



**Sarcoma
Patients
EuroNet**

Conference Booklet

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



19th – 21st November 2015

Dolce Hotel Chantilly/Paris (France)

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

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We would like to thank the following funders who have supported the 6th SPAEN Conference with an unrestricted educational grant: Bayer, Merck, Novartis, Pfizer, PharmaMar and Takeda. The funding is not related to any of the objectives of SPAEN or any of the objectives/content of the 6th SPAEN Conference in Chantilly, FR. The idea, conception, planning, preparation, realization, management and the summary of the 6th SPAEN Annual Conference is the responsibility of the SPAEN Board without any influence from the sponsors/funders.

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





On the 29th of October 2015, our friend and colleague Hans Keulen passed away due to the consequences of Chordoma, a rare type of bone cancer that affects the bone of the skull and spine.

The last years of his life Hans dedicated a lot of his time to the Chordoma foundation, to improve the lives of patients and to stimulate research for treatment of this disease. He did this with the great passion and drive that we were all very familiar with. He was a fantastic advocate for Chordoma Patients - but also a great representative of the European Sarcoma Patients and the European Rare Cancer Community. We will really miss him, his great competence, his friendship and his unlimited source of engagement.

SPAEN is dedicating this 6th Annual SPAEN Conference to Hans Keulen and we will remember him during a special ceremony.

The SPAEN Board of Directors

A Warm Welcome to SPAEN's 6th Annual Conference!

Dear Delegates,

Welcome to Chantilly and to the 6th Annual Meeting and General Assembly of Sarcoma Patients EuroNet.

It's been a long time since our first meeting 2010 in Madrid. Some of you went all the way with us, some joined us during the years. But no matter how long you've been with SPAEN so far, patient benefit is at the heart of what we are all trying to achieve! It is also the objective of our clinical specialist colleagues who join us for this meeting. They come from many parts of Europe and represent most of the disciplines involved in treating sarcoma.

Do not be timid in asking questions, whether in a formal session or afterwards over coffee or lunch. Our medical colleagues are very willing to share their knowledge of these rare cancers. Remember that we share the aim of delivering patient benefit.

We also have the opportunity to meet our sponsoring partners. Even though financial issues might make rarer cancers a low commercial priority, companies are starting to see patient benefit as the real priority. The growing commitment of industry to sarcoma is heartening. There are more clinical trials running than at any time any of us can recall - a real tribute to our research oncologists as well as to the developers of the new drugs.

Do try and meet as many people from as many countries as you can over our three days together. Share your good experiences and your disappointments also, we can learn so much from each other.

We welcome you all for what we hope will be three days of inspiration through shared learning and good company.

With best wishes,
The SPAEN Board of Directors



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© Stefan Krause on wikipedia

Capital: Paris
Population: 67 mio.
Area: 640,679 km² = 247,368 sq mi
Currency: EURO
Calling Code: +33
Internet: .fr

Welcome to France!

France, officially the French Republic, is a sovereign state comprising territory in western Europe and several overseas regions and territories, including island territories in the Atlantic, Pacific and Indian oceans, French Guiana on the South American continent, and several periantarctic islands as well as a claim in Antarctica. The European part of France is called Metropolitan France.

France spans 640,679 square kilometres (247,368 sq mi) and has a total population of 67 million, including all overseas departments and territories.

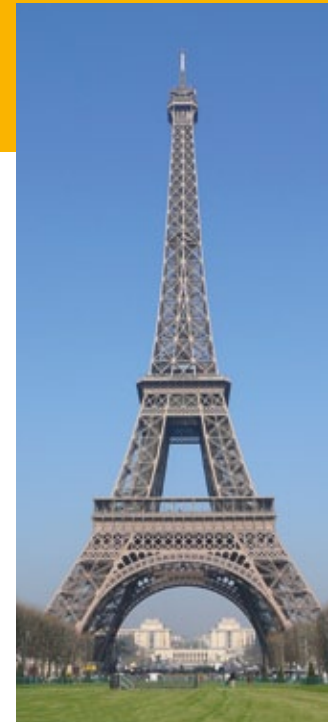
It is a unitary semi-presidential republic with the capital in Paris, the country's largest city and main cultural and commercial center.

The Kingdom of France was created in the Middle Ages, emerging as a major European power in the Late Middle Ages. During the Renaissance, France experienced a vast cultural development and established the beginning of a global colonial empire on the way to a centralized absolute monarchy.

Under Louis XIV France became Europe's dominant cultural, political, and military power. In the late 18th century, however, the monarchy was overthrown in the French Revolution. Among its legacies was the Declaration of the Rights of Man and of the Citizen, one of the earliest documents on human rights, which expresses the nation's ideals to this day.

France has almost always been a leading global center of culture, making significant contributions to art, science, and philosophy. It hosts Europe's third-largest number of cultural UNESCO World Heritage Sites (after Italy and Spain) and receives around 83 million foreign tourists annually, the most of any country in the world. It is a developed country with the world's sixth-largest economy by nominal GDP and eight-largest by purchasing power parity. According to Credit Suisse, France is the fourth wealthiest nation in the world in terms of aggregate household wealth.

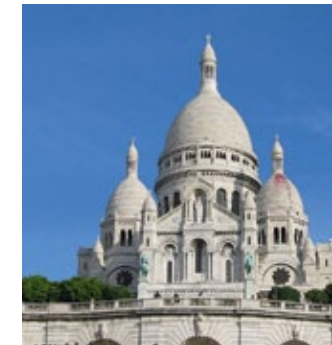
(Source: Wikipedia.com)



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Welcome to Paris!

Paris is the capital and most-populous city of France. Situated on the Seine River, in the north of the country, it is in the centre of the Île-de-France region, also known as the région parisienne, "Paris Region". The City of Paris has an area of 105.4 square kilometres (40.7 sq mi) and has a population of 2.24 million.

The Paris Region covers 12,012 square kilometres (4,638 sq mi), and has its own regional council and president. It has a population of 12 million, or 18.2 percent of the population of France.

Paris is the home of the most visited art museum in the world, the Louvre, as well as the Musée d'Orsay, noted for its collection of French Impressionist art, and the Musée National d'Art Moderne, a museum of modern and contemporary art. The notable architectural landmarks of Paris include Notre Dame Cathedral (12th century); the Sainte-Chapelle (13th century); the Eiffel Tower (1889); and the Basilica of Sacré-Cœur on Montmartre (1914).

In 2014 Paris received 22.4 million visitors, making it one of the world's top tourist destinations. Paris is also known for its fashion, particularly the twice-yearly Paris Fashion Week, and for its haute cuisine, and three-star restaurants.

Welcome to Chantilly!

Chantilly is a commune in the Oise department in the valley of the Nonette in the Picardy region of northern France. Surrounded by Chantilly Forest, the town of 11,000 inhabitants falls within the metropolitan area of Paris. It lies 38.4 km (23.9 miles) north-northeast from the centre of Paris and together with six neighbouring communes forms an urban area of 36,474 inhabitants (1999 census).

Intimately tied to the House of Montmorency in the 15th to 17th centuries, the Château de Chantilly was home to the princes of Condé, cousins of the kings of France, from the 17th to the 19th centuries. It now houses the Musée Condé.

Chantilly is also known for its horse racing track, the Chantilly Racecourse, where prestigious races are held for the prix du Jockey Club and the prix de Diane. Chantilly and the surrounding communities are home to the largest racehorse-training community in France.

(Source: Wikipedia.com)

All sessions will be held in room Albatros (1st Floor Conference Centre) unless otherwise indicated

DAY 1 – THURSDAY November 19, 2015

12:00 **LIGHT LUNCH – (60 minutes)**

13:00 – 13:30	OFFICIAL START OF THE CONFERENCE
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**Welcome to Paris/Chantilly –
on behalf of the SPAEN Board and the French Sarcoma Patient Groups**
Estelle Lecoine (FR) - George Moreau (FR)

FROM RESEARCH TO CLINIC
Moderator: Markus Wartenberg

13:30 - 14:30

What does “Personalized Medicine” currently mean in GIST/Sarcomas/Desmoids?
What are known targets in the different subtypes?
What are the current techniques/procedures used by pathologists?
How does Mutational Analysis work?
Anette Duensing (USA)

14:30 - 15:30

Discussion & Brainstorming:
Status/Practice Mutational Analysis in different countries?
What can Patient Groups do to support/improve the rate of patients receiving Mutational Analysis?
Markus Wartenberg (DE), SPAEN

15:30 – 16:00 **TEA / COFFEE BREAK (30 minutes)**

RESEARCH SPOTLIGHTS
Moderator: Estelle Lecoite

16:00 - 16:45 **Trends and challenges in (rare) cancer research?**
Janet Shipley (UK)

16:45 - 17:30 **Understanding the Immune-System and how Immuno-Therapies (Immune-Oncology) work?**
Silvie Rusakiewicz (FR)

MOTIVATIONAL LECTURE

17:30 – 19:00 **Keep Climbing! How I Beat Cancer and Reached the Top of the World...**
Presentation & Questions
Sean Swarner (USA)

BREAK BEFORE DINNER (60 minutes)

19:30 - 22:00	Get Together (Hotel)
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DAY 2 – FRIDAY November 20, 2015			
PARALLEL WORKING GROUPS ON IMPORTANT PATIENT ADVOCACY ISSUES			
8:30 – 10:00	Room: Van Gogh Sarcoma treatment reality/challenges in Eastern Europe: Status quo and ideas/solutions to improve the situation... <i>Chair: Michael Sayers, SPAEN</i> <i>Expert: Iwona Lugowska (PL)</i> <i>Reporter: Markus Wartenberg, SPAEN</i>	Room: Albatros What means “Awareness in Sarcomas”? Campaigning for Awareness? Do we have examples? What would be the main / common objectives and how could we achieve them with joined activities in Europe and in the different countries? <i>Chair: Sarah McDonald & Claire Kelleher (Sarcoma UK)</i> <i>Reporter: Estelle Lecointe, SPAEN</i>	
10:00 – 10:30	Presentation and discussion of workshops results		
10:30 – 11:00	TEA / COFFEE BREAK (30 minutes)		
	PARALLEL TRACKS FOR GIST, SARCOMA AND DESMOIDS		
	GIST TRACK Room: Albatros	SARCOMA TRACK Room: Van Gogh	DESMOID TRACK Room: Vermeer
11:00 – 11:45	Important topics that affect prognosis/ survival in GIST... <i>Sebastian Bauer</i>	Sarcoma Portrait: Gynaecological Sarcomas <i>Isabelle Ray-Coquard</i>	Pathology <i>Anette Duensing</i>
11:45 – 12:30	Long-term side effects: What do we know? What do we need to know? <i>Sarah Dumont</i>	Sarcoma Portrait: Retroperitoneal Sarcomas (incl. High Vol. Centers) <i>Alessandro Gronchi</i>	Results of the mutational analysis of the GISG-01 study <i>Bernd Kasper</i>
12:30 – 14:00	LIGHT LUNCH and NETWORKING (60 minutes)		
14:00 – 14:25	Upcoming soon: Generic Imatinib for CML with impact also on GIST: Let’s discuss status and potential actions... <i>Markus Wartenberg</i>	New radiotherapy techniques in Sarcomas... <i>Rick Haas</i>	Report from the international research workshop <i>Bernd Kasper</i> <i>Christina Baumgarten</i>
14:25 – 14:45	New strategies and protocols for diagnosis and treatment of GIST: the MITIGATE project <i>Stefan Schönberg</i>	4 short profiles of different international trials in Sarcomas: LINES, MEMOS, Lilly-trial and STRASS <i>Bas Hassan</i>	Cryoablation <i>Pramod Rao</i>
14:45 - 15:30	Localized treatment options under progression: Surgery, RFA, SIRT, etc. <i>Alessandro Gronchi</i>		
15:30 – 16:00	TEA / COFFEE BREAK (30 minutes)		

16:00 – 17:15	<p>Update on the research-journey in GIST:</p> <p>Basic research <i>Anette Duensing</i></p> <p>Clinical Trials <i>Sebastian Bauer</i></p>	<p>Lung Metast.: Making the right treatment choices. Collecting our questions to a route map for patients... <i>Aisha Miah</i></p>	<p>Radiotherapy in Desmoids <i>Rick Haas</i></p> <p>Surgery in Desmoids <i>Alessandro Gronchi</i></p> <p>Discussion <i>Alessandro Gronchi</i> <i>Bernd Kasper</i></p>
17:15 – 18:00	<p>SHARING BEST PRACTICE</p> <p>1. The Sarcoma UK Research Experience <i>Sarah McDonald, Sarcoma UK</i></p> <p>2. Crowdsourcing of patient data/experiences for GIST research? <i>Gerard van Oortmerssen, Contactgroep GIST NL</i></p>		
18:00 – 18:15	<p>Tribute to Hans Keulen</p>		
19:15	<p>Bus-Transfer & External Dinner</p>		

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DAY 3 – SATURDAY November 21, 2015	
08:30 - 10:30	Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2015/2016 All Conference Participants are welcome! (Voting Rights for SPAEN Members only...) This session has an official invitation / agenda
10:30 - 11:00	TEA / COFFEE BREAK (30 minutes)
11:00 – 12:00	CAPACITY BUILDING Risk-Management for Patient Advocacy Groups <i>Markus Wartenberg SPAEN</i>
12:00 – 12:45	SHORT LUNCH (45 minutes)
12:45 – 14:45	EDUCATIONAL: IMPROVING OUR CANCER RESEARCH KNOWLEDGE Learning more about “EVIDENCE” - What does evidence mean? - Different “types/level” of evidence? - How to collect/generate evidence? - Why is “Real World Evidence” becoming more and more important? <i>Amélie Anota</i> Lilly PACE: CII Continuous innovation indicator – a novel tool to measure progress in cancer treatments <i>Samuel Thomas, www.roseliassociates.com for Lilly</i>
14:45 – 15:00	Closing Remarks – End of Meeting <i>SPAEN Board</i>

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Participants

Country	Surname	First name	Organisation
Bulgaria	Mihaylova	Adelina	GIST Alliance for Patients Bulgaria
Bulgaria	Popova	Yuliana	GIST Alliance for Patients Bulgaria
Finland	Maaniittu	Inga-Katriina	Patient Group of Finland
France	Moreau	Georges	SOS Desmoide France
France	Sandakly	Angelika	Info Sarcomes
France	Lecointe	Estelle	SPAEN-Chair
France	Baconnier	Simon	World Sarcoma Network
Germany	Tettinek	Valérie Sanja	
Germany	Deck	Uli	ARTIS PHOTOGRAPHIE
Germany	Wartenberg	Markus	SPAEN-Chair
Germany	Baumgarten	Christina	SPAEN-Board
Germany	Pilgermann	Kai	SPAEN-Board
Germany	Schuster	Kathrin	Project Manager
India	Guhagarkar	Nikhil	Friends of Max India
India	Gupta	Vandana	V Care Foundation
Italy	Costato	Anna	A.I.G. Associazione Italiana GIST
Italy	Tamagni	Barbara	A.I.G. Associazione Italiana GIST
Italy	Tedone	Gabriella	A.I.G. Associazione Italiana GIST
Italy	Gonzato	Ornella	SPAEN-Board
Kenya	Micho	Ferdinand	Henzo Kenya
Kenya	Mwangura	Sereni	Henzo Kenya
Macedonia	Dimitrovski	Toni	gist-macedonia
Norway	Homb	Frode	Sarkomer, Norway
Poland	Dolecki	Kamil	Stowarzyszenie Pomocy Chorym na Miesaki „SARCOMA“
Poland	Fonrobert	Piotr	Stowarzyszenie Pomocy Chorym na GIST
Poland	Gmaj	Paulina	Stowarzyszenie Pomocy Chorym na Miesaki „SARCOMA“
Poland	Krzywicka	Malgorzata	POLISH GIST Patients Support Association
Spain	Abascal Briones	Encarnacion	AEAS Asociación Española de Afectados por Sarcoma
Spain	Garcia Lorente	Jesica	AEAS Asociación Española de Afectados por Sarcoma
Switzerland	Wettstein	Martin	GIST Gruppe Schweiz
The Netherlands	Mathot	Audrey	GIST Gruppe Schweiz
The Netherlands	Smit	Jasper	Contactgroep Sarcoma
The Netherlands	van der Ploeg	Robert	Contactgroep Sarcoma
The Netherlands	van Oortmerssen	Gerard	Contactgroep GIST Nederland - Belgie
The Netherlands	Van Rooijen	Hendrik	Contactgroep GIST

Country	Surname	First name	Organisation
Turkey	Yüce	Salih	Youth Acumulation Association
United Kingdom	Bressington	Jayne	PAWS-GIST
United Kingdom	Falconer	David	GIST Support UK
United Kingdom	Harrington	Julie	Bone Cancer Research Trust
United Kingdom	Robinson	Judith	GIST Support UK
United Kingdom	Bennister	Lindsey	SPAEN-Board
United Kingdom	Sayers	Michael	SPAEN-Board
United Kingdom	Wilson	Roger	SPAEN Honorary President
United Kingdom	McDonald	Sarah	Sarcoma UK
United States	Bellinger	Melissa	Amschwand Sarcoma Cancer Foundation
United States	Durborow	Michelle	The Life Raft Group

Invited Speakers

France	Dr. Amélie Anota University Hospital of Besançon
France	Dr. Sarah Dumont Institut de Cancérologie Gustave Roussy, Villejuif
France	Dr. Pramod Rao University Hospital Strasbourg
France	Dr. Isabelle Ray-Coquard Centre Léon Bérard, Lyon
France	Dr. Silvie Rusakiewicz Institut de Cancérologie Gustave Roussy, Villejuif
Germany	Prof. Sebastian Bauer Westdeutsches Tumorzentrum, Sarkomzentrum, Essen
Germany	Prof. Bernd Kasper Mannheim University Medical Center, University of Heidelberg
Germany	Prof. Stefan Schönberg Institut für klinische Radiologie und Nuklearmedizin, Universitätsklinikum Mannheim
Italy	Prof. Alessandro Gronchi Fondazione IRCCS Istituto Nazionale dei Tumori, Milan
The Netherlands	Dr. Rick Haas The Netherlands Cancer Institute, Amsterdam
Poland	Dr. Iwona Lugowska Centrum Onkologii-Instytutu, Warsaw
United Kingdom	Prof. Andrew Bassim Hassan Sir William Dunn School of Pathology, University of Oxford
United Kingdom	Dr. Aisha Miah Sarcoma Unit, The Royal Marsden NHS Foundation Trust
United Kingdom	Prof. Janet Shipley The Institute of Cancer, Belmont, Sutton
USA	Dr. Anette Duensing University of Pittsburgh Cancer Institute, Cancer Therapeutics Program, Pittsburgh
USA	Sean Swarner Inspirational Speaker, Denver
USA	Samuel Thomas Rose Li and Associates, Inc., Bethesda

Conference Logistics

Contact:	Your SPAEN Contact during the conference will be Kathrin Schuster
Phone:	+49 162 97 68 717
Email:	info@sarcoma-patients.eu
Venue:	Hotel Dolce Chantilly Avenue de Verdun 60500 Vineuil St Firmin/Chantilly France Tel: +33 (0)3 44 58 47 77
Web:	www.dolcechantilly.com
Hotel:	The hotel Dolce Chantilly is set in the very heart of the historic Chantilly Forest, just 40 minutes from Paris and only 25 minutes from the Roissy Charles de Gaulle International Airport, the hotel also enjoyed a complete refurbishment in 2008. Among other Chantilly hotels and resorts, Dolce Chantilly provides exceptional conference and meeting facilities. The hotel's guest rooms and suites feature an array of modern amenities complemented by lovely forest or golf course views.
Rooms:	En-suite facilities, including bath and shower, tea and coffee making facilities, minibar, TV, iron and hairdryer.
Wi-Fi Access:	Provided in your rooms and throughout the entire hotel free of charge.
Electricity:	The power outlets give out 220-240 volts AC (50 cycles) that require the same two round pin plugs as are used in most of Europe. You will need either a travel adaptor or transformer depending on where you are travelling from. The electric plugs used in France are Type C.
Special Requests:	If you have any special requirements or needs during the conference please don't hesitate to ask us for support.
Time Zone:	November = Central Eastern Time (CET)
Currency:	The valid currency in France is the Euro (€)
Conference Days:	Thursday, 19th of November 2015 13:00 Official start of the Conference (Light lunch at 12:00) 19:00 End of day 1 19:30 Get together and dinner at the hotel Friday, 20th of November 2015 8:30 Start of day 2 18:15 End of day 2 External dinner Saturday, 21st of November 2015 8:30 Start of day 3 15:00 Official End of the Conference
Meeting Rooms:	Main Conference Room: Albatros (Conference Center, 1st floor), breakout rooms for parallel tracks on Friday: Room Albatros for GIST track, Room Van Gogh for the sarcoma track and Room Vermeer for the desmoid track.
Language:	Conference language will be in English. Please do not be afraid to get involved at the conference even if you have limited English skills. (Note: Translation will not be available!)
Delegate Presentations:	We would like to thank those organizations for preparing and giving a short presentation during our 'Sharing Best Practices' session.
Evening Dinner/Get Together:	Thursday, 19th of November at 19:30, Par En Par, Hotel Dolce Chantilly, Conference Center, 1st floor
External Dinner:	Friday, 20th of November at 19:15, Le Vertugadin, 44 Rue du Connétable, 60500 Chantilly – Transfer will be provided

Reimbursement Rules

Travelling Expenses: Funding for travel, accommodation and conference expenses is available. Travel costs will be reimbursed by SPAEN. Please complete your Expenses Reimbursement Form and send it to SPAEN with original receipts within 30 days of the end of the conference.

IMPORTANT - Please use the attached Expense Reimbursement Form to reclaim your costs within 30 days of the end of the conference. We regret that we cannot reimburse costs without an original receipt after this time.

Travelling by plane, train, car and/or taxi will be reimbursed on the basis of the **most economical fare only**. The total travelling-budget for each participant should not exceed €350 (maximum of reimbursement).

Conference Expenses: Conference expenses such as meeting rooms, materials, snacks and meals, beverages, internal/external dinners, etc. for the days of the conference will be covered and paid by SPAEN directly.

Other Expenses: All other expenses (e.g. upgrade of rooms, difference from a single to double room, mini bar, hotel bar, additional meal orders, room service, telephone, laundry, etc.) will not be covered by SPAEN. Additional expenses incurred for accompanying persons will not be covered by SPAEN.

Funding Information

Sponsorship: The SPAEN conference will receive unrestricted grants from Bayer, Merck, Novartis, Pfizer, PharmaMar and Takeda. All sponsorships will be made transparent.

PLEASE NOTE: These grants will not be related to any objectives or any content of the Conference. The idea, conception, planning, preparation, realisation, management and the summary of the Conference will be the responsibility of SPAEN – **without any influence from the Sponsors.**

Liability Disclaimer

Liability & Insurance: Your participation in the SPAEN Annual Conference 2015 will be at your own risk. SPAEN will not be liable for any eventualities while travelling to and from or during the conference. We are not liable for injury, loss or damages suffered by participants or third parties. The SPAEN conference 2015 programme is carefully prepared and carried out on the basis of the current knowledge of the topics concerned. However, SPAEN accepts no liability for the accuracy or currency of the information presented during the conference.

Additionally, participants are advised to take out sufficient travel insurance to cover unforeseen events and losses including healthcare cover. In the event the trip is cancelled by the participant SPAEN will not reimburse expenditure incurred by intending participants as the presumption is that their travel insurance should cover this eventuality.



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

Sarcoma Patients EuroNet (SPAEN), the European Network of Sarcoma, GIST and Desmoid Patient Advocacy Groups was founded in April 2009. The organisation was born from a very strong desire among various national patient groups to network, cooperate and share materials, knowledge and experiences.

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

SPAEN is a European association, legally registered under German law. The network of currently 32 patient groups across Europe collaborates closely with international societies, networks or organisations such as ESMO, EORTC, EMSOS, CTOS, SARC, World Sarcoma Network, EMA or Rare Cancers Europe. SPAEN also seeks exchange and close collaboration with currently 18 international cancer patient advocacy networks representing other cancer diagnoses.

Our Vision:

All Sarcoma patients in Europe have access to

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

Our Objectives:

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

Our Core Values:

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

The current SPAEN Board of Directors:



Estelle Lecointe,
Chair (FR)



Markus Wartenberg,
Chair (DE)



Kai Pilgermann
Financial Director (DE)



Lindsey Bennister
Resigned 13th of Nov. 2015



Christina Baumgarten,
Board Member
Desmoids (DE)



Michael Sayers,
Board Member
GIST (UK)



Ornella Gonzato,
Board Member
Bone Sarcomas (IT)



Roger Wilson,
Honorary President
Sarcoma UK



Michaela Geissler,
(Germany)
Admin. Coordinator/PM

Office:

Sarcoma Patients EuroNet has established a Medical Advisory Board with a high level of scientific expertise. The objectives of the Medical Advisory Board is to support 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. Pjotr Rutkowski	Surgery	Poland/Warsaw	POLSG
Dr. Beatrice Seddon	Oncology	UK/London	BSG
Prof. Winette van der Graaf	Oncology	Netherlands/Nijmegen	EORTC STBSG
Dr. R.L.M. Haas	Radiotherapy	Netherlands/Amsterdam	EORTC STBSG



Sarcoma
Patients
EuroNet

SPAEN Full Members

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

SPAEN Associate Members

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



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