	<b>Doré</b>	Barbara	SPAEN/GIST Support UK	UK/US
22	<b>Dünsing</b>	Anette	University of Pittsburgh Cancer Institute	USA
23	<b>Emnese</b>	Darko	Romanian Rare Cancer Association	Romania
24	<b>Ene</b>	Simona	Hope Association	Romania
25	<b>Facey</b>	Karen	Health Policy Consultant	Scotland
26	<b>Falconer</b>	David	GIST Support UK	UK
27	<b>Fiore</b>	Marco	Istituto Nazionale Tumori Milan	Italy
28	<b>Fonrobert</b>	Piotr	Polish GIST Patients Support Association	Poland
29	<b>Francis</b>	Mike	Guy Francis Bone Cancer Research Fund	UK
30	<b>Geissler</b>	Michaela	SPAEN	Germany
31	<b>Gherlinzoni</b>	Francesco	Associazione Paola per i tumori muscolo.	Italy
32	<b>Gonzato</b>	Ornella	Associazione Paola per i tumori muscolo.	Italy
33	<b>Haas</b>	Rick	The Antoni van Leeuwenhoek Hospital Amsterdam	Netherlands
34	<b>Hacket</b>	Sam	The Royal Marsden Hospital	UK
35	<b>Hibberdine</b>	Leigh	Sarcoma UK	UK
36	<b>Hill</b>	Julia	National Cancer Peer Review	UK
37	<b>Hobson</b>	Gemma	Pfizer	UK
38	<b>Homb</b>	Frode	Sarkomer	Norway
39	<b>Hutchins</b>	Angela	The Royal Marsden Hospital	UK
40	<b>Ippolito</b>	Vincenzo	Le Ali Onlus	Italy
41	<b>Nogués</b>	Juan	PharmaMar	Spain
42	<b>Judson</b>	Ian	Royal Marsden Hospital	UK
43	<b>Julian</b>	Maria	PharmaMar	Spain
44	<b>Kasper</b>	Bernd	Mannheim University Medical Center	Germany
45	<b>Kelleher</b>	Claire	Sarcoma UK	UK
46	<b>Keulen</b>	Hans	Chordoma Foundation Europe	Netherlands
47	<b>Khan</b>	Sadya	GSK	UK
48	<b>King</b>	Alison	The Royal Marsden Hospital	UK
49	<b>Kollar</b>	Attila	The Royal Marsden Hospital	UK



50	<b>Krzywicka</b>	Malgorzata	POLISH GIST Patients Support Association	Poland
51	<b>Ladva</b>	Jay	GSK	UK
52	<b>Lecointe</b>	Estelle	SPAEN/Ensemble contre le GIST	France
53	<b>Lodi Rizzini</b>	Vanni	Aldo Arienti Amici C.O.O. Onlus	Italy
54	<b>Low</b>	Eric	Myeloma UK	UK
55	<b>Mahot</b>	Audrey	GIST Group Switzerland	Switzerland
56	<b>Manson</b>	Stephanie	GSK	UK
57	<b>Martin-Liberal</b>	Juan	The Royal Marsden Hospital	UK
58	<b>Meier-Schnorf</b>	Helga	GIST-Gruppe Schweiz	Switzerland
59	<b>Mihaylova</b>	Adelina	GIST Alliance for Patients	Bulgaria
60	<b>Mitchell</b>	Debra	GIST Support UK	UK
61	<b>Montemurro</b>	Michael	The Royal Marsden Hospital	UK
62	<b>Moreaux</b>	Georges	SOS Desmoide France	France
63	<b>Moshe</b>	Gideon	Israeli GIST group	Israel
64	<b>Petrikova</b>	Galina	The Royal Marsden Hospital	UK
65	<b>Piccinelli</b>	Claudia	Le Ali Onlus	Italy
66	<b>Piccolo</b>	Francesca	Le Ali Onlus	Italy
67	<b>Pilgermann</b>	Kai	Das Lebenshaus	Germany
68	<b>Popova</b>	Yuliana	GIST Alliance for Patients	Bulgaria
69	<b>Rasool</b>	Mohammad	The Royal Marsden Hospital	UK
70	<b>Reichardt</b>	Peter	HELIOS Klinikum Bad Saarow	Germany
71	<b>Rigaux</b>	Philippe	SOS Desmoide France	France
72	<b>Robinson</b>	David	GIST Support UK	UK
73	<b>Robinson</b>	Judith	GIST Support UK	UK
74	<b>Roffe</b>	Emma	Takeda UK	UK
75	<b>Sahri</b>	Raija	Finnish GIST Patients Network	Finland
76	<b>Sayers</b>	Michael	SPAEN/GIST Support UK	UK
77	<b>Seddon</b>	Beatrice	UCL Hospital NHS Trust	UK
78	<b>Seeli-Maduz</b>	Franziska	Sarcoma Center Zurich	Switzerland
79	<b>Segat</b>	Daniela	Desmon Association/BIRD Foundation	Italy
80	<b>Stenius</b>	Jan	Pfizer	Sweden
81	<b>Stewart</b>	Derek	National Institute for Health Research	UK
82	<b>Strauss</b>	Dirk	The Royal Marsden Hospital	UK
83	<b>Sylvanowicz</b>	Michelle	Bayer	Germany
84	<b>Tomassone</b>	Paolo	A.I.G. Associazione Italiana GIST Onlus	Italy
85	<b>Väisänen</b>	Marjo	Finnish GIST Patients Network	Finland
86	<b>van Arem de Haas</b>	Ellen	Sarcoma NL	NL
87	<b>van der Graaf</b>	Winette	Radboud University Nijmegen Medical Centre	Netherlands
88	<b>van der Zande</b>	Hilly	Sarcoma NL	NL
89	<b>van Ootmerssen</b>	Gerard	Contactgroep GIST Netherlands	Netherlands
90	<b>Wallace</b>	Anna	Living Beyond Diagnosis	UK
91	<b>Wartenberg</b>	Markus	SPAEN/Das Lebenshaus	Germany
92	<b>Wettstein</b>	Martin	GIST Group Switzerland	Switzerland
93	<b>Wiles</b>	Maya	Sarcoma UK	UK
94	<b>Wilson</b>	Roger	SPAEN/Sarcoma UK	UK
95	<b>Yüce</b>	Salih	Youth Accumulation Association	Turkey
96	<b>Zhong</b>	Zhenxi	Shanghai Roots & Shoots	Shanghai
97	<b>Zigdon</b>	Avi	Israeli GIST Group	Israel
98	<b>Zik</b>	Mehmet Ragip	Youth Accumulation Association	Turkey

# About Sarcoma Patients EuroNet



**Sarcoma  
Patients  
EuroNet**

Sarcoma Patients EuroNet Association (SPAEN), the European Network of Sarcoma, GIST and Desmoid Patient Advocacy Groups, was founded in April 2009 with the aim of extending information services, patient support and advocacy to patient organisations for the benefit of sarcoma patients across the whole of Europe. 11 founder members initiated the foundation of SPAEN, membership of which is open to patient groups working with sarcoma patients across Europe. SPAEN is a European association – legally registered under German law.

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 increasing the awareness of sarcoma with policymakers and the public. SPAEN currently has 24 members from 13 countries.

## Vision

- A Better Future For Patients With A Rare Cancer.
- Speaking with one voice at European level, advocating and cooperating professionally and in partnership; to create a better future for Sarcoma patients and their families in every nation.
- Acting in partnership with experts, the researching industry and other stakeholders SPAEN will work to improve 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.



## The main objectives of SPAEN are:

- Increasing the awareness of GIST, Desmoids and other sarcomas
- Providing information and support
- Improving treatment and care
- Supporting research
- Building capacity

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, Conticanet. In 2010 Sarcoma Patients EuroNet established an **Medical Advisory Board with a high level of scientific expertise.**

# About Sarcoma Patients EuroNet

## Medical Advisory Board

The objectives of the Medical Advisory Board are 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 have been 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	STBSG EORTC
Dr. Rick L.M. Haas	Radiotherapy	Netherlands / Amsterdam	EORTC STBSG

Through the Medical Advisory Board SPAEN aims to ensure patient representation in, and integration to, major scientific committees and groups of experts at national and European levels.



## SPAEN Board of Directors and Officers

The current members of the SPAEN Board of Directors are:

Roger Wilson,  
President (UK)  
Sarcoma UK

Christina Baumgarten,  
Vice President (Germany)  
SOS Desmoid

Estelle Lecointe,  
Vice President (France)  
l'A.F.P.G. "Ensemble contre le GIST" & Info Sarcomes

Markus Wartenberg,  
Financial Director (Germany)  
Das Lebenshaus e.V.

Barabara Doré,  
Secretary (UK/USA)  
GIST Support UK & GIST Support International

Michael Sayers,  
Board Member (UK)  
GIST Support UK

Ornella Gonzato  
Board Member (Italy)  
Associazione Paola per i tumori muscoloscheletrici Onlus

Michaela Geissler  
SPAEN Project Manager (Germany)  
SPAEN Secretariat



*Board Members from left to right: Michaela Geissler (Secretariat), Roger Wilson, Estelle Lecointe, Ornella Gonzato, Christina Baumgarten, Barbara Doré, Markus Wartenberg, Michael Sayers*

# SPAEN

## Member Organisations



SPAEN welcomes every Sarcoma, GIST or Desmoid Patient Group/Organisation in Europe as Full Members. Full Members are entitled to vote at the Annual General Assembly. All other PAGs from outside Europe are welcome to join SPAEN as Associate Members. Among the benefits of membership are: information exchange with other members, receiving SPAEN newsletters and briefings, an invitation to SPAEN's annual meeting, mention of your organisation on our website, and finally, as part of a united international sarcoma community we all have a better chance to have our voices heard.

#### **SPAEN Full Members are currently:**

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. Poland: Stow. Pomocy Chorym Na GIST
17. Poland: Stow. Pomocy Chorym Na Miesaki "Sarcoma"
18. Romania: Romanian GIST-Network
19. Sweden: GIST Sverige
20. Switzerland: GIST Gruppe Schweiz
21. UK: GIST Support UK
22. UK: Guy Francis Bone Cancer Research Fund
23. UK: Sarcoma UK
24. UK: Bone Cancer Research Trust

#### **SPAEN Associate Members:**

1. Turkey: Genç Birikim Dernegi & Youth Accumulation Association (Associate Member)
2. USA: GSI - GIST Support International
3. USA: Sarcoma Alliance
4. USA: The Liddy Shriver Sarcoma Initiative



#### **Research Networks**

SPAEN works in close collaboration with a variety of Research Networks, such as EORTC, SARC, EUROSARC, Conticanet, Sarcoma League, Sacoma Worldnet and national Sarcoma Expert Groups.



Prof. Dr. Jean Yes Blay (EORTC President and Director of Conticanet) who is one of the initiators of SPAEN states: "Sarcoma Patients EuroNet is a very welcome development. We need to involve patients in clinical trials at the design stage so that the relevance of what we do can be considered at the outset. In addition SPAEN will be valuable helping patients understand what being treated in a clinical trial could mean to them. Together we can complete research more quickly.



**Sarcoma  
Patients  
EuroNet**

## Contact

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

Mrs. Michaela Geissler (Project Manager)  
Am Rothenanger 1B  
D-85521 Riemerling, Germany  
Tel.: + 49 89 62836807  
Fax: + 49 89 62836808

Email: [info@sarcoma-patients.eu](mailto:info@sarcoma-patients.eu)  
Web: [www.sarcoma-patients.eu](http://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