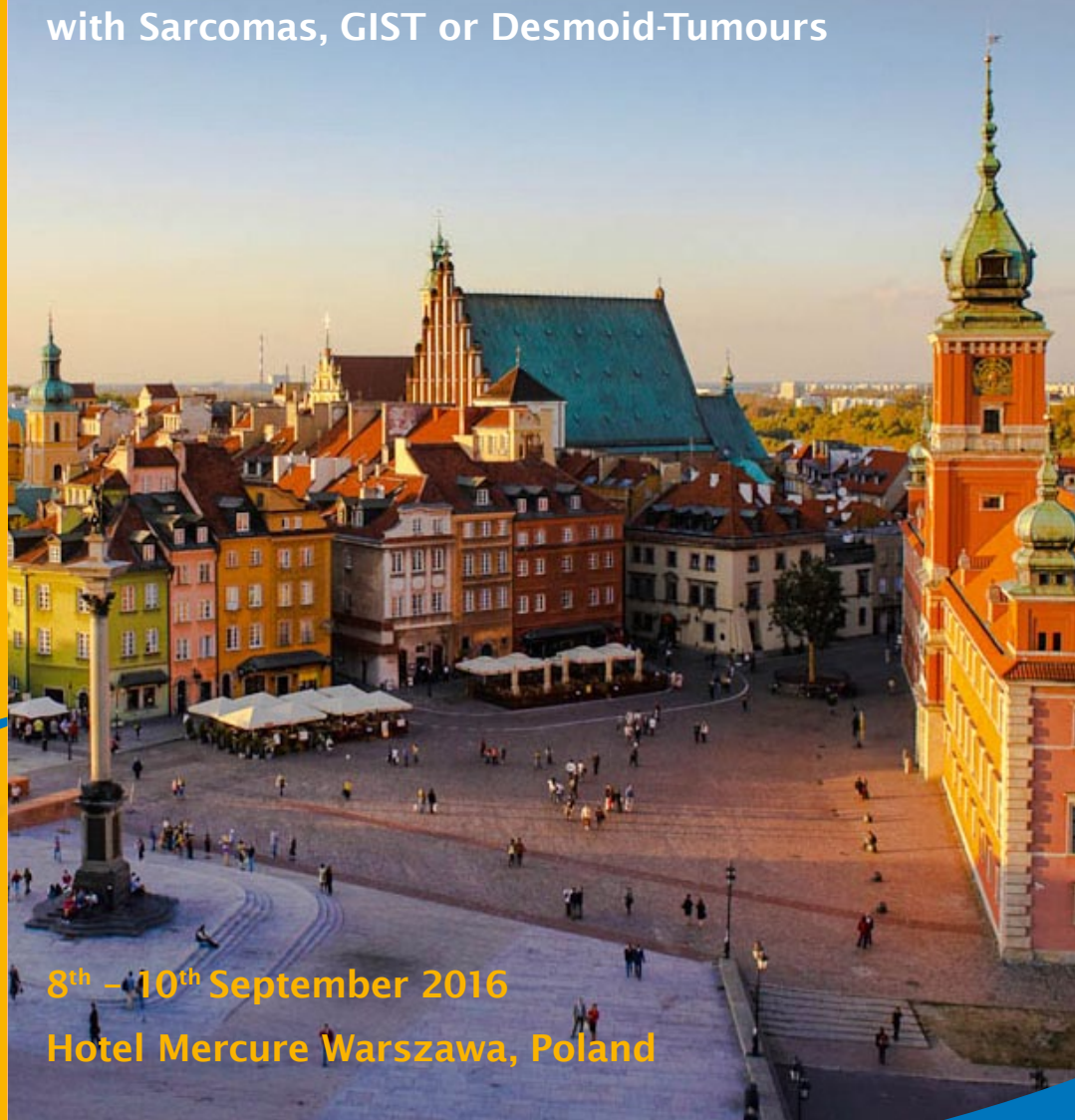




Sarcoma  
Patients  
EuroNet

# Conference Booklet

7<sup>th</sup> SPAEN Annual Conference  
for Organisations  
Representing Patients  
with Sarcomas, GIST or Desmoid-Tumours



8<sup>th</sup> – 10<sup>th</sup> September 2016  
Hotel Mercure Warszawa, Poland

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 7<sup>th</sup> SPAEN Conference with an unrestricted educational grant: Bayer, Lilly, 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 7<sup>th</sup> SPAEN Conference in Warsaw, Poland. The idea, conception, planning, preparation, realization, management and the summary of the 7th 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.



## A Warm Welcome to SPAEN's 7<sup>th</sup> Annual Conference!

Dear Delegates,

Welcome to Warsaw and to the 7<sup>th</sup> Annual Meeting and General Assembly of Sarcoma Patients EuroNet.

It's the first time that we hold the SPAEN Conference in Eastern Europe and we would like to thank our Polish colleagues for their wonderful support.

The 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 to 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 a lot from each other.

We welcome you all, for hopefully three days of inspiration through shared learning and good company.

With best wishes,  
*The SPAEN Board of Directors*



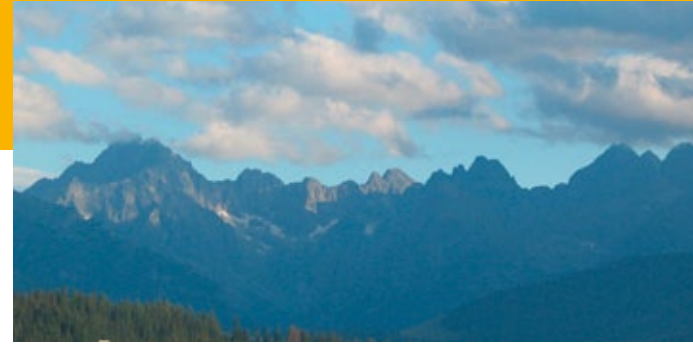


Chopin Memorial  
© Cezary Piwowarski on wikipedia



Mary Basilica in Gdansk  
©Tomasz Sienicki on wikipedia

**Capital:** Warsaw  
**Population:** 38.5 mio.  
**Area:** 312,679 km<sup>2</sup> = 120,726 sq miles  
**Currency:** Zloty  
**Calling Code:** +48  
**Internet:** .pl



Tatry Panorama  
©Polish Wikipedia by Dixie



Warsaw Ghetto Memorial  
©Szczebrzeszynski on wikipedia



Warsaw: Aula Leopoldina University  
©Stako on wikipedia



Warsaw at Night©Spens03 on wikipedia

## Welcome to Poland!

Poland, officially the Republic of Poland, is a country in Central Europe, situated between the Baltic Sea in the north and two mountain ranges (the Sudetes and Carpathian Mountains) in the south. Bordered by Germany to the west; the Czech Republic and Slovakia to the south; Ukraine and Belarus to the east; and the Baltic Sea, Kaliningrad Oblast (a Russian exclave) and Lithuania to the north. The total area of Poland is 312,679 square kilometres (120,726 sq mi), making it the 69<sup>th</sup> largest country in the world and the 9<sup>th</sup> largest in Europe. With a population of over 38.5 million people, Poland is the 34<sup>th</sup> most populous country in the world, the 8<sup>th</sup> most populous country in Europe and the sixth most populous member of the European Union, as well as the most populous post-communist member of the European Union. Poland is a unitary state divided into 16 administrative subdivisions.

(Source: Wikipedia.com)

## Welcome to Warsaw!

Warsaw is the capital and largest city of Poland. It stands on the Vistula River in east-central Poland, roughly 260 kilometres (160 miles) from the Baltic Sea and 300 kilometres (190 miles) from the Carpathian Mountains. Its population is estimated at 1.740 million residents within a greater metropolitan area of 2.666 million residents, which makes Warsaw the 9<sup>th</sup> most-populous capital city in the European Union. The city limits cover 516.9 square kilometres (199.6 sq miles), while the metropolitan area covers 6,100.43 square kilometres (2,355.39 sq miles).

In 2012 the Economist Intelligence Unit ranked Warsaw as the 32<sup>nd</sup> most liveable city in the world. It was also ranked as one of the most liveable cities in Central Europe. Today Warsaw is considered an “Alpha–” global city, a major international tourist destination and a significant cultural, political and economic hub. Warsaw’s economy, by a wide variety of industries, is characterised by FMCG manufacturing, metal processing, steel and electronic manufacturing and food processing. The city is a significant centre of research and development, BPO, ITO, as well as of the Polish media industry. The Warsaw Stock Exchange is one of the largest and most important in Central and Eastern Europe. Frontex, the European Union agency for external border security, has its headquarters in Warsaw. It has been said that Warsaw, together with Frankfurt, London, Paris and Barcelona is one of the cities with the highest number of skyscrapers in the European Union. Warsaw has also been called “Eastern Europe’s chic cultural capital with thriving art and club scenes and serious restaurants”.

The first historical reference to Warsaw dates back to the year 1313, at a time when Kraków served as the Polish capital city. Due to its central location between the Polish–Lithuanian Commonwealth’s capitals of Kraków and Vilnius, Warsaw became the capital of the Commonwealth and of the Crown of the Kingdom of Poland when King Sigismund III Vasa moved his court from Kraków to Warsaw in 1596. After the Third Partition of Poland in 1795, Warsaw was incorporated into the Kingdom of Prussia. In 1806 during the Napoleonic Wars, the city became the official capital of the Grand Duchy of Warsaw, a puppet state of the First French Empire established by Napoleon Bonaparte. In accordance with the decisions of the Congress of Vienna, the Russian Empire annexed Warsaw in 1815 and it became part of the “Congress Kingdom”. Only in 1918 did it regain independence from the foreign rule and emerge as a new capital of the independent Republic of Poland. The German invasion in 1939, the massacre of the Jewish population and deportations to concentration camps led to the uprising in the Warsaw ghetto in 1943 and to the major and devastating Warsaw Uprising between August and October 1944. Warsaw gained the title of the “Phoenix City” because it has survived many wars, conflicts and invasions throughout its long history. Most notably, the city required painstaking rebuilding after the extensive damage it suffered in World War II, which destroyed 85% of its buildings. On 9 November 1940, the city was awarded Poland’s highest military decoration for heroism, the Virtuti Militari, during the Siege of Warsaw (1939).

The city is the seat of a Roman Catholic archdiocese (left bank of the Vistula) and diocese (right bank), and possesses various universities, most notably the Polish Academy of Sciences and the University of Warsaw, two opera houses, theatres, museums, libraries and monuments. The historic city-centre of Warsaw with its picturesque Old Town in 1980 was listed as a UNESCO World Heritage Site. Other main architectural attractions include the Castle Square with the Royal Castle and the iconic King Sigismund’s Column, St. John’s Cathedral, Market Square, palaces, churches and mansions all displaying a richness of colour and architectural detail. Buildings represent examples of nearly every European architectural style and historical period. Warsaw provides many examples of architecture from the gothic, renaissance, baroque and neoclassical periods, and around a quarter of the city is filled with luxurious parks and royal gardens.

(Source: Wikipedia.com)

**DAY 1 – THURSDAY September 8<sup>th</sup>, 2016**

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<b>8:30</b>	<b>Understanding “proton beam technology” better</b> <ul style="list-style-type: none"> <li>▪ Radiation oncology and proton beam technology</li> <li>▪ Proton beam technology at the WPE in Essen</li> <li>▪ First experiences / patient cases with this treatment option</li> </ul> <i>Dr. Dirk Geismar, DE - WPE West German Cancer Center, Essen</i>
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## PARALLEL TRACKS FOR GIST, SARCOMA AND DESMOIDS

**10:15 – 10:45**                      **TEA / COFFEE BREAK (30 minutes)**

	<p><b>mutational analysis in practice...</b>  <b>Practice What patients should know Challenges/ Pitfalls</b>  <i>Eva Wardelmann (DE)</i></p>	<p><b>Sarcomas: What is current practice (important quality standards) and what could be innovative approaches?</b>  <i>Sylvie Bonvalot (FR)</i></p>	<p><b>options incl. studies (90)</b>  <i>Bernd Kasper (DE)</i></p>
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**A look into the future  
(20)**  
*Craig Gerrard (UK)*

**13:00 – 14:00**      **LIGHT LUNCH and NETWORKING (60 min.)**

**14:45** **Branding your organisation!**  
Learning more about logos, brands, identity, image...  
*Markus Wartenberg & Herbert Thum (DE)*

**5) TABLE 5: How could SPAEN support its member organisations and how can members better benefit from each other?**  
*Table Hosts: Kathrin Schuster (DE) & Estelle Lecoinge (FR)*

**18:00** **BREAK BEFORE DINNER (90 minutes)**


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DAY 3 – SATURDAY September 10 <sup>th</sup> , 2016	
08:30 - 9:30	<b>Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2015/2016</b>  All Conference Participants are welcome! (Voting Rights for SPAEN Members only...) This session has an official invitation / agenda – important topics are: <b>Report of the Board of Directors (2015)</b> <b>Financial Report (2015)</b> <b>Suggested changes of the Statutes</b> <i>SPAEN Board</i>
09:30 – 10:00	<b>SPAEN PROJECTS</b> <b>Introducing the International Sarcoma Online Platform</b> <i>Herbert Thum (DE) &amp; Kathrin Schuster (DE)</i>
10:00 – 10:30	<b>TEA / COFFEE BREAK (30 minutes)</b>
10:30 – 11:15	<b>INTERESTING PROJECTS FROM THE EU SARCOMA PATIENT COMMUNITY</b>  <b>Important findings from a UK-Survey on Diagnosis, Treatment and Care of Sarcoma Patients</b> <i>Claire Kelleher (UK)</i>  <b>Important findings from a Germany Survey on Follow up of Sarcoma Patients</b> <i>Kai Pilgermann (DE)</i>
11:15 – 12:00	<b>CAPACITY BUILDING</b> <b>Tips/Experiences/Exchange:</b> <b>How to write Grant Proposals/Funding Requests e.g. to the Pharma Industry</b> <ul style="list-style-type: none"> <li>▪ Short Introduction / Overview  <i>Markus Wartenberg (DE)</i></li> <li>▪ Exchange of Experience Audience – Audience  <i>Moderator: Estelle Lecointe (FR)</i></li> </ul>
11:15 – 12:00	<b>SHARING BEST PRACTICE</b> Sharing 5 different concepts/experiences of/with Patient Meetings: <ul style="list-style-type: none"> <li>▪ <b>Vandana Gupta - SPANDAN, India</b></li> <li>▪ <b>Gabriela Tedone - A.I.G., Italy</b></li> <li>▪ <b>Helga Meier-Schnorf – GIST Group Switzerland</b></li> <li>▪ <b>Gideon Moshe - Israeli GIST Group, Israel</b></li> <li>▪ <b>Estelle Lecointe – Ensemble contre le GIST/Info Sarcomes, France</b></li> </ul> <i>Moderator: Nikhil Guhagarkar (IND)</i>
11:15 – 12:00	<b>Closing Remarks – End of Meeting</b> <i>SPAEN Board</i>

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	Lecointe	Estelle	SPAEN-Chair
Germany	Deck	Uli	ARTIS PHOTOGRAPHIE
Germany	Wartenberg	Markus	SPAEN-Chair
Germany	Baumgarten	Christina	SPAEN-Board
Germany	Pilgermann	Kai	SPAEN-Board
Germany	Geissler	Michaela	SPAEN Project Manager
Germany	Schuster	Kathrin	SPAEN Project Manager
Germany	Thum	Herbert	SPAEN, VisKon
Hungary	Domokos	Mihaly	CML and GIST Patient Association
India	Guhagarkar	Nikhil	Friends of Max India
India	Gupta	Vandana	V Care Foundation
Israel	Moshe	Gideon	Israeli GIST Group
Italy	Tedone	Gabriella	A.I.G. Associazione Italiana GIST
Italy	Gulletta	Elio	A.I.G. Associazione Italiana GIST
Kenya	Ferdinand	Mwangura	Henzo Kenya
Poland	Fonrobert	Piotr	Stowarzyszenie Pomocy Chorym na GIST
Poland	Dolecki	Kamil	Stowarzyszenie Pomocy Chorym na Miesaki „SARCOMA“
Poland	Gmaj	Paulina	Stowarzyszenie Pomocy Chrym na Miesaki SARCOMA
Spain	Diaz	Angeles	AEAS Asociación Española de Afectados por Sarcoma
Spain	Garcia Lorente	Jesica	AEAS Asociación Española de Afectados por Sarcoma
Switzerland	Meier	Helga	GIST Group Switzerland
The Netherlands	Gommans	Stefanie	Contactgroep GIST Netherlands-Belgium
The Netherlands	Smit	Jasper	Contactgroep Sarcoma
The Netherlands	van der Ploeg	Robert	Contactgroep Sarcoma
The Netherlands	van Oortmerssen	Gerard	Contactgroep GIST Netherlands-Belgium
The Netherlands	van Kampen	Paul	Contactgroep GIST Netherlands-Belgium
United Kingdom	Bressington	Jayne	PAWS-GIST
United Kingdom	Falconer	David	GIST Support UK
United Kingdom	Sayers	Michael	SPAEN-Board
United Kingdom	Wilson	Sheelagh	SPAEN/Sarcoma UK
United Kingdom	Wilson	Roger	SPAEN Honorary President



Invited Speakers

France	<b>Dr. Sylvie Bonvalot</b> Institut Curie, Paris
France	<b>Dr. Olivier Mir</b> Gustave Roussy Cancer Institute, University of Paris-Sud
Germany	<b>Prof. Dr. Nikolas von Bubnoff</b>  cal Center - University of Freiburg
Germany	<b>Prof. Bernd Kasper</b> Mannheim University Medical Center, University of Heidelberg
Germany	<b>Prof. Dr. Eva Wardelmann</b> University Clinic Münster
Italy	<b>Paolo Casali</b> Fondazione IRCCS Istituto Nazionale dei Tumori, Milan
The Netherlands	<b>Dr. Rick Haas</b> The Netherlands Cancer Institute, Amsterdam
Poland	<b>Prof. Dr. Piotr Rutkowski</b> Institute of Oncology Warsaw
Sweden	<b>Dr. Michael Eriksson</b> Lund University
United Kingdom	<b>Craig Gerrand</b> Newcastle University
United Kingdom	<b>Dr. Robin Jones</b> Royal Marsden

Conference Logistics

<b>Contact:</b>	Your SPAEN Contact during the conference will be Michi Geißler
<b>Phone:</b>	+49 173 4517589
<b>Email:</b>	info@sarcoma-patients.eu
<b>Venue:</b>	HOTEL MERCURE WARSZAWA CENTRUM ul. Żłota 48/54 00-120 Warszawa – POLSKA
<b>TEL.:</b>	+48 22 697 38 69
<b>Web:</b>	www.mercure.com/gb/hotel-3385-mercure-warszawa-centrum
<b>Hotel:</b>	The Mercure Warszawa Centrum Hotel is located in the city center, next to the Złote Tarasy, the largest shopping center in Warsaw, and not far from the commercial buildings: Warsaw Financial Center, Warsaw Towers, and Rondo ONZ 1. Its location in the rapidly developing business heart of the city, and its proximity to the exhibition center (Palace of Culture and Science) and a number of cultural attractions makes the hotel the perfect location both for business travelers and tourists.
<b>Rooms:</b>	En-suite facilities, including bath and shower, tea and coffee making facilities, minibar, TV, iron and hairdryer.
<b>Wi-Fi Access:</b>	Provided in your rooms and throughout the entire hotel free of charge.
<b>Electricity:</b>	In Poland the standard voltage is 230 V. The standard frequency is 50 Hz. The power sockets that are used are of type E.
<b>Special Requests:</b>	If you have any special requirements or needs during the conference please don't hesitate to ask us for support.
<b>Time Zone:</b>	November = Central Eastern Time (CET)
<b>Currency:</b>	The valid currency in Poland is the Zloty (pln)
<b>Conference Days:</b>	<b>Thursday, 8<sup>th</sup> of September 2016</b> 12:30 Official start of the Conference (Light lunch at 11:30) 18:00 End of day 1 19:45 External dinner “Stary Dom” <b>Friday, 9<sup>th</sup> of September 2016</b> 8:30 Start of day 2 18:20 End of day 2 Internal dinner <b>Saturday, 10<sup>th</sup> of September 2016</b> 8:00 Start of day 3 13:00 Official End of the Conference
<b>Meeting Rooms:</b>	Main Conference Room: Scherzo, breakout rooms for parallel tracks on Friday: Room Scherzo for the GIST track, Sala/room 7 for the sarcoma track and Sala/room 4 for the desmoid track.
<b>Language:</b>	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!)
<b>Delegate Presentations:</b>	We would like to thank those organisations for preparing and giving a short presentation during our ‘Sharing Best Practices’ session and moderating a session of the Brainstorming Café.
<b>External Dinner:</b>	Thursday, 8 <sup>th</sup> of September at 19:45, Stary Dom, ul. Puławska 104 / 106, 02-620 Warsaw, www.restauracjastarydom.pl/restaurant-old-house – Transfer will be provided
<b>Evening Dinner/ Get Together:</b>	Friday, 9 <sup>th</sup> of September at 19:30, Mercure Hotel Warsaw Center

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, Lilly, 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 2016 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 2016 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)



**Christina Baumgarten,**  
Board Member  
Desmoids (DE)



**Michael Sayers,**  
Board Member  
GIST (UK)



**Roger Wilson,**  
Honorary President  
Sarcoma UK



**Michaela Geissler,**  
Event Manager (DE)



**Kathrin Schuster,**  
Communication Manager  
(DE)

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 <i>(Chair)</i>	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





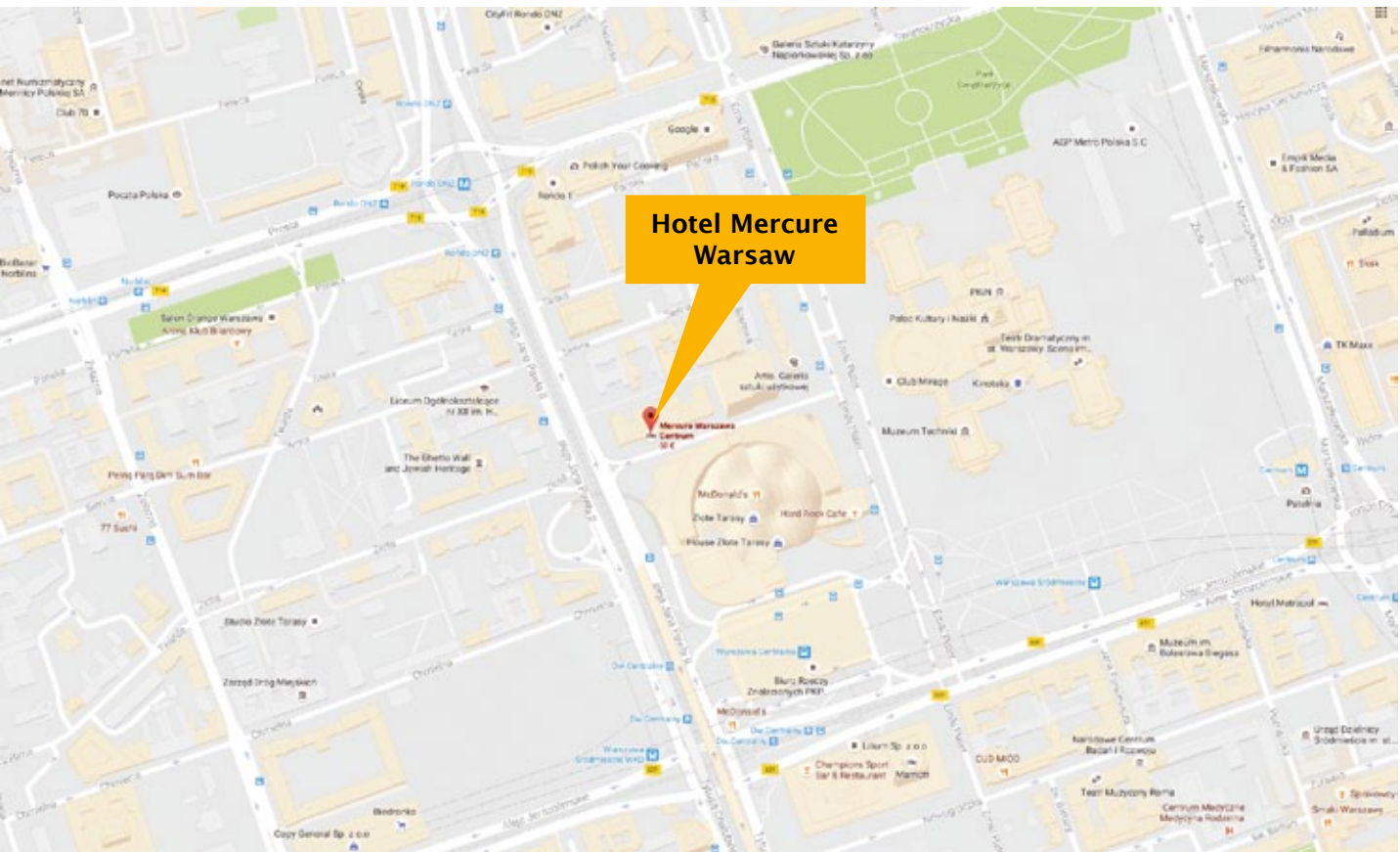
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SPAEN Full Members

- 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 Netherlands
- 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
- 9. USA: The National Leiomyosarcoma Foundation



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

Registered office/legal venue:

Sarcoma Patients EuroNet e.V./Assoc  
Untergasse 36  
61200 Wölfersheim/Germany

# R CANCERS EUROPE E

Joining forces for action



Show your support and sign the  
Call to Action Against Rare Cancers:

[www.rarecancerseurope.org](http://www.rarecancerseurope.org)

## RARE CANCERS:

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- » More common than you think!
- » More challenging than you think!