



**Sarcoma  
Patients  
EuroNet**

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

**22. - 24. November 2012  
NH Firenze, Florence/Italy**

***“A Better Future For Patients With A Rare Cancer!”***

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## Acknowledgements

*We would like to thank the following sponsors who are supporting the SPAEN Annual Conference 2012 with an unrestricted grant:*

***Bayer, GSK, MSD/Merck, Novartis, Pfizer, PharmaMar and Takeda***

*We are looking forward to continuing these partnerships on our way to creating  
"A Better Future For Patients With A Rare Cancer!"*



**Dear Delegates,**

Welcome to Florence and to the third annual meeting and General Assembly of Sarcoma Patients Euronet.

For many of us it is the first time we have met since Berlin last November, and for some of us it is the first time you have met with other sarcoma advocates. On behalf of my colleagues on the Board we welcome you all for what we hope will be three days of inspiration through shared learning and good company.



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.

But above all enjoy our meeting and enjoy the chance to experience the cultural sights of the world's greatest Renaissance city.

Kindest regards

A handwritten signature in black ink, appearing to read 'Roger Wilson'.

Roger Wilson CBE  
President Sarcoma Patients EuroNet Assoc.  
Hon President Sarcoma UK



# 3rd General Meeting of SPAEN



## INVITATION TO THE 3<sup>rd</sup> GENERAL MEETING of "Sarcoma Patients EuroNet e.V./Assoc."

2<sup>nd</sup> of October 2012

Dear SPAEN Full Members,

in accordance with the statutes of SPAEN we would like to announce and cordially invite you to our upcoming 3<sup>rd</sup> General Meeting of Sarcoma Patients EuroNet e.V./Assoc. which will be held during our 3<sup>rd</sup> Annual Conference in Florence, Italy.

**Date:** Saturday, the 24<sup>th</sup> of November 2012

**Location:** NH Hotel Firenze, Piazza Vittorio Veneto, 4/A, 50123 Florence/Italy

**Time:** 8:30 to 10:30 CET

**Participants:** SPAEN Board of Directors, SPAEN Full Members and guests

We are looking forward to welcoming you at the SPAEN General Meeting 2012 in Florence to discuss the 2011 achievements, our current work in 2012 and first projects for 2013.

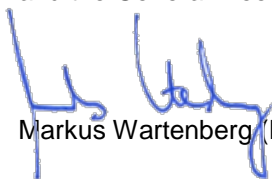
### AGENDA (TOPICS)

- Item 1 Welcome + Introduction
- Item 2 General check: Who is entitled to vote? (According to the statutes, full members have one voting right per organisation in the general assembly.)
- Item 3 Report of the President for 2011 Roger Wilson/Markus Wartenberg
- Item 4 Report of the Financial Director for 2011 Markus Wartenberg
- Item 5 Report of the Financial Auditors for 2011 David Robinson/Kai Pilgermann
- Item 6 Approval of Accounts for 2011 Members
- Item 7 One vacancy in the board (call for suggestions) Markus Wartenberg
- Item 8 Das Lebenshaus e.V. and SPAEN used the same registered office.  
Because Das Lebenshaus e.V. is moving in October 2012 – we need to change also the registered office of SPAEN. Our request for changing the statutes in § 1:  
**So far:** The association has its office in Bad Nauheim/Hessen/Germany.  
The place of execution and jurisdiction is Bad Nauheim.  
**For the future:** The association has its registered office in Wölfersheim/Hessen/ Germany.  
The place of execution and jurisdiction is Wölfersheim.
- Item 8 Requests, Applications, Proposals, Any Other Business - End of meeting

If you have any applications, suggestions, items, or requests for the AGENDA and/or the General Meeting, please send them until 15<sup>th</sup> of November 2012 in writing to:

Fax: +49-89-62836808 OR Email: [info@sarcoma-patients.eu](mailto:info@sarcoma-patients.eu)

We are looking forward to welcoming many of you in Florence for the 2012 SPAEN Conference and the General Meeting. On behalf of the SPAEN Board - kind regards



Markus Wartenberg (Financial Director)



Sarcoma Patients EuroNet Assoc./e.V.  
 Secretariat – Board of Directors  
 Am Rothenanger 1b  
 D-85521 Riemerling/Germany

Per FAX to fax-no.: **0049 (0)89 62836808**  
 Per EMAIL (as attached scan) to: **info@sarcoma-patients.eu**

## MEMBERSHIP FORM (FULL or ASSOCIATE MEMBER)

I hereby apply for: (Please, complete the boxes)

YES or NO	<b>Full membership in the Sarcoma Patients EuroNet e.V./Assoc.</b> Full members will be members of identifiable organisations from Europe who may or may not be legally incorporated according to their country's laws. An individual person from Europe can be a full member under the condition that he/she works for, has actively planned, or has already begun founding a sarcoma patient group. Full members have one voting right per organisation in the General Meeting.
YES or NO	<b>Associate membership in the Sarcoma Patients EuroNet e.V./Assoc.</b> Associate members wish to network with SPAEN and/or would like to support the association and its members. These Associate members can be individuals or organisations which may or may not be legally incorporated. They may have their base in the European countries or outside of Europe and they do not have voting rights.

### All requests for memberships

- must be addressed to the Association's Board of Directors, which will decide on acceptance of the application. Refusal by the Board of Directors is not subject to appeal. There is no obligation on the Directors of the Association to accept any application.
- are based on the Association's statutes. They are available in English and German. With this membership application form and his/her signature the applicant accepts these statutes and agrees to abide by them. See statutes at [http://www.sarcoma-patients.eu/index.php?option=com\\_docman&task=doc\\_download&gid=14](http://www.sarcoma-patients.eu/index.php?option=com_docman&task=doc_download&gid=14)

### Association/Organisation/Facility/Others:

<b>Name/Appellation:</b>	
<b>Additional Address Info:</b>	
<b>Postal Code / City:</b>	
<b>Country:</b>	
<b>Phone:</b>	
<b>Telefax:</b>	
<b>Email Address:</b>	
<b>Org. - Legal Form/Status:</b>	
<b>Org. - Established in (Year):</b>	
<b>Org. - Number of Members:</b>	
<b>Disease/Sarcoma Subtype:</b>	<b>General Cancer, Rare Cancer, Sarcomas, Bode Cancer, GIST, Desmoids, Spec. Sarcoma Subtype, Others?</b>
<b>URL/Domain/Website:</b>	



I/We will be the delegate/s, contact-person/s to SPAEN:

First Name/Name:	
Status:	Patient, Caregiver, Professional etc.
Role/Function inside the Org.:	
Phone:	
Mobile-Phone:	
Email Address:	
Job/Profession:	
Interests/Hobbies:	

I/We will be the delegate/s, contact-person/s to SPAEN:

First Name/Name:	
Status:	Patient, Caregiver, Professional etc.
Role/Function inside the Org.:	
Phone:	
Mobile-Phone:	
Email Address:	
Job/Profession:	
Interests/Hobbies:	

YES or NO	I/We agree to share my contact details (on the following page) with other members.
YES or NO	I/We agree to SPAEN publishing my/our association/organisation/facility as a member.
YES or NO	I/We will support SPAEN with an annual membership fee/subsidy/grant/donation.
YES or NO	<b>MINIMUM:</b> Official membership fee = minimum 20,- EURO per year (per association/organization)
Amount EUROS p.a.: ???	<b>SPECIAL:</b> Individual (voluntary) membership fee/subsidy/grant/donation in the amount of ??? EUROS per year.

The amount will be charged once a year per invoice to the association/organization!

In addition: We could/would support SPAEN with the following skills, expertise, contributions.....	e.g. translation from English into ? Others?
--	---

Signature: \_\_\_\_\_ Date: \_\_\_\_\_



# Program



**3<sup>rd</sup> SPAEN Annual Conference for Organizations  
Representing Patients With Sarcomas, GIST or Desmoid-Tumours  
NH Firenze, Florence/Italy  
22-24 November 2012**



**Sarcoma  
Patients  
EuroNet**

Supported by:  
Bayer - GSK - MSD/Merck - Novartis - Pfizer - PharmaMar - Takeda

## AGENDA

<b>DAY 1 – THURSDAY November 22, 2012</b>	
12:00	<i>L I G H T L U N C H (60 min.)</i>
13:00	<i>OFFICIAL START OF THE CONFERENCE Room Michel Angelo – Plenary Sessions:</i>
13:00 - 13:30	Opening, Welcome, Organizational Issues, Thanks to the Sponsors, etc. <i>Roger Wilson (SPAEN) &amp; Anna Costato (A.I.G.)</i>
13:30 – 14:00	Novartis Europe welcomes SPAEN in Italy <i>Susanna Leto di Priolo, Head Patient Advocacy and Professional Relations, Novartis Oncology Region Europe</i>
14:00 - 14:30	The position of the healthcare industry in a changing environment <i>Geraint Thomas, Director Patient Relations, GSK Europe, London/UK</i>
14:30 – 15:00	<i>C O F F E E B R E A K (30 min.)</i>
	<b>ACCESS TO INNOVATIVE MEDICINE</b> <i>Moderator: Barbara Dore (SPAEN)</i>
15:00 - 15:45	Clinical Trials: Learning more about “Good Clinical Practice (GCP)” <i>Prof. Dr. Michael Eriksson, University of Lund/Sweden</i>
15:45 - 16:30	Understanding some basic trial-designs in Sarcomas (incl. a placebo-trial) <i>Prof. Dr. Winette van der Graaf, EORTC Soft Tissue and Bone Sarcoma Group, Belgium</i>
16:30 - 17:15	What can be done to improve the methodology of clinical research on rare cancers? <i>Dr. Paolo Casali, Istituto Tumori, Milan/Italy</i>
17:15 - 18:00	Different ways to provide access to innovative treatments in Europe? What means Compassionate Use – Early Access Program – Off Label Drugs? <i>Silvia Comis, Novartis Oncology Region Europe</i>
<i>B R E A K B E F O R E D I N N E R</i>	
19:30 - 22:30	Internal Dinner Restaurant NH Firenze



## DAY 2 – FRIDAY November 23, 2012

### PARALLEL TRACKS FOR GIST, SARCOMAS AND DESMOIDS

	<b>GIST TRACK</b> <b>Room: Michel Angelo</b> <i>Moderator:</i> <i>Michael Sayers</i>	<b>SARCOMA TRACK</b> <b>Room: Leonardo</b> <i>Moderator:</i> <i>Roger Wilson</i>	<b>DESMOID TRACK</b> <b>Room: Cinelli</b> <i>Moderator:</i> <i>Christina Baumgarten</i>
08:30 - 09:15	Risk stratification in GIST and adjuvant treatment <i>Prof. Bernd Kasper, Mannheim/Germany</i>	Managing chemotherapy in Sarcomas: - The main agents - To administer chemo - Side effect mgmt. - Skin-toxicities	Understanding molecular genetics and pathology in Desmoids (40 min.) <i>Prof. Dr. Paolo Dei Tos, Treviso Hospital/Italy</i>
09:15 - 10:30	Understanding four key factors for successful therapy management in GIST: - Education/communication - Dosing - Treatment duration - Side effect mgmt. <i>Dr. Paolo Casali, Istituto Tumori, Milan/Italy</i>	- Important for patients to know? <i>Prof. Dr. Michael Eriksson, University of Lund/Sweden</i>  <i>Dr. Marc Anliker, St. Gallen/Switzerland</i>	The role of surgery in Desmoids (40 min.) <i>Prof. Dr. P. Hohenberger, Mannheim/Germany</i>  The role of radiotherapy in Desmoids (40 min.) <i>Dr. Marie-Pierre Sunyach, Centre Leon Berard, Lyon/France</i>
10:30 – 11:00 C O F F E E B R E A K (30 min.)			
11:00 – 11:45	<i>Moderator:</i> <i>Markus Wartenberg</i>  How to manage skin toxicities in GIST? <i>Dr. Marc Anliker, St. Gallen/Switzerland</i>	<i>Moderator:</i> <i>Roger Wilson</i>  Short profiles of sarcoma subtypes:  <u>Synovial Sarcomas</u> 40 min. <i>PD Dr. Lars Lindner, SarkUM/Germany</i>	<i>Moderator:</i> <i>Christina Baumgarten</i>  Update on systemic treatment options and clinical trials in Desmoids (45 min) <i>Prof. Bernd Kasper, Mannheim/Germany</i>
11:45 – 12:15	Sharing best Practice/ Brainstorming: How can GIST-patient groups help their patients in the field of side effect management? <i>Markus Wartenberg, SPAEN</i>	<u>Osteosarcomas</u> 40 min. <i>Prof. Dr. Piero Picci, Chairman Italian Sarcoma Group, Bologna/Italy</i>	Round Table with the experts to discuss common topics and needs (60 min.)
12:15 – 13:00	Regorafenib, Masitinib, Dovitinib and others: Update on systemic treatment options and clinical trials in GIST <i>Dr. Paolo Casali, Istituto Tumori, Milan/Italy</i>	Update on systemic treatment options and clinical trials in Sarcomas 40 min. <i>Antoine Italiano, Institut Bergonié Bordeaux/France</i>	
13:00 – 14:00 L I G H T L U N C H (60 min.)			



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



<b>DAY 3 – SATURDAY November 24, 2012</b>	
08:30 - 10:30	<p>Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2011/2012  <i>Moderator: Roger Wilson + SPAEN-Board</i>            All participants/delegates are welcomed (...only full members have the right to vote.)  <u>Incl. Networking activities of SPAEN with other organizations</u>  <u>(EORTC, EUROSARC, RARE CANCER EUROPE, etc.)</u>  <i>Markus Wartenberg, SPAEN</i>            Short report from EORTC:  <i>Estelle Lecointe &amp; Anastassia Negrouk, EORTC Brussels</i>            Short report from the EUROSARC-project:  <i>Estelle Lecointe, SPAEN</i></p>
10:30 - 11:00	<b>C O F F E E B R E A K (30 min.)</b>
11:00 - 13:00	<p><b>ADVOCACY – ACCESS TO TREATMENT</b>  <i>Moderator: Markus Wartenberg (SPAEN)</i>            Let's try to better understand the situation of healthcare in Eastern Europe – especially in the field of Sarcomas, GIST and Desmoids...  <u>Short presentations (15 Min. each) from:</u>            - Physicians: <i>Prof. Dr. Piotr Rutkowski, Institute of Oncology Warsaw, Poland</i>            - PAGs: <i>P. Fonrobert (Poland), S. Mandov (Bulgaria), J. Pelouchova (Czech Rep.)</i>            - Research: <i>Prof. Dr. Piotr Rutkowski, Institute of Oncology Warsaw, Poland</i>            Discussion:            What are needs, ideas, solutions to improve the situation in the field of Sarcomas, GIST and Desmoids? How could expert-networks and SPAEN support?</p>
13:00 – 14:00	<b>L I G H T L U N C H (60 min.)</b>
14:00 - 15:30	<p><b>ADVOCACY – ACCESS TO TREATMENT</b>  <i>Moderator: Roger Wilson (SPAEN)</i>            Improving the impact of patient participation in HTA = Health Technology Assessment (presentation + practical issues)  <i>Dr. Karen Facey, Health Policy Consultant, UK</i>              After more than 10 years working with HTA = NICE in the UK:            How is the current process of evaluating cost-effectiveness and what are the main findings/insights from a patients perspective?  <i>Roger Wilson, Sarcoma UK / SPAEN</i>              Questions and Discussions:            - What can/should patient groups claim from their national in the HTA-bodies?            - What are the main factors for a national HTA-process:            Understand – Get involved/heard – Work together – Create evidence?</p>
15:30 - 15:45	<p><i>End of meeting, Summary, Feedback-Forms, Closing Remarks, Thanks to the Presenters &amp; Sponsors</i>  <i>Markus Wartenberg &amp; Roger Wilson (SPAEN)</i></p>
15:45	<b>OFFICIAL END OF THE CONFERENCE</b>
<i>Depending on individual departures: If possible – shared taxis to the airport</i>	



# Logistics



## Logistic Information

### Conference Venue

The SPAEN Conference 2012 will be held at

NH Firenze  
Piazza Vittorio Veneto, 4/A.  
50123 Firenze  
Italy  
Tel. +39 055 2770  
E-mail: nhfirenze@nh-hotels.com

The main meeting room will be room „Michael Angelo“.

### Registration

The registration desk will be open from 11:30 and can be found in front of the main meeting room „Michael Angelo“. At the registration desk you will receive your name badge and conference book as well as final information.

### Program/Agenda

The conference will be held from Thursday 22nd Nov. (start at 13:30) to Saturday, 24th Nov. (conference close at 15:45).

- **Thursday, 22nd November:** Official Start of the Conference is 13:00. All participants are welcome to join the welcome lunch at the hotel restaurant „Delight“ from 12:00 to 13:00.
- **Friday, 23rd of November:** 9:00 - 17:30
- **Saturday, 24th of November:** 9:00 - 15:15 (end of the conference)

### Meeting Rooms

The main meeting room is room “Michael Angelo”. For the breakout sessions on Friday, 23rd of November we split the group for the GIST, Sarcoma and Desmoid tracks.

- The GIST track will be held in the main meeting room „Michael Angelo“
- The Sarcoma track will be held in room „Leonardo“
- The Desmoid track will be held in room „Cinelli“

### WiFi

The hotel offers free WiFi. To use the WIFI please get a free voucher at the reception.

### Dinner

- **Thursday, 22nd November:** 19:30 internal dinner in the hotel restaurant.
- **Friday, 23rd of November:** 19:15 short walk (ca. 5-10 minutes) to the Restaurant Antico Ristoro di Cambi, VIA S. ONOFRIO 1R ZONA PORTA SAN FREDIANO, 50124 Florence



## Contact

Mobile phone during the Conference:

- SPAEN Secretariat, Michaela Geißler: +49-173-4517589
- Markus Wartenberg, SPAEN Financial Director: +49-171-4700919

## Liability Disclaimer

Your participation in the SPAEN conference 2012 will be at your own risk. SPAEN will be not 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 2012 program 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.

## Maps and transportation

### Intl. Arrivals

Flights to/from Florence arrive at the Aeroporto di Firenze. More information can be found at <http://www.aeroporto.firenze.it/en/>

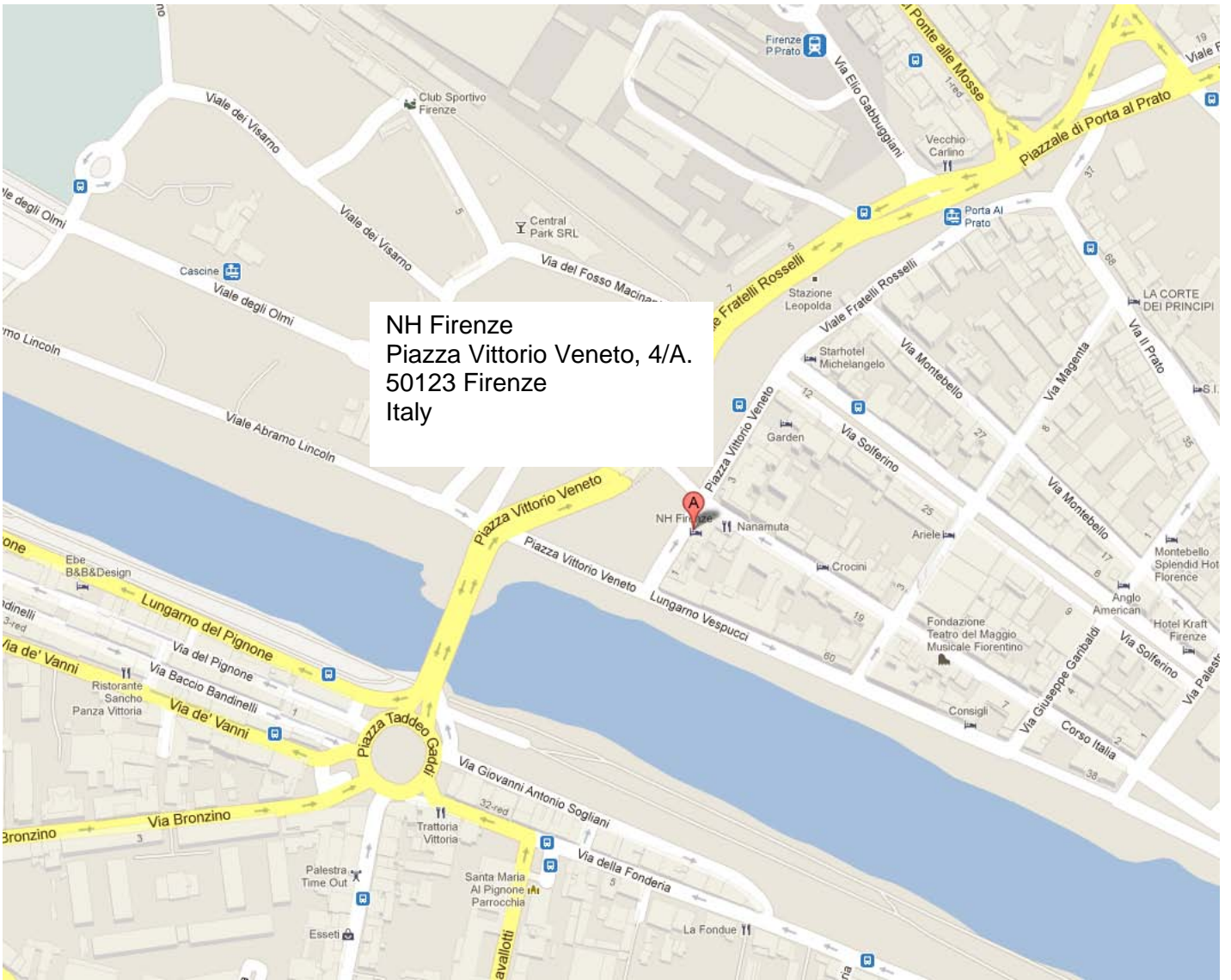
### Distances

Taxi journey time from the airport to Florence city center is about 15 minutes. Taxis are stationed in front of the terminal. There is a fixed rate of 20 EUR from the airport to the main hotels.

### Public Transport

You can take a bus from the airport (see timetable here <http://www.aeroporto.firenze.it/en/passengers/from-to-the-airport/bus.html> ) and, once at the station in Florence, take a taxi or tram to the hotel. From the right exit of the station, take tram line 1 and get off after the first stop in front of Stazione Leopolda. The NH Firenze hotel is on the opposite side of the street, 50 meters towards the river.





NH Firenze  
Piazza Vittorio Veneto, 4/A.  
50123 Firenze  
Italy



Sarcoma Patients EuroNet Assoc./e.V.  
 Financial Accounting  
 Tanja Ullersberger  
 Untergasse 36  
 D-61200 Wölfersheim / Germany



**3rd SPAEN Annual Conference 2012**  
**Florence/Italy "NH Hotel Firenze" 22 - 24 November 2012**

## TRAVELLING EXPENSES - REIMBURSEMENT FORM

<b>First Name</b>	
<b>Last Name</b>	
<b>Organization</b>	

**Travel expenses - please include all receipts (original documents).**

<b>Transfer - Air Fee, Railway Fee</b>		Euro _____
<b>Transfer - Metro, Bus, Taxi</b>		Euro _____
<b>Transfer - Own Car</b>	<b>(0,30Euro per km)</b>	Km: _____ Euro _____
<b>Parking</b>		Euro _____
<b>Others</b>		Euro _____
<b>Total</b>		Euro _____

**Home Address:**

<b>Address</b>	
<b>Address</b>	
<b>Postal Code / City</b>	
<b>Country</b>	

**Account Details:**

<b>Name of the Bank</b>	
<b>Address of the Bank</b>	
<b>Holder of the Account</b>	
<b>SWIFT-BIC</b>	
<b>IBAN</b>	
<b>Currency</b>	

Please return your expense claim until 14<sup>th</sup> of December 2012 the latest. Thank you!

\_\_\_\_\_  
**City/Date:**

\_\_\_\_\_  
**Signature:**



# **Who is Who Participants & Experts**



**3<sup>rd</sup> SPAEN Annual Conference for Organizations  
Representing Patients With Sarcomas, GIST or Desmoid-Tumours  
22 – 24 November 2012**



**Sarcoma  
Patients  
EuroNet**

**Participants List (A-Z)**

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



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



## Who is Who? Biographic Information A-Z

### **Dr. Mark Anliker, Switzerland**



Dr. Anliker is the head of the Department of Dermatology and Allergology at the Canton hospital of St. Gallen since 2004. Dr. Anliker has built up a new Department serving both specialities of dermatology as well as allergology and clinical immunology. This combination allows a greater insight into allergies or side effects of medical compounds. Dr. Anliker can bridge different aspects from a clinical, pathological, immunological and allergological point of view. The Hospital St. Gallen is well known for its Oncological department and access to new therapies especially in biologicals and antibodies such as TKI, EGFR-antibodies and m-Tor inhibition. Many novel compounds are also studied in clinical trials, so dermatological side effects are recognized early and the collaboration with the dermatological dept. is extensive.

### **Jack Asselbergs, Chairman of the Board of Contactgroep GIST The Netherlands**



Chairman as from January 1st, 2009 and Board Member since April 2008. I had a tumour removed at a regional hospital, which later turned out to be a GIST, diagnosed in June 2005. Since then I have had periodic checks in a GIST specialized hospital. Participated in EORTC-study 62024. Dedicated in pursuing good governance ensuring a well functioning organization in aid of the best care for patients. Contact: [voorzitter@contactgroepgist.nl](mailto:voorzitter@contactgroepgist.nl)

### **Christina Baumgarten, SOS Desmoid Germany**



In 2003 Christina Baumgarten was diagnosed with a desmoid tumor. Her surgery was performed by Prof. Peter Hohenberger in Berlins Charité hospital. Christina is the founder and president of the patient led organisation sos-desmoid, Germany which started its work in 2009. She co-founded Sarcoma Patients Euro Net, as vice president. Sos-desmoid Germany is widely supported on a national and international level by Dr. Anja Herrmann (psychologist), Prof. Peter Hohenberger and Prof. Bernd Kasper. Prof. Peter Hohenberger and Prof. Bernd Kasper are the initiators of an on going national clinical trial to evaluate imatinib in desmoid tumors.

Contact: [cbaumgarten@sos-desmoid.de](mailto:cbaumgarten@sos-desmoid.de) or [christina.baumgarten@sarcoma-patients.eu](mailto:christina.baumgarten@sarcoma-patients.eu)

### **Lindsey Bennister, Sarkoma UK**



Lindsey has worked in the UK health charity sector for over 15 years, in small organisations representing people with rare conditions, through to larger cancer charities. Her background includes developing support and information for patients, carers and relatives; leading cancer awareness campaigns; and providing education and training programmes for healthcare professionals. Lindsey joined Sarcoma UK in April 2010 as its first chief executive and professional member of staff, having worked previously at The Prostate Cancer Charity for six years. Contact: [lindsey.bennister@sarcoma.org.uk](mailto:lindsey.bennister@sarcoma.org.uk)

### **Jayne Bressington, PAWS-GIST (Paediatric, Adolescent, Wild-type & Syndromic GIST), UK**



Jayne's daughter was diagnosed with Paediatric Wild-type GIST in January 2010. Since then Jayne has become a Trustee of GIST Support UK and has worked to set up a subdivision called PAWS-GIST (Paediatric, Adolescent, Wild-type & Syndromic GIST). Working with Dr Ramesh Bulusu, who is the clinical lead for PAWS-GIST, the group is aiming to establish a specialist clinic for this group of patients which will lead to research, improved treatments and ultimately a cure. As part of the PAWS-GIST programme of work, approval has recently been given to set up a National GIST Tumour bank in the UK.



**Dr V. Ramesh Bulusu, Addenbrookes Hospital Cambridge, UK**



Dr V. Ramesh Bulusu is the Chairman of the Cambridge GIST Study Group and network lead for GISTS in Anglia Cancer Network. He is actively involved in the training and education of health care professionals in the management of GISTs and has lectured extensively nationally and internationally. His main focus at present is the development of the UK national GIST registry and he is the national lead for the project. Dr Bulusu has trained at the Beatson Oncology Centre, Oxford and Cambridge before taking up his consultant position in Addenbrookes hospital in Cambridge. He is passionate about GISTs and is currently heading a national focus group PAWS-GIST (paediatric, adolescent, wild type and syndromic) to bring together a national and Europe wide expertise to manage this difficult subgroup of GIST patients.

**Dr. Paolo G. Casali, Istituto Nazionale Tumori, Milan, Italy**



Paolo G. Casali, MD, medical oncologist, is head of the Adult Mesenchymal Tumour Medical Oncology Unit at the Istituto Nazionale Tumori, Milan, Italy. He is the secretary of the Italian Sarcoma Group and a member of the EORTC Soft Tissue & Bone Sarcoma Group. He chairs the Italian Rare Cancer Network and coordinates the multistakeholder initiative Rare Cancers Europe. He is a member of the Executive board of ESMO (European Society for Medical Oncology), as chair of the Public Policy/European Affairs Committee, and a member of the Oncopolicy Committee of ECCO (European Cancer Organization).

**Dr. Frédéric Chibon, Institut Bergonié - Bordeaux**



Dr Chibon graduated in molecular biology and genetics from the University of Paris 7 and joined Alain Aurias's lab at the Curie Institute in Paris in 1997. He obtained his PhD in molecular cytogenetics for work performed in the Aurias lab. In 2004, he was appointed as a post-doc in Jean-Michel Coindre's group at the Bergonie Cancer Institute and promoted to an independent group leader position in 2005. In 2011, Dr Chibon was appointed to an INSERM research position. His lab studies the molecular cytogenetics of sarcomas.

**Anna Costato, A.I.G. Associazione Italiana GIST Onlus**



I was born and live in Milan with my family. In 1995, at the age of 10, my elder daughter underwent stomach surgery for the resection of what was then believed and mis-diagnosed as leiomyoma. In December 2000, recurrence caused another stomach surgery and proper diagnoses was made: GIST. Surgery was complete and since then my daughter has been well, with no further treatment. She is now 27 and free of disease. In the period following my daughter's diagnoses, I joint the two major international Gist groups: Gist Support International, where I have been participating in the Science Committee, and Life Raft Group, where I have been country representative for Italy. I was a full-time employee in a primary Italian banking group until July 2010 when I applied for early retirement and quit my job. Since then I have been fully engaged in A.I.G. with the responsibility of Director. Contact: [anna.costato@virgilio.it](mailto:anna.costato@virgilio.it) and/or [info@gistonline.it](mailto:info@gistonline.it)

**Dr. Angelo Paolo Dei Tos, General Hospital of Treviso, Italy**



Dr. Angelo Paolo Dei Tos is Director of the Department of Oncology and Director of Pathology at the General Hospital in Treviso, Italy, and Consultant Pathologist at the Istituto Ortopedico Rizzoli in Bologna, Italy. He also serves as contract Professor of Pathology at the University of Padua School of Medicine. He is past Chairman and founder of the Working Group on Soft Tissue Tumour Pathology of the European Society of Pathology (ESP), Past President of the International



Society of Bone and Soft Tissue Pathology (ISBSTP), panel member for the WHO Working Group for the Classification of Tumours of Soft Tissue and Bone, member of the Board of Directors, and Treasurer of the Connective Tissue Oncology Society (CTOS), Chairman of the Pathology Subcommittee of the Soft Tissue and Bone Group of the European Organisation for Research and Treatment of Cancer (EORTC), and a faculty member of the European Society of Medical Oncology (ESMO).

#### **Barbara Dore, GIST Support UK and GIST Support International**



Barbara is a GIST patient and a volunteer with GIST Support UK from 2007, and served on the Board of GIST Support International (GSI) from 2008 - 2012 while living temporarily in Texas. There in Houston she started the GIST Summit series at M D Anderson in 2008, which has been held every year since and is attended by over 100 patients and carers from near and far - the last Summit attracted people from as far away as Alaska! Barbara is returning to her native Britain early in 2013. Barbara has been a member of GSI's science committee since 2008, and on the Steering Committee of New Horizons and a Board member of Sarcoma Patients EuroNet Association since 2009.

#### **Simona Ene, European Cancer Patient Coalition**



Due to the loss of friends due to cancer I have started to volunteer Association of Cancer Patients from Romania (ABC) on 2003 putting all my expertise from my full time job (computer and foreign language skills, innovative ideas, drafting financing applications etc.). I have a full time job as engineer to Water Company, Project Implementation Unit, projects financed by European Bank for Reconstruction and Development loan and European Union Funds. 2004 I have been diagnosed with a borderline ovarian tumour, which is very rare in Romania, where most of cancers are diagnosed in very advanced stages. From that moment I still think that I am privileged and God watch me. I have lobbied for GIST patients access to Glivec and I had offered guidance to them how to "trick" the long waiting list. In 2007 I had attended the New Horizons Conference and I had also joined the group that had set up SPAEN. Also in 2007 I have coordinated the advocacy campaign that has reach its peaks with a street protest in front of Health Ministry building. Cancer patients became partners in healthcare policy in Romania. On 2009 I stated to lobby the National Alliance for Rare Disease from Romania to support rare cancer advocates to setting up a work group. On 2011 the National Alliance has supported the foundation of National Association for Rare Cancers that will also include the GIST patients. I will be further supportive both to GIST and other type of sarcoma patients and also to the Association for Rare Cancers. Since 2007 I'm a board member of ECPC and since 2009 vice president.

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



Mikael Eriksson, MD, PhD, is a medical oncologist and head of the sarcoma unit at the Skane University Hospital in Lund, Sweden. He is the present scientific secretary of the Scandinavian Sarcoma Group (SSG). With a research background in cancer epidemiology, he is since more than ten years heavily involved in clinical trials in the field of sarcomas, both in bone and soft tissues including GIST.

#### **Karen Facey, Health Policy Consultant**



Karen Facey is medical statistician who has worked in the pharmaceutical industry and medicines regulation. Twelve years ago she went to Scotland to setup the first national health technology assessment (HTA) Agency, which sought to engage patients throughout the HTA process. She is now an independent HTA consultant and Honorary Senior Research Fellow at the University of Glasgow. She is a member of the Scottish Health Technologies



Group that appraises non medicinal technologies and is past Chair of the HTAi Interest Group on Patient/Citizen Involvement in HTA. Karen was guest editor on a special themed edition of the International Journal of Technology Assessment in Health Care about patient issues and is on the editorial board of The Patient.

#### **Piotr Fonrobert, President of Polish GIST Patients Support Association**



I met GIST four years ago on the path of my life. Fortunately after a surgery it left me forever, I hope. On my GIST way I have met many people who helped me in those hard days. Today as a President of Polish GIST Patients Support Association I have possibilities to help other people suffering from GIST. Contact: pfonrobert@gmail.com

#### **Dr. Franco Gherlinzoni, Associazione Paola pertumori muscoloscheletrici, Onlus**



Dr. Franco Gherlinzoni is currently Head of the Department of Orthopaedics and Traumatology at the General Hospital in Gorizia. He is also Chairman of the Scientific Board of the “Associazione Paola pertumori muscoloscheletrici, Onlus”. He is member of SIOT (Società Italiana di Ortopedia e Traumatologia), EMSOS (European Musculo-Skeletal Oncology Society), Founder of CIOSM (Club Italiano di Oncologia Muscoloscheletrica) and member of the Board of ISG (Italian Sarcoma Group).

#### **Dr.ssa Ornella Gonzato, Associazione Paola pertumori muscoloscheletrici, Onlus**

In her professional career Ornella is currently a regulatory consultant for biotech companies. Her sister Paola was diagnosed with a rare tumorskeletal cancer and died few months later (February 2006). She was a young human resources manager and overall she was a young mother. She faced her cancer with great courage and dignity. Ornella is currently President of “Associazione Paola per i tumori muscolo scheletrici-Onlus” and hopes that the Associazione Paola can be of help and support to other patients and families affected with this disease, offering them the hope and strength necessary to face a path full of uncertainty. In memory of Paola, my sister. Contact: ornellagonzato@yahoo.it

#### **Dr. Rick Haas, The Antoni van Leeuwenhoek Hospital Amsterdam, Netherlands**



Dr Rick Haas was born in 1963, he is married and has 3 children. He was trained in radiation oncology at the Netherlands Cancer Institute, The Antoni van Leeuwenhoek Hospital Amsterdam where he is still working as staff member. He is responsible for the training of the residents and his main research focuses on sarcomas resulting in several peer reviewed papers published by his group.

#### **Frode D. Homb, Sarkomer Norway**



Frode is the leader of *Sarkomer*, the Norwegian patient organization for sarcoma patients and those in close relations with sarcoma patients. The organization is also for those who want to help and support the organization and its work. Frode was diagnosed with Ewings sarcoma in his coccyx/sacrum in 1997 and is now considered cured of the cancer. His two most important reasons for working as a leader of Sarkomer is 1. to be part of the publishing and spreading of information

about symptoms of sarcomas and to contribute to earlier diagnosis and earlier start of treatment of sarcoma patients and 2. to advocate patient rights and welfare of sarcoma patients.



**Prof. Dr. Vincenzo Ippolito, Director Centro di Oncologia Ortopedica – Spedali Civili, Brescia, Italy**



Born in Brescia in 1955, he got his Degree in Medicine in 1980. In 1981 he started his Specialty in Orthopedic Surgery and his Special Training in MusculoSkeletal Oncology, at Rizzoli Institute in Bologna, initially, and in the U.S.A., later. He trained at Memorial Sloan Kettering Cancer Center in New York and at UCLA, Los Angeles. From 1991 to 1993 he worked as a Fellow in Orthopedic Oncology at Good Samaritan Hospital in Los Angeles. In 1993 he was offered the position as Director of the newly created Unit of Orthopedic Oncology of the Civil General Hospital of Brescia (COO-BS). Starting from zero, the COO-BS became in a few years one of the most important Italian Centers for MusculoSkeletal Tumors. In 1997, after successfully treating Francesca's daughter, they got deeply involved and married in 2006. Contact: [ippolito@coobs.it](mailto:ippolito@coobs.it)

**Dr. Antoine Italiano, Institut Bergonié Bordeaux, France**



Antoine Italiano, MD, PhD is a medical oncologist (Institut Bergonié, Bordeaux, France) with a special interest in new therapies for the treatment of soft tissue and bone sarcomas; new drugs to treat advanced disease; investigation of novel molecular targets and biomarkers of rare and heterogeneous tumours.

**Prof. Dr. Bernd Kasper, Interdisciplinary Tumor Center Mannheim (ITM) at the Mannheim University, Germany**



Prof. Bernd Kasper studied Medicine at the University of Heidelberg. In 2001, he finalised his thesis at the German Cancer Research Centre (DKFZ) in Heidelberg, dealing with new treatment strategies for chronic myelogenous leukaemia patients using the tyrosine kinase inhibitor imatinib. To deepen his training, he stayed in London (Imperial College School of Medicine, Hammersmith Hospital, Department of Haematology, under the supervision of Prof. J.M. Goldman) and Brussels (Jules Bordet Institute, Medical Oncology Clinic, under the supervision of Prof. M. Piccart-Gebhart). In 2007 and 2008, he specialized in Internal Medicine and Medical Haematology/Oncology at the Department of Internal Medicine V at the University of Heidelberg. Currently, he works together with Prof. Peter Hohenberger at the Sarcoma Unit of the Interdisciplinary Tumor Center Mannheim (ITM) at the Mannheim University Medical Center. Since 2011, he is the Leading Physician and coordinator of the ITM. Since 2002, his special interest lies in the treatment of patients with bone and soft tissue sarcomas including GIST and desmoids. He focuses on clinical research projects and clinical phase I/II/III trials and works on the molecular characterization of desmoid tumours. He is head of the study center of the German Interdisciplinary Sarcoma Group (GISG) and is active in national and international study groups (AIO, EORTC). The aim of Professor Kasper is to look for new active anticancer drugs in solid tumors which will be of increasing benefit to patients.

**Claire Kelleher, Sarcoma UK, UK**



Claire joined Sarcoma UK in September 2012 having previously worked as Information Manager for the Muscular Dystrophy Campaign where she produced information materials and developed a range of support initiatives. Claire is delighted to have joined such an enthusiastic team and is dedicated to developing Sarcoma UK's information and support initiatives for the benefit of sarcoma patients.



### **Hans Keulen, Chordoma Foundation Europe, Netherlands**



Hans Keulen (1957) is living in a small town near Eindhoven in the Netherlands, with his wife and three children. He is self employed, (co-)owning several small companies and working in the IT business, mostly focused on product and business development. After several years of un-/misdiagnosed symptoms he was finally diagnosed with a clival (skull base) chordoma in June 2009, that was surgically removed in Pittsburgh PA (US). Unfortunately a recurrence has developed for which surgery is a very risky solution. Based on his own experience he is convinced that patients suffering from a very rare (incidence < 1 : 1 million) disease like chordoma should form communities on the largest scale they can, possibly worldwide. Therefore he is both serving as a European liaison to the Chordoma Foundation (mother organization) based in the US and as president of the Chordoma Foundation Europe, a legal entity incorporated in 2012, to better help expand our activities and unite patients here.

### **Małgorzata Krzywicka, Polish GIST Patients Support Association**



I have been suffering from GIST since 2010. After the stomach polipus operation in June last year I got tragic diagnosis: GIST! 4 cm 6 mitoses 50 HPF. I was completely collapsed - my professor suggested me to join the Polish GIST Patients Support Association. I have been working there as volunteer for over a year which gives me not only satisfaction but also power to fight possible progression of disease. Working for patients suffering from the same kind of cancer lifts my spirit and gives my hope for the future. I have participated in meetings and medical conventions in Poland and abroad. In March 2011 I was appointed a board member of the association. Contact: malgorzata.krzywicka@gmail.com

### **Estelle Lecointe, Ensemble contre le GIST and SPAEN, France**



Estelle Lecointe was diagnosed with GIST in 2004. She is the Founder and President of the French GIST Patient organisation "Ensemble contre le GIST" created in October 2005 with the help of Dr Axel Le Cesne and Pr Jean-Yves Blay. Estelle works 80% as a guidance counsellor in a high school and dedicates the rest of her time to "Ensemble contre le GIST" and "Info Sarcomes", a sarcoma patient/expert organisation she launched in 2009 with the support of the French Sarcoma Group. Alongside her group activities, Estelle Lecointe sits in at the French "National Cancer Institute" advocating for patients suffering from rare cancers, and participating in major committees and national initiatives. She is also a co-founder and board member (Vice-President) of "Sarcoma Patients EuroNet Assoc. in which she is responsible for the relations with the sarcoma scientific networks such as Conticanet, EuroBonet, World Sarcoma Network.

### **PD Dr. Lars Lindner, SarkUM, Germany**



PD Dr. Lindner received his M.D. from the Ludwigs Maximilians University of Munich, Germany in 1999. He completed his residency in Internal Medicine and Hematology/Oncology at the Klinikum Grosshadern in 2011 and acquired subspecialisations in hemostaseology and palliative care. From 2008 - 2009 he spent a postdoctoral fellowship in the Laboratory for Experimental Surgical Oncology at the Erasmus Medical Center, Rotterdam, Netherlands. Since 2010, he serves as coordinating physician of the Interdisciplinary centre for bone and soft tissue sarcomas (SarkUM). Dr Lindner's laboratory currently focuses on targeted drug delivery using thermosensitive nanocarriers.



### **Helga Meier Schnorf, Swiss GIST Group**



Helga Meier Schnorf, widow of Dr. Ulrich Schnorf, GIST-Patient († 2009) and founding father of the SWISS GIST- Group in 2003. I am member of the board and run the administration. From the very beginning in 2000 I was involved with GIST as a caregiver. Ulrich's concern until the very end of his life was to ensure that the SWISS GIST Group would continue its important work. After the death of Ulrich in 2009 I stepped in and continued with his work. In 2010 an official association was founded in Zug.

### **Daniela Monfasani, Aldo Arienti Amici Chirurgia Ortopedica Oncologica Onlus, Italy**



Daniela has been working with NGOs for about 18 years. Her role within the Association is to carry out the instructions of the Board of Directors. Social solidarity to cancer patients is the reason that motivates her to work in this area. She thinks that everyone can help other people and even a small thing can be the beginning for a great step for mankind. This makes us better people.

### **Georges Moreau, SOS Desmoïde, France**



I joined the "core team" five years ago. What brought me there was a long-standing friendship with our founder (Marieke Podevin) and her parents. I was impressed by the energy and determination of the association team. I thought I could be helpful facilitating the international contacts with Desmoid tumours associations and international organizations, both within Europe (SPAEN being one of them) and outside it.

### **Gideon Moshe, Israel GIST Patients Organisation**



Age 58, married to Bracha, we have 3 boys and we live in Tel-Aviv, Israel. 2006 – I was diagnosed with GIST. A 10-15 mass was removed from my abdomen. The mass was close to the small intestine and bladder. 2007 – A metastasis appeared in the liver, and in the scapula. So I started taking Glivec 400 mg and still do, until today. I am an active board member in the committee of the Israel Gist Patients Organization and the financial manager.

### **Anastassia Negrouk, EORTC, Belgium**



Anastassia Negrouk is head of the international regulatory and intergroup office at the European Organisation for Research and Treatment of Cancer (EORTC). She holds two Master's degrees in Biology from the Université Catholique de Louvain, Belgium. She joined EORTC in 2000, as a data manager. In 2002, she joined EORTC's intergroup office, which was set-up to co-ordinate collaborative trials run together by different research groups. In 2004, she took responsibility for regulatory affairs, and in 2008 she became head of the regulatory affairs and intergroup unit. She took on her current position in January 2011. As part of this position, she is responsible for the Patient involvement project. Indeed, EORTC believes patient organization involvement in clinical research and more specifically in EORTC activities is essential. Therefore, it is her responsibility to explore the potential of collaboration with different patient organizations and to adapt to their specificities to maximize the added value of such a partnership.



**Claudia Piccinelli, Psycho-Oncologist, Le Ali Onlus, Brescia, Italy**



Born in Brescia (Italy) in 1968, she earned her Master Degree in Clinical Psychology in 1994 at University of Padua. She is a practitioner in the fields of clinical, counseling and legal psychology. Trained in Family and Social Mediation (Alternative Dispute Resolution) at University of Bergamo, she is a member of Italian Society of Family Mediation (SIMeF). She specialized in Psychotherapy at University of Milan and received her Special Training at IRCCS Foundation National Cancer Institute of Milan, where still cooperates with the Pastoral Care Unit in researches on psychological issues of spiritual care. With Francesca and Enzo Ippolito she shares the mission of Le Ali and the core idea that humanizing the medical care implicates integrating the biological, psychological and social aspects of the patient's needs. Contact: [claudia.piccinelli@unimi.it](mailto:claudia.piccinelli@unimi.it)

**Francesca Piccolo, President, Le Ali Onlus, Brescia, Italy**



Born in Naples in 1966; worked as Director of Human Resources in a large Software House. In 1997 she was referred to Dr. Ippolito to treat her daughter and her life changed: her girl was cured, she moved to Brescia in 2001, married him and switched to teaching and entrepreneurial activities. After her personal experience with several hospitals in Italy and in the U.S. - trying to get her daughter treated, in 2009 she decided that she wanted to give active support to tumor patients and to all the personnel working for them. So, she used her administrative skills to create Le Ali Onlus (and took care of all the paper-work needed to get the State Acknowledgement) in collaboration with Dr. Ippolito and Paula Sause, an American friend, to support the Unit of Orthopedic Oncology, the Sarcoma Unit, their patients and all the professionals working in this field. Contact: email [info@lealionsus.org](mailto:info@lealionsus.org) or email [frapiccol@libero.it](mailto:frapiccol@libero.it)

**Kai Pilgermann, Das Lebenshaus e.V.**



At the age of 27 I was diagnosed with GIST and the tumor was removed. For the first 7 1/2 years I successfully took 400 mg Imatinib. The tumor returned shortly before Christmas 2010. After a new surgery in January 2011 I am again free of any tumor and I continue to take 800 mg/day Imatinib with only slightly higher side effects. Shortly after my diagnosis I found the regional chapter of Das Lebenshaus in Bochum. In 9/2004 I was elected as a member of the board responsible for finances. Further projects included the different websites (Association, GIST, Kidney Cancer and Sarcomas) and different mailing lists for the patients. Nationally and internationally I have attended different conferences and events as representative of Das Lebenshaus. In 2009 the general assembly of Das Lebenshaus elected me as the chairman of the board. One of my main objectives is, that all our patients with rare tumors get the best information, the best care and the best available therapy. Also in 2009 I was one of the founding members of Sarcoma Patients Euronet (SPAEN) and became one of the financial auditors.

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



I'm living in Bulgaria and my daughter is a GIST survivor since 2005 – at age of 22. At first she was wrongly diagnosed – benign formation. Three years later, her disease has relapsed. Then the diagnosis was correctly done - GIST. Unfortunately, the tumor has already been spread to the liver and peritoneum. Since then, she's on treatment with imatinib and still feeling well. In the days following her diagnosis I've started to learn about the disease and I've seen how important the knowledge is. Now, I'm leading the Bulgarian supportive group for people dealing with GIST, and I'm so glad to join the 3rd Annual SPAEN Conference.



### **Peter Riegmann, European, Middle Eastern and African Society for Biopreservation and Biobanking (ESBB)**



Peter Riegman is a Molecular Biologist and at present the head of the Erasmus Medical Center Tissue Research Support Unit which includes the Erasmus MC Tissue Bank. He is involved in three European biobanking projects, EurocanPlatform SPIDIA and BIOPOOL. He coordinated the TuBaFrost project 2003-2006, which is still active for the OECl, where he was co-opted board member and chair of the OECl working group biobanking 2006-2010. 2009-2010 he was ISBER president and ESBB - ISBER chapter president in 2011-2012.

### **Prof. Dr. Piotr Rutkowski, Institute of Oncology Warsaw, Poland**



Dr. Rutkowski graduated from Medical University of Lodz, he received there MD. After residency he completed the general surgery board in Medical University of Warsaw (2005), Poland and then he received specialty in surgical oncology (2009) in Maria Skłodowska-Curie Memorial Cancer Center and Institute of Oncology, Warsaw, Poland. He was promoted to Associate Professor of Maria Skłodowska-Curie Memorial Cancer Center and Institute of Oncology in 2008. Currently he is taking the position in this institution as a Head of the Department of Soft Tissue/Bone Sarcoma and Melanoma. The Maria Skłodowska-Curie Memorial Cancer Center and Institute of Oncology in Warsaw, Poland is the leading Polish oncological Center in the field of melanoma and sarcoma research and therapy. His scientific activities are focused on sarcoma research (multimodal treatment and prognostic factors) and GIST (prognostic and predictive factors, molecular aspects of treatment of advance disease and mechanisms of resistance to targeted therapy). He has participated in several investigator driven trials in sarcoma and melanoma and is a member of the steering committee of the CAMN107A2201 GIST trial. He is coordinator of the Polish Clinical GIST Registry and is a reviewer for the European Journal of Surgical Oncology, the World Journal of Surgical Oncology and The Lancet journal. He is a member of several Polish (board member of Polish Society Surgical Oncology) and international scientific societies (member of Board of Directors of Connective Tissue Oncology Society), an active member of EORTC Soft Tissue and Bone Sarcoma Group (Chairman of Local Treatment Subcommittee, Chair of Membership Committee), EORTC Melanoma Group, and the Global Melanoma Task Force. Dr. Rutkowski has authored or co-authored over 80 scientific papers in Polish and international journals, and is co-author of national and international recommendations in sarcoma and melanoma. He is working very closely in national patients' advocacy groups for GIST and sarcoma.

### **Michael Sayers, Board Member GIST Support UK**



I'm a GIST patient and a member of the board of trustees of GIST Support UK and a Board Member of SPAEN. I was diagnosed with GIST in early 2004. I had a small tumour in the jejunum (just below the duodenum) and a larger, secondary tumour in the liver. I was immediately prescribed oral treatment. The tumours were both shrinking and in May 2005 I was admitted for liver surgery. During the surgery both tumours could be removed. I continued oral treatment and after all scans were clear in January 2006 I was taken off treatment. In October 2006 the CT scan revealed a small recurrence in my liver. I was back on Imatinib. Doctors assured me that I could safely stay on Imatinib for years, although they will keep me on 3-monthly scans for the foreseeable future. I continue to be monitored, every three months, by CT scan. In almost every scan since returning to Imatinib, my tumours were either stable or slightly smaller. However, in October 2009, a "nodule" was discovered, within one of the small tumours on my liver. This was successfully destroyed by Radio Frequency Ablation (RFA) in December 2009. After this, I continued to have "stable" results from my CT scans, up until October 2011, when the largest tumour was found to have increased in size, from 3 cm to 5 cm. As a result, I was prescribed Sutent (sunitinib) @ 50 mg per day, which I was to start after a 4 day break from Glivec. The



recommendation is that I take the drug for 4 weeks, then go 2 weeks off, repeating the "4 weeks on, 2 weeks off" cycle. Following the change of drug, my GIST specialist team wants me to come back two weeks after starting on Sutent, for them to assess how I am adapting to it. After three months on Sutent, not only was I suffering some quite difficult side effects (principally, sore feet with thickened skin on the soles, making walking slow and painful), a scan revealed that the Sutent was not working. My gist specialists said that a further liver resection would be too risky, because of the proximity of vascular blood vessels. So it was suggested that I take part in a clinical trial for new cancer drugs (but drugs not specifically intended to treat gist). I agreed to this but still wanted to pursue the possibility of liver resection. Accordingly, I approached the liver surgeon (not a GIST specialist) who had carried out my first liver resection in May 2005. He agreed to look at the scans and obtained them from my gist specialist team. He subsequently told me that he agreed with their assessment, that surgery was risky but, that he would be prepared to operate, if I was prepared to accept the risk. I readily agreed (as I had great confidence in him, based on the outcome of the 2005 operation) and, in March 2012, a totally successful liver resection was carried out. Two subsequent CT scans have revealed no evidence of disease. My next scan is on 19th November and (due to my attending SPAEN's conference in Florence) I get the results on 30th November.

**Dr. Daniela Segat, "Mauro Baschirotto" Institute for Rare Diseases (B.I.R.D. Europe Foundation), Italy**

Dott. Segat Daniela, has a degree in Biological Science (University of Padova) and a PhD in Physiological Chemistry (University of Cologne). In her professional carrier, she mostly, worked in oncological fields. First (1990-1995) she worked as a fellow at the Institute Experimental Oncology 2, Reference Center of Oncology, Aviano in projectes studing the binding ability of different neoplastic B-cell lines to purified ECM molecules in order to understand their dispersion through the tissues. Later, at the University of Padova, (2002-2007) she studied the centrosomal aberrations in patients with esophageal adenocarcinoma derived from Barrett's metaplasia. In the 2008 she was involved in a European project " Targeted nanosystems for improving photodynamic therapy and diagnosis of cancer". Actually she is a researcher at the B.I.R.D. Institute where she is responsible of a project aimed to identify the potential molecular and genetic factors responsible of the aggressive fibromatosis. Moreover she is study the splicing modulation in HPRT mutant Lesch-Nyhan patients.

**Paolo Tomassone, A.I.G. Associazione Italiana GIST Onlus**



I was born and live in Turin with my family. In August 2005, following a rapid swelling in my abdomen, I underwent surgery to remove a large mass in my bowel (25x15x10 cm). Pathology result was GIST, mitotic count of 2/10 HPF, high risk group. I have been followed up in Cadiolo (Turin) Cancer Center, with initially regular 3 month CT scans, then 4-6 month scans. Nowadays I have regular CT scans each year, I have never taken any drug, as adjuvant Gleevec was not an option in 2005. I have been free of disease since my surgery.

**Gabriella Tedone, A.I.G. Associazione Italiana GIST Onlus**



I am a GIST patient who joined A.I.G. Associazione Italiana GIST Onlus in 2007. I live in Messina, in Sicily and I am retired teacher. I was diagnosed with GIST in August 2002 and since that time I was on Imatinib, until February 2011, when I underwent surgery and I stopped taking Imatinib. I am board member of A.I.G. and with other volunteers I provide information and support to GIST patients, their families and caregivers in Italy, promoting knowledge of this rare disease among people and medical community, so that greater awareness can lead to accurate diagnosis and to better care. I enjoy my life, my family, and I want to help other people to fight GIST. Contact: g\_tedone@hotmail.com



### **Harriet Unsworth, Information and Research Officer at the Bone Cancer Research Trust**



I am the Information and Research Officer at the Bone Cancer Research Trust (BCRT). BCRT is a UK and Ireland-based charity that raises money to fund research into bone sarcomas, as well as providing information for patients, raising awareness of bone sarcomas and offering support to patients and their families. I joined BCRT in 2012 from a previous career in cancer research, which included research into the molecular biology of osteosarcoma. My motivation lies in finding ways to improve outcomes for bone sarcoma patients. Contact: [harriet.unsworth@bcrt.org.uk](mailto:harriet.unsworth@bcrt.org.uk)

### **Marjo Väisänen, Finnish GIST Patient Networks, Finland**



I am a GIST patient from Finland. I was born and live in Helsinki. In 2003 I had emergency surgery. I had about 7cm tumor in my small intestine, and diagnosed as benign GIST. Therefore, I got no treatment after surgery. In 2008 several metastases appeared in the liver. I started to take Glivec. In 2009 I underwent a liver resection. Still on Glivec. I am one of the founders of the Finnish GIST Patients group and also support person.

### **Ellen van Arem de Haas, chairman of the board of Sarcoma NL The Netherlands**



In 2012 I was asked by a GIST carney triad patient to set up a small website, [carneytriad.com](http://carneytriad.com) which proved to be a success. Then he asked me to set up another website: Sarcoma NL as well as to become a founding member of the board. Both websites are a co-production of my son and I. He is the programmer of the website and members-only forum. I'm the author, illustrator, moderator. My husband also joined as a volunteer worker. It's all in the family, but unfortunately so are borderline tumours. Sarcoma NL provides Dutch speaking patients in Europe with information about bone and soft tissue sarcomas and about rare borderline tumours, i.e. desmoid, GCT.

### **Helmer van Arem, volunteer at Sarcoma NL The Netherlands**



A month ago, I joined this brand new patient organization as forum administrator and for lots of other tasks to be done. My wife Ellen and our son are also heavily involved in this good work. Even our daughter provides us, if necessary, with legal advice. We were all tremendously touched by the kindness and enthusiasm of the sarcoma specialists in both The Netherlands and Belgium. Patients and patient carers on our forum also are delighted that there is now a patient organization for them (rare sarcomas of bone, soft tissue, and rare borderline tumours).

### **Laurens van Bavel, Contactgroep GIST The Netherlands**



I'm a G.P. (General Practitioner aka family doctor) and Board Member Medical Affairs since January 1st, 2011. I was asked to join the Contactgroep GIST association by GIST patient and Treasurer of the Board. I'm engaged in providing the best medical information, as well as directing the way to psychosocial problem solving. I'm working towards the establishment of a medical GIST advisory committee. Contact: [medisch@contactgroepgist.nl](mailto:medisch@contactgroepgist.nl)



### **Prof. Winette van der Graaf, EORTC Soft Tissue and Bone Sarcoma Group, Belgium**



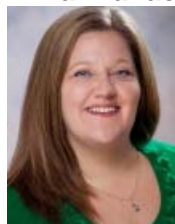
Professor Winette van der Graaf is head of the department of Medical Oncology at the Radboud University Medical Center of Nijmegen, The Netherlands. She is leading the Radboud preclinical and clinical sarcoma research group. She has been active in the EORTC Soft Tissue and Bone Sarcoma Group since many years and is chairing the group from 2012-2014. She is member of the World Sarcoma Network. She is also initiator of the Radboud Adolescent and Young Adult (AYA) cancer platform, which covers a.o. a digital community for patients and a taskforce in which AYA patients and caregivers meet at regular intervals. This initiative will be expanded to other AYA (and often sarcoma) centers in The Netherlands from early 2013.

### **Louisa (Wie) van Dun, Contactgroep GIST Belgium**



I'm a Founding Member (2007) of the Board of Contactgroep GIST Belgium and a GIST patient as from December 2004. In January 2005 part of my stomach was removed in a GIST specialized hospital at Leuven. No GIST traces were found in the cutting edges. Periodic checks twice a year. I'm passionate at organizing long walks and get together for our Flemish patients somewhere favourably at picturesque places in Belgium, two times a year. Contact: bestuur@contactgroepgist.be

### **Anna Wallace, Living Beyond Diagnosis**



I'm passionate about patient participation, advocacy and survivorship for cancer patients and improvement in cancer care. Since my diagnosis in 9/2009 with a rare soft tissue sarcoma, I have sought to utilise my experiences (good and bad) to bring about improvements and changes within the cancer field via a variety of charity, hospital and cancer network committees/boards/groups. I believe that 'cancer voices' should be heard, views considered and the patient perspective be presented. With more people 'surviving' a cancer diagnosis, it is imperative that consideration, planning and care is available to cancer survivors throughout their lifetime, this may be a long time after the initial diagnosis and the issues may be physical, emotional and/or psychological. Where appropriate, I also attend conferences such as the NCIN Conference, Rare Cancer Conference, NCRI Conference, Macmillan Voice Conference etc to speak with other patients, medics, participate in workshops and listen to speakers. I then share the information from each of these conferences, where appropriate, via the committees/boards/groups and also online forums that I am a member of and the two that I moderate for.

### **Markus Wartenberg, Das Lebenshaus e.V. Germany**



Markus is the Executive Director/Spokesperson of the patient advocacy organization Das Lebenshaus e.V./Assoc. He is responsible for conceiving and organizing all community activities with a small team of patients, employees and freelancers. After his commercial education in the industry, he completed his studies as a specialist in journalism & communication. He worked in several different German communication and PR-agencies as a consultant and creative director for national and international brands. In 1993 he founded his own agency, which had a focus on pharmaceutical, medical and health comm. After 10 years with his business, he left the agency in 2003 to manage Das Lebenshaus and Das Wissenshaus.

- From the early beginning of the intl. GIST-Conference NEW HORIZONS he was a member of the Steering Committee for the Global GIST Patient Community.
- To strengthen the collaboration with the medical experts and to support research and training in Germany – he established the (limited liability) non-profit company Das Wissenshaus GmbH (The House of Knowledge) in December 2008.



- Since 6th of April 2009 he is Co-Founder and a Board Member (Financial Director) of SPAEN and responsible for its relations with the healthcare industry.
- Since September 2009 Markus is involved in the IKCC Steering Committee (ikcc.org) to organize EXPANDING CIRCLES – the Intl. Conference for Organizations Representing Patients with Kidney Cancer (2nd Conference from 11 - 13 March 2012 in Rome) and to set up IKCC as a global network with a legal entity in the future.
- Together with the leading German GIST- and Sarcoma experts PD Dr. Peter Reichardt and Prof. Dr. Peter Hohenberger, Markus initiated and organized in March 2011 and 2012 the first two national sarcoma expert conferences in Germany. (www.sarkomkonferenz.de)

Contact: wartenberg@lebenshauspost.org or markus.wartenberg@daswissenshaus.de

### **Martin Wettstein, Swiss GIST Group**



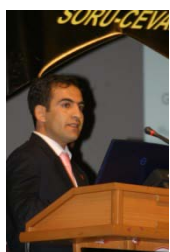
Martin Wettstein, father of 3 grown up children and engineer in his profession received his diagnosis of GIST in fall 2007. After one year of 800 mg neoadjuvant Gleevec treatment his surgery on the small intestine was successfully performed and he terminated his adjuvant Imatinib medication 4 months after the surgery. The bi-annual cat scans were all negative since then. Martin was asked by Helga Meier Schnorf and his surgeon to join the Swiss patient advocacy group. Since he had been extraordinary well informed about the GIST illness complex by the late Dr. Ulrich Schnorf and also very well treated in a remarkably competent and professional manner by his surgeon and his oncologist he accepted to act as president of the newly formed PAG as initiated by Dr. Schnorf and in commemoration to him. Martin is trying to lead the Swiss GIST Group into a stable and long lasting PAG the way Dr. Schnorf intended the group to be.

### **Roger Wilson, Sarcoma UK**



Roger Wilson was first diagnosed with a soft tissue sarcoma in 1999. He has had several recurrences, lots of surgery and chemotherapy. He founded Sarcoma UK as a patient led organisation in 2003, worked with the UK's specialist doctors to form the British Sarcoma Group in 2005, formed The Sarcoma Trust in 2007 to raise funds for research, and was a co-founder of SPAEN in 2009. He has also been active in cancer research, chairing the patient group associated with the UK's National Cancer Research Institute from 2004 to 2007 and continuing to work as an adviser to the NIHR Cancer Research Network. He is also active in Europe working with ECPC and ECCO. In early 2011 the Sarcoma Trust and Sarcoma UK merged as a UK national charity and Roger is now Honorary President of Sarcoma UK. Roger was appointed a Commander of the British Empire (CBE), and received an Honorary MD from Sheffield University in 2011.

### **Salih Yüce, Youth Accumulation Association, Turkey**



He was born in Bingol Province of Turkey in 1997. After graduated from the high school, he caught the soft tissue sarcoma (pleomorfik randomyo sarkom). He took up chemotherapy and radiotherapy treatment between 1999 and 2002 and he stayed under control until 2004. He established "Oncology Patients Assistance and Compassion Association" in 2004 in Mus Province with the aim of carrying volunteerism into health sector and he has started to get professional experience on health issues. He also established "Youth Accumulation Association" in 2006 in order to raise awareness of cancer aiming to work especially with youngsters. On the other hand, he implemented many important projects such as organizing "International Onchology Days" with the aim of raising awareness among youngsters through patients and sharing knowledge at national and international scale, establishing a federation and providing a mobile cancer screening vehicle. He was given the prize for his valuable work by the Ministry of Health in 2011. Due to his illness, Mr. YUCE selected cancer and health as his own professional



areas and he has been working as a full – time volunteer on these issues. He is married with two children.

**Avi Zigdon, Israeli GIST Organization**



Avi is the Chairman of the Israeli GIST Organization and aged 49. In February 2008 I was diagnosed as a GIST patient. On March 2008 I had a surgery. The tumor was situated on the external wall of the stomach and integrated the spleen, part of the lung and part of the diaphragm. Treated with Imatinib 400 mg.



# Group Profiles



## Patient Advocacy Group Profiles

### A.F.P.G. “Ensemble contre le GIST”

A.F.P.G. « Ensemble contre le GIST » was created in October 2005, several months after Estelle’s own GIST diagnosis. The main objectives of this organization consist in providing patients, caregivers and non specialist doctors a good level of information regarding:

- GIST tumours
- their management
- the various treatment options



In order to improve the level of knowledge on this rare cancer, A.F.P.G. « Ensemble contre le GIST » has developed several documents with the help of the French Sarcoma Group. These leaflets are disseminated in every French Cancer treatment centers.

These last years, A.F.P.G. « Ensemble contre le GIST » has been highly involved in the field of compliance, notably developing a specific brochure: «Compliance with treatment: be an active partner in your GIST care everyday» which has been translated in 12 different languages with the help of Conticanet and SPAEN so as to raise people’s awareness on this topic all over Europe and beyond. Following these brochures, Conticanet and A.F.P.G. « Ensemble contre le GIST » launched in 2010 the «GIST International Survey on Treatment » so as to better understand patients’ behaviours and difficulties with treatment and to develop an appropriate therapeutical educational programme in a near future. Today, A.F.P.G. is member of different pharmaceutical advisory boards focusing on compliance and management of patients treated with targeted therapy.

### A.I.G. Associazione Italiana GIST Onlus - Italy

#### Objectives

- To supply Information and knowledge about GIST to Italian patients, overcoming language barriers. News and information from worldwide scientific and clinical sources are made available to Italian patients.
- To offer support to patients and caregivers
- To represent GIST patient rights with local and national health authorities
- To promote scientific research on GIST with clinicians, pharma companies, hospitals
- To raise public awareness



#### Brief description of the organisation

- A.I.G. Is an all-volunteer, non-profit organization started in 2006 with the co-operation and help of Dr. Paolo G. Casali, Head of Sarcoma Dept. in the NCC (Fondazione IRCCS Istituto Nazionale dei Tumori, Milano) and with Novartis’s support.
- A.I.G. Is member of UNIAMO, Rare Disease Italian Federation, member of Global Gist Network and founding member of SPAEN.

#### Audience/Constituency

- GIST patients, caregivers and friends – Clinicians - Health institutions - Pharmaceutical companies - Other patients advocacy groups – Medias

**Website:** [http:// www.gistonline.it](http://www.gistonline.it)



## ALDO ARIENTI AMICI C.O.O. (Chirurgia Ortopedica Oncologica) Onlus

**Our Identity, our Purpose:** Our Association is an Ngo and was founded in Milan in 1990 by former patients and supporters with the purpose of helping to uphold the activities of the Department of Oncologic Orthopaedic Surgery (C.O.O.), at Gaetano Pini Orthopaedic Institute in Milan. Orthopaedic oncologic diseases have committed our association in promoting the development of research in the epidemiologic/diagnostic/therapeutic field of the musculoskeletal system cancer.



**What has been achieved in recent years:** the Association has maintained the management of a computerized clinical archive for many years, this is essential for the follow-up of patients and the research of new treatments, as well as the treatment protocols and the data or information exchange between primary National Scientific Institutions, and Hospitals which rely upon C.O.O. Moreover our Association directly helps C.O.O. patients with free supplies (prosthetic and rehabilitative aids, planning medical offices, and other comforts for the hospitalized patients). The production of the "Guide for the young patient" is a unique leaflet aimed at younger patients affected by neoplastic pathology and their families.

In addition, the Association has been organizing concerts of chamber music and opera and scientific conferences for social compass.

The Board directs the association carrying the instructions of the shareholders.

**Our future project:** One of our future projects is to support scientific evaluation of data related to oncologic pathologies. Supporting this activity means we can offer significant results and, most of all, we can offer them in real time to all those working in the field so they use this valuable information for patient care. We are digitalizing the pictures of all the operations performed in the last 30 years of the COO. Soon we'll also be able to build a medical ambulatory that will provide psychological support to family members of patients. Much more can be done!

Website: [www.gpini.it/servizi/associazioni/ARIENTI](http://www.gpini.it/servizi/associazioni/ARIENTI)  
e-mail: [arienti-pini@gpini.it](mailto:arienti-pini@gpini.it)

## The Association for Finnish Cancer Patients – GIST Patient Network



Suomen Syöpäpotilaat - Cancerpatienterna i Finland

One of the main activities of the Association for Finnish Cancer Patients are the national patient networks, currently there are nine of them, including the GIST Patient Network. Every patient network has its own patient leader. The goal is to offer peer support for patients and up-to-date information for patients, their families and medical staff. We do this by organizing nationwide information days and weekends. We also support patient groups to start conversational groups amongst each other. Each patient network also has at least one support persons and their help is available nationwide.

Website: [www.syopapotilaat.fi](http://www.syopapotilaat.fi) and [www.cancer.fi](http://www.cancer.fi)



## Associazione Paola per i tumori muscoloscheletrici Onlus

Associazione Paola per i tumori muscoloscheletrici Onlus, founded in 2008, is a non-profit association supporting patients with musculoskeletal tumors and the ir families



**Our philosophy** is: " KNOWING FOSTERS HOPE"

**Our mission** is "IMPROVING THE QUALITY LIFE OF PATIENTS AND THEIR FAMILIES"

**Our goals** are:

- to circulate scientific knowledge about the disease
- to encourage collaboration between professionals and research groups, for empowering the multidisciplinary of treatments;
- to support and promote scientific research;
- to provide support to patients, their families, developing a mutual solidarity.

**Our main activities** are the following:

- providing correct information to patients, because patients together clinicians are equal partners in their own therapeutic journey
- referrals for second opinion
- educational of health care professionals
- stakeholding in the Regional Health Care System
- cooperation in research/clinical projects

### Current projects

- Cooperation with Scientific Research Project on implementation of registries and tissue bank for Musculoskeletal Sarcoma
- Cooperation with Clinical Research Project on Interaction framework between Patient Advocacy Groups and Sarcoma Cancer Centers.

To pursue our objectives, we have established a Scientific Committee that includes experts in different branches of musculoskeletal oncology. Many of them are into the Boards/Committees of National/International Organizations and Scientific Societies.

Website: <http://www.associazionepaola.it/>

## Bone Cancer Research Trust (BCRT)

**Our vision: 'We want a world where lives are no longer limited by primary bone cancer'**

[www.brct.org.uk](http://www.brct.org.uk)

The Bone Cancer Research Trust (BCRT) is a UK and Ireland-based charity, which was set up in 2006 by a group of bereaved families with a common goal – to improve outcomes for people affected by bone sarcoma. We aim to achieve this through research, awareness, information and support.



Approximately 450 young people are diagnosed with primary bone cancer each year in the UK and Ireland. The four most common types of primary bone cancer are osteosarcoma, chondrosarcoma, Ewing's sarcoma and chordoma. Most osteosarcoma and Ewing's sarcoma patients are under the age of 30, with a peak age of diagnosis of 15 years old. Five year survival rates are just 54% and there has been no improvement in survival for the last 25 years.

BCRT will have spent over £1million on research into bone sarcomas by the end of 2012. Our patient information is has achieved Information Standard certification, a UK government mark of quality in health information. Our teenage information booklets were Highly Commended at the British Medical Association Patient Information Awards in 2012.

BCRT has instigated a system whereby all cases of Ewing's sarcoma in the UK are discussed nationally by medical teams across the country, via video-conferencing. BCRT acted as a patient advocate group to support the NICE approval of mepact for the treatment of bone sarcoma patients by the NHS. Our commitment to improving the outcomes of bone sarcoma patients has grown with us as the charity has grown, and we have high hopes for the future.

Website: [www.brct.org.uk](http://www.brct.org.uk)

### Chordoma Foundation

The Chordoma Foundation is a nonprofit organization dedicated to curing chordoma. Started in the USA in 2007, the Chordoma Foundation is still the only existing organization that unites and represents chordoma



patients. Given the rarity of this disease, and the resultant need to leverage all available resources and partners – wherever they may be – we are seeking to grow our network of doctors, researchers and patients around the globe. This is particularly important for patients, since the rarity of this disease means that there are often no other patients in the nearby area.

Since 2011 we are reaching out to Europe in an effort to provide better information and opportunities to patients here. In 2012 we organized for the first time in Europe meetings dedicated to Chordoma, both for physicians and patients. This meetings formed the start of establishing a European network. To be better able to exploit the European system we also incorporated a European legal entity in 2012.

Chordoma is a rare, slow-growing, relentless bone cancer that occurs in the head and spine in people of all ages, predominantly on the skull base and sacrum. The incidence of chordoma is approximately 1 in a million. Chordoma is typically resistant to chemotherapy and normal radiation, and is prone to multiple recurrences. The average survival after diagnosis is 7 years; astatistic we are determined to improve. Our mission is to improve the lives of chordoma patients by rapidly developing effective treatments and ultimately a cure for this devastating disease. We lead a coordinated international research effort with researchers across the world to accelerate the development of a cure, while improving the diagnosis, treatment, and quality of life for people affected by chordoma. We serve as a bridge between patients, doctors, researchers, drug companies, government and funding agencies, representing the interests of those with chordoma, and instilling a sense of urgency in the treatment development process.

To help patients get the best care possible, the Foundation provides accurate information about treatment options and clinical trials, refers patients to experienced doctors, and matches patients with trained peer support mentors. Additionally, bi-annually we organize Chordoma Community Conferences, both in the US and Europe. More information can be found on [www.chordoma.org](http://www.chordoma.org).

Contact Info: Hans Keulen, email: [hans@chordoma.org](mailto:hans@chordoma.org)  
Website: <http://www.chordoma.org>



## Contactgroep GIST The Netherlands - Belgium

### Profile

Established in 2003, Contactgroep GIST is the organization for Dutch and Flemish speaking GIST patients (and their families), with members in The Netherlands, Flemish Belgium, and i.e. in Germany, Italy, Norway, Portugal and the U.K. Our organization is managed entirely by highly skilled (non-paid) volunteers and is affiliated in the Netherlands with NFK (Dutch Federation of Cancer Patient Organizations) and in Belgium with VLK (Flemish League against Cancer). The Dutch branch receives funding from Dutch charity KWF Kankerbestrijding, and Fonds PGO (part of Dutch government). The Flemish branch receives funding from above mentioned VLK.



### Main goal

Providing the best GIST information by means of our website, newsletters, mailings, members-only forum, brochures, annual contact days and twitter. The latter is also used to stay in close contact with other GIST and sarcoma organizations throughout the world.

### Achievements

- Since 2010 we experience a greater increase in members, due to our attractive new website, the 2009 brochure, and due to referral by GIST-experts!
- GIST Patient book launch in 2010
- Daily contacts by means of mail and especially the members-only forum since 2010
- Annual Contact Days in both The Netherlands, Belgium experiencing more interest
- September 2011 New brochure, simplifying the message for a better GIST understanding by all patients, their loved ones, and interested persons, also sent to all oncology departments in general hospitals, and to psychosocial walk-in centers.

Contact: [info@contactgroepgist.nl](mailto:info@contactgroepgist.nl)  
Website: [www.contactgroepgist.nl](http://www.contactgroepgist.nl)

## Das Lebenshaus - Germany

Das Lebenshaus e.V./Assoc. is the non-profit umbrella organization for those affected by rare solid tumours: GIST, Sarcoma and Kidney Cancer. From the start, the organization's philosophy has been to work professionally with medical experts, researchers, the pharmaceutical industry and other patient organizations around the world to achieve the best possible outcome for those affected by rare solid cancers.

Lebenshaus' main areas of work are:

- Informing patients and caregivers
- Representing their interests
- Optimizing treatment
- Supporting research
- Giving hope



The section for patients with GIST and their families has existed since the association was founded in June 2003. The Kidney Cancer section was established in February 2008. Those affected by a type of Sarcoma and their families have also been supported by Lebenshaus since September 2009. Since 2009 the organization is representing around 6% of all new occurrences of cancers in Germany. Das Lebenshaus e.V. is a non-profit association with no influence from third parties. It is financed through sustaining membership, private funding, sponsoring, beneficiary activities and collaboration in EU-sponsored projects.



Member of:

- ECPC European Cancer Patient Coalition (incl. ECPCsRare Cancer Task Force)
- Global GIST-Network ([www.globalgist.net](http://www.globalgist.net))
- Partner of EU-funded networks

Founding Member of:

- SPAEN Sarcoma Patients EuroNet e.V./Assoc. (founded on th 6th of April 2009)
- IKCC - International Kidney Cancer Coalition

### GIST Alliance for patients Bulgaria

GIST Alliance for patients Bulgaria was created in January 2012 as a non-profit organization supporting people affected by GIST in Bulgaria.



Aims:

- To provide support to patients, their families and caregivers;
- To represent GIST patient rights with National Health Authorities;
- To provide a good information in local language;
- To help patients to obtain the appropriated treatment;
- To make people thinking about GIST.

Activities:

- Website [www.gist-bg.com](http://www.gist-bg.com) consisting in easily accessible information about GIST , diagnosis, treatment options and managing the side effects;
- Member of SPAEN (Sarcoma Patients EuroNet)
- Member of ECPC( European Cancer Patient Coalition)
- Two annual meeting of medical specialists, GIST survivors, their families and friends;
- Psychological support;
- Distribution of leaflets with basis information about GIST; emphasizing the patient's personal responsibility in their therapy; dealing with side effect such as Hand-Foot Skin Reaction.

Challenges:

- To make “compassionate use” accessible to patients;
- To assist in the inclusion of new medicinal products in the reimbursement list;
- To reach more patients;
- To involve the Bulgarian medical specialists in scientific GIST treatment researchs.

### GIST Support International

GIST Support International (GSI) is an all-volunteer group of patients with gastrointestinal stromal tumor (GIST), family members, friends, and interested professionals. Our e-mail listserv includes over 1550 subscribers who form an online community to share information about GIST treatment and to support each other in living with GIST.



## Mission

- To provide a respected international voice for GIST patients.
- To create a portal that GIST patients, caregivers, medical professionals, media and others can go to for complete, accurate, up-to-date information on GIST
- To continue to provide an online community where both patients and caregivers can interact and feel comfortable sharing thoughts, ideas and experiences while working through the emotional roller-coaster of living with cancer.
- To produce top-quality educational products about GIST in order to enable all patients to become their own best advocates.
- To maintain an educational, informative website with accurate information about practical issues as well as medical aspects of GIST and its treatment.
- To translate key sections of our website for international GIST patients.
- To reach out internationally to all GIST patients who do not have access to the internet.
- To remain focused solely on GIST patients.

## Guiding Principles

- Serve the general public and GIST patients in particular with the highest degree of ethics and professionalism in all matters.
- Maintain open and easy membership - no one will ever be asked to provide personal or medical information to join GSI.
- No fees - no member will ever be asked to pay fees or to make financial donations to GSI.
- Uphold our total commitment to GSI's open and transparent financial disclosure, as well as requiring the same from any organization seeking to advertise on our LISTSERV or website.
- To involve all GSI members who desire to participate in various working committees and daily activities of running the organization.

To achieve these ambitions GSI has a lively and interactive listserv for its members, an annual Summit which makes no charge to attend, educational publications which we mail out free on request all over the world ("Understanding your Pathology Report"), an extensive website updated continually with current information, and a wiki updated continually with information supplied by our members. Our website is at [www.gistsupport.org](http://www.gistsupport.org)

## GIST Support UK

GIST Support UK is a charitable trust which acquired its charitable status in April 2009. Before that time it was a subgroup of Sarcoma UK, and the two organisations continue to maintain a close relationship.



The stated objectives of GSUK are:

1. to promote and protect the physical and mental health of patients with Gastro-Intestinal Stromal Tumours (GIST) in the United Kingdom through the provision of information, support, education and practical advice to them and their carers;
2. the relief of sickness and the preservation of health by promoting and supporting research with the publication of the useful results thereof and the development of more effective treatment and care for patients with GIST;
3. to advance the education of the general public and health professionals in all areas relating to GIST



In order to promote these objectives we:

1. hold two meetings each year for GIST patients and their carers, at which experts in their fields give up to date information on treatments and research.
2. have a mailtalk group which enables patients and carers to develop friendships and support each other.
3. have a phone line which enables newly diagnosed patients and their carers to talk to another patient.
4. distribute leaflets with information about GIST to patients, carers and medical professionals.
5. represent GIST patients' interests to the pharmaceutical industry and UK government bodies.
6. have a sub-section promoting the better care and treatment of the ultra-rare group of GIST patients, with Paediatric, Adolescent, Wild-type and Syndromic GIST (PAWS-GIST)

### Israeli GIST Organization

The Israeli GIST Patients Organization has operated since Oct. 2007 in order to bring GIST patients the most updated information about new drugs, new research and supporting GIST patients and their families. We are also increasing the awareness of Health Authorities in Israel on the most updated information about GIST, GIST treatment, new “life saving” drugs for GIST and entering them to the “Israeli Health Basket”.



Due to the intensive activity of the management of the Israeli GIST patient's organization the awareness for GIST has increased dramatically among family physicians, oncologists and GIST patients in Israel. As the Israeli GIST patient's organization has started to be active there were only 6 members at the organization. Nowadays, there are 73 members at the Israeli GIST patient's organization. We estimate that there are 160 GIST patients in Israel in different stage of the disease. We are doing all we can and the best way in order to locate and to reach every GIST patients in Israel.

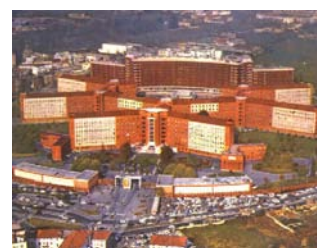


New activities for the year 2012:

- a. Beginning of co-operation with Dr. Gil Bar-Sela, Oncologist and the pathology lab at “Rambam” Medical Center in order to establish a public health clinic lab which will conduct genetic mutations examinations for GIST patients.
- b. Establishment of a fund which will help GIST patients who are members at the Israeli GIST patient's organization and have financial difficulties in financing GIST medications.

### Le Ali Onlus and COO-BS

The “Spedali Civili” in Brescia is one of the largest Italian Hospitals, with its 2400 beds. It's a General Hospital, rated as “of National Interest” in our Health System. Oncology is one of the main working-fields of the Hospital and it has all the resources needed to treat tumour patients of any kind.



The Department of Orthopedics hosts the “Centro di Oncologia Ortopedica” (COO-BS, “Unit of Orthopedic Oncology”, Director: Dr. V. Ippolito), which treats patients with all kinds of musculoskeletal Tumors. The Center has a deep interest in the treatment of Bone and Soft Tissue Sarcomas but also a wide experience in the surgical management of Bone Metastases: it was one of the first Centers in Europe to use Liquid Nitrogen in the surgery of Bone Metastases, in 1980. The COO-BS is part of the Sarcoma Unit, a multispecialist network which gathers all the physicians of the Hospital involved in the management of these patients.

COO-BS and Sarcoma Unit treat patients coming from all over Italy and from nearby countries and it is known as one the most important Bone-Tumor Centers in Italy.

Le Ali Onlus (*in Italian “Onlus” means “Non Profit Organization for Public Utility”*) was born in June 2009, from an idea of Francesca Piccolo. Her idea was to create an Association which could help the patients of the COO-BS and of the Sarcoma Unit: the association provides psychological support, financial support for patients who need it and to specialized rehabilitation. Another important target for Le Ali is to support all the personnel working on these patients, especially for what regards their Continuing Education and Training and the “Diffusion of Knowledge” out of the Hospital, favouring Meetings and Courses with Family Doctors and Doctors and Nurses of other Hospitals. Le Ali is funded by donations.



Contacts:

Le Ali Onlus  
Francesca Piccolo  
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Web: www.lealionlus.org

COO-BS (Centro di Oncologia Ortopedica – Brescia)  
Dr. V. Ippolito  
Tel.: (+39) 030.3995393  
Mail: ippolito@coobs.it  
Web: www.coobs.it

### Living Beyond Diagnosis

Living Beyond Diagnosis is a not for profit organisation created to share information, particularly with regard to survivorship, via a number of mediums for anyone affected by cancer.



Website: <http://www.livingbeyonddiagnosis.com>

### Polish GIST Patients Support Association

The Polish GIST Patients Support Association is a non profit, NGO representing GIST patients and their relatives. Our main goal is to promote all necessary knowledge to increase awareness concerning GIST. Thanks to participation in many Polish and International events we have possibilities to acquire and distribute to our members all the necessary information about most recent science, technology and practical achievements relating to our illness.



Website: <http://www.gist.pl>  
Facebook: <http://www.facebook.com/pages/Stowarzyszenie-Pomocy-Chorym-na-GIST/106737746078375>



## Romanian Rare Cancers Association – RCarare

Founded in June 2011; Member of The Romanian National Alliance for Rare Diseases; Joined the European Partnership for Action Against Cancer – ECPC (to identify and promote appropriate solutions and to share best practices on rare cancers).



### Aim

To represent people affected by rare cancers, their families, organizations and professionals involved in the diagnosis and treatment of the rare cancers from Romania

### Objectives

- To develop a national network formed from representatives of patient organizations, experts, community and public institutions;
- To organize information campaigns and counseling on rare cancers;
- To raise awareness about the issues of children and adults affected by rare cancers;
- To collaborate with individuals and organizations at national and international level;
- To influence administrative and economic structures in order to adopt responsible decisions for the future patients affected by rare cancers.
- To simulate scientific research – to identify and implement the most effective therapies and methods of care;
- To promote measures for early diagnosis through particular methods, depending on the diseases;
- To improve collaboration with specialists involved in the diagnosis and management of rare cancers;
- To guide and to support new organizations and groups of patients;
- To provide further education.

## Sarcoma UK

Sarcoma UK is the main charity in the UK dealing with all types of sarcomas.

Sarcoma UK's aim is to act as a lifeline for sarcoma patients and promote the best possible standard of treatment and care through:

- Funding scientific and medical research into causes and treatments
- Delivering a range of support and information services covering all aspects of sarcoma
- Raising awareness of sarcoma amongst the public, healthcare professionals and policy makers



Sarcoma UK relies on voluntary donations and fundraising activities to fund its work.

Sarcoma UK is staffed by a small team of 5 full-time staff, managed by a board of trustees (many with personal experience of sarcoma), and supported by experts in the sarcoma field.

Sarcoma UK works collaboratively with doctors, nurses, researchers, and other cancer charities.

Sarcoma UK is a co-founder member of Sarcoma Patients Euronet (SPAEN) and our Honorary President, Roger Wilson, is President of SPAEN.



## Sarkomer Norway

Sarkomer was founded 1<sup>st</sup> October this year. The board consist of 10 members, divided between 5 persons who are current and former sarcoma patients, 3 person who are next of kin or family members of deceased, and 2 persons who are cancer health care personnel, though it is possible also for other professional working with cancer to be a part of the board. There are currently 300 members of the organization, both main members and supporting members. We will establish a web site as soon as possible.



Contact: Frode Dyrnes Homb, email: [info@sarkomer.no](mailto:info@sarkomer.no)  
Website: <http://sarkomer.no/>

## SOS Desmoïde France



- Its aim: like most PAGs, it is to develop the awareness of this disease, stimulate research, inform & support patients. It started in 1998.
- The core of our organisation lies in a team of about ten persons who meet every month. It is worth noting that the association was created by a duo: one patient and one doctor. Today, this team includes three doctors.
- The patients committee works on communication aspects of our projects and gives their input on the shape and the content.
- We have a Medical & Scientific Council to advise us on medical and research subjects. Most specialities (oncology, surgery, anatomo-pathology, biology) are represented among its twenty members. They meet at least once a year.
- Support to individuals (patients and relatives) is provided by members of the core team, along with a psychological support offered by two psychiatrists members of the association
- Formalized communication channels are: our web site; a quarterly bulletin; and our annual meetings

## SOS Desmoid Germany



SOS- desmoid is a patient group instigated by a group of experts, medical and psychological. They saw the need for a desmoids patient group and helped to make it happen. In 2009 sos-desmoid Germany, a charitable organisation, was founded. At the moment the board consists of three people (Christina Baumgarten, Manuela Kusterer, Rudi Engelhart). Please find more information on desmoids tumors and our organisation on our website: [www.sos-desmoid.de](http://www.sos-desmoid.de).

### Our major goals are:

- to be a source of information for both patients and relatives
- to facilitate interaction between those affected
- to support cooperation between medical experts
- to create connections to other patient organisations, home and abroad
- to raise the public awareness of sarcomas/ desmoids

### Future projects:

- to built up local patient groups



- to discern the needs of our patients and their relatives through discussion and questionnaire
- to organise patient meetings with experts
- to dispense medical information in several languages and via different mediums
- to educate the public about desmoids tumors
- to encourage cooperation between oncologists, psychologists and physiotherapists
- to develop international cooperation on the subject of desmoids tumors

### Stichting Sarcoma Nederland (Sarcoma NL)

Foundation established in The Netherlands in 2012, for all Dutch speaking (ex-)patients with bone or soft tissue sarcomas, as well as for patients with other rare tumours, i.e. desmoids (which also should be treated by an expert team). Sarcoma NL wants to stimulate scientific research on sarcomas.



#### **The idea of founding Sarcoma NL comes from two special people**

A young sarcoma (GIST Carney Triad) patient (age 22 in 2012), surviving with 20 metastases in his liver since his 14th.

And also a sarcoma (grade II leiomyosarcoma) patient in his fifties, who unfortunately deceased at the end of 2009. He stood up for the rights of oncology patients.

The url [www.sarcoma.nl](http://www.sarcoma.nl) was granted to Sarcoma NL by his widow.

#### **Easy to read information about all sarcomas in Dutch**

We want to provide patients, their close family and friends, and other interested persons with easy to read information in Dutch about sarcomas and other rare tumours.

#### **Members-only forum**

Sarcoma patients, ex-patients, or their closest loved ones can communicate with each other at a members-only forum.

Contact: [info@sarcoma.nl](mailto:info@sarcoma.nl)

Website: [www.sarcoma.nl](http://www.sarcoma.nl)

### Swiss GIST group

On January 14, 2010 the *GIST-Group of Switzerland* was founded in accordance with the provisions of the Swiss Civil Code. The aim of the association is to support GIST patients and their dependants and relatives. The group was actually founded 2003 by the late Dr. Ulrich Schnorf, GIST-Patient since 2000 and husband of Helga Meier Schnorf.



As specified by Prof. Metzger during the SWISS annual GIST-meeting on April 24, 2009 in Zurich, one of the major concerns of the greatly missed Dr. Ulrich Schnorf was to avoid the Swiss patient advocacy group, which has been in existence now for 9 years, being dependent on one single individual, but rather to ensure its continuity by creating a legal entity. Ulrich Schnorf carried out the main part of the essential preparatory works for the foundation of this association. Thereafter, Prof. Urs Metzger and Helga Meier Schnorf implemented all the requirements necessary for this foundation. This is due to the strong commitment and essential role of Prof. Metzger in the drafting of the statutes and their adaptation to the requirements of the tax authorities. Primary notice from the tax authorities of the Kanton of Zug has been returned. It assures that according to these statutes the tax exemption requirements for a non-profit association have been fulfilled.



#### Board:

- Martin Wettstein\*, President, Meggen
- Herbert Blatter\*, Member, Sion
- Helga Meier Schnorf\*, Member, Zug
- Matthias Merki\*, Member, Basle (†)
- Martina Kuoni, Basle
- Urs Notter, Member\*, Bürgenstock
- Prof. Dr. Urs Metzger, Medical Consultant, Uitikon-Waldegg
- Dr. Michael Montemurro, Medical Consultant, Lausanne

\* founder members

#### Achievements of the SWISS GIST-Group:

- GIST-Documentary Film "Living with GIST" 2011, Silver Award Winner, Edi Prize 2011 for Quality Swiss films, (Federal Department of Home Affairs) November 3, 2011
- 2nd Annual GIST-Prize 2011, November 24, 2011
- Formation Member of the First Swiss Patient Coalition Group, September 10, 2011  
Helga Meier Schnorf, Board Member / Coordination

#### Foundation: A few words from the new president, Martin Wettstein:

I wish the newly created "Association for the support of GIST affected in Switzerland" good luck, much enthusiasm and perseverance. The association is important for all patients suffering from GIST, their families, treating physicians and partners in the pharmaceutical industry. Moreover, for me, the treatment of patients suffering from GIST has a particular significance, as it is a model for the treatment of other types of tumours and cancers. I want to express my great joy in the creation of the association. Thanks to the considerable preparatory works provided by the deceased, (and unfortunately himself affected) Dr. Ulrich Schnorf and the selfless continuation of this work by his widow, Mrs. Helga Meier Schnorf. A very invaluable basis for the setting up of a patient organisation was laid with remarkable presence and assuring continuity. I am taking the opportunity to express my particular thanks for all of that. I also want to thank all the founding members, in particular our highly qualified medical consultants, Prof. Dr. Urs Metzger and Dr. Michael Montemurro. They give us the courage to take control of this association with the guarantee of professional support along with broad knowledge. Finally, I would like to thank for the confidence and the privilege granted to me to act as the first president of this association.

Martin Wettstein, President

#### YOUTH ACCUMULATION ASSOCIATION

"Together with Youth, a Better Life for Young People..."

<http://www.gencbirikim.org/>



Youth Accumulation Association was established in 2006 in Muş (Turkey) by a group of young people in order to contribute to the social and personal development of young people. The four main objectives of our association are:

1. To enhance respect, friendship and tolerance among young people and to help them to become conscious individuals
2. To support the talents of young people by trainings
3. To help young people to participate and to harmonize not only in the business life but also in civil life successfully
4. To protect and to raise awareness among young people about any kind of health threat, especially about cancer



In order to realize our objectives, we cooperate with families, local authorities, related ministries, primary schools, high schools and universities and we develop projects with them. Until today, we organize many local, national and international projects and activities together with our stakeholders. We realized many international projects in Mus under the Youth Program of Center of European Union Education and Youth Programs (National Agency) and enabled the participation of young people of Mus to these projects as well as to the other projects abroad that we are partner of.

International projects that we organized in cooperation with various youth organizations from different countries are:

- Raising Awareness of Young People about Cancer, April 2008
- We are Coming, April 2008
- Young People Meet With Art, August 2009
- European Citizenship, October 2010

Under the frame of cooperating with different actors and institutions, in 2009 we realized a peer education project titled “From Youth to Future” supported by Embassy of United States of America. In 2008, under the Grand for Local Projects Program of Embassy of Japan, we started to realize the project titles “Healthy Development” and in 2009 within the project a vehicle consisting mammography instrument was bought. With the help of the protocol that we signed with Provincial Directorate of Health, our vehicle started to make breast cancer scan in 12 different cities. Our aim is to scan 4000 people every year within Health Development project.

International “Blooming Plant” Oncology Days, one of the most important international activities of ours for protecting children and young people against cancer, was realized in 2007 in Mus for the first time. Each year, International “Blooming Plant” Oncology Days is being organized with a different theme; among the participants there are representative of public institutions, non governmental organizations, youth centers, international institutions as well as scientists. The event has the characteristic of a platform where the best practices and experiences about combating cancer are being shared.

Unemployment rate in Mus is higher than any other cities in Turkey. By the nature of being a civil society organization, contributing to the development of our city and region by our work is a duty for us. Including more young people into our projects and enabling more young people from our city and region to participate actively in the civil society are our aims. By this, in 2009, with the participation of young people from our region we realized the project titles “Active and Democratic Young People Meet in East” supported by Civil Society Development Program of Central Finance and Contract Unit.

EURODESK is and European information network which provides information about the European opportunities and activities for young people in education and youth field. In 2010, our application to become EURODESK Local Relay approved and in April 2010 we become EURODESK Local Relay in Mush.

#### **Our Memberships:**

- EURODESK Turkey Network
- European Cancer Patient Coalition
- Hand in Hand against Cancer Federation
- Turkish Youth Federation



# About Sarcoma Patients EuroNet



## About Sarcoma Patients EuroNet

**Sarcoma Patients EuroNet Association (SPAEN), the European Network of Sarcoma, GIST and Desmoid Patient Advocacy Groups**, was founded in April 2009 with the aim of extending information services, patient support and advocacy to patient organisations for the benefit of sarcoma patients across the whole of Europe. 11 foundation members initiated the foundation of SPAEN and membership is open to patient groups working with sarcoma patients across Europe. SPAEN is an European association – legally registered under German law.



Acting in partnership with clinical experts, scientific researchers, industry and other stakeholders SPAEN is working to improve the treatment and care of sarcoma patients in Europe through improving information and support, and by increasing the visibility of sarcoma with policymakers and the public. SPAEN currently has 21 members from 13 countries.

### 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.

### The main objectives of SPAEN are:

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

Sarcoma Patients EuroNet e.V./Assoc. is supported by leading “European Sarcoma Experts (Expert Groups)” and the pan-European collaboration of sarcoma specialist researchers and doctors, Conticanet. In 2010 Sarcoma Patients EuroNet has established an **Medical Advisory Board with a high level of scientific expertise**.

### Medical Advisory Board

The objectives of the Medical Advisory Board is to support SPAEN in:

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



**The following 12 experts are appointed as members of the SPAEN Medical Advisory Board (2010 - 2013):**

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

Through the Medical Advisory Board SPAEN aims to ensure patient representation in, and integration to, major scientific committees and groups of experts at national and European levels.

**SPAEN Board of Directors and Officers**

The current members of the SPAEN Board of Directors (2010 – 2013) are:



Roger Wilson, President (UK)  
Sarcoma UK



Estelle Lecointe,  
Vice President (France)  
I'A.F.P.G. "Ensemble contre le  
GIST" & Info Sarcomes



Christina Baumgarten,  
Vice President (Germany)  
SOS Desmoid



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



Barabara Doré,  
Secretary (UK/USA)  
GIST Support UK & GIST Support  
International



Michael Sayers,  
Board Member (UK)  
GIST Support UK



Michaela Geissler  
SPAEN Project Manager (SPAEN Secretariat)



## SPAEN Member Organisations

SPAEN welcomes every Sarcoma, GIST or Desmoid Patient Group/Organisation in Europe as Full Member. Full Members are entitled to vote at the Annual General Assembly. All other PAGs from outside Europe are welcome to join SPAEN as Associate Members.

Among the benefits of membership are: information exchange with other members, receiving SPAEN newsletters and briefings, an invitation to SPAEN's annual meeting, mention of your organisation on our website, and finally, as part of a united international sarcoma community we all have a better chance to have our voices heard.

### **SPAEN Full Members are currently (as of 01.11.2012):**

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

### **SPAEN Associate Members (as of 01.11.2011):**

1. USA: GSI - GIST Support International
2. USA: Sarcoma Alliance
3. USA: The Liddy Shriver Sarcoma Initiative

## Research Networks

SPAEN works in close collaboration with a variety of Research Networks, such as EORTC, SARC, EUROSARC, Conticanet, Sarcoma League, Sacoma Worldnet and national Sarcoma Expert Groups.

Prof. Dr. Jean Yes Blay (EORTC President and Director of Conticanet) who is one of the initiators of SPAEN states: "Sarcoma Patients EuroNet is a very welcome development. We need to involve patients in clinical trials at the design stage so that the relevance of what we



do can be considered at the outset. In addition SPAEN will be valuable helping patients understand what being treated in a clinical trial could mean to them. Together we can complete research more quickly

## Contact

Sarcoma Patients EuroNet e.V./Assoc  
SPAEN Administration Office

Mrs. Michaela Geissler (Project Manager)  
Am Rothenanger 1B  
D-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  
Usa-Straße 1  
61321 Bad Nauheim/Germany



# **My request to SPAEN**





# Evaluation Form SPAEN Conference





## EVALUATION FORM

Please complete the form and return to the registration desk before you leave the conference. Otherwise we would be grateful to receive your feedback via email to [info@sarcoma-patients.eu](mailto:info@sarcoma-patients.eu) or per fax to +49 8962836808. Thank you very much!

- You are a representative of  a Sarcoma/GIST organization  
 an organization for patients with Desmoids  
 a general cancer organization  
 a research group interested in Sarcomas, GIST or Desmoids  
 the pharmaceutical industry
- You are  a sarcoma patient or relative, who is highly motivated to start a new patient group  
 a speaker/medical expert

### 1. Your general feedback on the conference

- |     |   |                    |   |   |   |   |   |                     |
|-----|---|--------------------|---|---|---|---|---|---------------------|
| 1A. | The conference was...                         | Not valuable       | 1 | 2 | 3 | 4 | 5 | Very valuable       |
| 1B. | Information provided was...                   | Not useful         | 1 | 2 | 3 | 4 | 5 | Very useful         |
| 1C. | The issues discussed were...                  | Not relevant       | 1 | 2 | 3 | 4 | 5 | Very relevant       |
| 1D. | The conference was...                         | Not well organized | 1 | 2 | 3 | 4 | 5 | Very well organized |
| 1E. | Time allocated for <u>each session</u> was... | Insufficient       | 1 | 2 | 3 | 4 | 5 | Sufficient          |
| 1F. | Time allocated for <u>networking</u> was      | Insufficient       | 1 | 2 | 3 | 4 | 5 | Sufficient          |

### 2. Your feedback on special sessions (please rate with points)

#### THURSDAY

##### 2A. Novartis Europe welcomes SPAEN in Italy

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_



**2B. The position of the healthcare industry in a changing environment**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**2C. Clinical Trials: Learning more about “Good Clinical Practice (GCP)”**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**2D. Understanding some basic trial-designs in Sarcomas (incl. a placebo-trial)**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**2E. What can be done to improve the methodology of clinical research on rare cancers?**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**2F. Different ways to provide access to innovative treatments in Europe?**

**What means Compassionate Use – Early Access Program – Off Label Drugs?**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**FRIDAY – GIST TRACK**

**2.1. Risk stratification in GIST and adjuvant treatment**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**2.2. Understanding four key factors for successful therapy management in GIST:**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_



**2.3. How to manage skin toxicities in GIST?**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.4. Sharing best Practice/Brainstorming: How can GIST-patient groups help their patients in the field of side effect management?**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.5. Regorafenib, Masitinib, Dovitinib and others: Update on systemic treatment options and clinical trials in GIST**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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## **FRIDAY – SARCOMA TRACK**

**2.6. Managing chemotherapy in Sarcomas**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.7. Short profiles of rare Sarcoma Subtypes: Synovial Sarcomas**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.8. Short profiles of rare Sarcoma subtypes: Osteosarcomas**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.9. Update on systemic treatment options and clinical trials in Sarcomas**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**FRIDAY – DESMOID TRACK**

**2.10. Understanding molecular genetics and pathology in Desmoids**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**2.11. The role of surgery in Desmoids**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**2.12. The role of radiotherapy in Desmoids**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**2.13. Update on systemic treatment options and clinical trials in Desmoids**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_

**Friday - common track**

**2.G. Understanding CINSARC in GIST and Sarcomas**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points  
Your comment/feedback: \_\_\_\_\_  
\_\_\_\_\_



**2.H. The role of tissue-/biobanks for sarcoma research**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.I. - How is tissue /biobanking normally organized?**

**- What are efforts/investments to establish a tissue-/biobank?**

**- What are the burdens/restrictions/problems we are facing in Europe?**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.J. Radiooncology in Sarcomas, GIST and Desmoids**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.K. Metastasectomy in Sarcomas and GIST**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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## Saturday

**2.L. Let's try to better understand the situation of healthcare in Eastern Europe – especially in the field of Sarcomas, GIST and Desmoids...**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.M. Improving the impact of patient participation in HTA = Health Technology Assessment (presentation + practical issues)**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

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**2.N. After more than 10 years working with HTA = NICE in the UK: How is the current process of evaluating cost-effectiveness and what are the main findings/insights from a patients perspective?**

Relevance for you? (please rate with max. 10 points) | \_\_\_\_\_ | points

Quality of the session? (please rate with max. 10 points) | \_\_\_\_\_ | points

Your comment/feedback: \_\_\_\_\_

\_\_\_\_\_

**3. Your feedback on special questions/topics**

**3A. Were any topics missing from the program?**

No  Yes

If yes, do you have any special topics/ideas/wishes for future conferences/sessions?

\_\_\_\_\_  
\_\_\_\_\_

**3B. What did you find the MOST valuable aspect of this conference?**

\_\_\_\_\_  
\_\_\_\_\_

**3C. What did you find the LEAST valuable aspect of this conference?**

\_\_\_\_\_  
\_\_\_\_\_

**3D. What worked well at this conference that we should continue to do?**

\_\_\_\_\_  
\_\_\_\_\_

**3E. What could we do to make this conference more relevant for you?**

\_\_\_\_\_  
\_\_\_\_\_

**4. Space for your special comments/suggestions/notes/ideas, etc.**

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