



**Sarcoma
Patients
EuroNet**

Conference Booklet

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

**13th–15th November 2014
The Crowne Plaza, Amsterdam-South**

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



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1. Acknowledgement

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

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

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



2. SPAEN Welcome Letter

A Warm Welcome to SPAEN's 5th Annual Conference!

Dear Delegates,

Welcome to Amsterdam, the Netherlands, and the 5th SPAEN Annual Conference and 4th General Assembly of Sarcoma Patients Euronet.

It has been a busy year for many of us and although some of us occasionally meet at events held by other organisations it is during these few days each year that we really can spend time getting to know our fellow sarcoma advocates. On behalf of the SPAEN Board we welcome you all for what we hope will be three days of inspiration through shared learning and good company.

None of us would be here today without our heart-felt desire to improve the lives of those diagnosed with sarcomas. As we go forward into these three days together, we invite you to share your experiences as well as your disappointments and the challenges you are facing.

We can learn a great deal from each other!

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. In recent years we have seen, each year, one new pharmaceutical treatment for sarcoma licensed in Europe, and there are currently two new treatments being appraised by EMA. 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.
Welcome!

With best wishes,
The SPAEN Board



Capital: Amsterdam
Population: 16,82 Mio. (Density = 405.3/km²)
Area: 41,543 km² = 16,039 sq mi
Currency: EURO
Calling Code: +31
Internet: .nl

3. Welcome to The Netherlands!

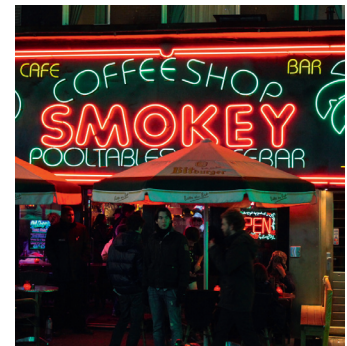
The Netherlands is a constituent country of the Kingdom of the Netherlands, consisting of twelve provinces in Western Europe and three islands in the Caribbean. The European part of the Netherlands borders the North Sea to the north and west, Belgium to the south, and Germany to the east; and shares maritime borders with Belgium, Germany and the United Kingdom. The country is a parliamentary democracy organised as a unitary state. The capital city of the Netherlands, mandated by the constitution, is Amsterdam, however, the seat of government is located in The Hague.

The Netherlands is a geographically low-lying country, with about 20% of its area and 21% of its population located below sea level, and 50% of its land lying less than one metre above sea level. This distinct feature contributes to the country's name: in Dutch (Nederland), English, and in many other European languages, its name literally means "Low Land" or "Low Countries." Most of the areas below sea level are man-made, caused by centuries of extensive and poorly controlled peat extraction, lowering the surface by several metres. Even in flooded areas peat extraction continued through turf dredging. From the late 16th century land reclamation started and large polder areas are now preserved through elaborate drainage systems with dikes, canals and pumping stations. Most of the country is very flat, with the exception of foothills in the far south-east and several low hill ranges in the central parts.

The Netherlands was one of the first countries to have an elected parliament, and the country is a founding member of the EU, G-10, NATO, OECD, WTO and a part of the trilateral Benelux economic union. The Netherlands had the tenth-highest per capita income in the world in 2011. The country is host to the Organisation for the Prohibition of Chemical Weapons and five international courts: the

Permanent Court of Arbitration, the International Court of Justice, the International Criminal Tribunal for the Former Yugoslavia, the International Criminal Court and the Special Tribunal for Lebanon. The first four are situated in The Hague, as is the EU's criminal intelligence agency Europol and judicial co-operation agency Eurojust. This has led to the city being dubbed "the world's legal capital". The Netherlands has a market-based mixed economy, ranking 17th of 177 countries according to the Index of Economic Freedom. In May 2011, the Netherlands was ranked as the "happiest" country according to results published by the OECD.

Holland? Or the Netherlands? And what's the difference between the two? The Netherlands is often referred to as Holland. Nevertheless, the official name of the country is the (Kingdom of the) Netherlands. The Netherlands consists out of twelve provinces. Two of them, North and South Holland, are the two provinces that together make Holland. Due to the maritime and economic power of these provinces in the 17th century, the Netherlands became known worldwide as Holland. To make matters even more confusing the inhabitants of the Netherlands are called Dutch. Internationally, 'Holland' is often used to indicate the Netherlands. Holland is also the brand that is used to promote business and leisure trips to the Netherlands. Officials have chosen Holland as brand name because Holland is internationally well-known, popular and an accessible name for our country. Furthermore Holland stands for all our country's positive elements, the elements that attract foreign leisure and business travellers. Holland also sounds more hospitable than the rather official 'the Netherlands'.



Welcome to Amsterdam!

Amsterdam is the capital city of and the most populous within the Kingdom of the Netherlands. Its status as the Dutch capital is mandated by the Constitution of the Netherlands though it is not the seat of the Dutch government, which is at The Hague (Den Haag). Amsterdam has a population of 810,909 within the city-proper, 1,108,297 in the urban region and 1,571,234 in the greater metropolitan area. The city is located in the province of North Holland in the west of the country. It comprises much of the northern part of the Randstad, one of the larger conurbations in Europe, with a population of approximately 7 million.

Amsterdam's name derives from Amstelredamme, indicative of the city's origin as a dam of the river Amstel. Originating as a small fishing village in the late 12th century, Amsterdam became one of the most important ports in the world during the Dutch Golden Age, a result of its innovative developments in trade. During that time, the city was the leading centre for finance and diamonds. In the 19th and 20th centuries, the city expanded, and many new neighbourhoods and suburbs were planned and built. The 17th-century canals of Amsterdam and the 19–20th century Defence Line of Amsterdam are on the UNESCO World Heritage List.

As the commercial capital of the Netherlands and one of the top financial centres in Europe, Amsterdam is considered an alpha world city by the Globalization and World Cities (GaWC) study group. The city is also the cultural capital of the Netherlands. Many large Dutch institutions have their headquarters there, and 7 of the world's top 500 companies, including Philips and ING, are based in the city. In 2012, Amsterdam was ranked 2nd best city to live by the Economist Intelligence Unit (EIU) and 12th globally on quality of living by Mercer.

The Amsterdam Stock Exchange, the oldest stock exchange in the world, is located in the city centre. Amsterdam's main attractions, including its historic canals, the Rijksmuseum, the Van Gogh Museum, Stedelijk Museum, Hermitage Amsterdam, Anne Frank House, Amsterdam Museum, its red-light district, and its many cannabis coffee shops draw more than 3.66 million international visitors annually. What makes Amsterdam so attractive is the 17th century historical atmosphere combined with the mentality of a modern metropolis creating a friendly and relaxed environment. The small scale of the buildings and the intimacy of the streets, canals and squares create an atmosphere that visitors find unique.

4. Conference Programme

All sessions will be held in The Broadway Room, (1st Floor Conference Suite) unless otherwise indicated

DAY 1 – THURSDAY November 13, 2014

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

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4. Conference Programme

DAY 2 – FRIDAY November 14, 2014

9:00- 9:45	TREATMENT AND CARE: DIAGNOSTICS		
9:45 - 10:30	The Role of Pathology in Sarcomas <i>Prof. Pancras Hogendoorn, NL</i> Radiology Modalities in Sarcomas <i>Dr. Christina Messiou, UK</i>		
10:30 – 11:00	TEA / COFFEE BREAK (30 minutes)		
	PARALLEL TRACKS FOR GIST, SARCOMA AND DESMOIDS		
	GIST TRACK Room: Broadway Chairs: <i>Kai Pilgermann & Markus Wartenberg</i>	SARCOMA TRACK Room: Times Chairs: <i>Estelle Lecointe</i>	DESMOID TRACK Room: Square Chairs: <i>Christina Baumgarten & Hilly van der Zande</i>
11:00 – 11:45	Overview Wild-Type / Non KIT/PDGFαR GIST <i>Dr. Ramesh Bulusu, UK</i>	Bone Sarcomas in Children, Teens and Young Adults: Osteosarcoma Ewing Sarcoma <i>Prof. Uta Dirksen, DE,</i>	Consensus paper on current treatment of desmoids <i>Prof. Bernd Kasper, DE</i>
11:45 – 12:30	After EMA-Approval: Evidence and Practical Experiences with Regorafenib <i>Prof. Bernd Kasper, DE</i>	STS Sarcomas: Gynaecological Sarcomas <i>Prof. Jean-Yves Blay, FR</i>	Surgery including „watch and wait“ <i>Dr. Alessandro Gronchi, IT</i>
12:30 – 13:30	LIGHT LUNCH (60 min.) Restaurant One O One		
13:30 – 14:15	Local Interventions at Progressive Disease: Surgery, Laser, RFA, Chemo-Embolisation, SIRT & Co. <i>Prof. Peter Hohenberger, DE</i>	Surgery in Sarcomas: - Treating the “Basic Limb Tumour” - Using Radiotherapy prior to Surgery - When to consider Adjuvant Therapy (Radio or Chemo?) - Using more Advanced Techniques such as ILP <i>Dr. Alessandro Gronchi, IT & Dr. Sylvie Bonvalot, FR</i>	New pathology <i>speaker tbd</i>
14:15 - 15:00	Circulating DNA, liquid biopsy <i>Dr. Nikolas v. Bubnoff, DE</i>		Pain Management in Desmoids <i>Dr. Odile Oberlin, FR & George Moreau, FR</i>
			Patient related problems in Desmoid type fibromatosis - the role of a nurse practitioner <i>Nicolette Leijerzapf, NL</i>
15:00 – 15:30	TEA / COFFEE BREAK (30 minutes)		
15:30 – 17:00	Actual spotlights on GIST Research: <i>Prof. Jean-Yves Blay, FR</i>	Oligo-Metastasis in Sarcomas: Local Surgery vs. Systemic Treatment? <i>Prof. Peter Hohenberger, DE</i>	Round Table “Challenges of desmoid patients in different countries”
		New UK-Research on “Quality of Life” in Advanced Sarcoma <i>Dr. Nicholas Gough, UK</i>	
17:00 – 18:30	MARKET PLACE SESSIONS (4 parallel sessions 25 min each + 5 min for change, delegate chooses 3 sessions) 1. Peer to Peer Support <i>Claire Kelleher, Sarcoma UK</i> 2. How to support scientific research as a patient group <i>Estelle Lecointe, SPAEN/Info Sarcomes, FR</i> 3. Who cares for the carers? <i>Judith Robinson, GIST Support UK</i> 4. Getting the Best out of Your Meetings <i>David Falconer, GIST Support UK</i>		
	Free Evening for Everyone		

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4. Conference Programme

DAY 3 – SATURDAY November 15, 2014

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

	Optional Session after the Conference:
15:30 - 18:00	Being prepared for the future: 1. Identify unmet medical needs in the patient community (45 min) 2. Generics (45 min) 3. What can SPAEN do to support? (45 min) SPAEN Working Group, Voluntary SPAEN Members + Medical Experts <i>Moderator: Markus Wartenberg & Roger Wilson</i>

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5. Participants

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

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

5. Invited Speakers

France	Dr. Antoine Italiano Institut Bergonie, Early Phase Trials and Sarcoma Units, Bordeaux
France	Prof. Jean-Yves Blay University Claude Bernard Lyon, Centre Léon Bérard, Department of Medecin
France	Dr. Sylvie Bonvalot Gustave Roussy, Villejuif, Department of Surgical Oncology
France	Dr. Odile Oberlin Gustave Roussy
Germany	Prof. Dr. Uta Dirksen University Hospital Münster, Pediatric Hematology and Oncology
Germany	Prof. Dr. Bernd Kasper Mannheim University Medical Center
Germany	Prof. Peter Hohenberger Div. of Surgical Oncology & Thoracic Surgery, Mannheim University Medical Center
Germany	Dr. Nikolas von Bubnoff Freiburg University Medical Center
Italy	Dr. Alessandro Gronchi Chair Sarcoma Service, Department of Surgery Fondazione IRCCS Istituto Nazionale dei Tumori, Milan
Netherlands	Prof. Winette van der Graaf Professor of Medical Oncology Radboud University Nijmegen Medical Center
Netherlands	Prof. Dr. Hans Gelderblom Leiden University Medical Center
Netherlands	Prof. Pancras Hogendoorn Leiden University Medical Center
Netherlands	Nicolette Leijerzapf Leiden University Medical Center
UK	Dr. Abigail Evans University College London/Euro Ewing Consortium
UK	Raz Dewji GSK, Director - Clinical Development Scientist
UK	Dr. Christina Messiou Consultant Radiologist, Royal Marsden Hospital, London
UK	Dr. Ramesh Bulusu Oncologist, Cambridge Cancer Center
UK	Dr. Nicholas Gough Specialist Registrar in Palliative Medicine, Royal Marsden Hospital, London

6. Conference Logistics

Contact:	Your SPAEN Contact during the conference will be Michaela Geissler
Phone:	+49 173 4517589
Email:	Michaela.geissler@sarcoma-patients.eu
Venue:	Crowne Plaza Amsterdam-South George Gershwinaan 101 1082 MT Amsterdam, The Netherlands
Tel:	+31 20 504 3613
Email:	joost.vandenberg@ihg.com
Web:	www.crowneplaza.com/amstsouth
Hotel:	The Crowne Plaza Amsterdam-South is situated in Amsterdam-Zuidas. This area is the new urban centre devoted to international commerce and knowledge development. The location is unique as Amsterdam Schiphol International Airport, the RAI Convention Center and the city centre are only a few minutes away by public transport. The hotel features 207 modern rooms, including 16 club rooms and 16 suites. With Amsterdam Schiphol Int. Airport and the city centre only minutes away, the Crowne Plaza Amsterdam-South is one of the best situated hotels in Amsterdam. The hotel is still new, as it opened in December 2011.
Rooms:	Rooms include en-suite facilities, including bath and shower, tea and coffee making facilities, TV, iron and hairdryer.
Wi-Fi Access:	Will be provided in your rooms and throughout the entire hotel free of charge.
Electricity:	Amsterdam's 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 the Netherlands 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 the Netherlands is the Euro (€)
Conference Days:	Thursday 13th of November 2014 12:00 – 13:00 Light Lunch 13:00 - Official start of the Conference 13:00 - 18:30 Conference Sessions 19:30 - 22:00 Get Together, Crowne Plaza Amsterdam-South Friday 14th of November 2014 09:00 - 18:30 Conference Sessions Free evening for everyone Saturday 15th of November 2014 09:00 - 10:30 SPAEN General Assembly 2014 (all delegates are welcome, rights for SPAEN members only) 10:30 – 15:15 Conference Sessions 15:15 Official end of the Conference 15:30 – 18:00 Being prepared for the future (optional session after the conference)
Meeting Rooms:	Main Conference Room: The Broadway Room (1st Floor Conference Suite), breakout rooms for parallel tracks on Friday: Room Times for the sarcoma track and room Square for the desmoid track.
Programme:	Please see Conference Programme
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 organisations for preparing and giving a short presentation during our 'Sharing Best Practices' session.
Evening Dinner/ Get Together:	Thursday 14th of November at 19:30, Manhattan Bar/Restaurant one o one, (Groundfloor)

7. Reimbursement / Funding / Liability

Reimbursement Rules

Funding for travel, accommodation and conference expenses will be reimbursed by SPAEN.

IMPORTANT - Please use **the Expenses Reimbursement Form to reclaim your costs within 30 days of the end of the conference. We regret we cannot reimburse costs without an original receipt or after 30 days.**

Meal expenses: SPAEN will provide snacks, meals, beverages including internal dinner for the duration of the conference. 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 cannot be covered by SPAEN. All additional expenses must be settled with the hotel at check out.

Funding Information

At the request of the SPAEN Board, this conference will receive unrestricted grants from Bayer, GSK Novartis, Pfizer, PharmaMar and Takeda. All sponsorships will be made transparent.

PLEASE NOTE:

These grants will not be related to any of the 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. This meeting is an independent SPAEN conference and is not connected with pharmaceutical representatives in each country. Please do not contact your local country pharmaceutical representatives for assistance or additional funding. SPAEN is an independent democratic network of patient organisations without commercial influence.

Liability Disclaimer

Your participation in the SPAEN Annual Conference 2014 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 2014 programme is carefully prepared and carried out on the basis of the current knowledge of the topics concerned. However, we accept 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 attending participants as the presumption is please their travel insurance should cover this eventuality.

8. About SPAEN

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

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



Our Vision:

- 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.



Our Objectives:

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

Our Core Values:

- 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 Code of Practice

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

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

9. SPAEN Board

Current Board Members:



Roger Wilson,
President (UK)
Sarcoma UK



Estelle Lecointe,
Vice President (France)
I'A.F.P.G. „Ensemble contre
le GIST“



Christina Baumgarten,
Vice President (Germany)
SOS Desmoid



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



Barbara Doré,
Secretary (UK/USA)
GIST Support UK



Michael Sayers,
Board Member (UK)
GIST Support UK



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



Office:
Michaela Geissler,
(Germany)
Admin. Coordinator/PM

10. Medical Advisory Board

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

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



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

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

11. SPAEN Member Organisations



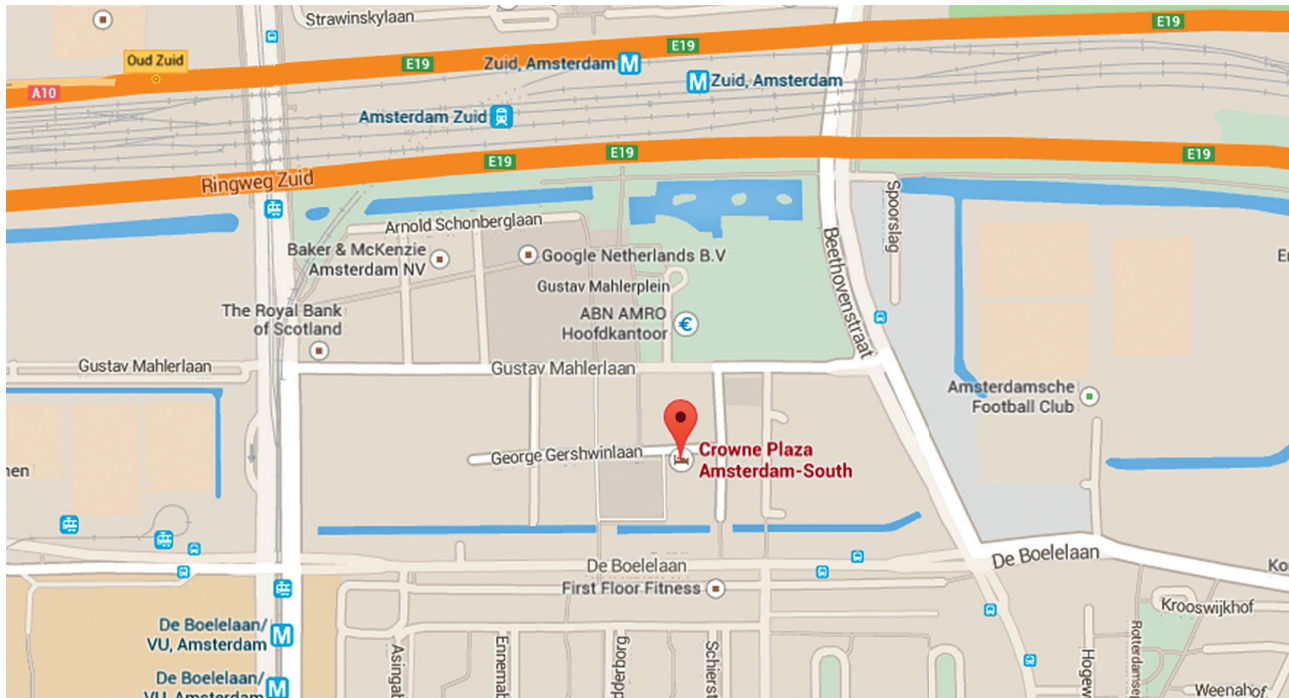
1. Bulgaria: GIST Alliance for Patients Bulgaria
2. Finland: Finnish GIST Patient Network
3. France: A.F.P.G. "Ensemble contre le GIST"
4. France: Info Sarcomes
5. France: SOS Desmoide France
6. Germany: Das Lebenshaus e.V./House of Life
7. Germany: SOS Desmoids
8. Italy: A.I.G. Associazione Italiana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

SPAEN Associate Members

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

12. Maps

Public Transport **AMSTERDAM ZUID** from/to Amsterdam Airport Schiphol
in walking distance: 350 Meters and 5 Min. from the Hotel



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

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