



Sarcoma  
Patients  
EuroNet

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

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

31<sup>st</sup> of January – 2<sup>nd</sup> of February 2020  
Milan/Italy

CONFERENCE BOOKLET



# SPAEN



|                                   |           |
|-----------------------------------|-----------|
| Content                           | <b>2</b>  |
| Acknowledgements                  | <b>4</b>  |
| Welcome Letter                    | <b>5</b>  |
| Welcome to Italy<br>and to Milan! | <b>6</b>  |
| Agenda Friday                     | <b>8</b>  |
| Agenda Saturday                   | <b>8</b>  |
| Agenda Sunday                     | <b>10</b> |

|  |           |
|--|-----------|
| Agenda<br>ESMO Sarcoma/GIST<br>Symposium 2020  | <b>12</b> |
| Participation at the<br>ESMO Training Sessions   |           |
| ESMO Preceptorship<br>on Sarcoma & GIST<br>(Beginners)<br>or parallel<br>ESMO Advanced Course<br>on Sarcoma & GIST |           |

# INFO



Participants  
**20**

Invited Speakers  
**21**

Conference Logistics  
**22**

Reimbursement/  
Funding/  
Liability  
**23**

Map  
**29**

About SPAEN  
**24**

Board of Directors  
**26**

Medical Advisory Board  
**27**

SPAEN Member Organisations  
**28**

SPAEN Contact and Office  
**30**



We would like to thank the following funders who have supported the 10<sup>th</sup> SPAEN Conference with an unrestricted educational grant: Novartis, Pfizer, PharmaMar, Bayer, Deciphera, B lueprint. The funding is not related to any of the objectives of SPAEN or any of the objectives/content of the 10<sup>th</sup> SPAEN Annual Conference in Milan, Italy.

The idea, conception, planning, preparation, implementation, management and the summary of the 10<sup>th</sup> 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 global level and to improve the lives of sarcoma cancer patients at a national level.

Photos: Uli Deck, ARTIS, Fotolia,  
Titel: Facade of the Milan Cathedral ©Jakub Hałun on wikipedia  
Layout and Typesetting: Herbert Thum, VisKon.de

# Welcome to Milan and to the 10<sup>th</sup> Annual Meeting and General Assembly of Sarcoma Patients EuroNet (SPAEN).

In 2019 we celebrated the 10<sup>th</sup> anniversary of the founding of SPAEN. It gave us the opportunity to look back at achievements over those ten years and to focus on plans for the next few years. The eleven national associations present at the founding meeting have gone through some changes but all have grown and are active. We now have 47 member associations and the number of countries represented is growing. SPAEN is now a global association.

It has also been exciting to see that the networks of the specialists who treat sarcoma have grown. We anticipate that the ESMO Sarcoma & GIST Symposium, which follows our meeting in Milan, will have more countries represented than ever before. We believe that the message about the importance of the multi-disciplinary management of sarcoma is gaining ground and is encouraging new specialists to engage internationally with their peers, ultimately for the benefit of their patients.

Many of our delegates will be attending the ESMO meeting and engaging with the professionals. This is a key part of our role as advocates for patients with sarcoma. The ESMO Symposium is known as an excellent networking event, encouraging collaboration and enabling practical educational opportunities to be realised. The exchange of research results is also an important feature with translational medicine featuring strongly as drug developers aim to bring new agents into clinical practice. Our involvement, meeting and questioning the experts, results in a more integrated approach which helps create better patient outcomes.

There is also a growing commitment from the industry to sarcoma. There are more clinical trials running than at any time any of us can recall. This is an indication of how scientists are developing our understanding of the genetics of sarcoma and are employing innovative technology to bring that to treatments which benefit patients. This is the consistent message. Patient benefit is at the heart of what we are all trying to achieve, whether as a patient advocate, a clinical specialist or a scientist working in a laboratory.

We welcome specialists from many parts of the world to our SPAEN Conference. They represent most of the disciplines involved in managing sarcoma. Do not be timid in asking questions, whether in a formal session or afterwards over coffee or lunch. Our medical colleagues are happy to share their knowledge of these rare cancers. Remember that we have the same objective of delivering patient benefit.

We welcome you all for what we hope will be two days of inspiration through shared learning and good company. Do try and meet as many people from as many countries as you can during our time together. Share your good experiences and your disappointments also, we can learn so much from each other. If you are staying on for ESMO we look forward to even more conversations!

With best wishes,

*The SPAEN Board of Directors*



Forum Romanum in Rome ©BeBo86 on wikipedia commons



Tavolara, Sardinia, from the top of Punta Cannone ©Roberto Mura on wikipedia



Gran Paradiso ©Fulvio Spada from Torino on wikipedia



Tremosine on Lake Garda ©Massimo Telò on wikipedia



Authentic Neapolitan  
Pizza Margherita  
©ElfQrin on wikipedia



Coliseum at dusk ©Photo by DAVID ILIFF. License: CC-BY-SA 3.0

## Welcome to Italy

Italy, officially the Italian Republic (Italian: Repubblica italiana), is a unitary parliamentary republic in Europe. Located in the heart of the Mediterranean Sea, Italy shares open land borders with France, Switzerland, Austria, Slovenia, San Marino and Vatican City. Italy covers an area of 301,338 km<sup>2</sup> (116,347 sq mi) and has a largely temperate seasonal and Mediterranean climate. Due to its shape, it is often referred to in Italy as lo Stivale (the Boot). With around 61 million inhabitants it is the fourth most populous EU member state.

Today Italy has the third largest nominal GDP in the Eurozone and the eighth largest in the world. As an advanced economy the country also has the sixth worldwide national wealth and it is ranked third for its central bank gold reserve. Italy has a very high level of human development and it is sixth in the world for life expectancy. The country plays a prominent role in regional and global economic, military, cultural and diplomatic affairs, and it is both a regional power and a great power.

Italy is a founding and leading member of the European Union and the member of numerous international institutions, including the UN, NATO, the OECD, the OSCE, the WTO, the G7, G20, the Union for the Mediterranean, the Council of Europe, Uniting for Consensus and many more. As a reflection of its cultural wealth, Italy is home to 53 World Heritage Sites, the most in the world, and is the fifth most visited country.

(Source: Wikipedia.com)

|                      |  |
|----------------------|--|
| <b>Capital:</b>      | <b>Rome</b>                                      |
| <b>Population:</b>   | <b>61 mio.</b>                                   |
| <b>Area:</b>         | <b>301,338 km<sup>2</sup> = 116,347 sq miles</b> |
| <b>Currency:</b>     | <b>EURO</b>                                      |
| <b>Calling Code:</b> | <b>+39</b>                                       |
| <b>Internet:</b>     | <b>.it</b>                                       |





Facade of the Milan Cathedral ©Jakub Hatun on wikipedia



Leonardo da Vinci (1452–1519) *The Last Supper*, Current location: Convent of Santa Maria delle Grazie, Milan ©wikidata:Q244952



The skyline of Milan from the roof of Duomo cathedral ©Setafano Stabile on wikipedia commons



Triumphal arch of Gallery Vittorio Emanuele II in Milan ©Jakub Hatun on wikipedia

## Welcome to Milan

Milan is the capital of Lombardy and the second most populous city in Italy after Rome, with the city proper having a population of 1,360,422 while its province-level municipality has a population of 3,228,000. Its continuously built-up urban area (that stretches beyond the boundaries of the Metropolitan City of Milan) has a population estimated to be about 5,270,000 over 1,891 square kilometres (730 square miles), ranking forth in the European Union. The wider Milan metropolitan area, known as Greater Milan, is a polycentric metropolitan region that extends over central Lombardy and eastern Piedmont and which counts an estimated total population of 8,173,176, making it by far the largest metropolitan area in Italy.

Milan is considered a leading Alpha Global City, with strengths in the arts, commerce, design, education, entertainment, fashion, finance, healthcare, media, services, research, and tourism. Its business district hosts Italy's Stock Exchange and the headquarters of the largest national and international banks and companies. In terms of GDP, it has the third largest economy among European cities and the wealthiest among European non-capital cities. Milan is considered part of the Blue Banana and one of the "Four Motors for Europe."

(Source: Wikipedia.com)

## Friday January 31<sup>st</sup> 2020

|       |                                     |
|-------|-------------------------------------|
| 17:00 | Opening of the Registration Desk    |
| 19:00 | Italian Get Together (La Brasserie) |

## DAY 1 – Saturday February 1<sup>st</sup> 2020 (Room Foscolo)

|               |  |
|---------------|--|
| 08:30         | <b>OFFICIAL START OF THE CONFERENCE (Room Foscolo)</b>   |
| 08:30 – 09:00 | <b>Welcome to Milan/Italy on behalf of the SPAEN Board, the Italian Sarcoma Patient Community and ESMO</b><br><i>Markus Wartenberg (DE), Ornella Gonzato (IT) and Paolo Casali (IT), Chair of the ESMO Symposium</i>   |
| 09:00 – 10:30 | <i>Chair: SPAEN Board Member</i><br><b>Sarcoma Treatment in the age of “Precision Oncology or Precision Medicine”</b><br>Short introduction to the Concept of “Precision Oncology”<br>Where are we in Sarcomas? Whole genome sequencing of sarcomas?<br>Why do it? What are we learning? Can we really make a difference? (45)<br><i>Speaker: Adrienne Flanagan (UK)</i><br>Precision Oncology: Chances & Challenges from the Patients and the Patient Advocacy Perspective (30)<br><i>Speaker: Markus Wartenberg (DE)</i><br>Discussion (15)  |
| 10:30 – 11:00 | C O F F E E B R E A K (Room Gazebo)  |
| 11:00 – 12:15 | <i>Chair: Board Member</i><br><b>News/Developments/Updates from the International Sarcoma Community:</b><br>Introducing the “US Sarcoma Coalition”<br><i>Speaker: Annie Achee (US)</i><br>The SELNET Project: Sarcoma as a model to improve diagnosis and clinical care of rare tumours through a European and Latin American multidisciplinary network<br><i>Speaker: Nadja Hindi (ESP) + Piga Fernandez (Chile)</i><br>Quality of Life Update<br><i>Speaker: Lesley Storey (UK) + Olga Husson (NL)</i>   |
| 12:15 – 13:30 | <i>Chair/Moderator: Amy-Bruno Lindner (AT)</i><br><b>How can we improve the way we communicate with our patients?</b><br>Improving Patient Advocate-Patient Communication:<br>Techniques for Sharing Information<br><i>Speaker: Amy-Bruno Lindner (AT)</i><br>How to run an effective and supportive “helpline” for patients?<br>The UK Experience<br><i>Speaker: Helen Stradling (Sarcoma UK)</i>   |
| 13:30 – 14:30 | L U N C H B R E A K (Room Gazebo)  |
| 14:30 – 16:00 | <b>MARKET PLACE SESSION – CAPACITY BUILDING</b><br>Three cycles/rounds a 25 mins. In between 5 mins break for changing the booth... <ul style="list-style-type: none"> <li>Booth 1: Finding, managing and motivating volunteers<br/><i>Host/Presenter: Vandana Gupta (IND)</i></li> <li>Booth 2: Organising successful patient meetings<br/><i>Host/Presenter: Michi Geissler (DE)</i></li> <li>Booth 3: Value assessment for better patient-doctor-communication<br/><i>Host/Presenter: Gerard van Oortmerssen (NL)</i></li> <li>Booth 4: Future-proofing your organisation<br/><i>Host/Presenter: Markus Wartenberg (DE)</i></li> <li>Booth 5: How to read and interpret scientific data<br/><i>Host/Presenter: Roger Wilson (UK) &amp; Bernd Kasper (DE)</i></li> </ul> |
| 16:00 – 16:30 | C O F F E E B R E A K (Room Gazebo)  |



**DAY 1 – Saturday February 1<sup>st</sup> 2020 (Room Foscolo)**

**16:30 – 18:00**

**Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2019/2020**

*All Conference Participants are welcome!*

*(Voting rights for SPAEN Members only)*

This session has an official invitation/agenda – important topics are:

- Report of the Board of Directors (2019)
- Financial Report (2019)
- Elections
- Outlook 2020 and beyond

SPAEN Board

**18:00**

## BREAK BEFORE DINNER

**19:30**

### Internal Dinner (Room “Le Baron2”)

**Including award ceremony “Advocacy in Action Award 2019”**

*Moderator: Lecointe-Artzner (FR)*



**Notes:**

## DAY 2 – Sunday February 2<sup>nd</sup> 2020

|                 |   |   |  |
|-----------------|---|---|--|
| 07:30 – 8:20    | <b>EARLY Breakfast Session: Sharing Practical Experiences</b><br>Standards of Excellence for Patient Organizations Setting the Scene (15)<br><i>Markus Wartenberg (DE)</i><br>The South African Experience (25)<br><i>Lauren Pretorius (ZA)</i><br>Questions (10) |   |  |
| 08:30 – 9:30    | <i>Chair: SPAEN Board Member</i><br><b>Key Note Lecture:</b><br><b>What is the status of sarcoma research so far and what needs to be changed in the future from an expert perspective?</b><br><i>Speaker: Robert G. Maki (US)</i>                                |   |  |
| 09:30 – 10:30   | <i>Chair: SPAEN Board Member</i><br><b>First Key Findings from the “Intl. Sarcoma Priority Setting Partnership Survey”</b><br><i>Speaker-Team: Olga Husson, Kathrin Schuster, Gerard van Oortmerssen</i>  |   |  |
| 10:30 – 11:00   | C O F F E E B R E A K (Room Gazebo)   |   |  |
| Parallel Tracks | <b>GIST-Track (Room Foscolo)</b><br><i>Chairs:</i><br>2 SPAEN Board Members   | <b>Sarcoma-Track (Room Porta)</b><br><i>Chairs:</i><br>2 SPAEN Board Members  | <b>Desmoide-Track (Room Parini)</b><br><i>Chairs:</i><br>2 SPAEN Board Members   |
| 11:00 – 12:15   | <b>Improving the outcome of GIST-treatment: 6 case stories - presented by international GIST experts</b><br><i>Peter Reichardt (DE)</i><br><i>Alessandro Gronchi (IT)</i><br><i>Mikael Eriksson (SWE)</i>   | <b>Profiles of Sarcoma Subtypes: Chondrosarcoma (30)</b><br><i>Kenneth Rankin (UK)</i><br><b>World Sarcoma Network (WSN): Sarcoma of the Year 2019: DSRCT Desmoplastic Small Round Cell Tumour</b><br><i>Jean-Yves Blay (FR)</i>  | <b>In patient-friendly language: Understanding the biology of Desmoids</b><br>Are we talking about one disease or different types of desmoids?<br><i>Eva Wardelmann (DE)</i>   |
| 12:15 – 13:15   | <b>Research-Forum GIST Updated on new targets/ agents and ongoing/ upcoming clinical trials in GIST</b><br><i>Sebastian Bauer (DE)</i><br><i>Jonathan Trent (US)</i>  | <b>Research-Forum Soft Tissue Sarcomas Update on new agent and ongoing/upcoming clinical trials in STS</b><br><i>Bernd Kasper (DE)</i>  | <b>Radiotherapy in Desmoids:</b><br>- Potential Use<br>- Operational Process<br>- Side Effects<br><b>Practice &gt; Case Stories</b><br><i>Rick L. Haas (NL)</i>  |
| 13:15 – 14:15   | L U N C H B R E A K and N E T W O R K I N G (Room Gazebo)   |   |  |
| 14:15 – 15:00   | <b>In patient friendly language: Understanding the biology, genetics and process of mutational analysis in GIST</b><br><i>Paolo Dei Tos (IT)</i>  | <b>Summaries from intl. roundtables and projects: The NLMSF Intl. Leiomyosarcoma Research Roundtable</b><br><i>Annie Achee (US)</i><br><i>Scott Okuno (US)</i><br><b>Drug development in paediatric oncology: Fostering Age Inclusive Research (FAIR) Trials</b><br><i>Chris Copland (UK)</i> | <b>Therapy- and Side Effect Mgmt. of Targeted Therapies such as Imatinib or Sorafenib</b><br>• The Expert Experience<br><i>Bernd Kasper (DE)</i><br>• The Patient Advocacy Experience from other diseases<br><i>Markus Wartenberg (DE)</i> |
| 15:00 – 16:00   | <b>Using “Social Media” in Sarcomas – Panel Discussion:</b><br><i>Moderator: Kathrin Schuster (DE)</i><br><i>Panellists: Jonathan Trent (US), Winette van der Graaf (NL), Annika Laakso (FIN)</i>   |   |  |
| 16:00           | <b>Closing Remarks – End of Meeting</b>   |   |  |

## DAY 2 – Sunday February 2<sup>nd</sup> 2020

**16:30 – 18:00**

Chordoma Foundation Europe/Patientenplatform Sarcomen & SPAEN invite to an informal meeting:  
**Bone tumour patient advocacy - synergy through cooperation**

Everybody, who has an interest is welcome to attend – patient advocates and experts

**Notes:**

### DAY 3 – Monday February 3<sup>rd</sup>, 2020

Depending on individual planning:

## Departure

*or*

### Participation at the ESMO Training Sessions (Beginners and Advanced)



**Sarcoma  
Patients  
EuroNet**

*Together We Can Make A Difference*

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

## 31<sup>st</sup> of January – 2<sup>nd</sup> of February 2020

### Milan/Italy



**Notes:**

*For Those Affected By Sarcomas!*



## ESMO SARCOMA AND GIST SYMPOSIUM

**3<sup>rd</sup> - 5<sup>th</sup> of February 2020**  
**Milan/Italy**

### DAY 3 – Monday February 3<sup>rd</sup>, 2020

|               |   |   |
|---------------|---|---|
| 9:00 – 13:30  | <b>Preceptorship Course on Sarcoma &amp; GIST (Beginners):</b><br>Le Club Room<br>Half-day meeting designed to provide young oncologists with a brief outline of both STS & GIST. It could be a first contact with these diseases for oncologists who are interested to know more about them and to have an introduction to the high-profile Conference in the two days afterwards. | <b>Advanced Course on Sarcoma &amp; GIST:</b><br>Room Washington A<br>Half-day event offering an intensive discussion of a set of clinical cases of STS & GIST for professionals who are already familiar with these diseases. Attendees will benefit from discussions about challenging clinical cases with specialists from both the EU and USA, leveraging the different perspectives and expertise across continents. This course is the ideal preparation for clinicians joining the ESMO Sarcoma & GIST Symposium 3-5 February. |
| 09:00 – 11:00 | <b>Session 1 Localised STS and GIST</b><br>Multidisciplinary tumor board discussion of Localized Soft Tissue Sarcoma and GIST<br><i>Chairs:</i><br><i>Presenter: A. Gronchi</i><br><i>Discussants on Panel table: C. Fletcher, Baldini, Haas, Bonvalot, Swallow, Le Cesne, W. Tap, Patel</i>  |   |
| 11:00 – 11:30 | COFFEE BREAK  |   |
| 11:30 – 13:30 | <b>Session 2 Advanced STS and GIST</b><br>Multidisciplinary tumor board discussion of Metastatic Soft Tissue Sarcoma and GIST<br><i>Chairs:</i><br><i>Presenter: A. Gronchi</i><br><i>Discussants on Panel table: AP Dei Tos, De Laney, A Miah, Hohenberger, Raut, Demetri, Blay, Martin Broto</i>  |   |
| 13:30 – 14:15 | LUNCH   |   |



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**Notes:**

# AGENDA DAY III

## DAY 3 – Monday February 3<sup>rd</sup>, 2020

14:15 – 14:30

### Opening & Welcome

*Chairs: P.G. Casali, Milan/IT, J.-Y. Blay, Lyon/FR, J. Bovée, Leiden/NL, A.P. Dei Tos, Padova/IT*

Welcome from ESMO

*Paolo G. Casali, Milan, Italy*

Introduction to European collaborative efforts in rare solid cancers

*Jean-Yves Blay, Lyon, France*

14:30 – 15:30

### Session 1: SPAEN/PAGs: Working together - using patient power

*Chairs: Jean-Yves Blay, Lyon, France, Markus Wartenberg, Wölferstheim, Germany*

- **From patient to advocacy**

- **Advocacy in Action: Case studies & Advocacy headlines**

- **From Advocacy to Power of Collaboration: Being a global player & Working with specialist doctors**

- **Targets for the future**

- **JARC: Recommendations on Rare Cancers**

Questions and Discussions

15:30 – 16:00

COFFEE BREAK

16:00 – 18:00

### Session 2: Challenges in classification

*Chairs: : P. Picci, Bologna, Italy J. Whelan, UK*

- **Pathology and genetics of STSC.**

*Fletcher, Boston/US*

- **Genetics of GIST**

*J.A.Fletcher, Boston/US*

- **What is in the WHO new sarcoma classification, what should be a pathologic subtype of STS?**

*A.P. Dei Tos, Padova/IT*

- **Challenges in sarcoma registration vis-a-vis the WHO new sarcoma classification**

*A. Trama, Milan/IT*

- **What a pathologic diagnosis of STS should say today**

*J. Bovée, Leiden/NL*

Discussion

18:10 – 19:10

Industry Satellite Symposium 1

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**Notes:**

# AGENDA DAY IV

## DAY 4 – Tuesday February 4<sup>th</sup>, 2020

08:30 – 10:30

### Session 3: Challenges in pathologic diagnosis

*Chairs: A.P. Dei Tos, J Bovee*

- **The clinically relevant immuno landscape of sarcomas**  
*R. Maki, New York/US*
  - **The technological potentials and challenges of NGS in STS**  
*F. Tirede, Lyon/FR*
  - **How can we be pathologically agnostic in diagnosing a STS?**  
*C. Antonescu, New York/US*
  - **What does being pathologically agnostic clinically mean in STS?**  
*J.-Y. Blay, Lyon/FR*
  - **The technological potentials and challenges of liquid biopsy**  
*R. Maestro, Aviano/IT*
- Discussion

10:30 – 11:00

COFFEE BREAK

11:00 – 12:40

### Session 4: Challenges in surgery

*Chairs: P. Collini, Milan, Italy Y. Schrage*

- **The requirements of good surgery of STS today**  
*P. Hohenberger, Mannheim/DE*
  - **The evolving approach to the surgical margin across sarcoma histologies and primary sites**  
*A. Gronchi, Milan/IT*
  - **The requirements of good surgery of GIST today**  
*P. Rutkowski, Warsaw/PL*
  - **Challenges in surgical decisions about residual disease after TKIs in GIST**  
*C. Swallow, Toronto/CA*
- Discussion

12:40 – 13:30

LUNCH BREAK

13:30 – 14:30

### Industry Satellite Symposium 2

14:30 – 16:00

### Session 5: Challenges in radiation therapy

*Chairs: R. Haas, A. De Paoli, Aviano, Italy*

- **The evolving indications to radiation therapy in STS today**  
*E. Baldini, Boston/US*
  - **Challenges in incorporating new technological options in radiation therapy of STS today**  
*T.F. Delaney, Boston/US*
  - **Pre-operative chemo-radiation therapy in STS**  
*S. Patel, Houston/US*
- Discussion

16:00 – 16:30

COFFEE BREAK

16:30 – 18:30

### Session 6: Challenges in medical treatment of STS

*Chairs: E. Grignani, Candiolo, Italy X. Garcia Del Muro*

- **The scope of medical therapy of STS today**  
*P.G. Casali, Milan/IT*
  - **How many “rare” STS are to single out in today’s medical therapy?**  
*S. Stacchiotti, Milan/IT*
  - **Reshaping vascular sarcomas**  
*R.S. Benjamin, Houston/US*
  - **The challenging model of epithelioid sarcomas**  
*A.M. Frezza, Milan/IT*
  - **Challenges in breaking down uterine sarcomas**  
*S. George, Boston/US*
- Discussion

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**Notes:**

# AGENDA DAY V



## DAY 5 – Wednesday February 5<sup>th</sup>, 2020

|               |  |
|---------------|--|
| 08:30 – 10:30 | <b>Session 7: Challenges in medical treatment of GIST</b><br><i>Chairs: M.A. Pantaleo, , Bologna, Italy I. Judson, London, UK</i> <ul style="list-style-type: none"> <li>• <b>How to tailor, how to stretch adjuvant therapy in GIST</b><br/><i>N.N</i></li> <li>• <b>Challenges in current use of standard agents in GIST today</b><br/><i>P. Reichardt, Berlin/DE</i></li> <li>• <b>Challenges in approaching a non-KIT/PDGFRA mutated GIST patient today</b><br/><i>S. Bauer, Essen/DE</i></li> <li>• <b>New avenues of medical therapy in GIST</b><br/><i>G. Demetri, Boston/US</i></li> <li>• <b>How could we clinically exploit liquid biopsy in GIST?</b><br/><i>A. Wagner, Boston/US</i></li> </ul> Discussion                           |
| 10:30 – 11:00 | COFFEE BREAK   |
| 11:00 – 12:20 | <b>Session 8: Challenges in desmoids</b><br><i>Chairs: S. Piperno-Neumann, Bordeaux, France M. Fiore, Milan, Italy</i> <ul style="list-style-type: none"> <li>• <b>Is there room for surgery today?</b><br/><i>S. Bonvalot, Paris/FR</i></li> <li>• <b>Is there room for radiation therapy today?</b><br/><i>R.L. Haas, Amsterdam/NL</i></li> <li>• <b>Challenges in exploiting and assessing medical therapy of desmoid tumours</b><br/><i>B. Kasper, Mannheim/DE</i></li> </ul> Discussion   |
| 12:20 – 13:10 | LUNCH BREAK  |
| 13:10 – 14:10 | <b>Industry Satellite Symposium 3</b>  |
| 14:20 – 16:20 | <b>Session 9: The challenging immuno landscape of sarcomas and GIST</b><br><i>Chairs: M. Aglietta, Turin, Italy H. Gelderblom, Leiden, The Netherlands</i> <ul style="list-style-type: none"> <li>• <b>The challenging state of the art of immuno therapy of STS today</b><br/><i>W.D. Tap, New York/US</i></li> <li>• <b>The challenging state of the art of immuno therapy of GIST today</b><br/><i>N.N</i></li> <li>• <b>Adoptive immuno therapy in STS</b><br/><i>L. Helman, Los Angeles/US</i></li> <li>• <b>Combination immuno therapy attempts</b><br/><i>J. Martin Broto, Palma de Mallorca/ES</i></li> <li>• <b>New targets, new agents and new strategies for immuno therapy</b><br/><i>A. Dufresne, Lyon/FR</i></li> </ul> Discussion |
| 16:20 – 16:30 | <b>Conclusions</b><br><b>Take home messages and close</b><br><i>Speaker: Paolo G. Casali</i>   |

# Participants

| Country      | First name         | Surname          | Organisation  |
|--------------|--------------------|------------------|---|
| Austria      | Bruno Lindner      | Amy              | GIST Support Österreich   |
| Austria      | Bruno              | Martin           | GIST Support Österreich   |
| Belgium      | Vissenaeken        | Lina             | Cum Cura  |
| Bulgaria     | Mihailova          | Adelina          | Alliance for patients - GIST & STS- Bulgaria                                |
| Bulgaria     | Popova             | Yuliana          | Alliance for patients - GIST & STS- Bulgaria                                |
| Chile        | Fernandez          | Piga             | Alianza GIST/Life Raft Group  |
| Finland      | Laakso             | Annika           | SPAEN / Association of Cancer Patients in Finland / Suomen Syöpäpotilaat    |
| Finland      | Hiihtola           | Hanna            | Association of Cancer Patients in Finland                                   |
| Finland      | Mattila            | Saila            | Association of Cancer Patients in Finland                                   |
| France       | Sandakly           | Sami             | SPAEN   |
| France       | Lecointe-Artzner   | Estelle          | SPAEN   |
| France       | Helaine            | Audrey           | SOS Desmoïde France   |
| Germany      | Geissler           | Michaela         | SPAEN   |
| Germany      | Schuster           | Kathrin          | SPAEN   |
| Germany      | Wartenberg         | Markus           | SPAEN/German Sarcoma Foundation   |
| Germany      | Pilgermann         | Kai              | SPAEN/German Sarcoma Foundation   |
| Germany      | Baumgarten         | Christina        | SPAEN/Sos Desmoid Germany   |
| Hungary      | Domokos            | Mihaly           | Recovering Together Association   |
| Hungary      | Kalo               | Zoltan           | Recovering Together Association   |
| Hungary      | Szücs-Somlyó       | Eva              | Érintettek Egyesület Hungarian Parents Association for Children with Cancer |
| India        | Gupta              | Vandana          | V Care Foundation   |
| India        | Magwani            | Jogita           | V Care Foundation   |
| Italy        | Tamagni            | Barbara          | ASSOCIAZIONE ITALIANA GIST ONLUS  |
| Italy        | Personeni          | Giuliana         | Desmoid Foundation Italy  |
| Italy        | Rossi              | Enrica           | Desmoid Foundation Italy  |
| Italy        | Ferreri            | Marilena         | Desmoid Foundation Italy  |
| Italy        | Ciaci              | Chiara           | Desmoid Foundation Italy  |
| Italy        | Bolzicco           | Andrea           | Orchestra per la vita   |
| Italy        | Tamagni            | Barbara          | A.I.G.  |
| Italy        | Baldoin            | Elisa            | Luogo d incontro Desmoide   |
| Italy        | Gonzato            | Ornella          | Trust Paola Gonzato - Rete Sarcoma Onlus                                    |
| Macedonia    | Dimitrovski        | Toni             | Macedonian GIST Group   |
| Macedonia    | Krstevski          | Dejan            | Macedonian GIST Group   |
| Netherlands  | van Lierop         | Jet              | Patiëntenplatform Sarcomen  |
| Netherlands  | den Hollander      | Dide             | Radboud University Medical Center   |
| Netherlands  | Soomers            | Vicky            | Radboud University Medical Center   |
| Netherlands  | Weidema            | Marije           | Radboud University Medical Center   |
| Netherlands  | van Kampen         | Paul             | Patiëntenplatform Sarcomen  |
| NL           | van Oortmerssen    | Gerard           | SPAEN/Patiëntenplatform Sarcomen  |
| NL           | Roets              | Evelyne          | Patiëntenplatform Sarcomen  |
| NL           | Kooy               | Caroline         | Patiëntenplatform Sarcomen/Chordoma Foundation Europe                       |
| Norway       | Nedrelid           | Pal              | Sarkomer Norway   |
| Poland       | Fonrobert          | Piotr            | Polish GIST Patients Aid Association  |
| Poland       | Dolecki            | Kamil            | Stosarzyszenie SARCOMA  |
| Romania      | Ene                | Simona           | HomeCare Association / European Network of Gynaecological Advocay Groups    |
| South Africa | Pretorius          | Lauren           | Campaign for Cancer   |
| Spain        | Garcia             | Jessica          | SPAEN/AEAS  |
| Spain        | Martinez Gutierrez | Alberto          | FUNDACION MARI PAZ JIMENEZ CASADO   |
| Spain        | de la Llana        | Olga             | AEAS  |
| Sweden       | Wessen             | Christian        | Sarkomföreningen Sweden   |
| Sweden       | Carlsson           | Ewa              | Sarkomföreningen Sweden   |
| Swiss        | Quintyn            | Annick           | Swiss Sarcoma   |
| Switzerland  | Meier-Schnorf      | Helga            | GIST Group Switzerland  |
| Switzerland  | Forster            | Jürg             | GIST Group Switzerland  |
| UK           | Wilson             | Roger + Sheelagh | SPAEN   |
| UK           | Davidson           | Richard          | SPAEN/Sarcoma UK  |
| UK           | Copland            | Chris            | Unite2Cure  |
| UK           | Bressington        | Jayne            | PAWS GIST   |
| UK           | Vinander           | Viqui            | Bone Cancer Research Trust (BCRT)   |
| UK           | Kirby              | Louise           | Bone Cancer Research Trust (BCRT)   |
| UK           | Price              | Bradley          | Sarcoma UK  |
| UK           | Stradling          | Helen            | Sarcoma UK  |
| UK           | Green              | Philip           | Bone Cancer Research Trust and the NCRI Sarcoma Clinical Studies Group      |
| USA          | Achee              | Annie            | National Leiomyosarcoma Foundation (NLMF)                                   |
| USA          | Achee              | Mitchell         | National Leiomyosarcoma Foundation (NLMF)                                   |
| USA          | Reinke             | Denise           | SARC  |
| USA          | Lozinsky           | Shannon          | Chordoma Foundation   |
| USA          | Levy               | Joan             | Chordoma Foundation   |





# Invited Experts

|                       |                              |  |
|-----------------------|------------------------------|--|
| <b>France</b>         | <b>Jean-Yves Blay</b>        | Centre Leon-Berard, Lyon   |
| <b>Germany</b>        | <b>Sebastian Bauer</b>       | University Clinic Essen  |
| <b>Germany</b>        | <b>Bernd Kasper</b>          | Mannheim University Medical Center, University of Heidelberg                     |
| <b>Germany</b>        | <b>Peter Reichardt</b>       | Helios Klinikum Berlin-Buch  |
| <b>Germany</b>        | <b>Eva Wardelmann</b>        | University Clinic Münster  |
| <b>Italy</b>          | <b>Paolo Casali</b>          | Fondazione IRCCS Istituto Nazionale dei Tumori, Milan                            |
| <b>Italy</b>          | <b>Alessandro Gronchi</b>    | Fondazione IRCCS Istituto Nazionale dei Tumori, Milan                            |
| <b>Italy</b>          | <b>Paolo Dei Tos</b>         | Fondazione IRCCS Istituto Nazionale dei Tumori, Milan                            |
| <b>Netherlands</b>    | <b>Olga Husson</b>           | Netherlands Cancer Institute, Amsterdam  |
| <b>Netherlands</b>    | <b>Rick L. Haas</b>          | Netherlands Cancer Institute, Amsterdam  |
| <b>Netherlands</b>    | <b>Winette van der Graaf</b> | Netherlands Cancer Institute<br>and Radboud University Medical Center, Amsterdam |
| <b>United Kingdom</b> | <b>Adrienne Flanagan</b>     | Royal National Orthopedic Hospital, London                                       |
| <b>United Kingdom</b> | <b>Lesley Storey</b>         | School of Social Sciences Birmingham   |
| <b>United Kingdom</b> | <b>Kenneth Rankin</b>        | The Newcastle Upon Tyne Hospitals  |
| <b>Spain</b>          | <b>Nadja Hindi</b>           | Virgen del Rocío University Hospital, Sevilla                                    |
| <b>Sweden</b>         | <b>Mikael Eriksson</b>       | University of Lund   |
| <b>USA</b>            | <b>Robert G. Maki</b>        | Northwell Health Cancer Institute, New York                                      |
| <b>USA</b>            | <b>Jonathan Trent</b>        | Sylvester Comprehensive Cancer Center, University of Miami                       |
| <b>USA</b>            | <b>Scott Okuno</b>           | Mayo Clinic, Rochester   |





# Conference Logistics

|                   |  |
|-------------------|--|
| Contact:          | Your SPAEN Contact during the conference will be Michi Geißler   |
| Phone:            | +49 173 4517589  |
| Email:            | info@sarcoma-patients.eu   |
| Venue:            | Via Washington 66<br>20146 Milan<br>Italy  |
| Tel.:             | +39 02 48521   |
| Web:              | www.milanmarriotthotel.com   |
| Hotel:            | The Marriott Hotel Milan offers elegant and contemporary accommodation.<br>The comfortably appointed hotel rooms and suites offer space, style and perks like high-speed Wi-Fi.  |
| Wi-Fi Access:     | Provided in your room and throughout the entire hotel free of charge.  |
| Electricity:      | In Italy the standard voltage is 230 V. The standard frequency is 50 Hz.<br>The power sockets that are used are of type E.   |
| Special Requests: | If you have any special requirements or needs during the conference please don't hesitate to ask us for support.   |
| Time Zone:        | Central European Time (CET)  |
| Currency:         | The valid currency in Italy is the EURO (€)  |
| Conference Days:  | <b>Friday, 31<sup>st</sup> of January 2020</b><br>19:00 Get Together in Restaurant La Brasserie (Marriott Hotel)<br><br><b>Saturday, 1<sup>st</sup> of February 2020</b><br>0:30 Official start of the SPAEN Conference 2020<br>18:00 End of day 1<br>19:30 Internal Dinner (Room "Le Baron 2")<br><br><b>Sunday, 2<sup>nd</sup> of February 2020</b><br>07:30 Start of day 2<br>16:15 Official end of SPAEN Conference 2020 |
| Rooms:            | Main Meeting Room: Foscolo<br>Breakout Room for parallel sessions (Sunday):<br>Porta and Parini  |



# Reimbursement / Funding / Liability

## Reimbursement Rules

**Travelling Expenses:** Funding for travel, accommodation and conference expenses is available. Travel costs will be reimbursed by SPAEN for one representative per member organisation up to a max. of 350 EUR. 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 SPAEN 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 is limited to €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 is covered by unrestricted grants from : Bayer, Blueprint, Deciphera, Novartis, Pfizer, PharmaMar. 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, implementation, 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 2020 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 2020 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.



# About Sarcoma Patients EuroNet (SPAEN)

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

Sarcoma Patients EuroNet (SPAEN), the International 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 through improving information and support and by increasing the visibility of sarcoma with policymakers and the public.

SPAEN is an international association, legally registered under German law. The network of currently 47 patient groups 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 20 international cancer patient advocacy networks representing other cancer diagnoses.



## Our Vision

All sarcoma patients 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.



## Sarcoma Patients EuroNet

### Our Objectives

- 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 international collaboration between these centres.
- 3** Clinical research, studies and generating evidence/data are essential parts in the process of developing better and innovative treatment solutions. SPAEN aims to be involved as early as possible in clinical trials, to improve patients' access to studies and to support meaningful research – following the specific needs of rare cancer patients.
- 4** Sarcoma patients and their carers need a strong “International Sarcoma Patient Voice” and strong “National Patient Support Opportunities”. That’s why SPAEN cares for their members (national patient organisations) and encourages the creation of new ones.

### 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

## Board of Directors

The “SPAEN Board of Directors” is a voluntary body of currently seven elected members who jointly run the organisation with the support of a part-time professional, different freelancers and two elected financial auditors. Board members are elected by the Annual General Assembly for the duration of four years.

The elected board of directors has the right to appoint up to seven persons to support them in their tasks. The Board appointed Jesica Garcia, Spain, Sami Sandakly, France and Richard Davidson, UK as observers to the Board as well as Professor Bernd Kasper, medical oncologist and chair-elect of the EORTC Soft Tissue and Bone Sarcoma Group.

### Appointed board members



*Estelle Lecointe-Artzner, Chair (FR)*



*Markus Wartenberg, Chair (DE)*



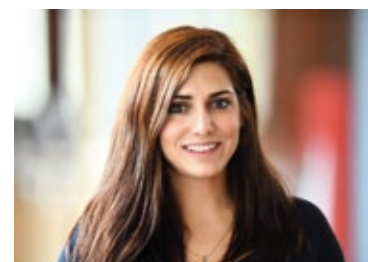
*Sami Sandakly, France*



*Kai Pilgermann, Financial Director (DE)*



*Christina Baumgarten, Board Member (DE)*



*Jesica Garcia, Spain*



*Gerard van Oortmerssen, Board Member (NL)*



*Nikhil Guhagarkar, Board Member (IND)*



*Richard Davidson, UK*



*Annika Laakso, Board Member (FN)*



*Roger Wilson, Honorary President (UK)*



*Prof. Bernd Kasper, Germany*



**Sarcoma  
Patients  
EuroNet**

## Medical Advisory Board

Sarcoma Patients EuroNet has established a Medical Advisory Board with a high level of scientific expertise. Currently the following 15 experts are appointed as members of the SPAEN Medical Advisory Board:

|                              |                       |
|------------------------------|-----------------------|
| Prof. Jean-Yves Blay (Chair) | France/Lyon           |
| Prof. Javier Martin Broto    | Spain/Sevilla         |
| Prof. Paolo Casali           | Italy/Milano          |
| Prof. Jean Michel Coindre    | France/Bordeaux       |
| Prof. Mikael Eriksson        | Sweden/Lund           |
| Craig Gerrand                | UK/Newcastle          |
| Dr. Alessandro Gronchi       | Italy/Milan           |
| Prof. Peter Hohenberger      | Germany/Mannheim      |
| Dr. Robin Jones              | UK/London             |
| Prof. Bernd Kasper           | Germany/Mannheim      |
| PD Dr. Peter Reichardt       | Germany/Berlin        |
| Prof. Piotr Rutkowski        | Poland/Warsaw         |
| Dr. Beatrice Seddon          | UK/London             |
| Prof. Winette van der Graaf  | Netherlands/Amsterdam |
| Dr. Rick Haas                | Netherlands/Amsterdam |







## SPAEN Member Organisations

SPAEN welcomes every sarcoma, GIST or desmoid patient organisation worldwide, who pledge to conform our Code of Practice, as full member. Full members are entitled to vote at the Annual General Meeting (AGM).

SPAEN also invites individuals who are interested in starting sarcoma, GIST or Desmoid support groups in their own countries as well as professionals and other stakeholders who want to be an integral part of this network, to become supporters of SPAEN.

## Types of Membership

1. The association has full members who have one voting right per organisation in the Annual General Meeting. These organisations will be identifiable organisations who may or may not be legally incorporated according to their country's laws.  
An individual person can be a full member on an interim basis under the condition that he/she has actively planned, prepared or already begun founding a sarcoma patient group.
2. The association has corporate members. These can be commercial enterprises, companies or other organisations, that would like support the association financially (long-term sustaining partners). Corporate members don't have voting rights at the Annual General Meeting. The Board organises a yearly meeting with these specific members to inform them about the development of the association.

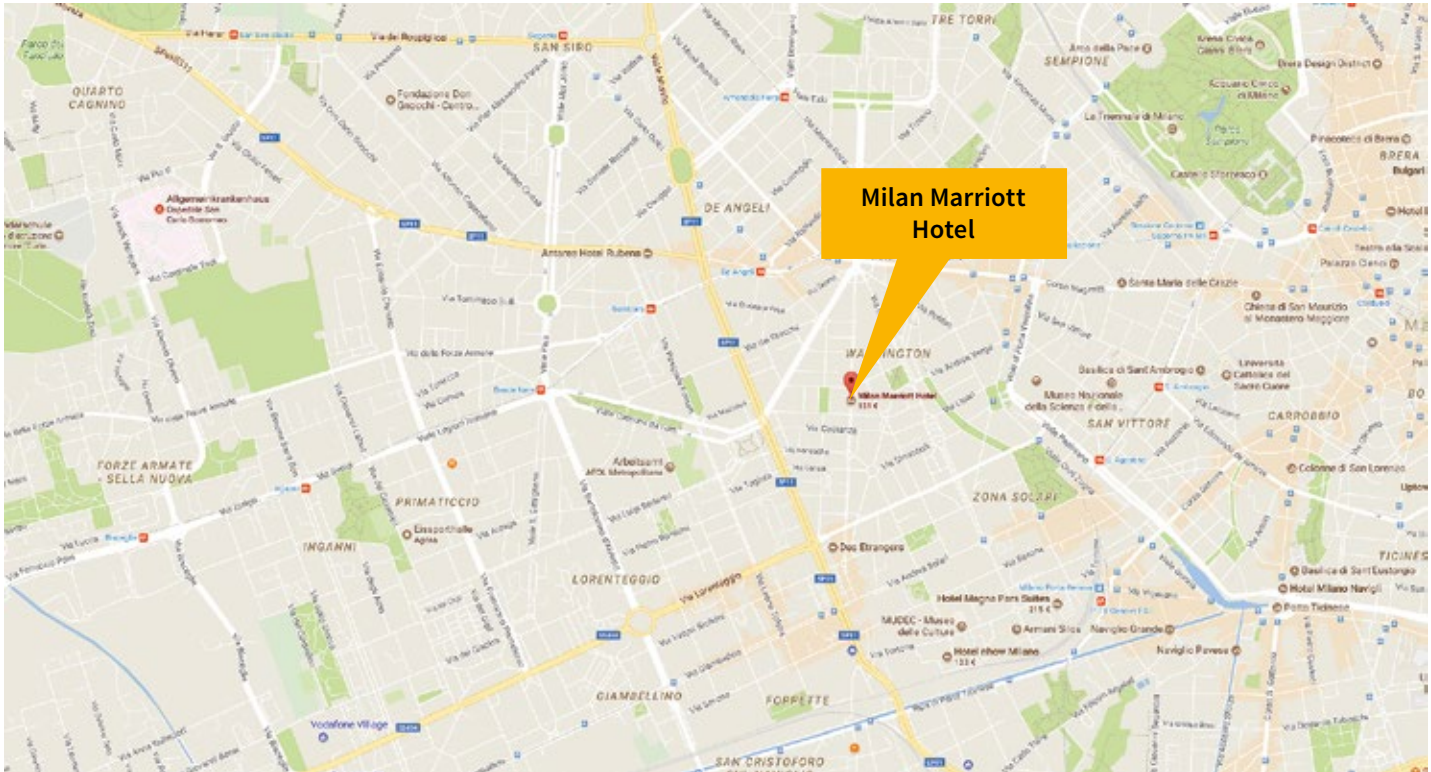
## SPAEN Full Members

1. Australia: Sock it to Sarcoma
2. Austria: GIST Support Österreich
3. Belgium: Cum Cura
4. Bulgaria: GIST and STS Alliance for Patients - Bulgaria
5. Curacao: Synovial Sarcoma Research Foundation
6. Finland: Finnish GIST Patient Network
7. France: Info Sarcomes
8. France: SOS Desmoide France
9. Germany: Das Lebenshaus e.V./House of Life
10. Germany: SOS Desmoid Germany
11. India: Friends of Max GIST
12. India: SPANDAN (part of V Care)
13. Israel: Israeli GIST Patients Organisation
14. Italy: A.I.G. Associazione Italiana GIST
15. Italy: Italian Desmoid Foundation
16. Italy: Le Ali Onlus and COO-BS (Centro di Oncologia Ortopedica – Brescia)
17. Italy: Luogo di incontro per scambiarsi informazioni sui tumori Desmoide o Fibromatosi aggressiva
18. Italy: Trust Paola Gonzato-Rete Sarcoma Onlus
19. Italy: Orchestra per la Vita Onlus
20. Kenya: Henzo Kenya
21. Macedonia: GIST Patient Group Macedonia
22. Netherlands: Patiëntenplatform Sarcomen0
23. Netherlands: Chordoma Foundation Europe
24. Norway: Sarkomer Norway
25. Poland: Stow. Pomocy Chorym Na GIST
26. Poland: Stow. Pomocy Chorym Na Miesaki "SARCOMA"
27. Romania: HomeCare Association
28. South America: Alianza GIST
29. Spain: Sarcoma Patients Spanish Association/Asociación Española de Afectados por Sarcoma (AEAS)
30. Spain: FUNDACIÓN MARI PAZ JIMENEZ CASADO
31. Sweden: GIST Sverige
32. Sweden: Sarkomföreningen
33. Switzerland: Swiss GIST Group
34. Switzerland: Swiss Sarcoma
35. Turkey: Genç Birikim Derneği & Youth Accumulation Association
36. UK: GIST Support UK and PAWS GIST
37. UK: Bone Cancer Research Trust
38. UK: Guy Francis Bone Cancer Research Fund
39. UK: Sarcoma UK
40. UK: Desmoid Fibromatosis UK Patients & Caregivers
41. USA: Chordoma Foundation
42. USA: Desmoid Tumour Research Foundation
43. USA: GSI - GIST Support International
44. USA: Sarcoma Alliance
45. USA: The Liddy Shriver Sarcoma Initiative
46. USA: National Leiomyosarcoma Foundation
47. USA: The Life Raft Group





# Map





## Sarcoma Patients EuroNet

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



*Michaela Geissler, Administration Office  
and Event Manager (DE)*



*Kathrin Schuster,  
Communications (DE)*

### **SPAEN Administration Office**

Mrs. Michaela Geissler  
Am Rothenanger 1B  
85521 Riemerling, Germany  
Tel.: + 49 89 62836807  
Fax: + 49 89 62836808  
Email: [info@sarcoma-patients.eu](mailto:info@sarcoma-patients.eu)  
Web: [www.sarcoma-patients.eu](http://www.sarcoma-patients.eu)

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

### **Registered office/legal venue:**

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

### **Conference Booklet 2020 – Imprint:**

**Concept/Text:** Michaela Geissler & Markus Wartenberg & Kathrin Schuster, SPAEN  
**Graphic Design:** Herbert Thum, VisKon.de, Maikammer/Germany  
**Printing:** Englam&Partner, Germany





# ESMO 2020 Patient Advocacy Track

Help us solve crucial questions  
for patients and survivors

MADRID  
2020 **ESMO** congress

An Annual Congress

## IMPORTANT DEADLINES

|                |                         |
|----------------|-------------------------|
| 6 May 2020     | Abstract submission     |
| 17 June 2020   | Early registration      |
| 12 August 2020 | Late registration       |
| 17 August 2020 | Late-breaking abstracts |

**MADRID SPAIN**  
**18-22 SEPTEMBER 2020**

Take part in our Patient Advocacy Track and share your perspective with all stakeholders in oncology. Bring your unique insights to the hottest topics in cancer patient care.



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Patients  
EuroNet**

**The International Network  
of Sarcoma, GIST and Desmoid  
Patient Advocacy Groups**

[www.sarcoma-patients.eu](http://www.sarcoma-patients.eu)



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Member of:  
Rare Cancers Europe (RCE)  
[www.rarecancerseurope.org](http://www.rarecancerseurope.org)



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