



**Sarcoma  
Patients  
EuroNet**

## **Conference Report**

**3rd SPAEN Annual Conference  
for Organizations  
Representing Patients  
with Sarcomas, GIST or Desmoid-Tumours**

**November, 22nd – 24th 2012  
NH Hotel, Florence/Italy**

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

# Acknowledgements

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





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This funding is not related to any objectives of SPAEN or any  
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The idea, conception, planning, preparation, realisation,  
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SPAEN is an independent European network of patient  
advocacy groups – without commercial influence.  
The SPAEN 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 both 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 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 established a Medical Advisory Board including 14 leading sarcoma experts covering all relevant disciplines and from several nationalities.





From 22nd to 24th November 2012 the 3rd SPAEN Annual Conference for member organisations and those seeking membership was held in Florence, Italy. The conference aimed to provide sarcoma, GIST and desmoid patient advocates an opportunity to share experience and best practice, as well as to learn about advances and challenges in the treatment of these rare cancers. The three day conference focused on research and treatment, advocacy and capacity building. Leading European sarcoma experts joined the meeting to present the latest news, to answer questions and to be available for discussions.

Among the topics were:

- Access to innovative medicine
- Design of clinical studies in rare cancers
- Parallel tracks for GIST, desmoid tumours and sarcomas with medical updates on current treatment options and ongoing clinical trials
- Educational research session (CINSARC in GIST and sarcomas, role of tissue- and biobanking)
- Educational session on treatment options in GIST, sarcomas and desmoids (e.g. radiotherapy and metastectomy)
- Advocacy Session - Access to treatment (e.g. understanding the situation of healthcare in Eastern Europe and how expert-networks and SPAEN can support development) and Health Technology Assessment – with a focus on improving the involvement of patient participation in HTA.

The Conference gave patient advocates the opportunity to share best practice examples and to network across borders. Last year, the 2nd SPAEN Conference in Berlin was attended by around 70 participants from 14 countries covering patient advocates, medical experts and the healthcare industry. This year, 90 participants from 20 different countries demonstrated the increasing interest in this disease group.

During the conference there was a felt common sense between patient advocates, sarcoma experts and the industry that together 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 a industry representative, to take part in “Changing the World” and contributing their share to make a difference for the benefit of Sarcoma patients.



## Statements of Participants





**Juliana Popova**  
**GIST Alliance for patients, Bulgaria**

Our patient organization is new and it was my first participation in conference at an international level. We are coming from a small country where people generally avoid talking about cancer and suddenly we felt like part of a

community in which all have joined forces in support for people affected by these rare tumors. Making contacts and listening some of the best GIST specialists was particularly of great help to us.



**Jayne Bressington,**  
**"PAWS-GIST" (Paediatric, Adolescent, Wildtype, Syndromic-GIST) Clinical Focus Group, UK**

The conference creates a situation where you meet experts and representatives from other patient groups in Europe that you would not normally meet in

everyday life. It presents an opportunity to network with these individuals and creates a platform for innovation, ideas and potential solutions to issues that on an individual basis seem insurmountable. We gained insight in to clinical trials and research, and the methods used to access treatments for rare cancers as well as new drugs that are in development for GIST. We learned about side effect management and the importance of bio banking for research as well as having Human Technology Assessment demystified.

All of the topics covered, coupled with the new connections made, make this conference very special. It is specifically tailored to our rare disease in a way that many other conferences are not able to achieve. All of the insights are relayed to our patients who are hungry for any new information that may help in their battle to overcome GIST. We would like to thank the SPAEN board for allowing us the opportunity to meet with the other European Sarcoma patient groups and for the fantastic opportunity it offers to interact first-hand with specialist doctors and pharmaceutical representatives.



**Prof. Michael Eriksson,**  
**University of Lund, Sweden**

The format, nice atmosphere and mutual exchange of knowledge and experience between sarcoma patients, advocates and experts within the sarcoma field made the SPAEN conference a meeting to remember!



**Geraint Thomas,**  
**Director Patient Relations GSK Europe, UK**

It was a pleasure and privilege to be able to talk to SPAEN about the challenging European environment for the pharma industry. We are facing austere times for the foreseeable future across

the whole of Europe so finding a way to provide a sustainable platform for industry and having access to new innovative treatments for patients requires everyone involved to work together to find a pragmatic solution. SPAEN is an important stakeholder in this debate to articulate the patient voice and to ensure that patients with rare cancers are represented.



**George Moreau,**  
**sos desmoid, France**

Where else can we find both access to leading specialists of our rare diseases, and the opportunity to share our experiences with fellow patient organizations ? And we find more than sheer medical information: the possibility to understand what the

therapeutical strategies are, the progresses in clinical trials and the advantages new methodologies can bring. I also particularly appreciate the fact that, each year, the Desmoid truck is gaining in substance. And to end with, a great "bravo" to the organising team.



**Thursday,  
November the 22nd 2012  
Access to innovative medicine**







*Roger Wilson*



*Susanna Leto di Priolo*



*Anna Costata*

After the opening of the 3rd Annual SPAEN conference by Roger Wilson (SPAEN President) and Anna Costata (Associazione Italiana GIST Onlus, Italy), Susanna Leto, Head of Patient Advocacy from Novartis Oncology Region Europe welcomed SPAEN to Italy. As a global leader in oncology Novartis focuses on research programs exploring new targets on the way to a more personalized medicine and, therefore, provides access to new agents for a large number of patients. She addressed the question "How can we work together to advance the future of cancer patients" and emphasized the importance of cooperation and partnership.

Geraint Thomas, Director Patient Relations from GSK Europe, London/UK, explained the position of the healthcare industry in a challenging environment – including the current European financial crisis.

There are several structural challenges in the healthcare system such as the ageing population with the associated rise of chronic diseases and multiple-morbidity. The focus is still on treating rather than preventing diseases, new technologies are seen as a cost and innovation is only slowly integrated into healthcare provision. In consequence, medicine will be dominated by cost control in the near future. Measures will focus on the rationale and cost-effectiveness of new drugs. Tailored solutions in each country are necessary to solve these problems. On the one hand people should be prepared to pay more for health but does rational drug use really mean decreasing patient access to new agents? Possible solutions could be efficiency improvements, developing new payment systems, increasing the role of prevention and reaching a better integration by using synergies between digital technology, diagnostics and personalized medicine as well as increasing peoples' own responsibility. Finally, he stressed that in this debate the patients' voice is crucial!



*Geraint Thomas*



# Thursday, November the 22nd 2012

## Access to innovative medicine

### **The main topic of the first day “Access to innovative medicine” was discussed from different perspectives.**

Prof. Michael Eriksson, University of Lund, Sweden, addressed the topic of learning more about “Good clinical practice (GCP)” in cancer clinical trials. The initial purpose of introducing these guidelines was to make recommendations about requirements on product registration. Since 2004, GCP forms the methodological standard for performing clinical trials in Europe. It is an international ethical and scientific quality standard for the design, performance, data collection and reporting of clinical trials. Some basic definitions of this regulation were explained such as “sponsor” or “patient’s informed consent”.

Prof. Winette van der Graaf, current Chairman of the EORTC Soft Tissue and Bone Sarcoma Group (STBSG), gave basic definitions aimed at understanding trial designs in sarcomas including placebo controlled trials. The fundamental aim of a clinical trial is generating evidence for a specific treatment which subsequently may be incorporated into treatment guidelines. Certain aspects have to be taken into account such as the age of the patients. More than one third of soft tissue sarcomas arise in patients older than 60 years. However, there are not many clinical trials addressing this patient population and many trials have an age limit of 60 or 65 years. Techniques such as randomization and blinded assessment are key tools to avoid a statistical bias and get valid and objective study results. A number of examples of recently published I phase III trials in sarcomas and GIST were presented to share different trial designs, methods and interpretations. A placebo design for a randomised-controlled trial may be chosen if no standard treatment is available. Crossover is a technique to give more patients the possibility of receiving the experimental (new) treatment if they show progressive disease while being treated in the placebo arm. The choice of the primary endpoint of a study (eg progression-free survival (PFS) or (OS) overall survival), incorporating patient related outcomes, and introducing biomarker-driven study designs, are becoming more important and will be essential in future sarcoma clinical trials.





Michael Eriksson



Winette van der Graaf



Paolo Casali



Silvia Comis

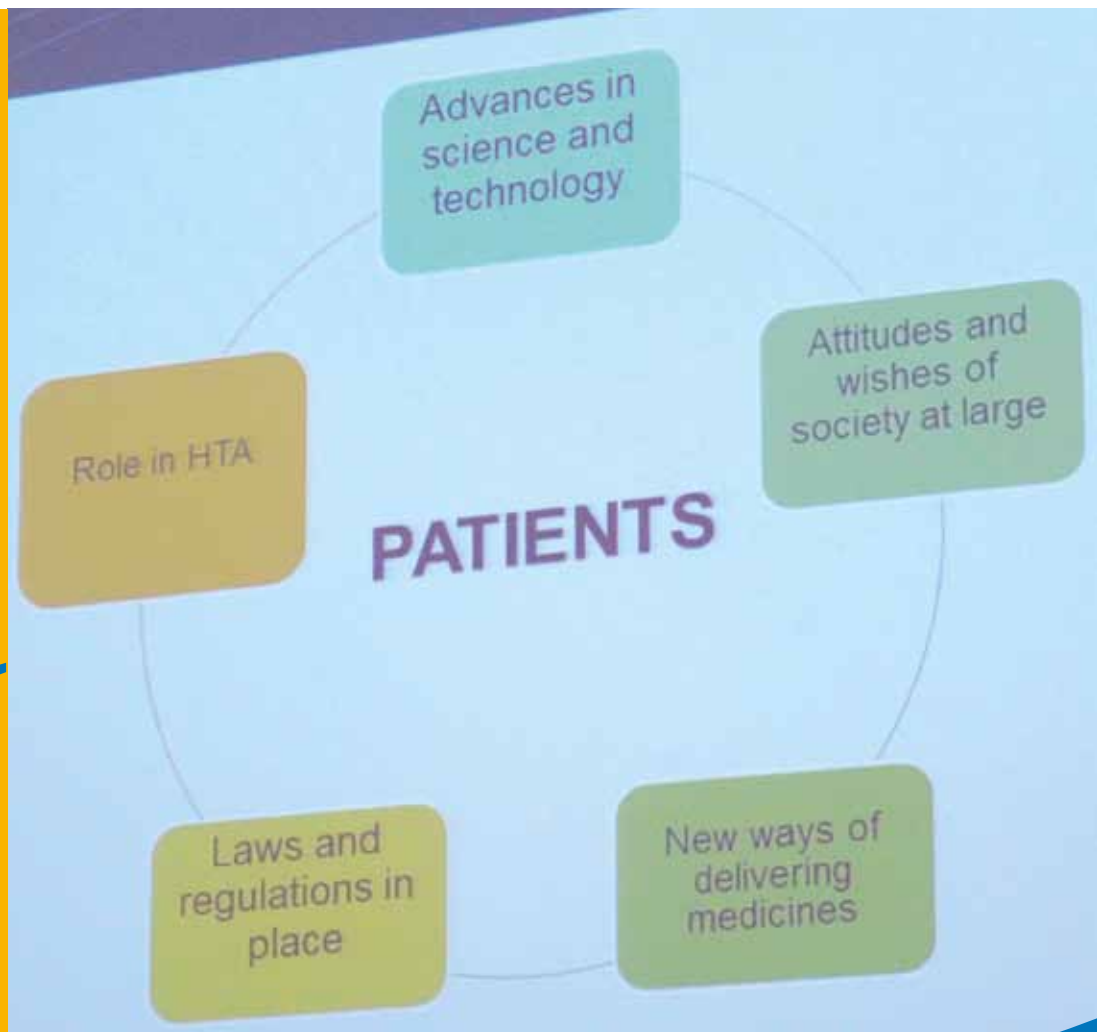
Dr. Paolo Casali from Milan addressed the challenge of what can be done to improve the methodology of clinical research in rare cancers. He explained the characteristics of a Bayesian statistical design interpreting the observations and data acquired during a clinical trial to define the degree of 'probability' that the experimental treatment is effective, rather than the traditional Frequentist statistician's view of 'significance'.

Different ways to provide early access to innovative treatments in Europe such as "compassionate use" or "off-label use" were explained by Silvia Comis from Novartis Oncology Region Europe. "Compassionate use" is designed for a product lacking market authorization, but meeting the needs of a specific patient group as demonstrated in clinical studies. These may be patients with a chronic, seriously debilitating or life-threatening disease who cannot be treated satisfactorily with an authorized drug. In contrast, "off-label use" means that a product does have a marketing authorization, but is used in another indication, at a different dose or dosage frequency or duration of treatment in another group of patients. Compassionate use is at the discretion of the drug manufacturer following recommendation by a specialist doctor. Off-label use is a medical decision but usually requires a funder's support. The "off-label use" of targeted therapies is particularly widespread in paediatric patients and rare or orphan diseases such as GIST and sarcomas. An important suggestion came from patient advocates in the audience: Very often Compassionate Use and other Programs are not very transparent to the medical community and to patient advocates. The healthcare industry and the regulators could do a better job in making public, in which countries these programs are available, who are the involved experts and what are the criteria for participation in these programs. More patients need the chance to get early access to innovative options and not only patients who are treated by a limited number of experts. Non expert centres should be aware to whom they can refer their patients with limited options.





**Friday,  
November the 23rd 2012  
Treatment Day**





During the treatment day several known Sarcoma experts presented in parallel educational sessions about new agents and clinical trials in Sarcomas, GIST and Desmoid tumours. Also very rare types of sarcomas were covered on the agenda.

We thank the following who provided the expert input (some in more than one session): Prof. Michael Eriksson, Dr. Marc Anliker, PD Dr. Lars Lindner, Prof. Piero Picci and Dr. Antoine Italiano, Prof. Bernd Kasper, Prof. Paolo Casali, Prof. Paolo Dei Tos, Prof. Peter Hohenberger, Dr. Marie-Pierre Sunyach and Markus Wartenberg.



*Michael Eriksson*



*Lars Lindner*



*Marc Anliker*



*Piero Picci*



*Antoine Italiano*



*Bernd Kasper*



*Paolo Casali*



*Paolo Dei Tos*



*Peter Hohenberger*



*Marie-Pierre Sunyach*



*Markus Wartenberg*

### GIST

This year's highlight in GIST was the presentation of the results of the phase III GRID trial with Regorafenib in advanced GIST patients. The GRID study met its primary endpoint of improvement in PFS (HR = 0.27,  $p < 0.0001$ ). The median PFS was 4.8 months in the Regorafenib arm versus 0.9 months in the placebo arm. The most common drug-related, treatment-emergent adverse events (occurring in at least 10 % of patients during double-blind treatment) included hand-foot skin reaction (56 % vs. 15 %), hypertension (48 % vs. 16 %), diarrhea (40 % vs. 7 %), fatigue (38 % vs. 27 %), oral mucositis (37 % vs. 9 %), alopecia (23 % vs. 3 %), anorexia (20 % vs. 7 %), rash (18 % vs. 3 %), nausea (15 % vs. 9 %), constipation (15 % vs. 7 %), myalgia (13 % vs. 9 %), and voice alteration (11 % vs. 3 %) for patients receiving Regorafenib as compared to placebo. With the secondary endpoint of OS, there was no statistically significant difference between the two study arms (HR = 0.77; 95 % CI, 0.42-1.41;  $p = 0.199$ ). However, this result was expected because as part of the trial design patients receiving placebo whose disease progressed were unblinded and allowed to cross over to the Regorafenib arm. Interestingly, a huge number of the recruited patients came from Europe demonstrating how engaged European GIST experts and patient advocacy groups are in terms of information and recruitment in clinical trials in GIST and sarcomas.

Targeted therapies such as imatinib and sunitinib, have dramatically improved GIST treatment over the past few years. Regorafenib is likely to be authorised and similar new agents such as pazopanib for soft tissue sarcomas are registered or will be available soon. All these treatments are in the form of tablets or capsules. As a result, the vast majority of treatment takes place at home and the patient is expected to share the responsibility for managing their therapy. For a "targeted drug" to be successful, i.e. effective in the long term, the patient must comply with the dosage and usage conditions exactly according to the product label - to be "compliant" or "adherent". Patient advocacy organisations represented in SPAEN continue to report that the patient is often given full responsibility. On an increasingly frequent basis, the physician providing treatment fails to take the time to explain the medication to the patient and caregiver. Medication is simply "prescribed" and therapy management falls by the wayside, is left to community physicians or pharmacists, or is handled on a crisis-basis when serious adverse events occur. As a result patients are left alone with their questions, the treatment, the side-effects, the consequences of dose modification through inappropriate self-management. Dr. Marc Anliker from St. Gallen - a dermatologist with great experiences in TKIs - showed very dramatically the broad range of skin toxicities caused

by targeted therapies and the ways to manage them. The following discussion showed very clearly that adherence and therapy - and side effect management will be an increasing challenge for GIST/Sarcoma patients and the member organizations in SPAEN.

To address this issue better Markus Wartenberg offered spontaneously - on behalf of SPAEN - to found a special "SPAEN Task Force Group" on this topic. Patient Group Leaders from Bulgaria, Germany, Netherlands, Israel and Switzerland will come fast forward to establish this task force in early 2013. Activity fields of the Task Force could be

- Sharing best practice: What can patient groups do to better support their members?
- Collaborations with research networks, experts and the industry on these topic (incl. research, survey, studies, etc.)...
- Common projects by SPAEN – that could be used by the national groups...



## Bone and Soft Tissue Sarcomas

The strategies and treatments used for managing advanced sarcomas were described and discussed. The surgical option should not be overlooked. The importance of understanding curative intent and palliative intent, the prognostic analysis which lies behind the clinical decision on how to treat a patient. Some patients may not wish to have chemotherapy, but most want a longer life. The topic covered the main chemotherapeutic agents, the administration of chemotherapy, the management of common side effects and skin toxicities, with a particular consideration of pazopanib.

Short profiles of sarcoma subtypes synovial sarcoma and osteosarcoma were presented. In both cases the presentation covered disease incidence, the biological knowledge of the disease, treatment approaches and options, especially when recurrent. Why some patients do better than others is a continuing topic for research and knowledge is improving, together with an understanding of the applicability of different treatments.

Future possible approaches for new therapies were considered. The mTor inhibition approach has not been proven to be of significant value. Stability of disease may be an objective for targeted therapies (rather than complete remission) in future studies. Analysis of current chemotherapies suggests that some sub-types of sarcoma may be more sensitive to particular therapies, and by identifying bio-markers this knowledge may become clinically useful in a prognostic way.

This year the treatment options for soft tissue sarcoma increased with the approval of Votrient (pazopanib) following a large EORTC phase III trial (PALETTE). There was a significant advantage for PFS of about three months in favour of the pazopanib arm compared with the placebo arm. Pazopanib is the first anti-angiogenic drug that has scientifically shown activity in advanced/metastatic soft tissue sarcomas. These results led to approval in the United States and Europe for all types of soft tissue sarcomas except adipocytic sarcomas (which include liposarcoma) and GIST.

## Desmoid Tumours

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. Starting with basic definitions about diagnosis, clinical presentation and molecular pathology of desmoids, different treatment options including surgery, radiotherapy and systemic therapy were discussed. Due to the heterogeneity of desmoids and their often unpredictable clinical course, there is no established standard of care for this disease which especially affects young females between 30 and 35 years. On the molecular level, desmoids are characterized by mutations in the beta-catenin gene, CTNNB1, or the Adenomatous Polyposis Coli gene. The proof of a CTNNB1 mutation may be useful when the pathological differential diagnosis is difficult and the location of the mutation might be predictive for disease recurrence. Therefore, the mutation status of the beta-catenin gene, CTNNB1, may be used to guide the therapeutic management comprising surgical resection, medical treatment and observation.

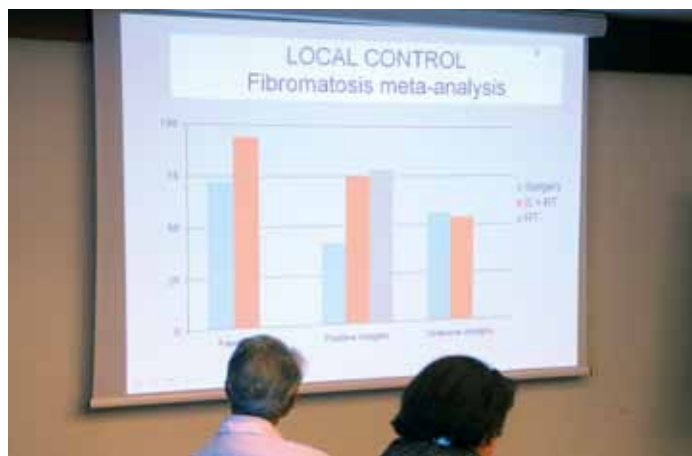


Surgery is the therapeutic mainstay for this disease. However, a period of watchful waiting or a front-line conservative approach may be the most appropriate management in selected asymptomatic patients which could be demonstrated recently. To evaluate the efficacy of radiotherapy for inoperable desmoid tumors, the EORTC STBSG performed a study assessing moderate dose radiotherapy for aggressive fibromatosis in patients not amenable to resection without significant function loss. Patients received radiotherapy for a total of 56 Gy in 28 fractions. The non-randomized phase II study finalized recruitment with 44 patients in April 2008 and could demonstrate a positive result with an 81.5 % local disease control rate at 3 years after a median follow-up period of 4.8 years with very moderate side effects. In summary, treatment needs to be individualized to optimize local tumor control and the preservation of patients' quality of life.

# Friday, November the 23rd 2012

## Treatment Day

The application of an interdisciplinary assessment with multimodality treatment options forms the basis of care for these patients. Current systemic treatment options and upcoming clinical trials for patients with desmoid tumors were presented such as the randomized trial of the French Sarcoma Group evaluating the activity of Pazopanib versus chemotherapy with methotrexate and vinblastine in about 80 adult patients with desmoid tumors (DESMO-PAZ). 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.



### Plenary Educational Session

The research project CINSARC (= complexity index in sarcomas) was presented by Dr. Frederic Chibon (Bordeaux). The project is to look for a signature in sarcomas and GIST which can be used as a prognostic parameter in sarcoma patients. In GIST the study suggests it might be helpful to split the intermediate risk group of post-surgery GIST patients into two subsets with a good or bad prognosis. This could help decision-making regarding adjuvant imatinib treatment. This analysis could be used for patient selection in new clinical trials.

Dr. Peter Riegman explained the organization of tissue- and biobanking, the efforts and investments required to establish a tissue- or biobank and the burdens, restrictions and problems we are facing in Europe from legislation and regulation.

The final session of the day focused on special treatment options. Dr Rick Haas gave an overview on radiotherapy as a method of fighting against sarcoma cells. In sarcomas, radiotherapy is usually used in grade II/III sarcomas, after radical excision or narrow margins or after recurrence of the disease. It can be given after surgery (adjuvant) or preoperatively (neoadjuvant) each having certain advantages and disadvantages. New developments include individualized dose prescriptions, altered fractionation and adding chemotherapy to radiotherapy. The role of early and late toxicity due to radiotherapy was also described. The second topic covered the role of metastectomy in sarcomas and GIST (Prof. Piotr Rutkowski). Different strategies can be chosen for local treatment of metastases such as conventional surgery, lasertherapy (e.g. lungs), radiofrequency ablation (RFA), kryoablation (e.g. liver), chemoembolisation or selective internal radiotherapy (SIRT). Each of these procedures is very individual to the nature of the patient's disease. Metastectomy can be a viable strategy for GIST patients to prolong a durable remission or gain added overall survival.





*Frederic Chibon*



*Peter Riegman*



*Rick Haas*

After a long day full of information the social evening program was a welcome change for all participants. The group took a walk along the Arno river to a typical Tuscan restaurant with excellent Italian food and time to talk and to enjoy the evening.



**Saturday,  
November the 24th 2012  
Advocacy Day**





*Winette van der Graaf*



*Piotr Rutkowski*

The advocacy day started with the general assembly 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 for collaboration with experts and industry. 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 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, the World Sarcoma Network and EUROSARC. Upcoming challenges SPAEN is facing are establishing where are the centres of excellence in each country in Europe, identifying where expert centres are needed and where new support organisations can be created, improving the quality of treatment, discussing the management of treatment side effects of oral targeted therapies and addressing problems of reimbursement. The financial cooperation with the pharmaceutical industry is structured as a sustaining partnership.

Prof. Winette van der Graaf presented the work and ambitions of the EORTC Soft Tissue and Bone Sarcoma Group (STBSG). Currently open clinical trials are the STRASS study (surgery plus or minus radiotherapy in retroperitoneal sarcomas), the TRUSTS study (trabectedin versus doxorubicin in the first line treatment of metastatic soft tissue sarcomas) and the CREATE trial (crizotinib targeting the ALK pathway in rare subtypes of soft tissue sarcomas such as clear cell sarcomas). New initiatives include many database related projects, bone sarcoma trials, imaging studies, quality of life evaluations and trials in the elderly population. A preclinical consortium of research centres will be implemented and another aim of the STBSG is to raise funding for more academic clinical trials.

The advocacy session dealt with the main topic of "Access to treatment" for patients with rare cancers. Participants tried to better understand the situation of healthcare in Central-Eastern Europe for patients with sarcomas and GIST. Prof. Piotr Rutkowski from Warsaw, Poland summarized the situation with a focus on soft tissue sarcomas and addressed the main problems: There are very few centres of excellence for sarcomas and none at all in some countries in Eastern Europe. There is a lack of reliable epidemiological data in many countries, the access to innovative drugs and clinical trials is limited and there are different systems of healthcare and reimbursement in place.

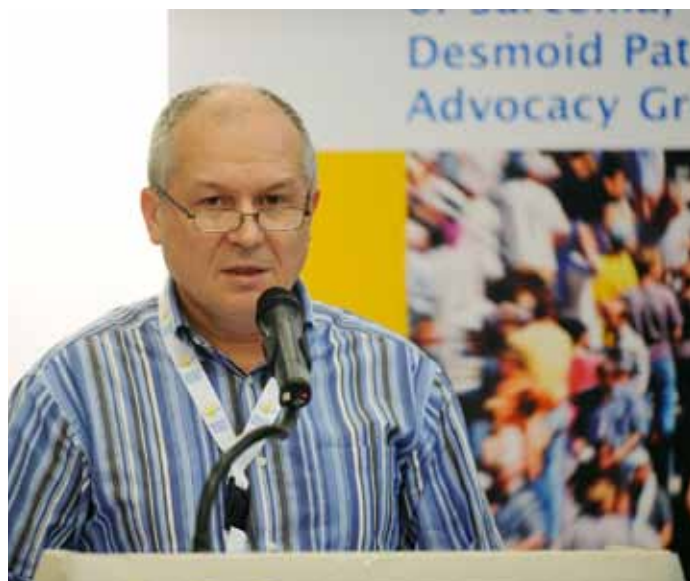




# Saturday, November the 24th 2012

## Advocacy Day

Representatives of different patient advocacy groups showed their perspective by presenting their individual group and addressing the issues they are facing in their own countries. Piotr Fonrobert spoke for the GIST patient advocacy group in Poland, Stefan Mandov for the GIST Alliance for Patients Bulgaria and Simona Ene for the "Hope" Support Group for Women with Cancer in Romania. The main issues being raised can be summarized as: the lack of information, the lack of reference pathology and molecular analysis, the lack of a multidisciplinary team of specialists, problematic reimbursement processes, no compassionate and off-label use programs and no access to clinical trials.



Piotr Fonrobert



Simona Ene



Stefan Mandov







Karen Facey

The last session started with Dr. Karen Facey highlighting the role of patient participation in the process of Health Technology Assessment (HTA). 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? How do we include them in the process? Patients' views and preferences contribute to HTA principally in two ways: by providing robust evidence and through participation in the analysis and decision processes. Evidence from patient organisations may include partnerships in research (e.g. study design, patient related outcomes), surveys and questionnaires, social networking, collecting patient stories and building an evidence base. Involvement should mean that the whole process should result in patient-influenced decision-making leading to stronger and more robust recommendations.

After more than 10 years working on HTA with NICE in the UK, the current process of evaluating cost-effectiveness was described by Roger Wilson (Sarcoma UK). HTA offers a review of clinical effectiveness and considers cost effectiveness. The patient advocacy groups can comment and give input on these reviews thereby influencing the process of approval. The potential role of patient advocacy groups may be summarized as follows: understand - get involved - work together - create evidence! It is

important that patient advocacy groups make up their own mind about the value of the treatment and contribute whenever there is an opportunity, they should work together with reviewers and should not hesitate to bring their concerns to higher authorities and they should challenge decisions if they believe they are wrong.



Karen Facey and Roger Wilson



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 2012 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".

# Impressions







# Conference Program

<b>DAY 1</b>	<b>THURSDAY November 22nd, 2012</b>
<b>12:00</b>	<b>LIGHT LUNCH</b>
<b>13:00</b>	<b>OFFICIAL START OF THE CONFERENCE</b> Main room – Plenary Sessions
<b>13:00 - 13:30</b>	<b>Opening, Welcome, Organizational Issues, Thanks to the S ponsors, etc.</b> <i>Roger Wilson (SPAEN) &amp; Anna Costato (A.I.G.)</i>
<b>13:30 - 14:00</b>	<b>Novartis Europe welcomes SPAEN in Italy</b> <i>Susanna Leto di Priolo, Head Patient Advocacy and Professional Relations, Novartis Oncology Region Europe</i>
<b>14:00 - 14:30</b>	<b>The position of the healthcare industry in a changing environment</b> <i>Geraint Thomas, Director Patient Relations, GSK Europe, London/UK</i>
<b>14:30 - 15:00</b>	<b>COFFEE BREAK</b>
	<b>ACCESS TO INNOVATIVE MEDICINE</b> <i>Moderator: Barbara Dore (SPAEN)</i>
<b>15:00 - 15:45</b>	<b>Clinical Trials: Learning more about “Good Clinical Practice (GCP)”</b> <i>Prof. Dr. Michael Eriksson, University of Lund/Sweden</i>
<b>15:45 - 16:30</b>	<b>Understanding some basic trial-designs in Sarcomas (incl. a placebo-trial)</b> <i>Prof. Dr. Winette van der Graaf, EORTC Soft Tissue and Bone Sarcoma Group, Belgium</i>
<b>16:30 - 17:15</b>	<b>What can be done to improve the methodology of clinical research on rare cancers?</b> <i>Dr. Paolo Casali, Istituto Tumori, Milan/Italy</i>
<b>17:15 - 18:00</b>	<b>Different ways to provide access to innovative treatments in Europe?</b> <b>What means Compassionate Use – Early Access Program – Off Label Drugs?</b> <i>Silvia Comis, Novartis Oncology Region Europe</i>
	<b>BREAK BEFORE DINNER</b>
<b>19:30 - 22:30</b>	<b>Internal Dinner</b>



DAY 2

FRIDAY November 23rd, 2012

PARALLEL TRACKS FOR GIST, SARCOMAS AND DESMOIDS

	GIST Track Room: Michel Angelo	Sarcoma Track Room: Leonardo	Desmoid Track Room: Cinelli
08:30 - 09:15	<b>Moderator:</b> <i>Michael Sayers</i>  <b>Risk stratification in GIST and adjuvant treatment</b> <i>Prof. Bernd Kasper, Mannheim/Germany</i>	<b>Moderator:</b> <i>Roger Wilson</i>  <b>Managing chemotherapy in Sarcomas:</b> - The main agents - To administer chemo - Side effect mgmt. - Skin-toxicities - Important for patients to know? <i>Prof. Dr. Michael Eriksson, University of Lund/Sweden</i> <i>Dr. Marc Anliker, St. Gallen/Switzerland</i>	<b>Moderator:</b> <i>Christina Baumgarten</i>  <b>Understanding molecular genetics and pathology in Desmoids</b> <i>Prof. Dr. Paolo Dei Tos, T reviso Hospital/Italy</i>
09:15 - 10:30	<b>Understanding four key factors for successful therapy management in GIST:</b> - Education/communication - Dosing - Treatment duration - Side effect mgmt. <i>Dr. Paolo Casali, Istituto Tumori, Milan/Italy</i>	<b>The role of surgery in Desmoids</b> <i>Prof. Dr. P. Hohenberger, Mannheim/Germany</i>  <b>The role of radiotherapy in Desmoids</b> <i>Dr. Marie-Pierre Sunyach, Centre Leon Berard, Lyon/France</i>	
10:30 - 11:00	COFFEE BREAK		
11:00 - 11:45	<b>Moderator:</b> <i>Markus Wartenberg</i>  <b>How to manage skin toxicities in GIST?</b> <i>Dr. Marc Anliker, St. Gallen/Switzerland</i>	<b>Moderator:</b> <i>Roger Wilson</i>  <b>Short profiles of sarcoma subtypes:</b>  <b>Synovial Sarcomas</b> 30 min. <i>PD Dr. Lars Lindner, Klinikum der Universität München/Germany</i> <b>Osteosarcomas</b> 30 min. <i>Prof. Dr. Piero Picci, Chairman Italian Sarcoma Group, Bologna/Italy</i> <b>Update on systemic treatment options and clinical trials in Sarcomas</b> 30 min. <i>Antoine Italiano, Bordeaux/France</i> <b>Update on systemic treatment options and clinical trials in Desmoids</b> 30 min <i>Prof. Bernd Kasper, Mannheim/Germany</i>	<b>Moderator:</b> <i>Christina Baumgarten</i>  <b>Round Table with the experts to discuss common topics and needs</b> 60 min.
11:45 - 12:15	<b>Sharing best Practice/ Brainstorming: How can GIST-patient groups help their patients in the field of side effect management?</b> <i>Markus Wartenberg</i>		
12:15 - 13:00	<b>Regorafenib, Masitinib, Dovitinib and others: Update on systemic treatment options and clinical trials in GIST</b> <i>PD Dr. Peter Reichardt, Sarcoma-Center Berlin-Brandenburg/Germany</i>		

# Conference Program

<b>DAY 2</b>	<b>FRIDAY November 23rd, 2012</b>
<b>13:00 – 14:00</b>	<b>LIGHT LUNCH</b>
	<b>EDUCATIONAL RESEARCH SESSIONS</b>
	<b>Moderator:</b> <i>Estelle Lecointe (SPAEN)</i>
<b>14:00 - 14:30</b>	<b>Understanding CINSARC in GIST and Sarcomas</b> <i>Frederic Chibon, Institut Bergonie, Bordeaux/France</i>
<b>14.30 - 15:00</b>	<b>The role of tissue-/biobanks for sarcoma research:</b> <b>- The value of tissue- and biobanks for sarcoma research?</b> <b>- Are there first ideas/concepts/examples in Sarcomas?</b> <i>Prof. Dr. Paolo Dei Tos, Treviso Hospital/Italy</i>
<b>15:00 – 15:30</b>	<b>- How is tissue /biobanking normally organized?</b> <b>- What are efforts/investments to establish a tissue-/biobank?</b> <b>- What are the burdens/restrictions/problems we are facing in Europe?</b> <i>Dr. Peter Riegman, President European, Middle Eastern and African Society for Biopreservation and Biobanking (ESBB)</i>
<b>15:30 – 16:00</b>	<b>COFFEE BREAK</b>
	<b>EDUCATIONALS - SPECIAL TREATMENT OPTIONS</b>
<b>16:00 - 17:15</b>	<b>Moderator:</b> <i>Barbara Dore</i>
	<b>Radiooncology in Sarcomas, GIST and Desmoids</b> <b>Fighting against sarcoma cells with radiation</b> <b>Situations, where radiation could be an option</b> <b>The process – understandable for patients</b> <b>Understanding different methods of radiotherapy:</b> <b>Standard, IORT, Brachy, SIRT, cyber-knife, proton</b> <b>Common side effects in radiation</b> <i>Dr. Rick Haas, Amsterdam/Netherlands</i> <i>Metastasectomy in Sarcomas and GIST</i>
<b>17:15 - 18:00</b>	<b>Different methods to treat metastasis in Sarcomas and GIST:</b> <b>Surgery, RFA, Kryoablation, Laser, Microwave, Chemoembolisation, SIRT</b> <b>How to treat metastasis in different sites of the body: (lung, liver, bones, etc.)</b> <i>Prof. Dr. Piotr Rutkowski, Warsaw, Poland</i>
	<b>BREAK BEFORE DINNER</b>
<b>19:15 – 23:00</b>	<b>External Tuscan Dinner at ANTICO RISTORO DI CAMBI</b>  Dinner Speech <b>Novartis Europe welcomes SPAEN in Italy</b> <i>Veronica Foote, Head of Patients Strategy, Novartis Oncology Region Europe</i>

<b>DAY 3</b>	<b>SATURDAY November 24th, 2012</b>
<b>08:30 - 10:30</b>	<p><b>Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2011/2012</b></p> <p><b>Moderator:</b> <i>Roger Wilson + SPAEN-Board</i></p> <p><b>All participants/delegates are welcomed</b> Incl. Networking activities of SPAEN with other organizations (EORTC, EUROSARC, RARE CANCER EUROPE, etc.) <i>Markus Wartenberg (SPAEN)</i></p> <p><b>Short report from EORTC:</b> <i>Estelle Lecointe &amp; Anastassia Negrouk, EORTC Brussels</i></p> <p><b>Short report from the EUROSARC-project:</b> <i>Estelle Lecointe (SPAEN)</i></p>
<b>10:30 - 11:00</b>	<b>COFFEE BREAK</b>
<b>11:00 - 13:00</b>	<p><b>ADVOCACY – ACCESS TO TREATMENT</b></p> <p><b>Moderator:</b> <i>Markus Wartenberg (SPAEN)</i></p> <p><b>Let's try to better understand the situation of healthcare in Eastern Europe – especially in the field of Sarcomas, GIST and Desmoids...</b> <i>Short presentations (15 Min. each) from:</i>  <ul style="list-style-type: none"> <li>- Physicians: <i>Prof. Dr. Piotr Rutkowski, Warsaw, Poland</i></li> <li>- PAGs: <i>Piotr Fonrobert, Juliana Popova, Jana Pelouchova</i></li> <li>- Research: <i>Prof. Dr. Piotr Rutkowski, Warsaw, Poland</i></li> </ul> </p> <p><b>Discussion:</b> What are needs, ideas, solutions to improve the situation in the field of Sarcomas, GIST and Desmoids? How could expert-networks and SPAEN support?</p>
<b>13:00 – 14:00</b>	<b>LIGHT LUNCH</b>
<b>14:00 - 15:30</b>	<p><b>Moderator:</b> <i>Roger Wilson (SPAEN)</i></p> <p><b>Improving the impact of patient participation in HTA = Health Technology Assessment (presentation + practical issues)</b> <i>Dr. Karen Facey, Health Policy Consultant, UK</i></p> <p><b>After more than 10 years working with HTA = NICE in the UK: How is the current process of evaluating cost-effectiveness and what are the main findings/insights from a patients perspective?</b> <i>Roger Wilson, Sarcoma UK / SPAEN</i></p> <p><b>Questions and Discussions:</b>  <ul style="list-style-type: none"> <li>- What can/should patient groups claim from their national in the HTA-bodies?</li> <li>- What are the main factors for a national HTA-process: <i>Understand – Get involved/heard – Work together – Create evidence?</i></li> </ul> </p>
<b>15:30 - 15:45</b>	<p><b>End of meeting, Summary, Feedback-Forms, Closing Remarks, Thanks to the Presenters &amp; Sponsors</b> <i>Markus Wartenberg &amp; Roger Wilson (SPAEN)</i></p>

# Participants List

1	<b>Aanesen</b>	Jens Joakim	Norway	Desmoid Patient
2	<b>Anliker</b>	Mark	Switzerland	Kantonsspital St. Gallen (Dermatologie)
3	<b>Asselbergs</b>	Jack	Netherlands	Contactgroep GIST Netherlands
4	<b>Bacconier</b>	Simon	France	World Sarcoma Network
5	<b>Baumgarten</b>	Christina	Germany	SPAEN
6	<b>Bennister</b>	Lindsey	UK	Sarcoma UK
7	<b>Bressington</b>	Jayne	UK	PAWS-GIST
8	<b>Brice</b>	Joe	US	Bayer
9	<b>Bulusu</b>	Venkata	UK	PAWS-GIST
10	<b>Casal</b>	Alfonso	Spain	Pharmamar
11	<b>Casali</b>	Paolo	Italy	Istituto Tumori
12	<b>Chibon</b>	Frederic	France	Institut Bergonié - Bordeaux
13	<b>Comis</b>	Silvia	Italy	Novartis Europe
14	<b>Costato</b>	Anna	Italy	A.I.G. Associazione Italiana GIST Onlus
14	<b>DeiTos</b>	Paolo	Italy	Treviso General Hospital
16	<b>Dewji</b>	Mohamed	US	GSK Director, Clinical Development Scientist Votrient
17	<b>Djordjevic</b>	Senka	Switzerland	Bayer
18	<b>Dore</b>	Barbara	UK/US	SPAEN
19	<b>Ene</b>	Simona	Romania	"Hope" Support Group for Women with Cancer
20	<b>Eriksson</b>	Michael	Sweden	University of Lund
21	<b>Facey</b>	Karen	UK	HTAi Policy Consultant
22	<b>Fonrobert</b>	Piotr	Poland	Polish GIST patients support association
23	<b>Foothe</b>	Veronica	Italy	Novartis Europe
24	<b>Geissler</b>	Michaela	Germany	SPAEN
25	<b>Gherlinzoni</b>	Franco	Italy	Associazione Paola per i tumori muscoloscheletrici
26	<b>Gonzato</b>	Ornella	Italy	Associazione Paola per i tumori muscoloscheletrici
27	<b>Gueguin</b>	Francois	France	Institute Gustav Roussy
28	<b>Haas</b>	Rick	Netherlands	The Antoni van Leeuwenhoek Hospital Amsterdam
29	<b>Hohenberger</b>	Peter	Germany	Mannheim University Medical Center
30	<b>Homb</b>	Frode	Norway	Sarkomer
31	<b>Ippolito</b>	Vincenzo	Italy	Le Ali Onlus
32	<b>Italiano</b>	Antoine	France	Institut Bergonié Bordeaux
33	<b>Jagger</b>	Stephanie	UK	Takeda Europe
34	<b>Julian</b>	Maria	Spain	Pharmamar
35	<b>Kasper</b>	Bernd	Germany	Mannheim University Medical Center
36	<b>Kaya</b>	Betül	Turkey	Youth Accumulation
37	<b>Kelleher</b>	Claire	UK	Sarcoma UK
38	<b>Keulen</b>	Hans	Netherlands	Chordoma Foundation
39	<b>Krstevska</b>	Sonja	Macedonia	GIST Patient Group Macedonia
40	<b>Krstevski</b>	Dejan	Macedonia	GIST Patient Group Macedonia
41	<b>Krzywicka</b>	Malgorzata	Poland	Polish GIST patients support association
42	<b>Lecointe</b>	Estelle	France	SPAEN
43	<b>Leto di Priolo</b>	Susanna	Italy	Novartis
44	<b>Lindner</b>	Lars	Germany	Interdisciplinary centre for bone and soft tissue sarcomas (SarkUM)



45	<b>Mandov</b>	Stefan	Bulgaria	GIST Alliance for Patients Bulgaria
46	<b>Mapelli</b>	Sergio	Italy	Ass.Aldo Arienti Amici Chirurgia Ortopedica Oncologica Onlus Ist.G.Pini Milano
47	<b>Mathot</b>	Audrey	Switzerland	Swiss GIST Group
48	<b>Meier-Schnorf</b>	Helga	Switzerland	GIST-Group Switzerland
49	<b>Mitchell</b>	Debbie	UK	GIST Support UK
50	<b>Monfasani</b>	Daniela	Italy	Ass.Aldo Arienti Amici Chirurgia Ortopedica Oncologica Onlus Ist.G.Pini Milano
51	<b>Moreau</b>	Georges	France	sos desmoid France
52	<b>Moshe</b>	Gideon	Israel	Israeli GIST patients organization
53	<b>Negrout</b>	Anastassia	Belgium	EORTC
54	<b>Picci</b>	Piero	Italy	Bologna
55	<b>Piccinelli</b>	Claudia	Italy	Le Ali Onlus
56	<b>Piccolo</b>	Francesca	Italy	Le Ali Onlus
57	<b>Pilgermann</b>	Kai	Germany	Das Lebenshaus
58	<b>Popova</b>	Yuliana	Bulgaria	GIST Alliance for Patients Bulgaria
59	<b>Riegmann</b>	Peter	Netherlands	European, Middle Eastern and African Society for Biopreservation and Biobanking (ESBB)
60	<b>Rigaux</b>	Philippe	France	SOS Desmoide France
61	<b>Rondena</b>	Roberta	Italy	Novartis (Responsible Market Access, Rare Tumours, Region Europe)
62	<b>Rutkowski</b>	Piotr	Poland	Institute of Oncology Warsaw
63	<b>Sayers</b>	Michael	UK	SPAEN
64	<b>Schröfel</b>	Gunnar	Germany	Bayer Global Advocay
65	<b>Schumacher</b>	Kathrin	Sweden/Germany	Das Lebenshaus
66	<b>Seewald</b>	Ricarda	Germany	Das Lebenshaus
67	<b>Segat</b>	Daniela	Italy	“Mauro Baschiroto” Institute for Rare Diseases
68	<b>Sunyach</b>	Agnes	France	Centre Leon Berard, Lyon
69	<b>Tedone</b>	Gabriella	Italy	A.I.G. Associazione Italiana GIST Onlus
70	<b>Thomas</b>	Geraint	UK	GSK (Diretor Patient Relations)
71	<b>Tomasello</b>	Cinzia	Italy	GSK spa (Advocacy Specialist)
72	<b>Tomassone</b>	Paolo	Italy	A.I.G. Associazione Italiana GIST Onlus
73	<b>Tulimiero</b>	Pasquale	Italy	Noi per Voi
74	<b>Unsworth</b>	Dr Harriet	UK	Bone Cancer Research Trust
75	<b>Väisänen</b>	Marjo	Finland	Finnish cancer patient organization
76	<b>van Arem</b>	Ellen	NL	Stichting Sarcoma NL
77	<b>van Arem</b>	Helmer	NL	Stichting Sarcoma NL
78	<b>van Bavel</b>	Laurens	NL	Contactgroep GIST Netherlands
79	<b>van der Graaf</b>	Winette	Belgium	EORTC Soft Tissue and Bone Sarcoma Group
80	<b>van Dun</b>	Wie	Belgium	Contractgroep GIST Belgium
81	<b>Wallace</b>	Anna	UK	Living Beyond Diagnosis
82	<b>Wartenberg</b>	Markus	Germany	SPAEN
83	<b>Wettstein</b>	Martin	Switzerland	Swiss GIST Group
84	<b>Wilson</b>	Roger	UK	SPAEN
85	<b>Yuce</b>	Salih	Turkey	Youth Accumulation
86	<b>Zigdon</b>	Avi	Israel	Israeli GIST patients organization

# 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 foundation members initiated the foundation of SPAEN and membership 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 raising the profile sarcoma with policymakers and the public.

27 members from 15 countries and constantly works to extend the patient group network and tries to support the formation of new patient groups.

## 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 raising the profile 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 has 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 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/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 (2010 – 2013) 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

Michaela Geissler  
SPAEN Project Manager (Germany)  
SPAEN Secretariat



# SPAEN

## Member Organisations







SPAEN welcomes every Sarcoma, GIST or Desmoid Patient Group/Organisation in Europe as Full Member. 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. 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

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

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

#### **Research Networks**

SPAEN works in close collaboration with a variety of Research Networks, such as EORTC, SARC, EUROSARC, Conticanet, Sarcoma League, Sarcoma 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

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D-85521 Riemerling, Germany  
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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.  
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