

NEW HORIZONS GIST

MAY 18 – 21, 2016 – SITGES/BARCELONA, SPAIN



**The NEW HORIZONS GIST Patient Advocacy Roundtable:
Improving access to treatment and quality of care
through global exchange.**



Conference Booklet

NEW HORIZONS GIST Steering Committee

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2015/2016 supported by

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NEW HORIZONS GIST 2016

Participants in total	51
GIST-Patient Advocates	33
Invited GIST-Experts and Speakers	10
Guests from the HealthCare Industry	4
GIST-Patient Advocates	44
Countries	25
Organisations	26
(+ Alianza GIST + Sarcoma Patients EuroNet)	

1. Acknowledgement

We would like to thank the following funders who supported

NEW HORIZONS GIST 2016 with an unrestricted educational grant:

Initial Funder of NEW HORIZONS:



Co-Funders since 2012:



Supporter since 2016:



At the request of the Steering Committee, NEW HORIZONS GIST received grants from these four companies. This funding is not related to any objectives/content of the Conference 2016 in Spain.

The idea, conception, planning, preparation, realization, management and the summary of the NEW HORIZONS GIST 2016 Conference are the responsibilities of the Steering Committee and Sarcoma Patients EuroNet (SPAEN) without any influence from the sponsors/funders.

We are looking forward to continuing these open and transparent partnerships with the healthcare industry towards achieving our goal of collaboration among independent GIST patient organizations on an international level.

We also would like to thank our friends/colleagues from the medical GIST-Expert Community. Thank you very much for agreeing to speak at NEW HORIZONS GIST 2016. We very much appreciate that you are taking time out of your very busy schedules to come to NEW HORIZONS. We are very grateful for the valuable, trustful and long-term partnership between leading medical GIST-Experts worldwide and the Global GIST-Patient Advocacy Community.

2. Welcome Letter

Welcome to NEW HORIZONS GIST 2016 in Spain!

Dear Delegates,

a warm Welcome to Sitges/Barcelona, Spain and the 2016 NEW HORIZONS GIST Patient Advocacy Roundtable: Improving access to treatment and quality of care through global exchange.

We all share a story and we all share one desire: To improve the lives of those affected by GIST, no matter where they come from. That is why we – the patient advocates, the clinical specialists and the industry representatives – travel once a year from all over the world to meet, to talk, to share and to learn: The GIST New Horizons Conference has become an essential event for patient advocates from the international GIST community. We come together, interact with top experts, have access to state-of-the-art medical and scientific information and can exchange best practice among each other in terms of patient advocacy.

This year's conference will once again be a balanced symbiosis of medical content, advocacy topics and capacity building sessions. We invite and encourage you to share your experiences as well as your disappointments and the challenges you are facing. We can learn a great deal from each other!

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. Remember that we share the aim of delivering patient benefit.

Thank you for taking the time to attend NEW HORIZONS GIST 2016. We very much hope that this meeting will help you develop new knowledge and skills to support your role as a patient advocate. We hope that you will be inspired, motivated and renewed in your efforts to support the patients who depend on your work. With best wishes,

The NEW HORIZONS GIST Steering Committee



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© S de Santi, Madrid Skyline on Flickr



© Yearofthedragon, Santiago de Compostela, Cathedral on wikipedia

Capital: Madrid
Population: 46,423,064 (2015)
Density: 92/km² or 240/sq miles
8.014,000 (2012)
Area: 505,990 km² or 195,364 sq miles
Currency: Euro
Calling Code: +43
Internet: .es

3. Welcome to Spain!

Spain, officially the Kingdom of Spain ("Reino de España"), is a sovereign state largely located on the Iberian Peninsula in southwestern Europe, with archipelagos in the Atlantic Ocean and Mediterranean Sea, and several small territories on and near the north African coast. Its mainland is bordered to the south and east by the Mediterranean Sea except for a small land boundary with Gibraltar; to the north and northeast by France, Andorra, and the Bay of Biscay; and to the west and northwest by Portugal and the Atlantic Ocean. Along with France and Morocco, it is one of only three countries to have both Atlantic and Mediterranean coastlines. Extending to 1,214 km (754 miles), the Portugal–Spain border is the longest uninterrupted border within the European Union.

Spanish territory includes two archipelagos: the Balearic Islands, in the Mediterranean Sea, and the Canary Islands, in the Atlantic Ocean off the African coast. It also includes two major exclaves, Ceuta and Melilla, in continental North Africa; and the islands and peñones (rocks) of Alborán, Alhucemas, Chafarinas and Vélez de la Gomera. With an area of 505,990 km² (195,360 sq miles), Spain is the second largest country in Western Europe and the European Union, and the fourth largest country in Europe. By population, Spain is the sixth largest in Europe and the fifth in the European Union.

Modern humans first arrived in the Iberian Peninsula around 35,000 years ago. It came under Roman rule around 200 BCE, after which the region was named Hispania. In the early modern period, Spain became one of history's first global colonial empires, leaving a vast cultural and linguistic legacy that includes over 500 million Spanish speakers, making Spanish the world's second most spoken first language, after Chinese and before English.

The climate of Spain, its geographic location, popular coastlines, diverse landscapes, historical legacy, vibrant culture and excellent infrastructure, has made Spain's international tourist industry among the largest in the world. In the last five decades, international tourism in Spain has grown to become the second largest in the world in terms of spending, worth approximately 40 billion Euros or about 5% of GDP in 2006.

(Source: Wikipedia.com)



© Ralf Roletschek, *Sagrada Família, Barcelona* on wikipedia



© Stiges



© Antoni63, *Torre Agbar, Barcelona* on wikipedia

Welcome to Barcelona / Sitges!

Barcelona is the capital city of the autonomous community of Catalonia in Spain and Spain's second most populated city, with a population of 1.6 million within its administrative limits. Its urban area extends beyond the administrative city limits with a population of around 4.7 million people, being the seventh-most populous urban area in the European Union after Paris, London, Madrid, the Ruhr area, Berlin and Milan. It is the largest metropolis on the Mediterranean Sea. It is located on the northeast coast of the Iberian Peninsula, facing the Mediterranean Sea, on a plain approximately 5 km (3 mi) wide limited by the mountain range of Collserola, the Llobregat river to the southwest and the Besòs river to the north. This plain covers an area of 170 km² (66 sq miles), of which 101 km² (39.0 sq miles) are occupied by the city itself. It is 120 kilometres (75 miles) south of the Pyrenees and the Catalan border with France.

The Barri Gòtic (Catalan for "Gothic Quarter") is the center of the old city of Barcelona. Many of the buildings date from medieval times, some from as far back as the Roman settlement of Barcelona. Catalan modernista architecture (related to the movement known as Art Nouveau in the rest of Europe), developed between 1885 and 1950 and left an important legacy in Barcelona. Several of these buildings are World Heritage Sites. Especially remarkable is the work of architect Antoni Gaudí, which can be seen throughout the city. His best-known work is the immense but still unfinished church of the Sagrada Família, which has been under construction since 1882, and is still financed by private donations. As of 2007, completion is planned for 2026.

Barcelona is the home of many points of interest declared World Heritage Sites by UNESCO, the Sagrada Família among them.

Sitges is a town about 35 kilometres southwest of Barcelona, renowned worldwide for its Film Festival and Carnival. Located between the Garraf Massif and the sea, it is known for its beaches, nightspots, and historical sites.

While the roots of Sitges' artsy reputation date back to the late 19th century, when Catalan painter Santiago Rusiñol took up residence there during the summer, the town became a centre for the 1960s counterculture in mainland Spain, then still under the dictatorship of Francisco Franco, and became known as "Ibiza in miniature".

Today, Sitges' economy is based on tourism and culture offering more than 4,500 hotel beds, half of them in four-star hotels.

Sitges has been referred to as the Saint-Tropez of Spain, with property prices approaching those of the most expensive European cities, the main reason for this being the setting by the sea and the surrounding Parc Natural del Garraf.

4. Conference Programme

Plenary Sessions in Room Llevant 1 - 3 (unless otherwise indicated)

ARRIVAL / REGISTRATION - WEDNESDAY May 18, 2016

During the day	Arrival of all Participants / Registration / Conference Package
16:30 – 18:00	General Meeting of the “Organizational Team” and the “Steering Committee” Room: Catalunya (Conference Office)
19:00	Get Together: “Tapas y Paella” <i>(Late arrivals could join any time!)</i> In the Garden (or room Atrium in bad weather)

DAY 1 – THURSDAY May 19, 2016 – Part 1

08:30	OFFICIAL START OF THE CONFERENCE Plenary Sessions in Room: Llevant 1 - 3
08:30 (30)	Opening, Welcome, Organizational Issues, Thanks to the Sponsors, etc. <i>Vicky Ossio & Markus Wartenberg (on behalf of the NH-GIST Steering Committee)</i> & <i>Representative of the Spanish GIST- or Sarcoma Patient Group</i>
09:00 – 10:30 (90)	GIST 1: Quality of Diagnosis, Treatment and Follow Up in GIST Important parameters determining the prognosis and/or survival of GIST-patients... <i>PA-Chair: Markus Wartenberg</i> Setting the scene – general parameters (15) <i>Markus Wartenberg, SPAEN (DE)</i> The localized disease (25) <i>Piotr Rutkowski, Warsaw (PL)</i> The metastatic disease (25) <i>Piotr Rutkowski, Warsaw (PL)</i> The progressive disease (25) <i>Breelyn Wilky, Team Jonathan Trent, Miami (USA)</i>
10:30 – 11:00	TEA / COFFEE BREAK (30 minutes)
11:00 – 12:30 (90)	GIST 2: Genotyping / Mutational Analysis in GIST: <i>PA-Chair: Ginger Sawyer</i> Science & rationale for mutational analysis in GIST (40) <i>Maria Debiec-Rychter, Leuven (BE)</i> Process & practice of performing mutational analysis (40) (incl. quality aspects and potential pitfalls) <i>Sabrina Rossi, Team Paolo Dei Tos, Treviso (IT)</i> Additional questions from the auditorium (10)
12:30 – 14:00	NETWORKING LUNCH (90 minutes)

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DAY 1 – THURSDAY May 19, 2016 – Part 2

14:00 – 15:30 (90)	<p>GIST 3: Following the research journey in GIST <i>PA-Chair: Norman Scherzer / Sara Rothschild</i></p> <p>Interesting targets in GIST & selected current / upcoming clinical trials in GIST... <i>Breelyn Wilky, Team Jonathan Trent, Miami (USA)</i></p> <p>Additional questions from the auditorium</p>
15:30 – 16:00	<p>TEA / COFFEE BREAK (30 minutes)</p>
16:00 – 17:15 (75)	<p>EDUCATION: The MITIGATE project <i>PA-Chair: Markus Wartenberg</i></p> <p>New strategies and protocols for diagnosis and treatment of GIST <i>Stefan Schönberg, Mannheim (DE)</i></p>
17:15 – 18:00 (45)	<p>SPECIAL LECTURE: The Indian Experience...</p> <ul style="list-style-type: none"> ● Challenges of rare cancer patients in low income countries ● First examples to achieve changes in India ● Programmes, giving patients access to innovations <p><i>Viji Venkatesh, Region Head (India & South Asia), The Max Foundation</i></p>
18:00 – 19:30	<p>BREAK BEFORE DINNER (90 minutes)</p>
19:30	<p>Internal Dinner (Meliá Hotel)</p>

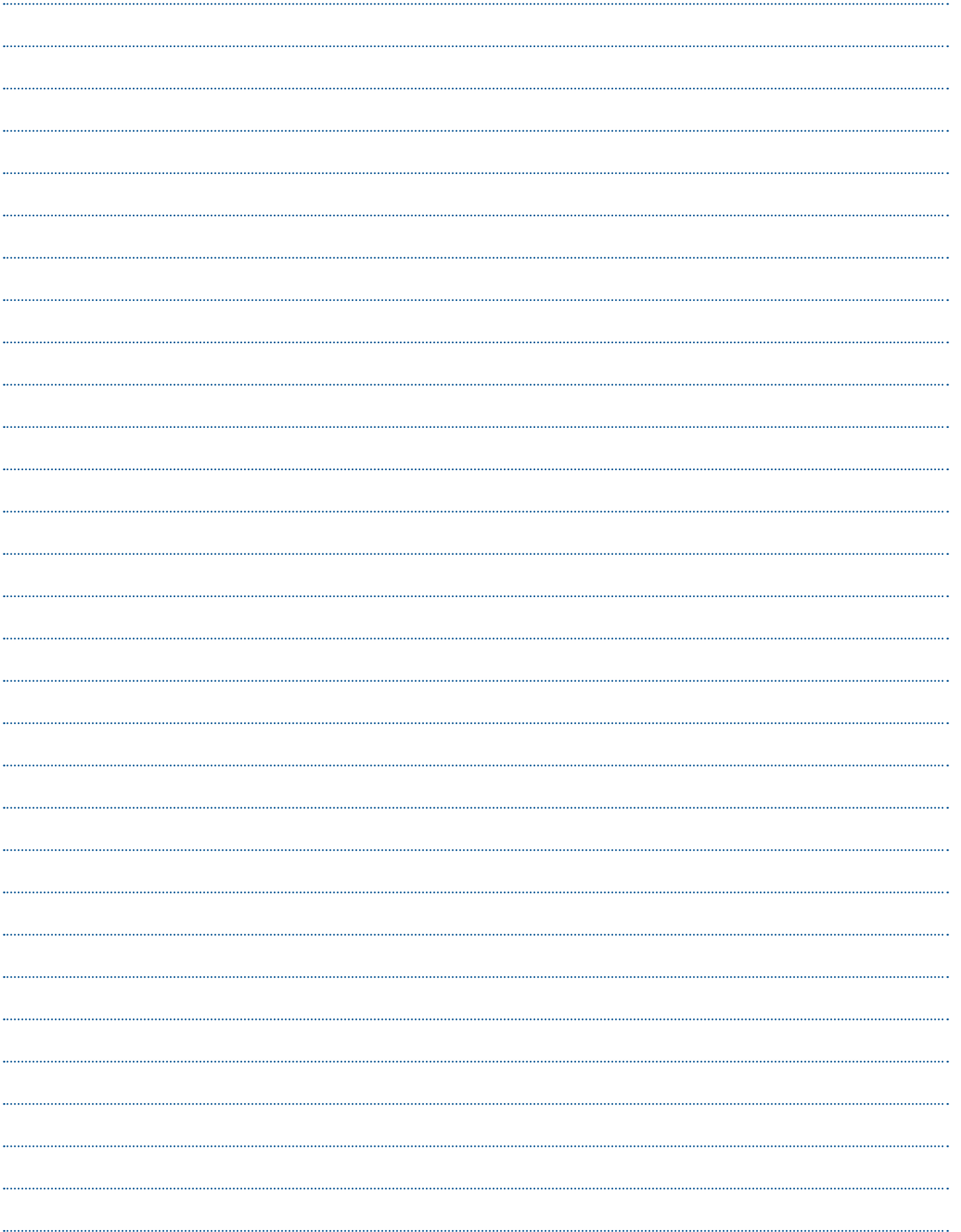
DAY 2 – FRIDAY May 20, 2016 – Focus on Regional Challenges

<p>08:30 EU 09:00 LatAM</p>	 <p>Room: Llevant 1 - 3 <i>PA-Chairs of the day:</i> <i>Martin Wettstein & Markus Wartenberg</i></p> <p>The EUROPEAN Breakout Group</p> <p>08:30 Learning more about GIST by discussing real cases with leading GIST-Experts 2 cases for the localized disease <i>Bernd Kasper (DE)</i> 2 cases for the metastatic disease <i>Javier Martin Broto (ES)</i> 2 cases for the progressive disease <i>Peter Reichardt (DE)</i></p>	 <p>Room: Barcelona <i>PA-Chairs of the day:</i> <i>Sara Rothschild & Vicky Ossio</i></p> <p>The AMERICAN Breakout-Group</p> <p>09:00 Welcome <i>Alianza GIST Report 2015</i></p> <p>09:30 LRG Patient Registry: Update and Implementation</p>
<p>10:30 – 11:00 TEA / COFFEE BREAK (30 minutes)</p>		
	<p>11:00 Clinical Trials: Introducing and discussing multicenter studies in Europe <i>Peter Reichardt & Sebastian Bauer</i></p> <p>Discussion with GIST-Experts: <i>Bauer, Broto, Kasper, Reichardt</i></p>	<p>11:00 Generics Update and Surveillance Program</p> <p>11:45 Clinical Trials: Introducing multicenter studies in Latin America</p>
<p>13:00 – 14:00 LUNCH – (60 minutes)</p>		
	<p>14:00 Generics in Cancer: Introduction The EMA Perspective Our experiences in GIST – so far <i>Presenter: Elias Péan, EMA</i></p> <p>Discussion with GIST-Experts: <i>Bauer, Broto, Kasper, Reichardt</i></p>	<p>14:00 Workshop: Learning from best practices and how to apply them in our countries...</p>
<p>15:30 TEA / COFFEE BREAK (30 minutes)</p>		
	<p>16:00 Discussion/brainstorming with our medical expert colleagues: Unmet medical needs in GIST and how can we collaborate better in EU to overcome them?</p> <p>Discussion with GIST-Experts: <i>Bauer, Broto, Kasper, Reichardt</i></p>	<p>16:00 Conclusion and Action Steps for 2016 – 2017</p>
<p>19:30</p>	<p>Meeting in the Hotel Lobby</p>	
<p>20:00 External Dinner</p>		

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DAY 3 – SATURDAY May 21, 2016

08:00 – 09:00 (60)	<p>Feedback / Reports from the previous day / from the two Breakout Groups:</p> <p>What to do next? GIST-Advocacy in Action? <i>PA-Chair: David Josephy</i></p> <p>Reporter from the AMERICAN Breakout Group (20 Min.)</p> <p>Reporter from the EUROPEAN Breakout Group (20 Min.)</p> <p>Questions & Discussion (35 Min.)</p>
09:00 – 09:45 (45)	<p>CAPACITY BUILDING: Medical Knowledge – I.O. Immuno-Oncology <i>PA-Chair: Markus Wartenberg</i></p> <p>A short introduction to I.O. As valuable preparation for this session please use: www.10forIO.info</p> <p>Current available treatments in I.O. – used in Melanoma, Lung Cancer, Kidney Cancer. Practical experiences with I.O. <i>Peter Reichardt, Berlin (DE)</i></p>
09:45 – 10:15	<p>TEA / COFFEE BREAK (30 minutes)</p>
10:15 – 11:45 (90)	<p>CAPACITY BUILDING: <i>PA-Chair: Gabriella Tedone</i></p> <p>Patient Information & Education – Sharing Best Practice: Seven plenary bursts on activities/initiatives/projects around the globe (10 minutes each)</p> <p><i>Canada</i></p> <p><i>Latin America</i></p> <p><i>UK</i></p> <p><i>Netherlands</i></p> <p><i>Italy</i></p> <p><i>Kenya</i></p> <p><i>India</i></p> <p>Questions, Discussion</p>
11:45 – 13:00 (75)	<p>Exchange – Future Developments:</p> <p>Moving from “GIST only” to other Rare Cancers e.g. to Sarcomas >>> <i>PA-Chairs: Norman Scherzer/Sara Rothschild & Markus Wartenberg</i></p> <p>Opportunities & Challenges... The German Experience Questions/Comments from the Audience</p> <p>How to move forward with the Global GIST Patient Community? Exchange/Discussion</p>
13:00	<p>OFFICIAL END OF THE CONFERENCE</p>
	<p>Depending on individual departures: Travelling by train or shared taxis to the airport</p>



5. Participants

COUNTRY	NAME	GIST-ORG./-GROUP	SC-MEMBER
Argentina	Mesri Florinda Sandra	AGA (Asociación GIST Argentina)	
Austria	Bruno-Lindner Amy	GIST-Support Austria	
	Bruno Martin	GIST-Support Austria	
Bolivia	Ossio Vicky	Alianza GIST	SC
Bulgaria	Popova Yuliana	GIST Alliance for Patients-Bulgaria	
Canada	Josephy David	Life Raft Group Canada	SC
	Tam Laetitia	Life Raft Group Canada	
Chile	Fernandez Piga	Alianza GIST / Fundación GIST Chile	
China	Liu Xian	Shanghai Roots & Shoots	
	Yu Xia	Shanghai Roots & Shoots	
Colombia	Becerra Jairo	Fundacion GIST Colombia	
Finland	Väisänen Marjo	Finnish GIST Patients Network	
Germany	Wartenberg Markus	Das Lebenshaus e.V.	SC
	Pilgermann Kai	Das Lebenshaus e.V.	
Greece	Visvardis Evangelos Efstathios	University of Athens	
Guatemala	Castillo de Armas Silvia	Asoc. de Pacientes con LMC ASOPALEU	
Hungary	Szekfü András	Association of CML-GIST Patients	
India	Guhagarkar Nikhil	The Friends of Max	
	Venkatesh Viji	The Max Foundation	
Israel	Moshe Gideon	Israeli GIST Group	
	Moshe Bracha	Israeli GIST Group	
Italy	Tedone Gabriella	A.I.G. Associazione Italiana GIST	SC
	Tamagni Barbara	A.I.G. Associazione Italiana GIST	
Kenya	Mwangura Ferdinand	Henzo Kenya	
Macedonia	Dimitrovski Toni	gist-macedonia	
	Dimitrovska Meri	gist-macedonia	
Mexico	Salas Rodrigo	Fundacion GIST Mexico	
Netherlands	van Oortmerssen Gerard	Contactgroep GIST Nederland/België	
Netherlands	Jansen Ton	Stichting Contactgroep-GIST	
Poland	Fonrobert Piotr	Polish GIST Patients Support Assoc.	
Spain	Herrero Luis	GIST Espana	
	Mejías García Dora	GIST Espana	
	Alabau Calvet Xantal	GIST Espana	
Switzerland	Wettstein Martin	GIST-Gruppe Schweiz	SC
	Meier-Schnorf Helga	GIST-Gruppe Schweiz	
UK	Bressington Jayne	PAWS-GIST (SDH deficient GISTs)	
UK	Falconer David	GIST Support UK	
	Falconer Doris Blair	GIST Support UK	
USA	Scherzer Norman	The Life Raft Group	SC
	Rothschild Sara	The Life Raft Group	
USA	Sawyer Ginger	GIST-Support International	SC

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Invited GIST-Experts/Speakers**Sebastian Bauer**

Westdeutsches Tumorzentrum, Sarkomzentrum,
Essen, Germany
sebastian.bauer@uk-essen.de

Javier Martin Broto

Hospital Universitari Son Espases, Spain
jmartin@mustbesevilla.org

Maria Debiec-Richter

Catholic University of Leuven, Belgium
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Bernd Kasper

Sarkom Zentrum, Interdisziplinäres Tumorzentrum
Mannheim (ITM)
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Elias Péan

European Medicines Agency, London, UK
Elias.Pean@ema.europa.eu

Peter Reichadt

HELIOS Klinikum Berlin-Buch, Sarcoma Center Berlin-
Brandenburg, Berlin, Germany

Sabrina Rossi

Treviso General Hospital
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Piotr Rutkowski

Skłodowska-Curie Memorial Cancer Center and Institute
of Oncology, Warsaw, Poland
rutkowskip@coi.waw.pl

Stefan Schönberg

Universitätsklinikum Mannheim, Germany
stefan.schoenberg@umm.de

Breelyn Wilky

University of Miami Health System, Miami, USA
b.wilky@med.miami.edu

6. Conference Logistics

Contact:	Kathrin Schuster: 0049 162 97 68 717 Markus Wartenberg: 0049 170 7914 989
Venue:	The Meliá Sitges Calle Joan Salvat Papasseit, 38, 08870 Sitges, Barcelona Spain Telephone: +34 938 11 08 11 www.melia.com/en/hotels/spain/sitges/melia-sitges/index.html
Rooms:	Equipped with a comfortable king-size bed or two single beds, these rooms provide individually controlled air conditioning / heating, functional work space with WiFi internet and socket for laptop, armchair and coffee table, stylish bathroom.
WiFi access:	WiFi will be available to you on a complimentary basis in your bedrooms and throughout the hotel.
Breakfast:	Breakfast will be served in the hotel dining room and is buffet style. Breakfast is included free of charge for the three mornings of 19th, 20th and 21st May. Breakfast is served in the hotel from 6.30 am.
Electricity:	A useful website which explains Spanish electricity and shows a photograph of a European electrical socket can be accessed via this link: http://www.idealspain.com/pages/information/electricity.html
Special Requests:	If you have any special requirements or needs during the conference please don't hesitate to ask us or the Hotel reception for support.
Time Zone:	May = Central European Summer Time (MESZ/CEST/CEDT)
Currency:	Spain is a member of the European Union and uses the Euro as its currency. For information on the Euro in Spain, please see: www.barcelona-tourist-guide.com/en/services/currency-converter.html
Security:	If you plan to visit the city of Barcelona during your stay, and as with all major cities and tourist areas in the world, please be aware that there are pickpockets and you should protect your property, credit cards, cash, passport, etc appropriately. It is of course sensible to protect your personal safety and valuables whenever and wherever you travel. There are many websites which provide safety tips in this regard, specific to Barcelona and in general. So please do be "travel-aware".

Conference Days:**Wednesday, May 18th, 2016****During the day**

Arrival of all Participants / Registration

16:30 – 18:00

General Meeting of the “Organizational Team” and the “Steering Committee”

19:30 – 23:00

Get Together: “Tapas y Paella” (Late arrivals welcome to join any time!)

Thursday, May 19th, 2016**08:30**

Official Start of the Conference

08:30 – 18:00

Conference (incl. breaks)

18:00 – 19:30

Break before Internal Dinner

19:30

Internal Dinner at Hotel Meliá

Friday, May 20th, 2016**08:30/9:00 – 17:30**

Conference (incl. breaks); Breakout Groups

17:30 – 19:30

Break before External Dinner

19:30

Meeting in Hotel Lobby

20:00

External Dinner

Saturday, May 21st, 2016**08:00 – 13:00**

Conference (incl. breaks)

13:00

Official End of the Conference

Travelling by train or shared taxis to the Airport

Meeting Rooms:

Main Conference Room: Llevant 1-3

Breakout Rooms:

European: Llevant 1-3

American: Barcelona

Conference Office:

Catalunya

Programme:

Please see Conference Programme

Language:

Conference language will be in English.

Please do not be afraid to get involved at the conference even if you have limited English skills
(Note: Translation will be not available!)

Delegates Presentations:

We would like to thank those delegates for preparing and giving a short presentation during our ‘
Sharing Best Practices’ session:

David Josephy

Life Raft Group Canada: Supporting Basic Research

Gabriella Tedone

A.I.G. Associazione Italiana GIST, Italy: Social Network on the air

Nikhil Guhagarkar

Friends of Max, India: Friends of Max and GIST awareness in India

Ferdinand Mwangura

Henzo Kenya, Kenya: Patient Education at Henzo Kenya: The signature activity

Gerard van Oortmerssen

Contactgroep GIST Nederland/België, The Netherlands

David Falconer

GIST Support UK: The value of an interactive web forum for patients.

Rodrigo Salas

Fundacion GIST Mexico: Latin America: A Big Challenge

7. Get-Together, Internal & External Dinner

ARRIVAL – WEDNESDAY May 18th, 2016 – Get Together “Tapas y Paella”

From 19:00 Get Together “Tapas y Paella” in the garden (or room Atrium in bad weather), Hotel Meliá Sitges

DAY 1 – THURSDAY May 19th, 2016 – Internal Dinner

19:30 Internal Dinner at the Restaurant Noray, Hotel Meliá Sitges

DAY 2 – FRIDAY May 20th, 2016 – External Dinner

Until 19:30 Meeting at the Hotel Lobby
10-minute walk to the restaurant

Address of the Restaurant:



Restaurante Fragata.

Paseo Ribera 1

08870 Sitges

Phone: +34 938 94 10 86

8. Reimbursement / Funding / Liability

Reimbursement Rules

Funding for travel, accommodation and conference expenses will be reimbursed by NEW HORIZONS GIST via Sarcoma Patients EuroNet Assoc. (SPAEN) in Wölfersheim/Germany. NEW HORIZONS GIST will cover the expenses for max. one delegate per national GIST Patient Group.

Meal expenses: NEW HORIZONS GIST will provide snacks, meals, beverages including internal/external dinners for the duration of the conference.

Other expenses: All other expenses (e.g. upgrade of rooms, difference from a single to double room, mini bar, hotel bar, additional meal orders, room service, telephone, laundry, etc.) will not be covered by NEW HORIZONS GIST. Additional expenses incurred for a 2nd delegate from a national GIST Patient Group or accompanying persons cannot be covered by NEW HORIZONS GIST. All additional expenses must be settled with the hotel at check out.

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

Funding Information

At the request of the Steering Committee, NEW HORIZONS GIST received grants from NOVARTIS Oncology Global, PFIZER Oncology Global, BAYER HealthCare Global and Blueprint Medicines.

PLEASE NOTE:

This funding is not related to any objectives/content of the Conference 2016 in Spain. The idea, conception, planning, preparation, realisation, management and the summary of the NEW HORIZONS GIST 2016 Conference are the responsibilities of the Steering Committee without any influence from the sponsors/funders.

This meeting is an independent global conference and is not connected with pharmaceutical representatives in each country. Please do not contact your local country pharmaceutical representatives for assistance or additional funding.

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NEW HORIZONS GIST is an independent democratic conference project of the Global GIST Patient Advocacy Community without commercial influence.

Liability Disclaimer

Your participation in the NEW HORIZONS GIST Conference 2016 will be at your own risk. NEW HORIZONS GIST, the Steering Committee Members, Sarcoma Patients EuroNet (SPAEN) and Funders will not be liable for any eventualities while travelling to and from or during the conference. We are not liable for injury, loss or damages suffered by participants or third parties. The NEW HORIZONS GIST conference 2016 programme is carefully prepared and carried out on the basis of the current knowledge of the topics concerned. However, we accept no liability for the accuracy or currency of the information presented during the conference.

Additionally, participants are advised to take out sufficient travel insurance to cover unforeseen events and losses including healthcare cover. In the event the trip is cancelled by the participant, NEW HORIZONS GIST, the Steering Committee Members, SPAEN or Funders will not reimburse expenditure incurred by intending participants as the presumption is that their travel insurance should cover this eventuality.

9. "The 2014 Zürich Declaration"



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The NEW HORIZONS GIST Patient Advocacy Roundtable:
Improving access to treatment and quality of care through global exchange.

"THE 2014 ZÜRICH DECLARATION"

Principles for the transition to "Generic Drugs" for GIST (Gastrointestinal Stromal Tumours)

Background & Purpose

GIST (Gastrointestinal Stromal Tumour) is a rare sarcoma, with an annual incidence of about 15 persons per million population. The oral drugs breakthrough for treating GIST began with the introduction of Gleevec/Glivec (imatinib) around 2000, followed by second- and third-line drugs, Sutent (sunitinib) and Stivarga (regorafenib). We hope and expect that additional drugs are coming soon. These therapies have hugely improved the management of GIST. As the patents on these drugs expire, generic versions will be introduced. This process has begun with the recent introduction of generic imatinib in some jurisdictions.

Generally, we welcome the introduction of generic products, which have the potential to greatly lower costs and to improve patient access to lifesaving drugs for the treatment of GIST. However, the transition to generic drugs raises many concerns, some of which are true for all generic drugs and some of which are specific for GIST treatment. GIST is a life-threatening cancer, and therefore the choice of drug therapies is of critical significance and warrants the most careful consideration.

This declaration was developed, agreed and signed by representatives of worldwide "GIST Patient Advocacy Groups" during an international conference in Rüslikon/Zürich/Switzerland, May 2014.

The Declaration

The following principles are endorsed by the undersigned GIST Patient Advocacy Groups.

- **Patients first!** The first priority must be patient well-being, based on consideration of drug product quality, efficacy, and safety, rather than drug cost.
- **Corporate Transparency:** Manufacturers of drugs for GIST must clarify their positions and timetables with respect to the expiry of patents, with as much transparency and openness as possible, so that doctors and patients can plan for the introduction of generic drugs.
- **"Precautionary principle":** Substitution of generic drugs for brand name drugs must be based on clinically demonstrated efficacy and safety, rather than on assumptions and expectations.

NEW HORIZONS GIST

MAY 14 – 17, 2014 – ZÜRICH, SWITZERLAND











- **Good manufacturing practice:** Active pharmaceutical ingredients (APIs) in generic drug products must be manufactured to equally high quality standards as brand-name drugs, and these standards must be carefully monitored by authorities such as the FDA, EMA or national equivalent. (We are already aware of cases where evidence indicates that generic substitutes of GIST drugs have not been of equal quality.) No generic product is to be prescribed until it has been specifically approved for use in GIST by the appropriate national regulatory authority, which must apply quality and evidence standards at least as rigorous as those of the FDA or EMA.
- **Evaluation of “bioequivalence”:** A drug is not simply an API. Drug manufacture is a complex and sophisticated process, involving factors such as drug crystal form, types and qualities of excipients, the design of pills and capsules, etc. Health authorities must recognize that equivalence of APIs does not guarantee equivalents of the drug products.
- **GIST is a unique disease entity.** Many drugs used for GIST treatment are also used for treatment of other cancers and other diseases. The GIST application of a drug must be treated as a specific situation and is not necessarily to be handled in the same way as other applications of the same drug.
- **Evaluation of efficacy:** With many drugs, assessment of efficacy can be carried out reliably and quickly, for example by blood testing. This is not yet true of drugs for GIST. Efficacy can usually be assessed only after a period of months and following procedures such as CT scanning, which, of themselves, pose non-zero risk. Consequently, a generic drug substituted for a brand name “equivalent” should not be assumed to have equal efficacy until and unless this can be demonstrated by clinical evidence.
- **Patient Stress:** For patients who are responding well to a brand name drug (in some cases, for many years) substitution of a generic form may result in major psychological stress and worry, in addition to possible pharmacological issues. This factor must be borne in mind by doctors and health authorities.
- **Patients must be informed of any changes to their drug treatment.** When a health authority, doctor, or insurance provider mandates substitution of a generic form of a drug, the affected patient and his/her doctor must be fully informed of the change.
- **Pharmacovigilance:** The impact of generic drug substitution must be monitored by the appropriate health authorities so that issues of concern, such as possible lower efficacy or unexpected toxicities, can be detected and reported as soon as possible.
- **“No substitutions” principle:** If a doctor states on a prescription that a specific form of the drug, e.g. a generic or brand name product, be supplied, the doctor’s orders must be respected.

9. "The 2014 Zürich Declaration"



The NEW HORIZONS GIST Patient Advocacy Roundtable:
Improving access to treatment and quality of care through global exchange.

Signed in Rüschlikon/Zürich/Switzerland - Friday, 16th of May 2014

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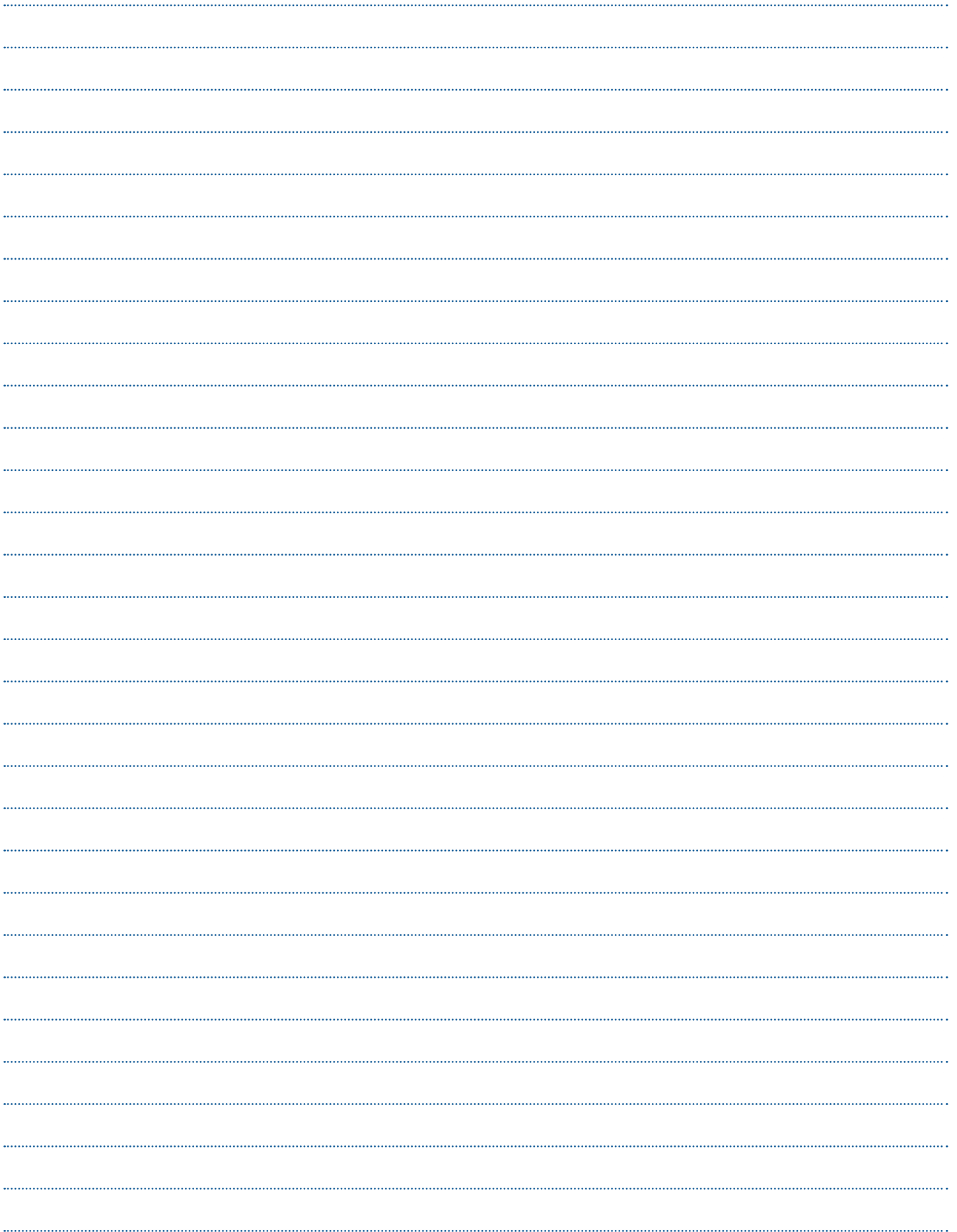
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GIST Patient Group Network in South/Latin America: www.alianzagist.org

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REUNIÓN ANUAL ALIANZA GIST 2015

ALIANZA GIST

CONECTAMOS PACIENTES CON MEDICOS

Una asociación de defensores de los pacientes representando a diez países de América Latina que se han unido para crear la Iniciativa GIST de América Latina para la comunidad GIST, la misma que se centró en cuatro principios clave:

- Mejorar el conocimiento de los pacientes y los médicos.
- Permitir que los pacientes accedan a tratamientos y recursos adecuados.
- Apoyar a las organizaciones locales de apoyo al paciente, incluyendo la creación de otras nuevas.

GIST Patient Group Network in Europe: www.sarcoma-patients.eu

Sarcoma Patients EuroNet

Together We Can Make A Difference For Those Affected By Sarcoma!

SPAEN | Sarcoma | Desmoids

Home

Welcome to Sarcoma Patients EuroNet

Last Updated: Tuesday, 23 July 2015 12:27 | Published: Thursday, 17 February 2016 15:57 | [RSS](#)

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. 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: A Better Future For Patients With A Rare Cancer! [Read more about the Network.](#)

Report on 3rd European Bone Sarcoma Meeting - Vienna 24-25 Sept. 2015

Last Updated: Tuesday, 09 February 2016 07:42 | Published: Tuesday, 09 February 2016 07:36 | [RSS](#)

By Ornella Gonzato

The 3rd joint ENCCA-WP7/EuroSarc/EEC/PROVABES/EURAMOS European Bone Sarcoma Network Meeting held in Vienna, on 24-25 September 2015, titled "Integration of clinical trials with tumor biology" brought together preclinical and clinical bone sarcoma investigators and

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