



## Conference Book

**4th SPAEN Annual Conference for  
Organizations  
Representing Patients With  
Sarcoma, GIST or Desmoid-Tumours**

**10. - 12. October 2013  
Novotel London Paddington, London/UK**

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

**Dear Delegates,**

It is my pleasure to welcome you to London and the fourth annual meeting and General Assembly of Sarcoma Patients Euronet.

It has been a busy year for many of us and although some of us occasionally meet at events held by other organisations it is during these few days each year that we really can spend time getting to know our fellow sarcoma advocates. On behalf of my colleagues on the SPAEN 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 I hope you will have the opportunity to see more of London with its extraordinary mixture of history, culture and life lived to the full 24/7.

Kindest regards

A handwritten signature in black ink, appearing to read 'Roger Wilson', with a stylized flourish at the end.

Roger Wilson CBE  
President Sarcoma Patients EuroNet  
Hon President Sarcoma UK



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**4th SPAEN Annual Conference for Organizations  
Representing Patients With Sarcomas, GIST or Desmoid-Tumours  
Novotel Paddington Hotel  
10-12 October 2013**



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

## AGENDA

<b>DAY 1 – THURSDAY 10th October 2013</b>	
12:30	<i>L I G H T L U N C H - Novotel Paddington Restaurant (60 min.)</i>
13:30	<b>OFFICIAL START OF THE CONFERENCE</b> <i>Main room "Sheldon Suite"</i>
13:30 - 14:00	Opening, Welcome, Organizational Issues, Thanks to the Sponsors, etc. <i>Roger Wilson, SPAEN, UK &amp; Markus Wartenberg, SPAEN, Germany</i>
14:00 – 14:30	GSK Europe welcomes SPAEN in UK/London <i>Raz Dewji, GlaxoSmithKline Oncology Global Medical Affairs, UK</i>
14:30 – 15:15	<b>GETTING THE BEST OUT OF YOUR THERAPY</b> Status report from the SPAEN Task Force "Therapy and side effect management" Problems and experiences from other advocates - examples of adherence tools? <i>Markus Wartenberg, SPAEN, Germany</i>
15:15 - 16:00	The process of authorisation for new generic drugs <i>Dr. Francesco Pignatti, Scientific and Regulatory Management Department, European Medicines Agency, UK</i>
16:00 – 16:30	<i>C O F F E E B R E A K (30 min.)</i>
16:30 - 17:00	<b>REIMBURSEMENT PROCESS: BEING INVOLVED, BEING LISTENED TO AND BUILDING OWN EVIDENCE</b> Introduction to Health Technology Assessment (HTA) How can patient groups be involved in the process of access to new therapies? <i>Dr. Karen Facey, Health Policy Consultant, UK</i>
17:00 - 17:30	Build your own evidence base - experiences with NICE in UK <i>Eric Low, Myeloma UK</i>
17:30 - 18:00	Questions & Answers
<i>B R E A K B E F O R E D I N N E R</i>	
19:30 - 22:00	<b>Internal Dinner (Novotel Paddington Restaurant)</b>



## Notes for SPAEN Conference

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## DAY 2 – FRIDAY 11th October 2013

7:30 Optional: *Morning Talk - What to do, when treatment comes to an end? (60 Minutes - Sheldon Suite)*  
*Elaine Stewart & Rachel Brindley, London Maggie's Centre*

9:00 - 10:30	<b>ADVOCACY MARKET PLACE SESSION</b> (4 parallel sessions, delegates can choose 3 sessions each 25 minutes + 5 min switch) <ol style="list-style-type: none"> <li>Working with the experts, <i>Estelle Lecointe, SPAEN</i></li> <li>Working with the pharma and other funding sources, <i>Markus Wartenberg, SPAEN</i></li> <li>How to run a patient group meeting, <i>Barbara Dore, SPAEN</i></li> <li>Patient group survey, <i>Roger Wilson &amp; Claire Kelleher, Sarcoma UK</i></li> </ol>
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10:30 – 11:00 **C O F F E E B R E A K** (30 min.)

11:00 - 12:30	<b>STRATEGIES FOR METASTASIS IN SARCOMAS AND GIST</b> Perspectives of oncologist and surgeon <i>Ian Judson, The Royal Marsden Hospital, UK</i> <i>Marco Fiore, Istituto Nazionale Tumori Milan, Italy</i>
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12:30 – 13:30 **L I G H T L U N C H** - Novotel Paddington Restaurant (60 min.)

### PARALLEL TRACKS FOR GIST, SARCOMA AND DESMOIDS

	<b>GIST TRACK</b> <b>Sheldon Suite</b> <b>Chair: Barbara Doré</b>	<b>SARCOMA TRACK</b> <b>Room Bishops</b> <b>Chair: Estelle Lecointe</b>	<b>DESMOID TRACK</b> <b>Room Westbourne</b> <b>Chair: Christina Baumgarten</b>
	Profiles of and clinical practice with the currently approved therapies in GIST: Getting the best out of your therapy	Update on new and ongoing trials <i>Jean Yves Blay, Centre Leon Berard Lyon, France</i>	Radiooncology (45 min.) <i>Rick Haas, The Antoni van Leeuwenhoek Hospital Amsterdam, Netherlands</i>
13:30 – 14:00	Imatinib <i>Ian Judson, The Royal Marsden Hospital, UK</i>	Short profiles of sarcoma subtypes <ul style="list-style-type: none"> <li>Chordoma  <i>Hans Keulen, Chordoma Foundation, NL</i> </li> </ul>	Unravelling the desmoid-type fibromatosis tumor at the cellular level: GSK-3beta, a new piece of the puzzle (15 min) <i>Daniela Segat, Istituto Malattie Rare "Mauro Baschirotto", Italy</i>
14:00 – 15:00	Sunitinib and Regorafenib <i>PD Dr. Peter Reichardt, HELIOS Klinikum Bad Saarow, Germany</i>	<ul style="list-style-type: none"> <li>Uterine Sarcoma  <i>Beatrice Seddon, UCL Hospital NHS Trust, UK</i> </li> </ul>	Brainstorming for a European Round Table on Desmoids in 2014 (30 min)

15:00 – 15:30 **C O F F E E B R E A K** (30 min.)

	<b>GIST TRACK</b>	<b>SARCOMA TRACK</b>	<b>DESMOID TRACK</b>
15:30 – 16:15	Surgery of GIST <i>Sylvie Bonvalot, Institut Gustave Roussy, Villejuif, France</i>	The interdisciplinary process of diagnosis <i>Marco Fiore, Istituto Nazionale Tumori Milan, Italy</i>	Update from clinical trials and new clinical trials <i>Prof. Bernd Kasper, Mannheim University Medical Center, Germany</i>
16:15 - 17:00	Clinical trials and innovations in GIST <i>Sebastian Bauer, Universitätsklinikum Essen, Germany</i>	Peer review of quality of treatment, access to treatment and centres of excellence <i>Julia Hill, National Cancer Peer Review, UK</i>	Management of desmoids <i>Sylvie Bonvalot, Institut Gustave Roussy, Villejuif, France</i>



## Notes for SPAEN Conference

A full page of blank graph paper. The grid consists of small squares formed by thin gray lines. There are 20 columns and 20 rows of squares, creating a total area of 400 small squares. The grid covers the entire page except for a narrow margin at the top.



17:00 - 17:20	<b>SPAEN Partnerships and Collaborations</b> Introduction World Sarcoma Network <i>Jean Yves Blay, Lyon, France</i>
17:20 - 17:40	EORTC and EUROSARC <i>Winette van der Graaf, Chair EORTC STBSG, Netherlands and Estelle Lecointe, SPAEN, France</i>
17:40 - 17:50	Patient database for chordoma patients <i>Hans Keulen &amp; Sierk Bakker, Chordoma Foundation</i>
17:50 - 18:00	Formation of a European Consortium for Wild Type and Paediatric GIST <i>Barbara Dore, SPAEN &amp; Jayne Bressington, PAWS/GIST Support UK</i>
<b>BREAK BEFORE DINNER</b>	
19:00 – 23:00	<b>Departure to External Dinner</b>

<b>DAY 3 – SATURDAY 12th October 2013</b>	
7:30 Optional:	<i>Morning Talk - Who cares for the carer? (60 Minutes - Sheldon Suite)</i> <i>Elaine Stewart &amp; Rachel Brindley, London Maggie's Centre</i>
09:00 - 10:30	<b>Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2013/2014</b> All delegates are welcome (voting rights for SPAEN Members only)
10:30 - 11:00	<b>COFFEE BREAK (30 min.)</b>
11:00 - 11:45	<b>PATIENT INVOLVEMENT IN CLINICAL RESEARCH</b> Public involvement in clinical research <i>Derek Stewart, Associate Director for Involvement at National Institute for Health Research - Clinical Research Network, England</i>
11:45 - 12:30	Practical experiences and examples from patient organisations <i>Markus Wartenberg, SPAEN, Germany</i>
12:30 – 13:30	<b>LIGHT LUNCH (60 min.)</b>
13:30 - 15:00	<b>BASICS OF STRATEGIC PLANNING FOR PATIENT GROUPS</b> Lecture: The basics of strategic planning and practical experiences from a patient group <i>Markus Wartenberg, SPAEN, Germany &amp; Lindsey Bennister, Sarcoma UK</i>
15:00 - 15:15	<b>End of meeting, Summary, Feedback-Forms, Closing Remarks, Thanks to the Presenters &amp; Sponsors</b>
15:15	<b>OFFICIAL END OF THE CONFERENCE</b>
15:30 - 19:00 (2 x 90 min + 30 min break)	<b>"Understanding Cancer: Biology 101 for Patient Advocates"</b> <ul style="list-style-type: none"> <li>• The healthy cell</li> <li>• Definition and characteristics of tumors</li> <li>• Reasons for the development of a tumor</li> <li>• Mechanisms and pathways of tumor development</li> <li>• Development of sarcomas</li> <li>• Targets and targeted therapy</li> </ul> <i>Anette Duensing, M.D., Pathologist and GIST Scientist/Researcher University of Pittsburgh Cancer Institute, USA</i>





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## Logistic Information

### Conference Venue

#### **Novotel London Paddington**

3 Kingdom Street  
Sheldon Square  
Paddington  
London, W2 6BD  
UNITED KINGDOM

Web: <http://www.novotel.com/gb/hotel-6455-novotel-london-paddington/index.shtml>

Tel (+44)207/6600679

Fax (+44)207/2666010

E-mail H6455-re10@accor.com

### Registration

The registration desk will be open at Thursday, 10th of October from ca. 11:00 and can be found in front of the main meeting room „Sheldon Suite“. At the registration desk you will receive your name badge and conference book as well as final information.

### Conference programme

The official programme will start on Thursday 10th October 2013 at 13:30 and will close at 15:15 on Saturday, 12th of October.

Thursday, 10th of October: 13:30 – 18:00

Friday, 11th of October: 8:30 – 18:00

Saturday, 12th of October: 8:30 - 15:15 (end of the conference)

On Saturday afternoon an optional training course "Understanding Cancer: Biology 101 for Patient Advocates" will be offered from 15:30 to 19:00.

### Meeting Rooms

The main meeting room is “Sheldon Suite”. For the parallel sessions on Friday, 11<sup>th</sup> of October we will split the group for the GIST, sarcoma and desmoid track.

- The GIST track will be held in the main meeting room „Sheldon Suite“
- The Sarcoma track will be held in room „Bishops“
- The Desmoid track will be held in room „Westbourne“

Coffee breaks will be served in front of the main meeting rooms. Lunch will be served in the Novotel Paddington restaurant.



## Dinner

Thursday, 10th of October: 19:30 Internal Dinner at the Novotel London Paddington restaurant  
Friday, 11th of October: 19:00 meeting in the hotel lobby and transfer to an external dinner at the Dickens Inn ([www.dickensinn.co.uk](http://www.dickensinn.co.uk)) with a double deck coach, return at ca. 22:45.

## Conference Secretariat

Mobile phone during the Conference:  
+49-173-4517589 (SPAEN Secretariat, Michaela Geißler) or +49-171-4700919  
(Markus Wartenberg, SPAEN Financial Director)

## WiFi

The hotel offers free WiFi.

## Liability Disclaimer

Your participation in the SPAEN conference 2013 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 2013 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

Novotel London Paddington

3 Kingdom Street  
Sheldon Square  
Paddington  
London, W2 6BD  
UNITED KINGDOM



### Arrivals per plane

Taking the Heathrow express from Heathrow airport to Paddington station is the best option for transportation to the hotel. Travel time is ca. 15 minutes. At Paddington Station head towards the Hammersmith & City underground line running adjacent to platform 8. Once out of the station, bear left and follow the signs towards Sheldon Square and Kingdom Street. Follow the waterline until you reach Starbucks, at which point turn left. On the far side of Sheldon Square you will see Kingdom Street with the Novotel at the end (signage visible from this point).

**Recommendation:** Check the timetable of the Heathrow express and **buy online ticket in advance** here: <https://www.heathrowexpress.com>

### Arrivals per train

Take the Bakerloo, Circle, District or Hammersmith & City line to Paddington Station. At Paddington Station head towards the Hammersmith & City underground line running adjacent to platform 8. Once out of the station, bear left and follow the signs towards Sheldon Square and Kingdom Street. Follow the waterline until you reach Starbucks, at which point turn left. On the far side of Sheldon Square you will see Kingdom Street with the Novotel at the end (signage visible from this point).

A London tube map can be found here: <http://www.tfl.gov.uk/assets/downloads/standard-tube-map.pdf>



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Representing Patients With Sarcomas, GIST or Desmoid-Tumours  
10 - 12 October 2013**



**Sarcoma  
Patients  
EuroNet**

**Participants List (A-Z)**

1	Abascal Briones	Encarnita	Sarcoma Patients Spanish Association (AEAS)	Spain
2	Alvarado	Rolyn	The Royal Marsden Hospital	UK
3	Asselberg	Jack	Contactgroep GIST Netherlands	Netherlands
4	Bacconier	Simon	World Sarcoma Network	France
5	Bakker	Sierk	Chordoma Foundation Europe	Netherlands
6	Barrett	Jane	Sarcoma UK	UK
7	Bauer	Sebastian	Universitätsklinikum Essen	Germany
8	Baumgarten	Christina	SPAEN/SOS Desmoids	Germany
9	Bennister	Lindsey	Sarcoma UK	UK
10	Benson	Charlotte	The Royal Marsden Hospital	UK
11	Berezin	Nancy	GIST Support International	USA
12	Blay	Jean Yves	Centre Leon Berard Lyon	France
13	Bonvalot	Sylvie	Institut Gustave Roussy	France
14	Breban	Florina	Romanian Rare Cancer Association	Romania
15	Bressington	Jayne	GIST Support UK/PAWS-GIST	UK
16	Castiglione	Federica	Novartis Oncology Region Europe	Italy
17	Deck	Uli	ARTIS-Photographie	Germany
18	Delin	Karen	Sarcoma UK	UK
19	Dewji	Mohamad	GSK	UK
20	Díaz León	Angeles	Sarcoma Patients Spanish Association (AEAS)	Spain
21	Dibabu	Darara	Bayer	UK
22	Decise	Donatella	Novartis Farma S.p.A.	Italy
23	Dore	Barbara	SPAEN/GIST Support UK	UK
24	Dünsing	Anette	University of Pittsburgh Cancer Institute	USA
25	Emnese	Darko	Romanian Rare Cancer Association	Romania
26	Ene	Simona	Hope Association	Romania
27	Facey	Karen	Health Policy Consultant	Scotland
28	Falconer	David	GIST Support UK	UK
29	Fiore	Marco	Istituto Nazionale Tumori Milan	Italy
30	Fonrobert	Piotr	Polish GIST Patients Support Association	Poland
31	Francis	Mike	Guy Francis Bone Cancer Research Fund	UK
32	Geissler	Michaela	SPAEN	Germany
33	Gherlinzoni	Francesco	Associazione Paola per i tumori muscolo.	Italy
34	Gonzato	Ornella	Associazione Paola per i tumori muscolo.	Italy
35	Haas	Rick	The Antoni van Leeuwenhoek Hospital	Netherlands
36	Hacket	Sam	The Royal Marsden Hospital	UK
37	Hibberdine	Leigh	Sarcoma UK	UK



38	Hill	Julia	National Cancer Peer Review	UK
39	Hobson	Gemma	Pfizer	UK
40	Homb	Frode	Sarkomer	Norway
41	Hutchins	Angela	The Royal Marsden Hospital	UK
42	Ippolito	Vincenzo	Le Ali Onlus	Italy
43	Juan Nogués	Juan	PharmaMar	Spain
44	Judson	Ian	Royal Marsden Hospital	UK
45	Julian	Maria	PharmaMar	Spain
46	Kasper	Bernd	Mannheim University Medical Center	Germany
47	Kelleher	Claire	Sarcoma UK	UK
48	Keulen	Hans	Chordoma Foundation Europe	Netherlands
49	Khan	Sadya	GSK	UK
50	King	Alison	The Royal Marsden Hospital	UK
51	Kollar	Attila	The Royal Marsden Hospital	UK
52	Krstevska	Sonja	GIST patient group Macedonia	Macedonia
53	Krstevski	Dejan	GIST patient group Macedonia	Macedonia
55	Krzywicka	Malgorzata	POLISH GIST Patients Support Association	Poland
56	Labreveux	Claire	GSK	France
57	Ladva	Jay	GSK	UK
58	Lecointe	Estelle	SPAEN/Ensemble contre le GIST	France
59	Lodi Rizzini	Vanni	Aldo Arienti Amici C.O.O. Onlus	Italy
60	Low	Eric	Myeloma UK	UK
61	Mahot	Audrey	GIST Group Switzerland	Switzerland
62	Manson	Stephanie	GSK	UK
63	Martin-Liberal	Juan	The Royal Marsden Hospital	UK
64	Meier-Schnorf	Helga	GIST-Gruppe Schweiz	Switzerland
65	Mihaylova	Adelina	GIST Alliance for Patients	Bulgaria
66	Mitchell	Debra	GIST Support UK	UK
67	Montemurro	Michael	The Royal Marsden Hospital	UK
68	Moreaux	Georges	SOS Desmoide France	France
69	Moshe	Gideon	Israeli GIST group	Israel
70	Moshi	Grace	Sarah Grace Sarcoma Foundation	Australia
71	Petrikova	Galina	The Royal Marsden Hospital	UK
72	Piccinelli	Claudia	Le Ali Onlus	Italy
73	Piccolo	Francesca	Le Ali Onlus	Italy
74	Pilgermann	Kai	Das Lebenshaus	Germany
75	Popova	Yuliana	GIST Alliance for Patients	Bulgaria
76	Rasool	Mohammad	The Royal Marsden Hospital	UK
77	Reichardt	Peter	HELIOS Klinikum Bad Saarow	Germany
78	Rigaux	Philippe	SOS Desmoide France	France
79	Robinson	David	GIST Support UK	UK
80	Robinson	Judith	GIST Support UK	UK
81	Roffe	Emma	Takeda UK	UK
82	Sahri	Raija	Finnish GIST Patients Network	Finland



<b>83</b>	Sayers	Michael	SPAEN/GIST Support UK	UK
<b>84</b>	Seddon	Beatrice	UCL Hospital NHS Trust	UK
<b>85</b>	Seeli-Maduz	Franziska	Sarcoma Center Zurich	Switzerland
<b>86</b>	Segat	Daniela	Desmon Association/BIRD Foundation	Italy
<b>87</b>	Stenius	Jan	Pfizer	Sweden
<b>88</b>	Stewart	Derek	National Institute for Health Research	UK
<b>89</b>	Strauss	Dirk	The Royal Marsden Hospital	UK
<b>90</b>	Sylvanowicz	Michelle	Bayer	Germany
<b>91</b>	Tomassone	Paolo	A.I.G. Associazione Italiana GIST Onlus	Italy
<b>92</b>	Väisänen	Marjo	Finnish GIST Patients Network	Finland
<b>93</b>	van Arem de Haas	Ellen	Sarcoma NL	Netherlands
<b>94</b>	van der Graaf	Winette	Radboud University Nijmegen Medical Centre	Netherlands
<b>95</b>	van der Zande	Hilly	Sarcoma NL	Netherlands
<b>96</b>	van Ootmerssen	Gerard	Contactgroep GIST Belgium	Belgium
<b>97</b>	Wallace	Anna	Living Beyond Diagnosis	UK
<b>98</b>	Wartenberg	Markus	SPAEN/Das Lebenshaus	Germany
<b>99</b>	Wettstein	Martin	GIST Group Switzerland	Switzerland
<b>100</b>	Wiles	Maya	Sarcoma UK	UK
<b>101</b>	Wilson	Roger	SPAEN/Sarcoma UK	UK
<b>102</b>	Yüce	Salih	Youth Accumulation Association	Turkey
<b>103</b>	Zhong	Zhenxi	Shanghai Roots & Shoots	Shanghai
<b>104</b>	Zigdon	Avi	Israeli GIST Group	Israel
<b>105</b>	Zik	Ragip	Youth Accumulation Association	Turkey





## Speaker Who is Who?

### **Dr. Sebastian Bauer, University Hospital Essen, Germany**



Sebastian Bauer is working at the Tumour Center of the University Hospital Essen and is heading the sarcoma field in the Internal Clinic (tumour research). His clinical main research focus is on phase I and II studies for the treatment of soft tissue sarcomas including GIST and therapy-optimisation-studies of bone and soft tissue sarcomas.

### **Prof. Dr. Jean-Yves Blay, Université Claude Bernard Lyon, France**



Jean-Yves Blay, MD, PhD, is Professor of Medicine in Medical Oncology at the Université Claude Bernard in Lyon, France, currently Head of the Medical Oncology Department and the Institute for Clinical Science at the Centre Leon Berard, the regional Cancer Center in Lyon France. Dr. Blay obtained his medical degree in 1990 specialising in oncology. In 1994 he received his PhD from the Université Claude Bernard, for his research on the role of interleukin 6 in tumour progression and resistance to treatment in renal cell carcinomas. He also holds a Masters in Biological Oncology "Bases Fondamentales de l'Oncogénèse, 1988, Paris VII, and a Masters in Statistics, Paris XI, in 1989. Since 2001, Dr. Blay has served as Chairman of the French Sarcoma Group and currently acts as the Network Director of Conticanet, a network of excellence funded by the EU commission dedicated to novel treatment approaches in sarcomas ([www.conticanet.eu](http://www.conticanet.eu)). At the EORTC, Dr Blay has been active in the Translational Research Advisory Committee, the Protocol Review Committee, and as a faculty member on EORTC educational programs. He is the former Chair of the EORTC Soft Tissue and Bone Sarcoma Group. Dr. Blay is an active member of a number of professional groups including the American Society of Clinical Oncology, the American Association for Cancer Research, the American Society of Haematology, the Connective Tissue Oncology Society (Board member 2001-2004), the French Society of Cancer (Board member 2005-2011), the European Association of Cancer research, and the European Society of Medical Oncology (National Representative for France). Dr Blay is currently serving as the President of the European Organisation for Research and Treatment of Cancer (EORTC).

### **Dr. Sylvie Bonvalot, Institut Gustave Roussy, Villejuif, France**



Sylvie Bonvalot received her MD with surgical specialty in 1990. She was formed to Good Clinical Practice as fellow in Paris XI University. Then, she completed her residency training in General Surgery c/o Institut Gustave Roussy (IGR) in Villejuif, France. She is Chief of the sarcoma surgery at IGR since 1997, with her clinical practice and research interests focused exclusively on this disease. She graduated as PhD in 2006. She is the Principal Investigator of several French and international trials on sarcoma and desmoids and has authored more than 90 scientific publications. For 2006, she is Head of visceral surgery at the Gustave Roussy Institute in France. She serves as chairman of regional treatments of the French Sarcoma Group, is a member of the Sarcoma Task Force of the European Society for Medical Oncology (ESMO) and a member of EORTC Soft Tissue and Bone Sarcoma Group. She served from 2005 to 2008 at the Board of Directors of the Connective Tissue Oncology Society (CTOS) and is a full Member of the National Academy of Surgery in France. She operates about 180 sarcomas per year including visceral, retro-peritoneal and soft tissue.



**Dr. Rachel Brindley, London Maggie's Center, UK**

Dr Rachel Brindley is a clinical psychologist with 5 years experience specialising in working with people with physical health problems. In the NHS she has worked with people with chronic pain and chronic lung conditions. Since joining the team at Maggie's she has developed a strong interest in using a psychological approaches to understanding and supporting anyone affected by cancer. Maggie's centres are for anyone affected by cancer. They are places where people are welcome whenever they need us – from just being diagnosed, or undergoing treatment, post-treatment, recurrence, and end of life or in bereavement. We also welcome family and friends, as they are often deeply affected by cancer too. We know that those who love and look after someone with cancer can feel just as frightened, vulnerable and uncertain.

**Dr. Anette Duensing, M.D., Assistant Professor of Pathology, University of Pittsburgh School of Medicine, USA**

Dr. Anette Duensing received her M.D. as well as training in Pathology from the University of Hannover School of Medicine (MHH), Hannover, Germany. In 1999, she joined Dr. Jonathan Fletcher's laboratory (Brigham and Women's Hospital, Harvard Medical School, Boston, MA) for a post-doctoral research fellowship that was funded, in part, by the Dr. Mildred Scheel Stiftung für Krebsforschung. Since 2003, Dr. Duensing heads her own, independent research laboratory at the University of Pittsburgh Cancer Institute, Hillman Cancer Center. Her major research interests include the molecular biology of gastrointestinal stromal tumors (GISTs), novel treatment options for patients who have imatinib-resistant tumors, and targeted therapies for GISTs. Dr. Duensing is currently an Assistant Professor of Pathology at the University of Pittsburgh School of Medicine.

**Karen Facey, Health Policy Consultant, UK**

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 a member of the Scottish Health Technologies Group that appraises non medicinal technologies. Karen was Chair of the HTAi Interest Group on Patient/Citizen Involvement in HTA for seven years and is now undertaking two research projects for them – developing principles for patient engagement in HTA and outlining processes to support patient organizations to submit patient perspectives to HTA. Karen was guest editor on a special themed edition of the International Journal of Technology Assessment in Health Care about patient issues and she is currently co-editing a special edition of The Patient journal about rare diseases.

**Dr. Marco Fiore, Surgical Oncology Consultant at Sarcoma Service of Fondazione IRCCS Istituto Nazionale Tumori (INT), Milan – Italy**

Dr. Fiore graduated in Medicine in 2000 with distinction at Univeristy of Milan-Bicocca and obtained the General Surgery Board Certification in Milan. Since 2002 he started his full-time collaboration at the Sarcoma Service at INT under the supervision of dr. Alessandro Gronchi. In 2004 Dr. Fiore won the Terry Fox scholarship for international exchange program at Institute Gustave Roussy (Villejuif, France) participating to local Sarcoma Board clinical activity. Since 2005 he continuously joined the Sarcoma Service (INT), with special commitment for Soft Tissue Sarcomas, GISTs and Rare Tumors surgery. Since July 2005 he has been Co-moderator of the Rare Tumor Network (Rete Nazionale Tumori Rari, <https://eonc.istitutotumori.mi.it/rtr/>) with responsibility for surgical teleconsulting. Presently he is in charge as Attending Surgeon and gained extensive surgical experience on soft tissue sarcoma surgery of the limbs, trunk and retroperitoneum, with more than 150 surgical procedures yearly as first surgeon. Dr. Fiore is affiliated to American Society of Clinical Oncology (ASCO), Connective



Tissue Oncology Society (CTOS), Italian Sarcoma Group (ISG), European Pediatric Soft-tissue Sarcoma Study Group (EpSSG). Since 2003, dr. Fiore co-authored more than 40 original papers in high ranking international journals, and participated to several international meetings as presenter or invited speaker.

**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 Radiotherapy by Prof Dr Bartelink in the Netherlands Cancer Institute Amsterdam where he is still working as a staff member. His current research focuses mainly on sarcomas. He has initiated several clinical phase I, II and III trials on sarcomas.

**Julia Hill, National Cancer Peer Review Programme, UK**

Julia has been working with the National Cancer Peer Review programme since 2007 and has been Deputy National Programme Director since November 2009. Julia's role is to work with and deputise for the National Programme Director in the delivery of the National Peer Review programme. She leads on the development of measures for the Manual for Cancer Services and has responsibility for the development and implementation of the national database Cancer Quality Improvement Network System (CQuINS). Julia has a background in nursing and has worked within the NHS for a number of years in both nursing and management roles including cancer services.

**Prof. Ian Judson, Royal Marsden Hospital, London, UK**



Ian Judson is Professor of Cancer Pharmacology at The Institute of Cancer Research and Head of the Sarcoma Unit at the Royal Marsden Hospital, London, UK. He has been treating sarcomas for >20 years and has a particular interest in the management of gastrointestinal stromal tumours (GIST), having been involved in research in this disease since the phase I trial of imatinib for GIST in 2000. He is actively involved in clinical and translational sarcoma research and has been PI for a number of national and international sarcoma trials. He has previously been Chair of the NCRI Sarcoma Clinical Studies Group, Chairman of the EORTC Soft Tissue and Bone Sarcoma Group (STBSG), President of CTOS and is currently President of the British Sarcoma Group and Treasurer of the STBSG.

**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) 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 is head of the study center of the German Interdisciplinary Sarcoma Group (GISG) and is active in national and international study groups (AIO, EORTC).



**Eric Low, Executive Director Myeloma UK**

Eric has been involved in the field of myeloma for over 15 years. Working as a volunteer in the United States for the International Myeloma Foundation, he recognised the need and the benefit of providing information and support to people affected by myeloma. Returning to the UK, Eric identified the need for a similar organisation in the UK and as a result he set up Myeloma UK in 1997. As Chief Executive, Eric has been instrumental in developing the organisation's 'bench-to-bedside' strategy, an integrated model to systematically address and remove the barriers that are preventing or slowing down research and the development and access to new treatments, optimal treatment and care and information and support.

**Dr. Peter Reichardt, HELIOS Klinikum Berlin-Buch, Germany**

Peter Reichardt is Assistant Professor and Head of the Department of Interdisciplinary Oncology at the HELIOS Klinikum Berlin-Buch in Berlin, Germany, and is Director of the Sarcoma Center Berlin-Brandenburg. He trained in internal medicine and haematology/oncology at the University of Heidelberg and at the M.D. Anderson Cancer Center, Houston, TX, USA. From 1992 to 2007, he was a Consultant at the Charité University Hospital in Berlin. Dr Reichardt has led and conducted multiple clinical trials in gastrointestinal stromal tumour (GIST) in the adjuvant, advanced, and refractory settings. Dr Reichardt is a co-author of the current European Society for Medical Oncology (ESMO) guidelines for the management of GIST, soft tissue and bone sarcomas and a member of the ESMO Sarcoma Faculty. He is Chairman of the Scientific Committee of the GIST patients' organization 'Das Lebenshaus' and has been a Chairman of the GIST Global Opinion Leader Symposium since 2005. Dr. Reichardt has contributed to numerous publications on soft tissue sarcoma and GIST management in leading oncology journals.

**Beatrice Seddon, UCL Hospital NHS Trust, UK**

Dr Beatrice Seddon is Consultant Clinical Oncologist on the Sarcoma Unit at University College Hospital, specialising exclusively soft tissue and bone sarcomas. She currently lectures and teaches on the management of sarcomas, and is actively involved in clinical research projects in this area. She is a member of the EORTC Soft Tissue and Bone Sarcoma Group and the NCRN Sarcoma Group. She has a special interest in gynaecological sarcomas, GIST, and radiotherapy for sarcomas.

**Derek Stewart, Associate Director for Involvement at National Institute for Health Research, Clinical Research Network, UK**

Born in Scotland, Derek was treated successfully for cancer of the larynx in 1995 and became involved in numerous aspects of patient involvement at local, network and national levels. As the founder Chair of the Consumer Liaison Group, Derek assisted with the development of patient participation in the establishment and work of the National Cancer Research Network /Institute and was a board member. Derek is Chair of the Confederation of Cancer Biobanks and a member of the Steering Group for the Experimental Cancer Medicines Centres (ECMCs). From 2001 until 2006 Derek was Chair of Gedling Primary Care Trust in Nottinghamshire which gained 3 stars on inspection. From 2005–09 he was Chair of Nottingham City Crime and Drugs Partnership where crime was reduced by more than 34% and more than 3000 people received drug treatment. This contribution to health services in particular cancer led to being awarded an OBE in the Queen's Birthday Honours list 2006. Currently Derek is the Associate Director for Patient & Public Involvement at the National Institute for Health Research for the Clinical Research Network (NIHR CRN).



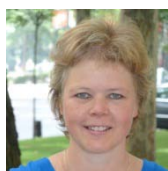


The Network provides the infrastructure for the delivery of Diabetes, Mental Health, Dementias, Stroke, Cancer, Medicines for Children as well as a Primary Care and Comprehensive studies in research. In the charity sector Derek is Chair of the Throat Cancer Foundation charity launched in February 2013 and Chair of Nottingham and District Citizens Advice Bureau. Derek lives in Nottinghamshire works as a freelance consultant with his own company providing training and development mainly in the charity and public sector.

**Elaine Stewart, London Maggie's Center, UK**

Elaine Stewart is a cancer support specialist with many years experience working as cancer nurse within the NHS. During her period in the NHS she worked within the field of haematology, more recently as a clinical nurse specialist in acute leukaemia. She joined Maggie's over 2 years ago and is very much involved in supporting people with a cancer diagnosis and also in supporting those caring for those individuals. Maggie's centres are for anyone affected by cancer. They are places where people are welcome whenever they need us – from just being diagnosed, or undergoing treatment, post-treatment, recurrence, and end of life or in bereavement. We also welcome family and friends, as they are often deeply affected by cancer too. We know that those who love and look after someone with cancer can feel just as frightened, vulnerable and uncertain.

**Prof. Winette van der Graaf, Radboud University Medical Center of Nijmegen, NL**



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.



## Patient Advocacy Group Profiles and Patient Advocates Biographies

### AEAS - The Sarcoma Patients Spanish Association, Spain

AEAS, the Sarcoma Patients Spanish Association, is a non profit organization that advocates on behalf of people affected by sarcoma. It was set up in 2008, in Madrid, by a group of sarcoma patients and their relatives, aiming to provide support not only to patients but also to their caregivers and, in general, to anyone involved with sarcomas.

Our mission is to promote the following activities:

- Referring patients to experienced doctors and health centres, and providing referrals for medical second opinions.
- Providing accurate information to share knowledge and training of sarcoma care.
- Clinical research, treatment options and clinical trials diffusion, in order to make available as much knowledge as possible.
- Collaborative links, serving as a bridge among patients, doctors, researchers, drug companies, public administration and funding agencies.

Asociación  
Española de  
Afectados por  
Sarcomas



AEAS

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

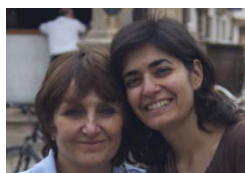
Giving the rarity of this disease we are seeking to grow our network of doctors, researchers and patients all over the country. This is particularly important for patients, to avoid facing the situation all alone, since there are often no other patients in the nearby area.

It is important to highlight that we work together with Mari Paz Jiménez Casado Foundation, supporting common goals.

Mari Paz was our former President, a born fighter, working hard for at least nine years, not only insisting on defeating sarcoma, but trying to relieve others pain, that as her, suffered the disease consequences.

Website: <http://www.aeasarcomas.org>

### M<sup>a</sup> Angeles Díaz León, Sarcoma Patients Spanish Association (AEAS), Spain



I live in Madrid and work as environmental technician at Madrid town hall. My daughter's problem begun in 2005 from a routine spine control and after an open biopsy was diagnosed Chondrosarcoma . As a result, her 9 dorsal vertebra was removed and a titanium structure was replaced. She now is 31 years old and is leading a normal life. In order to keep updated, six years ago I joined an american group the "Chondrosarcoma Support Group" I still contact with, started by a charming woman, Elizabeth Munroz, aiming for knowledge and experience interchange. Short after, I found out the "Sarcoma Patients Spanish Association (AEAS)", and currently, as a management board's active member, I try to participate in the scheduled activities, helping people affected by sarcoma in Spain. We collaborate with the "Foundation M<sup>a</sup> Paz Jiménez Casado", who was the former AEAS President and we all miss greatly.

Contact: [diazlan@madrid.es](mailto:diazlan@madrid.es)



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

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. A.F.P.G. is member of different pharmaceutical advisory boards focusing on compliance and management of patients treated with targeted therapy.

Website: <http://www.ensemblecontrelegist.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 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.

Contact: [ensemblecontrelegist@yahoo.fr](mailto:ensemblecontrelegist@yahoo.fr)

## 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>

### 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.

### 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.

**Our future projects:** 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)





## 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: <http://www.syopapotilaat.fi> and <http://www.cancer.fi>

### 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.

### Raija Sahri, M.Pol.Sc., GIST Patient Network, Finland



Born in Helsinki 1941. An active member in the patient network, motivated in keeping up contacts, spirit and light of hope. A malignant GIST (Wild Type) in the abdomen removed surgically 2008. Attended 12 months in an international research testing Imanitib against GIST. A new maligni Gist (Exon 11) and surgery 2012.

### 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/>

### **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).

Contact: [gherlinzoni@yahoo.it](mailto:gherlinzoni@yahoo.it)

### **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](mailto:ornellagonzato@yahoo.it)



## **“Mauro Baschirotto” Institute for Rare Diseases (B.I.R.D. Europe Foundation)**



### **Diagnostic and rehabilitative center for diagnosis, therapy and cure of rare diseases**

The institute is a reference centre for rare diseases from genetic and non-genetic origins and contributes to the actual possibilities for diagnosis and treatment of these pathologies. The aims of the institute are to acquire deep knowledges of the genetic diseases and to develop reliable methods and diagnostic instruments.

The institute has an important role in supporting universities and private organizations, by the establishment of collaborations and research projects.

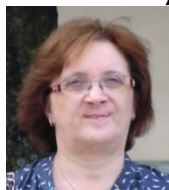
The activities of the institute are:

1. Diagnosis of Rare Diseases performed in the Medical Genetics Labs.
2. Clinical activities and patient rehabilitations
3. Research on rare neoplasia, desmoid fibromatosis and genetic diseases, as Lesch-Nyhan and Prader-Willi.

In 2011 a group of patients of aggressive fibromatosis founded the “Desmon Association” contributing to a reseach project for this pathology. In collaboration with clinicians and pathologist of the “Veneto Institute of Oncology, IOV-IRCSS” of Padova my group started up with a aggressive fibromatosis project.

Website: [http:// www.birdfoundation.org](http://www.birdfoundation.org)

### **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”. Since 2011 her scientific activities are focused on desmoid fibromatosis research, aimed to identify the molecular and genetic factors responsible of this pathology. Dott. Segat has authored or co-authored almost 30 scientific papers in international journals.



## Bone Cancer Research Trust (BCRT)

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

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: <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.

Website: <http://www.chordoma.org>

### **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). He has had systemic therapy for recurrences and two additional brain surgeries in 2013. 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 in Europe.

Contact Info: Hans Keulen, email: [hans@chordoma.org](mailto:hans@chordoma.org)

### **Sierk Bakker, Leiden University Medical Center, The Netherlands**



Sierk is a 6th year medical student at Leiden University Medical Center in The Netherlands. Since three years, he has been involved in chordoma research at the department of neurosurgery. One of the main projects he is currently working on, in cooperation with the Chordoma Foundation and specialists from several European institutions, is the creation of a prospective chordoma patient database, which can be used for trials and other research purposes.

### **Contactgroep GIST The Netherlands - Belgium**

The Contactgroep-GIST was founded in 2003 by a small group of GIST-patients and we just reached the number of 300 members. It receives its means from member-contributions and donations, by subsidies from KWF (national cancer-fund), the Ministry of Health and by grants from pharmaceutical concerns. We are one of the 24 members of the Dutch Federation of Cancer organisations.



**Contactgroep GIST  
Nederland - België**

### **Objectives**

The aim of the Contactgroep-Gist is contact, advocacy, support and information for all its members.



### **Main activities**

We maintain an closed internet forum where members exchange information and experience. We keep members informed by a Newsletter, four times a year, we have a brochure and an GIST patientbook. We give personal information and advice, we have close relations with the GIST experts. This year we organised in september our 10th meeting day for our members with an attendance of 140 people.

### **Current or future projects**

We are discussing about a new four years policy document and a strategic marketing and PR plan for getting a stronger positioning and a solid base for PR campaigns, all in order to reach more patients.

Website: <http://www.contactgroepgist.nl>

### **Jack Asselbergs, Contactgroep GIST The Netherlands**



Diagnosed in 2005 with a tumor, stomach surgery in a regional hospital and resection of the tumor, diagnosed as a GIST. Further treatment in the Daniel den Hoed Clinic (Erasmus University hospital) Rotterdam, one of the 5 GIST specialized centers in the Netherlands. Participant in EORTC study 62024. Since 2012 yearly medical control. Member of the board of Contactgroep GIST in 2008, chairman from 2009. Dedicated in pursuing good governance ensuring a well functioning organisation in aid of the best care for patients.

Contact: [voorzitter@contactgroepgist.nl](mailto:voorzitter@contactgroepgist.nl)

### **Gerard van Oortmerssen, Contactgroep GIST Netherlands - Belgium**



I am 68 years old, still active as part-time professor in ICT and private consultant. My passion is the fast development of technology and its effect on our life and our society. The new technology provides us with powerful tools (Internet, Social Media) to empower patients to connect with peers and contribute to medical research by sharing information and experience. GIST came into my life in various ways: first a younger colleague died of the disease, next my brother was diagnosed with GIST, and just a few years later I got the diagnose myself. Recently found another family member with GIST and now I am determined to search worldwide for similar cases, thus hopefully helping research into genetic mechanisms of GIST.

Contact: [gerard.vanoortmerssen@gmail.com](mailto:gerard.vanoortmerssen@gmail.com)

### **Das Lebenshaus**

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 the 6th of April 2009)
- IKCC - International Kidney Cancer Coalition

### **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](http://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](http://www.sarkomkonferenz.de))

Contact: [wartenberg@lebenshauspost.org](mailto:wartenberg@lebenshauspost.org)

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



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.

### **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.



#### **OBJECTIVES**

- 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 <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 meetings 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, training seminars regarding the GIST follow-up, drug-drug and drug-food interaction, and treatment with generic medicinal products.

#### **CHALLENGES:**

- To make "compassionate use" accessible to Bulgarian patients;
- To make available the imatinib plasma level testing for Bulgarian GIST patients;
- To assist in the inclusion of new medicinal products in the reimbursement list;
- To involve the Bulgarian medical specialists in scientific GIST treatment research.
- To set up collaboration between Southeastern European PAGs.

Website: [http:// http://www.gist-bg.com/](http://www.gist-bg.com/)

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



I am living in Sofia, Bulgaria with my family. In 2005 my lovely daughter underwent an urgent surgery to remove "a strange tumor". Actually, it was the first presentation of GIST, but she was misdiagnosed. Three years later, when the disease was already widespread, I knew that the lack of information for rare cancers could kill the patients. Now, I am the chairperson to Bulgarian GIST support group and I am trying to raise information and understanding of the disease and hospital system so that other patients' journeys will not be as frightening as my daughter's.

Contact: [info@gist-bg.com](mailto:info@gist-bg.com)



**Adelina Mihaylova, GIST Alliance for patients Bulgaria**

I am a GIST(Pediatric GIST) patient from Bulgaria. I was born and live in Sofia. In 1991 I had an emergency surgery. I had multipul polyps in my stomach, and diagnosed as blastom . Therefore, I got no treatment after surgery. In 2009 several metastases appeared in the liver. I underwent a liver resection and after that I started to take Glivec. Today I'm still on Glivec. I'm actively involved in the GIST Patient group and also support patients.

**GIST Support International (GSI), US**

GIST Support International (GSI) is an all-volunteer, non-profit organization that reaches out to GIST patients and their families and friends to provide education and support. GSI promotes and encourages ongoing research in the quest for a cure for gastrointestinal stromal tumor. Currently GSI has 1898 listserve subscribers and 1140 Facebook subscribers.



Our mission is:

- To be recognized as the premier GIST patient group: independent, unbiased and providing a respected international voice for GIST patients
- To create a portal that GIST patients, caregivers, medical professionals, media and others think of as the FIRST place to go for complete, accurate, up-to-date information on gastrointestinal stromal tumors
- 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

Our guiding principles are:

- 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 dues - no member will ever be asked to pay dues 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

Website: <http://www.gistsupport.org/>



### **Nancy Berezin, GIST Support International (GSI), USA**



Nancy is a GIST patient and Board member of GIST Support International (GSI). A retired medical journalist and author, she covers the annual meeting of the American Society of Clinical Oncology (ASCO) for GSI and conducts one-on-one interviews with leading GIST experts in the US. She believes strongly that information is life saving, and that sarcoma patients should have access to the most current and comprehensive information possible in order to make informed medical decisions.

### **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)

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

### **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.





### **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.

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



I first became involved with Gist Support UK in 2005, about a year after first being diagnosed with GIST. My consultant referred me to GIST Support UK and I was invited to their Autumn conference, in London. By this time, I was already an active participant in GIST Support UK's patients' email forum and it was not long before the Chair, Judith Robinson, asked me if I would be interested in serving on the Board of Trustees. I immediately accepted. Ever since then, I have been a Trustee of GIST Support UK, helping to formulate policy and plan conferences. My speciality has been advising patients, particularly new ones, as to the treatment that they should be getting and how to deal with side affects, as well as problems, such as what to do when local oncologists are unwilling to refer patients to GIST specialists.

### **Debbie Mitchell, GIST Support UK**



Debbie was diagnosed with Wild Type Gist in 1999, she has been a member of GIST Support UK since 2006 and became a trustee in July 2012. Her role within the organisation involves organising patient/carers meetings and working with the other trustees supporting all of the groups members and updating them regarding new treatments and research.

### **David Falconer, GIST Support UK**



Until I retired in May 2013 I was employed by Pfizer Oncology where I was involved in a number of tumour sites. My final role was as Commercial Manager for GIST in the UK and I also worked closely with my European colleagues for GIST in Europe. I am now a Special Advisor to GIST Support UK where I bring my awareness of cancer drugs and knowledge to the trustees. I also assist pharma companies interact with health care professionals in the GIST tumour areas and have been recently involved with arranging clinical trials and compassionate use programmes. Additionally I have been providing guidance on NICE applications.

### **Guy Francis Bone Cancer Research Fund**

Founded by teenage Osteosarcoma patient Guy Francis shortly before his death in 2002, the Fund asks **Why?** primary bone cancer is Britain's Number 1 Teenage Cancer.



The **Why Guy?** campaign questions the Causes? Lifestyle? Environment? Detection? Treatment? & Survival? of bone cancer in Teenagers & Young Adults.

Guy's Fund raises money for vital research into Osteosarcoma and Ewing's Sarcoma; promotes awareness and education, particularly through its S.I.G.N.S™ Patient Checklist Initiative; advocates a "Patient Voice"; and also campaigns for patients' rights including important welfare



reform for young people undergoing long term treatment programmes which may result in permanent physical disability.

Website: <http://www.gfbonecancer.org.uk>

#### **Mike Francis, Guy Francis Bone Cancer Research Fund, UK**



When my son Guy set up his Research Fund in 2002, I little expected that such a localised organisation based in a small village south of York, and constructed around the life-with-cancer of one young man would have such an impact in the long run. By joining, in 2004, with 4 other osteosarcoma patient families we established what was to become the Bone Cancer Research Trust, of which I was a Founding Trustee and its first Chairman (2005-10) and Head of Campaigning & Advocacy (2010-11). Now, as Chairman of Guy's Fund, I represent the charity on the Executive Committee of the Childhood Cancer Parents Alliance (CCPA) and am on the Editorial Board of the Children's Cancer & Leukaemia Group (CCLG) Contact magazine. I am also a Stakeholder representative on two National Institute for Health and Care Excellence (NICE) Guideline Groups - "Referral for Suspected Cancer" and "Children & Young People with Cancer". For some 6 years I have been a Registered Expert Witness (Patient Carer) with NICE, and am extremely proud that, after over 3 years and 6 Technical Appraisal Committee hearings with NICE as the Lay-Expert Lead, the drug Mifamurtide (MEPACT) achieved approval for administration to appropriate osteosarcoma patients. Guy's Fund is currently developing its S.I.G.N.S<sup>TM</sup> Patient Checklist Initiative and is working with schools, colleges & universities to raise awareness through curriculum development. It is also funding a partnership pilot study into "Improving the number of children & young people having an optimal route to cancer diagnosis" through the London South Bank University and the Great Ormond Street Hospital for Children.

Contact: [info@gfbonecancer.org.uk](mailto:info@gfbonecancer.org.uk)

#### **Home of Hope - Shanghai Roots & Shoots, China**

Home of Hope, working under Jane Goodall Institute-Shanghai Roots&Shoots, was established in August, 2008. It is the first patient support group in China focused on people who live with CML. In November 2013, the program expanded to include patients living with GIST. The number of patients that are actively involved with Home of Hope has risen from 3 in 2008 to Over 1200+ to date.



#### **Mission**

Shanghai Roots & Shoots Home of Hope Program strives to provide CML and GIST patients and their families with up-to-date information about the disease, to improve the quality of their lives, and to instill in them confidence and hope for a better future. Home of Hope works closely with patients, doctors, and other stakeholders in the community to raise awareness of cancer and to help patients.

#### **Zhenxi Zhong, Home of Hope Shanghai Roots & Shoots, China**



Zhenxi Zhong is the Executive Director of Shanghai Roots & Shoots. Before assuming this position, Zhenxi began at Roots & Shoots as a student volunteer and eventually an office Intern, demonstrating her commitment to grassroots activism very early on in her career. She received training from The Swedish International Development Agency, Future Leaders for South East Asia Program of the Japan Foundation and Global Institute for Health and Public Health.

Contact: [zhenxi.zhong@jgi-shanghai.org](mailto:zhenxi.zhong@jgi-shanghai.org)



## 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.

### Avi Zigdon, Israeli GIST Organization, Israel



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.

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



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.

## Le Ali Onlus and COO-BS

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.





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 phisicians 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.

Web: [http:// www.lealionlus.org](http://www.lealionlus.org)

Web: <http://www.coobs.it>

**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)

**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: [info@lealionlus.org](mailto:info@lealionlus.org) or [frapiccol@libero.it](mailto:frapiccol@libero.it)



### **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)

### **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.

Twitter: @Beyonddiagnosis

Facebook: [www.facebook.com/LivingBeyondDiagnosis](http://www.facebook.com/LivingBeyondDiagnosis)

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



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



I'm passionate about patient participation, advocacy and survivorship for cancer patients and improvement in cancer care. Since my diagnosis in September 2009 with a rare soft tissue sarcoma, malignant Cystosarcoma Phyllodes, 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, NHS, NCAT and cancer network committees/boards/groups. I also administer a support group within Facebook for anyone diagnosed with this rare cancer. Our group, "Phyllodes Support Group" has over 580 members globally. We have created information sheets for users together with online polls. In addition a database of research papers and data has been indexed and is accessible and searchable to users. We are now also beginning to host small meetups with users in each country to share experiences and support one another.

### **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>



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



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

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



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

### **Romanian Rare Cancers Association – ARCrare**

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.

Website: <http://www.arcrareromania.ro>



### **Emese Darko, Romanian Rare Cancers Association – ARCrare, Romania**



I work at the RPWA as a special education teacher. The activities I am involved are: therapy for children diagnosed of autism spectrum disorder or rare diseases, social and educational activities, offer emotional support for parents, helpline operator – referring our beneficiaries towards other information sources. 2011 – Member founder and board member of RCA-rare. We fight against the ongoing isolation that the health system, mass media, and scientific researchers in our country foster, in order to bring together the specialists efforts, patients, and families affected by rare cancers. Activities so far: public awareness, campaigns about rare cancers, information, advice for patients, we created a database of patients and started recording calls, counseling and guidance: social, legal and medical aspects, a group of patients diagnosed with rare cancer.

### **Florina Breban, Romanian Rare Cancers Association – ARCrare, Romania**



I am working for the Romanian Rare Cancers Association - RCArare as legal adviser since 2011. 2011 – Member founder and board member of RCArare. We fight against the ongoing isolation that the health system, mass media, and scientific researchers in our country foster, in order to bring together the specialists efforts, patients, and families affected by rare cancers. Activities so far: public awareness, campaigns about rare cancers, information, advice for patients, we created a database of patients and started recording calls, counseling and guidance: social, legal and medical aspects, a group of patients diagnosed with rare cancer.

## **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. Website: <http://www.sarcoma.org.uk/>

### **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.





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



Sarcoma UK is the main charity in the UK dealing with all types of sarcoma. Sarcoma UK was founded, and continues to be directed, by people with first-hand experience of sarcoma – patients and carers – who had identified a clear need for greater information and support. Sarcoma UK has made good progress in establishing new programmes for research, information and support services, as well as significantly increasing the profile of sarcoma with health professionals and the public. Sarcoma UK has a small, professional staff team led by Lindsey Bennister, the Chief Executive. Lindsey has worked in the UK health charity sector for around 20 years, in small organisation representing people with rare conditions, through to larger cancer charities. She is also a director of Cancer 52, an alliance of organisations representing less common cancers in the UK.

Contact: [lindsey.bennister@sarcoma.org.uk](mailto:lindsey.bennister@sarcoma.org.uk)

### **Claire Kelleher, Sarkoma UK**



Claire Kelleher is Head of Information and Support at Sarcoma UK. Her background is in developing health information materials for patients, carers and families and has recently produced a guide for newly diagnosed sarcoma patients called Understanding sarcoma: a new patient's guide. Claire is currently establishing a range of support initiatives for the benefit of sarcoma patients in the UK.

Contact: [claire.kelleher@sarcoma.org.uk](mailto:claire.kelleher@sarcoma.org.uk)

### **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.



Website: <http://sarkomer.no/>

### **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.

Contact: [info@sarkomer.no](mailto:info@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

### 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.

### Philippe Rigaux, SOS Desmoïde, France



When my tumour broke out (4 years ago), I looked for a patients association which could help me to understand what was happening to me. I found on internet SOS Desmoïde and met immediately the group. As a health professional (physiotherapist), it was, at first, very strange for me to be a sick person but very quickly, I found it was very rich, including for my job. This is why it seems very important to me to know how Desmoïd ‘tumour is cared for in Europe. I met SPAEN 2 years ago.

## 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).

### 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

Website: <http://www.sos-desmoid.de>

**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)

**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 a sarcoma expert team). Representing PAWS-GIST in The Netherlands and in the Dutch-speaking northern part of Belgium. Sarcoma NL wants to stimulate scientific research.

**Easy to read information in Dutch about sarcomas and borderline tumours**

We provide patients, their close family and friends, and other interested persons with easy to read information.

**Members-only forum**

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

**Membership umbrella organizations**

European: SPAEN, and ECPC (European Cancer Patient Coalition)

National: VSOP (Dutch National Alliance for Genetic and Rare Diseases)

**Working with sarcoma oncology experts**

Sarcoma NL has a Medical Advisory Board. Close relationship with professional network SarcomaNet NL, an initiative of Prof.dr. Winette van der Graaf (current chair EORTC STBSG, and member of the SPAEN Medical Advisory Board).

Website: <http://www.sarcoma.nl>



### **Ellen van Arem de Haas, Chair of the Board of Sarcoma NL, The Netherlands**



In 2012 I was asked to set up a small website for PAWS-GIST patients, carneytriad.com and very soon after this I set up the website sarcoma.nl and the patient organization Sarcoma NL, thus becoming a founding member of the board. Both websites have become one in 2013 (sarcoma.nl) and 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 like desmoid and GCT.

Contact: voorzitter@sarcoma.nl

### **Hilly van der Zande, Member of the Board of Sarcoma NL, The Netherlands**



In 2010 my youngest daughter was diagnosed with a desmoid tumour. When Sarcoma NL went online in October 2012 I registered myself as a participant of the members-only forum. In the same month I became a volunteer worker, assisting the board in lots of tasks to be done. Since June 2013 I am appointed Member of the Board. Amongst other things I'm the contact person for Desmoid tumours and I keep in touch with other international Desmoid advocacy groups. Sarcoma NL provides Dutch speaking patients in Europe with information about bone and soft tissue sarcomas and about rare borderline tumours like desmoid and GCT.

### **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.

#### **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.

**Martin Wettstein, Swiss GIST Group, Switzerland**

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.

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

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.

**Swiss Sarcoma Patient Group**

The Sarcoma Center Zurich is currently the driving force to found an independent and patient led Swiss Sarcoma Patient Group for all sarcoma patients. The first event is planned for spring 2014 and it aims to convene as many involved and interested people to establish the new Swiss Sarcoma Patient Organisation.

**Franziska Seeli, Balgrist University Hospital, Zurich/Sarcoma Center Zurich, Switzerland**

After ten years of nursing, in 2010 I started to work for the tumor team at Balgrist University Hospital, Zurich as a translational coordinator. The main focus of this team is the surgical treatment of all kinds of bone and soft tissue sarcomas, as well as the basic research, which is performed at the institution for years. Since the debate of the interdisciplinary treatment of sarcoma patients became more important during the last years, in 2012 we decided to establish the first officially acknowledged sarcoma center in Switzerland, where I function as center



coordinator and quality management officer. In 2014 we plan to fund the first Swiss Sarcoma Patient Group which is independent from any institution and shall be led by patients and their relatives.

## World Sarcoma Network

WSN is a cooperative group gathering the main reference centres for sarcomas around the World dedicated to the development and the support of innovative and collaborative clinical trials and to the drug development in Sarcomas. The WSN has been created to stimulate rapid clinical drug development for sarcomas and enable performant clinical studies that could not be completed by the cooperative groups at a National level. Sarcomas are rare tumors representing more than 150 diseases for which clinical studies on targeted therapies are not possible at the national level, what makes an international collaboration mandatory.



The WSN intends to:

- Serve as a communication and facilitation platform between cooperative sarcoma clinical research groups worldwide
- Stimulate discussions between designated representatives of the participating cooperative groups, with a focus on collaborations in trial execution

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

### Simon Baconnier, World Sarcoma Network, France



Simon Baconnier is the scientific manager of the World Sarcoma Network (WSN). He is supporting the Sarcoma community and its key opinion leaders since 8 years through the management of international collaborative groups and networks (Conticanet, EuroSarc). In addition, Simon Baconnier is the Chief Scientific Officer of OncoTherapy Science Inc, French affiliate developing innovative treatment in cancer.

## Youth Accumulation Association

**“Together with Youth, a Better Life for Young People...”**

Youth Accumulation Association was established in 2006 in Muş 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. 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

Our Memberships:

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

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

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



He was born in Bingöl Province of Turkey in 1997. After graduated from the high school, he caught the soft tissue sarcoma (pleomorphic liposarcoma). 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 issue. He also established “Youth Accumulation Association” in 2006 in order to raise awareness on 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.





## 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 27 members from 14 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 14 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. Alessandaro Gronchi	Surgery	Italy/Milano	ISG
Prof. Dr. Peter Hohenberger	Surgery	Germany/Mannheim	GISG/KO.SAR
Prof. Dr. Ian Judson	Oncology	UK/London	BSG
PD Dr. Peter Reichardt	Oncology	Germany/Berlin	GISG
Prof. Dr. Piotr Rutkowski	Surgery	Poland/Warsaw	POLSG
Dr. Beatrice Seddon	Oncology	UK/London	BSG
Prof. Winette van der Graaf	Oncology	Netherlands/Nijmegen	STBSG EORTC
Dr. R.L.M. Haas	Radiotherapy	Netherlands/Amsterdam	EORTC STBSG

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)  
l'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 01.10.2013):***

1. Bulgaria: GIST Alliance for Patients Bulgaria
2. Finland: Finnish GIST Patient Network
3. France: A.F.P.G. "Ensemble contre le GIST"
4. France: Info Sarcomes
5. France: SOS Desmoide France
6. Germany: Das Lebenshaus e.V./House of Life
7. Germany: SOS Desmoids
8. Italy: A.I.G. Associazione Italiana GIST
9. Italy: Le Ali Onlus
10. Italy: Luogo di incontro per scambiarsi informazioni sul tumori Desmoide o Fibromatosi aggressiva
11. Italy: Associazione Paola per i Tumori Muscoloscheletrici. Onlus
12. Macedonia: Patient Advocate from Macedonia
13. Netherlands: Contactgroep GIST
14. Netherlands: Stichting Sarcoma Netherlands
15. Netherlands: Chordoma Foundation Europe
16. 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 01.10.2013):***

1. Turkey: Genç Birikim Derneği & Youth Accumulation Association
2. USA: GSI - GIST Support International
3. USA: Sarcoma Alliance
4. USA: The Liddy Shriver Sarcoma Initiative



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Pharma  
Mar  
Grupo Zeltia



**Takeda Pharma GmbH**

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





## Contact

Sarcoma Patients EuroNet e.V./Assoc  
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SPAEN is registered as an association under German law in  
Friedberg/Germany - Registration-No. VR 2609

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