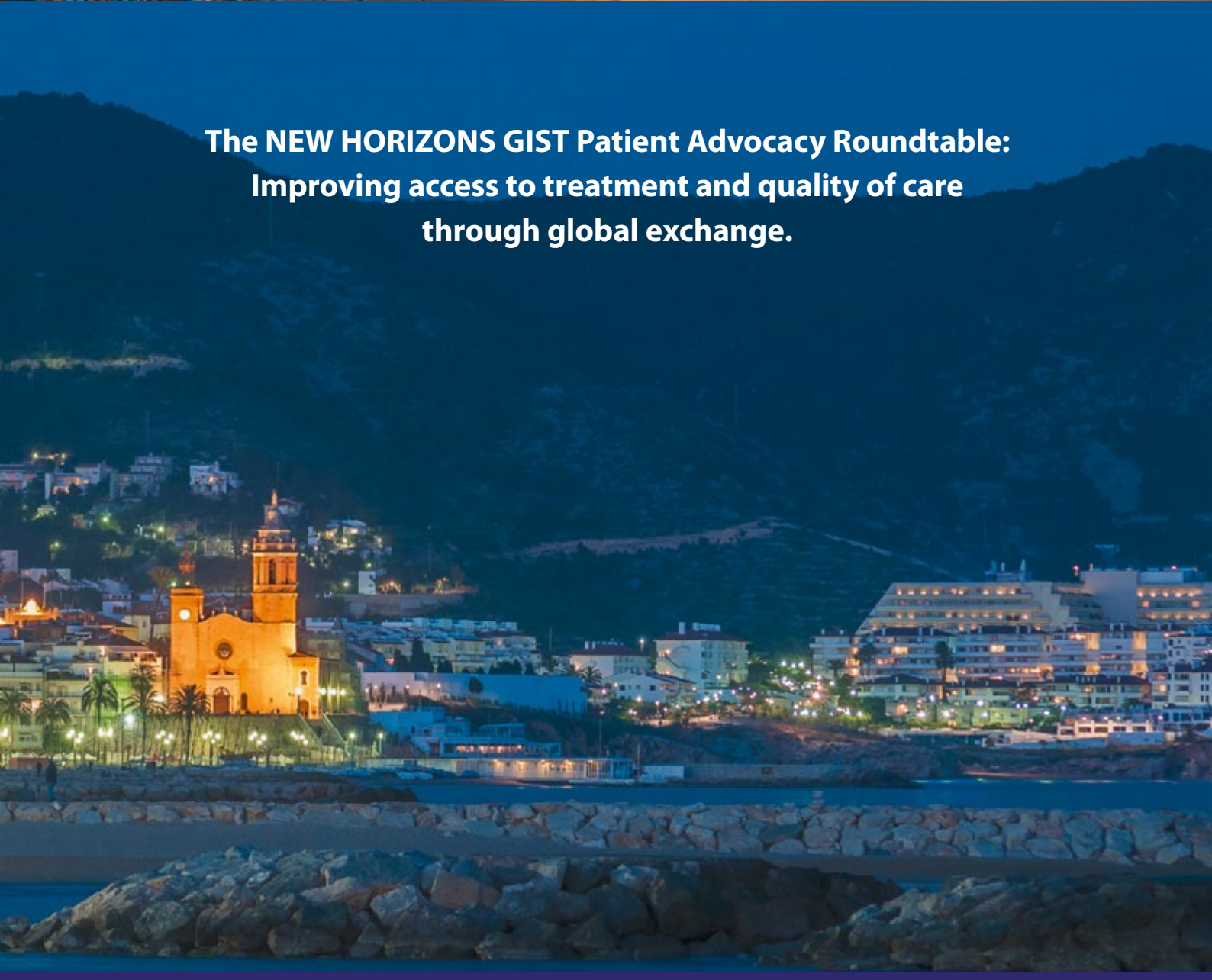
NEW HORIZONS GIST

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 Report

NEW HORIZONS GIST Steering Committee

David JOSEPHY (The Life Raft Group, CA)	djosephy@uoguelph.ca
Vicky OSSIO (Alianza GIST, Bolivia)	vossiop@gmail.com
Ginger SAWYER (GIST Support International, US)	grsawyer@icloud.com
Norman SCHERZER (The Life Raft Group, US)	nscherzer@liferaftgroup.org
Gabriella TEDONE (A.I.G. Associazione Italiana GIST, IT)	g_tedone@hotmail.com
Markus WARTENBERG (Das Lebenshaus, DE / SPAEN, EU)	markus.wartenberg@daswissenshaus.de
Martin WETTSTEIN (GIST Gruppe Schweiz, CH)	m.wettstein@wp-ing.ch

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Sara ROTHSCHILD (The Life Raft Group, US)	srothschild@liferaftgroup.org
Kathrin SCHUSTER (Sarcoma Patients EuroNet, SPAEN, EU)	kathrin.schuster@sarcoma-patients.eu
Tanja ULLERSBERGER (Das Lebenshaus, DE / SPAEN, EU)	tanja.ullersberger@daswissenshaus.de

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GIST-Patient Advocates	33
Invited GIST-Experts and Speakers	10
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GIST-Patient Advocates	**33**
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 or the 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 organisations on an international level.

We also would like to thank our friends/colleagues from the medical GIST-Expert Community. Thank you very much for speaking at NEW HORIZONS GIST 2016. We very much appreciate that you took the time out of your very busy schedules to participate 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. Introduction

For several years now NEW HORIZONS GIST is the most important global annual conference for GIST patient advocates.
The 2016 New Horizons GIST conference was held at the Melia Hotel in Sitges/Barcelona, Spain from May 18 – 21, 2016. It was again very well attended with over 50 participants of 26 different organisations from 25 countries, 10 medical experts and 4 representatives from the pharmaceutical industry. Once again, this conference was a great event for patients from the global GIST patient community to come together, to interact with top GIST experts, to have access to state-of-the-art medical and scientific information and to exchange best practice in patient advocacy among each other. The 2016 conference was balanced symbiosis of medical content, advocacy topics and capacity building sessions.

The 2016 conference was chaired and planned by a steering committee and Sarcoma Patients EuroNet e.V./Assoc.

● Gabriella Tedone,	A.I.G. Associazione Italiana GIST (Italy)
● David Josephy,	The Life Raft Group (Canada)
● Vicky Ossio,	Alianza GIST (Bolivia)
● Ginger Sawyer,	GIST Support International (USA)
● Norman Scherzer,,	The Life Raft Group (USA)
● Markus Wartenberg,	Das Lebenshaus (Germany)
● Martin Wettstein,	Swiss GIST Group (Switzerland)

NEW HORIZONS GIST 2016 Steering Committee

(Piga Fernández for Vicky Ossio, Norman Scherzer excused)

Vicky Ossia, Bolivia, Alianza GIST and Markus Wartenberg, Germany, SPAEN officially opened the 2016 NEW HORIZONS conference in Sitges/Barcelona with a very warm welcome thanking all participants – patient advocates, medical experts, industry representatives – who travelled long ways to join this important meeting in May 2016.

GIST 1: Quality of Diagnosis, Treatment and Follow-up in GIST

Markus Wartenberg, SPAEN /
Prof. Dr. Piotr Rutkowski, Warsaw, Poland /
Dr. Breelyn Wilky, Miami, USA
Written by Markus Wartenberg and Kathrin Schuster

In this first session, Markus Wartenberg gave a short introduction about the most important facts to remember when being a GIST patient. Above all, he reminded the community that GIST – a rare disease with need of specific treatment – must be treated by experts and multi-disciplinary teams (MDTs). Furthermore, he called for patients to ask for testing their mutational status as early as possible as it has significant impact on therapy strategy.

However, Markus also mentioned some topics to be dealt with now and in the future. Among them were access to approved therapies, professional therapy- and side effect management, the handling of generic imatinib and access to clinical trials.

Professor Piotr Rutkowski, Warsaw, Poland, followed with an overview of the main aspects and news in localized and metastatic disease. Rutkowski emphasized that surgery is not the first step – the first step is proper diagnosis, as GISTs are different and so is the tumour behaviour and its nature. In order to define the right treatment strategy, a thorough evaluation has to be done before the start of any treatment. Additionally, it is also crucial to stratify the risk of recurrence for each individual patient in order to evaluate the patient's prognosis, to take the possibility of adjuvant and neoadjuvant therapy into account as well as to assess the follow-up schedule. Important factors for risk stratification are tumor size and site, mitotic count, gender, but also potential tumour rupture and specific KIT/PDGFRA mutations (e.g. KIT exon 11 Del 557-558).

Rutkowski further highlighted that imatinib shouldn't be stopped in advanced GIST in order to avoid a disease progression – if necessary, it should be given life-long. There are only three different situations in which surgery in the advanced situation should be considered: Removal of residual lesions that have remained despite TKI therapy after previous response, resection of focal progressive disease to delay resistance to TKI and treatment of emergency complications during TKI therapy (gastrointestinal bleeding, bowel obstruction, perforation). However, the time of the implementation of surgical treatment in this advanced setting needs to be studied further, says Rutkowski.

Dr. Breelyn Wilky, Miami, USA, focused her talk on progressing GIST. She explains that proper imaging is crucial to determine the extent and the degree of the progression. Furthermore, genomic sequencing can be very helpful to understand the biology of the particular GIST and tailor systemic therapy. She emphasized that, in case of tolerance issues, a modification of the dosing and/or schedule should be considered rather than switching to another TKI prior to radiographic progression. Local therapy can also be an option for progressing isolated lesions before changing the systemic treatment.

GIST 2: Genotyping/Mutational Analysis in GIST

Prof. Maria Debiec-Rychter, Leuven, Belgium /
Dr. Sabrina Rossi, Team Paolo DeiTos, Treviso , Italy
Written by Ginger Sawyer

Dr. Debiec-Rychter explained that we've only known about the human genome for about 15 years, whereas with GIST, research continues to provide more and more information about the various mutations. Basic KIT or PDGFRA kinases make up 90 to 95% of the GIST tumours, and these are the tumours that are most responsive to therapeutic inhibition. Because of the divergences in response to treatments, it is critical to match treatment to an individual's cancer through mutational analysis particularly among GIST patients. In some countries, mutational analysis is widely used; however, it is not routine around the world and is not used at all in some countries.

Dr. Debiec-Rychter's slide presentation gave the audience various information about the KIT protein and the signal transduction pathways which led to a discussion of the regulation of cell growth, development and survival. She explained normal KIT signalling and showed what happens when the protein mutates and eliminates the need for an activator, creating the "gas pedal that is stuck." She noted that inhibition of the signalling by Imatinib, but also that wild-type GISTs which make up as much as 10% or more. She explained the various GIST sub-types, with Exon 11 representing about 65%; Exon, 9%; and the others between 0.1 and 5% each.

In her summary, she tells the GIST community that Genotyping should be an integral part of clinical management of GIST as it aids in prognostication, prediction of efficacy, and selection of drugs and dosing. Further, it reduces the risk of both unnecessary adjuvant treatment as well as under-treatment and over-treatment in the palliative setting.

In the second part of this section, Sabrina Rossi, from team DeiTos in Treviso, Italy, covered the "Process and Practice of performing Mutational Analysis." While Dr. Rossi focused on the methods of analysis, she also discussed the factors that influence the success of the analysis. She explained that size of sample as well as location of the sample could have a bearing on the analysis, specifically the DNA quality and the tissue quality. She explained her general preferences between doing sampling on fresh tissue as compared to frozen tissue samples, and she noted the critical timing of fixing the tissue samples. Much of what Dr. Rossi discussed dealt with a pathologist's job of dealing with wild-type GISTs, specifically SDH-deficient GISTs.

GIST 3:
Following the research journey in GIST:
Interesting targets in GIST & selected current / upcoming clinical trials in GIST

Dr. Breelyn Wilky, Team Jonathan Trent, Miami (USA)
Written by Sara Rothschild

Dr. Breelyn Wilky, oncologist from the Sylvester Comprehensive Cancer Center in Miami, gave a talk entitled "In Pursuit of a Cure—Current and Future Clinical Trials in GIST." She discussed five main areas that are connected to the future direction and active research in finding a cure: Improving KIT Inhibitors, Novel Targets for GIST, Combination Approaches, Incorporating Precision Medicine, and a Role for Immunotherapy.

As Imatinib remains the most powerful drug against GIST, it may kill off a majority of cancer cells, but there are still living cells that need to be targeted.

Dr. Wilky discussed therapy from a front line approach to see if there are better drugs or combination of approaches to help improve response prior to emergence of resistance. The challenge is for patients to forgo the current standard of treatment of imatinib for something experimental.

Regarding second line and beyond, there are three main approaches:
1. Improve targeting of the KIT receptor including secondary mutations,
2. Target escape pathways that tumour cells utilize to bypass blocked KIT signalling by imatinib and similar drugs, and
3. Target alternative machinery/mechanisms within the cancer cells.

Dr. Wilky walked participants through a variety of different clinical trial approaches that are being explored currently. She emphasized the application of precision medicine when treating a patient as it is important to select a trial for the individual patient based on understanding of the molecular genetics.

Lastly, she discussed an emerging interest area among researchers and clinicians which is the role of immunotherapy. She reviewed therapeutic strategies for immunotherapy and if it has a role in GIST.

The takeaway points for advocates are that we need to increase patient awareness of clinical trials for GIST as all GISTs are not created equal. We need to increase more awareness about mutational analysis and next generation sequencing so that clinicians know how to explore the right treatment for the right patient at the right time. Education is also important when considering new methods in clinical trial design, the importance of scientific rationale, as well as access to clinical trials.

EDUCATION:
The MITIGATE project
New strategies and protocols for diagnosis and treatment of GIST

Prof. Dr. Stefan Schönberg, Mannheim, Germany
Written by Markus Wartenberg and Kathrin Schuster

In the first educational session of the conference, Professor Stefan Schönberg, Mannheim, Germany, introduced the so-called MITIGATE-project. It aims at finding new strategies in diagnosis and treatment of GISTs. Currently running and to date still recruiting is a clinical trial to evaluate the value of a novel PET-CT tracer specifically developed to target cell surface receptors of GIST cells. This is not, as many other trials, an evaluation of a specific medication, but a new and possibly improved means of diagnosing GIST. Patients with metastatic GIST who show progression under current standard therapy are eligible to participate. These patients will receive a PET CT examination with a new PET-CT tracer. Schönberg points out, that patients undergoing a PET-CT with the novel tracer may benefit from improved images regarding their primary tumour as well as detecting potential metastasis. This may lead to improved and possibly earlier treatment, Schönberg says.

More information about the project can be found on www.mitigate-project.eu.

SPECIAL LECTURE:
The Indian Experience

Viji Venkatesh, Region Head (India & South Asia), The Max Foundation

In a special lecture, Viji Venkatesh, Region Head of India and South Asia of "The Max Foundation" takes us on a trip to India and reports about the challenges of rare cancer patients in low income countries, also giving first examples to achieve changes in India and present programmes for patients to gain access to innovations.

The labelled indications of the drug and the patient access programme (PAP) put in place by Novartis made strange bedfellows of CML and GIST patients. Yoked together even though their disease determined different paths for them. However, for the few hundreds of GIST patients and their families lost in the thousands of CML patients, it was navigating those very different paths together, says Viji, that created an environment for seeking answers to questions still unformed, still unrecognised, still unacknowledged.

- GIST was not CML.
- GIST patients' needs were different.
- GIST needed the attention of specialised physicians.
- There was still much unknown about GIST.
- GIST was a more difficult disease to bear physically.
- GIST patients were dying.

And here were the road blocks that were being recognised and identified as challenges.

- No Access to correct Information.
- No Access to GIST Specialist Doctors.
- Poor Compliance in taking the drug.
- Language barrier
- Myths associated with Cancer.
- Insurance hurdles
- Difficulty in procuring second generation drugs

What was needed to overcome these:

- Disease Information
- Support Group Meetings
- Exposure to international peers
- Workshops
- Access programmes

The biggest and most pressing challenge of course was to find amongst this group of people who were willing to stand up and speak for themselves and lead the way for those whose voices could not be heard. Lack of education, crippling stigma, fear and poverty, belief in myths all stood in the way. This is when Max decided to step in and do something specifically for the GIST patients, explains Viji. With encouragement and assurance that a safe platform would be provided for them. Slowly but surely, patient leaders emerged, eager to learn and share. Physicians The Max Foundation worked with welcomed this move and committed their time and resources to the Project GIST Focus.

Besides any other challenge The Max Foundation may face, the most immediate one is that of the vastness and diversity of this land, this region. "I have always thought how India is like the European Union. Our 29 odd states like the different countries that make up the EU. The language we speak, the food we eat and the clothes we wear, all are different from each other. Region specific differences in language and other socio cultural factors only increase the distance in many other ways." It is impossible for all the patients to come to one treatment centre. They find it well-nigh impossible as it is to get to a Centre in their own region as it is miles away from their town or village. "If we had to reach out to the patients we had to go to where they were. And so we did."

In the past two years, working with the physicians in the different hospitals in the major centres in the country, The Max Foundation has been arranging support group meetings especially for GIST patients and their caregivers. For the first time, patients and physicians too, have been given a platform where they can interact with each other face to face in a safe and secure space. Over 12 meetings held in the last 2 years and over 240 Pts in 6 cities

Many kinds of barriers are broken and bonds formed in these gatherings. The Max Foundation and its support group arm, the Friends of Max has by now been recognised and accepted as they go to unit for any issues the group may have to contend with. By both the patients and the physicians.

Besides disease information booklets in the form of FAQ and nutrition guides, created especially for the group by physicians and patient leaders and translated into different languages and distributed, the Q & A sessions with the medical experts conducted during these meetings are of great value to the participants. In a non-threatening and friendly environment, with enough time on hand, patients and families have the opportunity to ask as many questions as they want to and clear their doubts. The physicians spend quality time with the patients and field their queries with patience and compassion. Together we Share and Learn - The Patient Testimonial – these meetings offer the perfect platform to put this into effective action. "There is no greater comfort to be found than in the telling of your story and in the company of peers", summarizes Viji.

The next day the group split into an American breakout track and a European/Worldwide breakout track. We thank the following who provided their expert input: Prof. Sebastian Bauer, Prof. Bernd Kasper, PD Dr. Peter Reichardt, Dr. Elias Péan and Dr. Breelyn Wilky.

Report and feedback from two Breakout Groups

Written by David Josephy

American Breakout Group

Rodrigo Salas reported back on behalf of the group.

Alianza GIST has been working as a group for eight years. They meet regularly, every year. An important goal for the coming year is enhanced coverage. Presently, there are representatives from Argentina, Bolivia, Chile, Colombia, Dominican Republic, Guatemala, and Mexico. This is only about 43% coverage; the goal is to reach 80%, expanding to include Brazil and the remaining countries of Central America. Another major issue is clinical trials. At present, there are no clinical trials for GIST in Latin America. There is access to first-line and, in some countries, second-line drugs, but no further treatments are available. The goal is to identify the leading investigators/ key opinion leaders/ major treatment sites for GIST in each country. Alianza GIST can then sit down with pharma representatives to find out which clinical trials would make most sense to prioritize, with regard to bringing them to Latin America. In Mexico, for example, the slow pace of approval for clinical trials by the health authorities is a major obstacle; by the time approval is obtained, the trial may already be over! The task is to bring pharma and doctors to the table and then make things happen - create a GIST clinical trial network.

The Alianza GIST group also shared best practices and described their activities over the past year. All countries face many similar problems, e.g. doctors' lack of knowledge about GIST; limited access to drugs.

The group connected to Michelle Durborow at the Life Raft Group and heard a presentation about the LRG patient registry. This initiative will help, because there is, to date, no reliable compilation of GIST patient data for Latin America. It is hoped that the Registry can be used to monitor possible adverse reactions to generic imatinib. In Mexico, the government switched to purchasing only generic imatinib (off-label, because it is not approved for use in GIST). But the Mexican group hired a lawyer and complained to the government, and now brand Gleevec is once again available, at a much reduced price, in Mexico. The generic price is 10% of regular price of NVS Gleevec. It was noted that there are difficulties associated with having a single patient registry database for all of Latin America, the main reason is because of legal frameworks (e.g. privacy regulations) are different in each country.

In the past two years, 25% of the GIST samples that the group sent from Mexico to Stanford proved not to be GIST. Misdiagnosis is a big problem. Some hospitals do not have the kit for testing for CD117 by IHC; or else, they have the kit, but the reagents have expired. We hope to make a webinar presentation soon, aimed at pathologists.

In Chile, LRG identified one good pathology lab at the Catholic University of Chile and then did a small quality-control test, sending duplicate samples to that lab and to a USA reference lab. All the results were in agreement. But this was a very expensive effort.

The possibilities of partnering between GIST patient groups and other disease groups were discussed.

The European Breakout Group

Markus Wartenberg reported back on behalf of the group.

First, Prof. Kasper and PD Dr. Reichardt taught a "mini preceptorship" on GIST treatment, presenting case studies to the group and asking us challenge questions. The patient advocates performed admirably well in answering the questions from the doctors. The goal is not for the advocates to "play doctor", but rather for them to know which questions the patients should ask.

Risk stratification for localized GIST still needs further improvement. The question of how to be sure that a GIST diagnosed as "progressive" really is a progression was discussed.

Generics were discussed. The doctors had a "matter-of-fact" attitude to generic imatinib - they are completely comfortable with using generic drugs - they expressed no concerns. EMA also has no quality concerns about generics.

Clinical trials in Europe were discussed. There are unfortunately very few GIST clinical trials in Europe - far fewer than in the USA, and only a few countries are participating.

SPAEN can increase the political influence of the sarcoma groups and it also acts as a conduit for sharing best practices.

Short-term Goals:

1. Generics. Develop information package for patients about generics; translate/ adapt// distribute it throughout Europe.

2. Tips for newly-diagnosed patients - important questions to ask. David and Ginger will work on this task.

3. Develop a template letter to clinicians to inform them about SPAEN and GIST organisations. David (UK delegate) will work on this.

4. Wild-type GIST: Jayne Bressington is an expert and will write an article about this, for patients. There has been a lot recent progress in understanding WT GIST.

SPAEN plans to develop an "information platform" for all sarcoma patients. This is a big project; it needs substantial funding. It is much harder to do this for sarcomas than for GIST. There will be both an external part and an internal part - create an environment where patient organisations can work together better. Markus noted the move to establish ERNs: European Reference Networks. Three ERNs will be created: rare solid tumours, leukaemia, and paediatric cancers.

The annual conference of SPAEN will be held in Warsaw, Sept 8-10, 2016.

External dinner at the "Restaurante Fragata" on Friday, May 20, 2016.

CAPACITY BUILDING: Medical Knowledge – I.O. Immuno-Oncology

A short introduction to I.O.
PD Dr. Peter Reichardt, Berlin, Germany
Written by Markus Wartenberg and Kathrin Schuster

Immuno-Oncology:
A new therapeutic approach with a long history

It's more than a century now that researchers have raised the question whether or not the immune system is capable of fighting cancer, says PD Dr. Peter Reichart, Berlin-Buch during his talk "Introduction to ImmunoOncology". And if so, is it possible to elicit immune response against malignant tumours? Today, there's overwhelming evidence available to support the view that both the innate and adaptive immune responses can recognize and eliminate tumours. However, there are a lot of unanswered questions still to be addressed.

In theory, the generation of immunity to cancer is a cyclic process. It starts with the presentation of antigens on cancer cells. Antigens are proteins on the surface of the cells. They act like little flags for the immune system to identify and distinguish the cells. The dendritic cells present those antigens to the T-cells to activate them against these antigens. The T-cells, now being alert to these antigens, circulate the body. If they find the tumour presenting these antigens, they will try and kill it.

However, this obviously doesn't work for all cancers because tumour cells are clever and can avoid detection by the immune system.

Dr. Reichardt therefore explains: „Cancer is not a result of a frail immune system. In the grand majority of cancer patients, the immune system is working completely normal. It's just not able to recognize and kill the cancer cells due to very clever mechanisms the cancer cells follow to avoid detection by the immune system."

There are currently two different kinds of modes of action available to overcome those "escapes mechanisms" of the tumour cells: The CTLA-4-Checkpoint-Inhibitors and the PD1-/PDL1-Inhibitors.

CTLA-4-Checkpoint-Inhibitors influence the interaction between two cells of the immune system, the T-cells and dendritic cells, in order to activate or even over-activate the immune system to attack the cancer. However, as this activation is not cancer-specific, the immune system also attacks healthy cell, which can lead to severe immunological side effects.

The PD1-/PDL1-Inhibitors intervene in the interaction between T-cells and cancer cells. This "communication" between cancer and T-cells results in inhibition of the T-cell-activity and the T-cells don't attack the cancer. By interrupting this interaction with a PD1-Inhibitor, the T-cell can act normally again and attacks cancer cells. This approach is more targeted and cancer-specific and therefore results in a lower rate of so called autoimmune side effects. There are two PD1-Inhibtors already approved for different kinds of cancers, Nivolumab and Pembrolizumab, and two PDL1-Inhibitors still in clinical testing: Atezolizumab and Durvalumab.

To date, the cancer types with the highest probability to respond to immune-oncological drugs are melanoma, lung cancer and kidney cancer. Those tumour types have a high rate of mutations in their cancer cells – they "look very different" from normal cells and can most easily be detected. Therefore, Dr. Reichardt assumes, that immune-oncology probably will not (that) profitable in GIST. GIST cells -and also most of the different types of sarcoma cells as well – only have very specific mutations. This makes it very hard for the immune system to detect them at all. And if detection is not granted, the activation of the immune system doesn't make a difference. However, more clinical studies have to be conducted to prove or hopefully refute this statement.

CAPACITY BUILDING:
Patient Information and Education – Sharing Best Practice

PA-Chair: Gabriella Tedone

A GIST PAG's first steps in supporting research - the Canadian experience

David Josephy, President,
GIST Sarcoma Life Raft Group Canada

GIST Sarcoma Life Raft Group Canada was incorporated in 2008 and received registered-charity status in 2012. One of our objectives is to support GIST research in Canada. In 2015, we took our first step in this direction. The opportunity was presented in 2014 when Melissa and Melanie Garcia, the daughters of Glenita Mungcal, started a fundraising campaign for GIST research. We were inspired by the presentation made by Estelle Lecointe (France) at New Horizons 2014, who emphasized that it is possible to get started funding research even with only modest financial resources. So, we established the "Glenita Mungcal Memorial GIST Research Studentship" and sent out a Request for Proposal in October 2014. The award is a $5,000 grant to defray the salary of a summer student. The RFA was distributed to Canadian universities and medical schools in Fall 2014 and one application was received by the Feb. 2015 deadline. This application was peer reviewed and approved.

The project is: "Prevalence of PD-L1 Overexpression in GIST"; Principal Investigator: Dr. Yoo-Joung Ko, Medical Oncologist, Sunnybrook Health Sciences Centre, Toronto. The student was Rehana Jamani, a 4th year, Arts & Science Program student at McMaster University, Hamilton.

The rationale is that PD-L1 protein is a possible target for immuno-therapy of GIST; but only if it is expressed by GIST tumour cells, and this is not yet known. In some cancers, PD-L1 is expressed by tumour cells and binds to PD-1 on the surface of T-cells, leading to deactivation of the T cells and allowing the tumour cells to evade the immune system. PD-1 and PD-L1 inhibitors can prevent this deactivation process. Many PD-1 and PD-L1 inhibitors (biologicals) are in clinical development.

In the project, Dr Ko will use banked GIST tumour samples from Sunnybrook and perform immunohistochemistry to analyse expression of PD-L1. Unfortunately, technical difficulties have delayed completion of the research, but results are anticipated.

LRG Canada's ongoing challenges in this research initiative include: assuring the long-term financial sustainability of the award; eliciting more interest from the research community (no applications were received in 2016); and "getting the word out" to potential applicants.

The value of an interactive forum for patients

David Falconer,
GIST Support UK

We have been using our interactive forum for patients in the UK for 9 years. As the membership grows so too does the information and support that patients can give to each other based on personal experience. The topics discussed and shared range from surgery to drug treatment and many other aspects that patients and carers with GIST disease are happy to share.

Very often the subjects revolve around questions that the patients had wished they had asked their clinician but had not thought of at the time or were too reserved to ask.

Sharing hopes, fears and experiences with other patients is invaluable and we have very good response from our members.

We recommend such an interactive forum to all GIST Groups.

Patient Forum Miner

Gérard van Oortmerssen,
Contactgroep GIST, The Netherlands

Gerard van Oortmerssen presented the project Patient Forum Miner which was started by Contactgroep GIST, the GIST patient group in the Netherlands. The idea for this project was presented earlier at New Horizons 2014 in Zurich. The aim of the project is to extract valuable information from discussions among GIST patients on discussion fora and social media on Internet. Patients support each other on these fora but also share a lot of information about the development of their disease, treatment, their quality of life, side effects and strategies they have developed to manage the side effects. Mining these "gold nuggets" of information is the objective of the project. Intelligent software is used to analyse the discussions and extract interesting information. A small "proof of concept" project was carried out in 2015 with promising results. A prototype of the software was demonstrated by Gerard during the presentation. Early 2016 a larger project started, in which the tool will be further developed. Discussion fora of several cancer patient organisations in the Netherlands are being used as test data. Due attention is being paid to privacy aspects and oncologists are participating in the project.

The tool is already used by the Dutch GIST group in the context of a project on patient participation that is now carried out by the Erasmus Medical Center in Rotterdam, one of the GIST expertise centers in the Netherlands. GIST patients are participating in development of treatment procedures and defining a research agenda. The tool is used to generate a long list of interesting topics for GIST research.
The long list will be used for a survey among GIST patients to define a few topics that are considered as most important to GIST patients. These topics will be input for the new research agenda of the Erasmus Medical Center.

The role of pharmacist in a patient GIST group

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

GIST patients, mostly treated with targeted therapies, take pills at home with autonomy of care but with greater personal responsibility for managing therapy. In advanced disease, continuing therapy indefinitely can wear down and tire the patient and the adherence to medication is often low. Non-adherence severely compromises the effectiveness of treatment. Lack of sufficient knowledge is one cause of patients' non-adherence to therapy.

Pharmacists can contribute to positive outcomes by educating and counselling patients to improve adherence and reduce medication-related problems.

The aim of our project is to create a listening/reference point to assist patients in order to ensure the continuity of care; to support the patient's efforts in developing medication management skills, moving in the direction of self responsibility. Pharmacist is ideally placed to bridge the gap between patients and physicians.

Pharmacist helps our members counselling by telephone; starting a personalized relationship; motivating patients to learn about their treatment and to be active partners in their care; verifying that patients have sufficient understanding and skill to follow their pharmaco-therapeutic regimens; promoting proper health information and encouraging an healthy lifestyle; giving useful advice for appropriate use of other drugs. The Pharmacist writes on our website info pages on medical issues related to the disease.

Patients have a greater health benefit from this initiative, save time and money. Patients and caregivers perceive the counselling as comfortable, confidential and safe. They do not feel lonely and assess positively to have a reference point, to vent their anxieties and fears and talk about their illness.

Patient Education at Henzo Kenya: The signature activity

Ferdinand Mwangura,
Henzo Kenya

Henzo Kenya was an idea realized by three patients and two volunteers out of a need for emotional support in June 2007. In 2009 it was registered as a support group – community based organisation with Ministry of Gender, Children and Social Development. Henzo membership consists of victors of CML (Chronic Myeloid Leukaemia a form of blood cancer) and GIST (Gastrointestinal Stromal Tumour a form of Stomach Cancer), caregivers and volunteers.

At Henzo, you belong to a community of survivors, care givers and partners with a common goal of supporting each other in all aspects, not only at the time of illness.

The immediate benefit you derive by joining Henzo, which means Love in Kiswahili, is the flow of love from this special membership, which have the adage that "if you want to run fast, you run alone, but if you want to run for a long time, you run as a group".

What we do

One of our missions is to support and empower each other in order to improve the quality of life of cancer survivors. Our strategic plan is organized into four goals derived from WHO global strategies on cancer control, namely: to Prevent, Cure, Care and Manage.

Goal I: Support: To establish support systems such as counselling and support groups for CML & GIST patients, survivors and their families.

Goal II: Information: To establish education resources for CML & GIST in order to empower the community with knowledge on the two rare forms of cancer.

Goal III: Research: To research the availability of resources for people diagnosed with CML & GIST and identify existing information gaps and needs.

Goal IV: Awareness: To design and implement awareness and training workshops and seminars based on information derived from the research.

Our trade mark activity is usually Patient Education. Patient Education is defined as any set of planned educational activities designed to improve patients' health behaviours and health status. Its main purpose is to maintain or to improve patient health or, in some cases, to slow deterioration. However, patient and family education goes beyond this main purpose. An informed and educated patient can actively participate in his or her own treatment, improve outcomes, help identify errors before they occur, and reduce his or her length of stay.

Benefits of Patient Education

1. Increasing the patient's ability to cope with and manage his or her health

2. Facilitating understandings of health statuses, diagnosis and treatment options, and consequences of care for patients and their families

3. Empowering patients to make decisions related to their care

4. Increasing patients' potential to follow a health care plan

5. Helping patients learn healthier behaviours

6. Promoting recovery and improved function

7. Increasing patient confidence in his or her self care

8. Decreasing treatment complications

Good Nutrition: The diet topic being covered well by the Dietician. One notable issue are the many myths surrounding what food to eat as a cancer patient. This highlighted a need to just hold a 1-day conference just to discuss good diet so as to get rid of the many myths that are not substantiated

Sharing Experiences: Patients had an opportunity to share their experiences and encourage one another. Learning from each other.

Friends of Max

Nikhil Guhagarkar,
The Friends of Max, India

Activities

- **Patient Support**: Regular GIST Meets,
- **Patient Education:** Creating and distributing FAQ and disease information material. New booklet on Nutrition and Holistic way for GIST.
- **Patient Counselling**: one on one
- **Sharing knowledge**: NH GIST & SPAEN meets.
- **Fundraising:** Chai For Cancer.
- **Advocacy:** Approached the Central Government for continuing exemption on import tax on Glivec.
- **Meetings:** Q&A with Oncologist and Surgeon, Special GAD agenda, Drama and Art-therapy, Nutritionist talk and Yoga Therapy
- **Covering more cities:** Mumbai, Delhi, Bangalore, Kolkata, Hyderabad, Cochin

Challenges

- Access to correct information.
- Access to GIST Specialist Doctors.
- Compliance In taking the drug.
- Language barrier.
- Myths and Stigma associated with Cancer.
- Difficulty in procuring drugs like Sorafenib & Regorafenib.
- Finances and Insurance coverage.

The meeting ended with a short discussion about the future of the GIST patient community, hosted by Norman Scherzer, The Life Raft Group and Markus Wartenberg, SPAEN, followed by a summary, closing remarks and a big thank you to the presenters and the "sustaining partners".

The NEW HORIZONS GIST Steering Committee would especially like to thank the following healthcare companies which supported the GIST NEW HORIZONS 2016: Novartis Oncology as initial funder, Bayer HealthCare and Pfizer Oncology as co-funders since 2012 and Blueprint as supporter since 2016.

NEW HORIZONS is looking forward to continuing these partnerships on the way of achieving its vision: "Improving access to treatment and quality of care through global exchange".

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 "Organisational Team" and the "Steering Committee"** Room: Catalunya (Conference Office)
19:00	**Get Together: "Tapas y Paella"** ***(Late arrivals could join any time!)*** 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, Organisational Issues, Thanks to the Sponsors, etc.** *Vicky Ossio & Markus Wartenberg (on behalf of the NH-GIST Steering Committee)* *& Representative of the Spanish GIST- or Sarcoma Patient Group*
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…** *PA-Chair: Markus Wartenberg* **Setting the scene – general parameters (15)** *Markus Wartenberg, SPAEN (DE)* **The localized disease (25)** *Piotr Rutkowski, Warsaw (PL)* **The metastatic disease (25)** *Piotr Rutkowski, Warsaw (PL)* **The progressive disease (25)** *Breelyn Wilky, Team Jonathan Trent, Miami (USA)*
10:30 – 11:00	**TEA / COFFEE BREAK (30 minutes)**
11:00 – 12:30 (90)	**GIST 2: Genotyping / Mutational Analysis in GIST:** *PA-Chair: Ginger Sawyer* **Science & rationale for mutational analysis in GIST (40)** *Maria Debiec-Rychter, Leuven (BE)* **Process & practice of performing mutational analysis (40)** **(incl. quality aspects and potential pitfalls)** *Sabrina Rossi, Team Paolo DeiTos, Treviso (IT)* **Additional questions from the auditorium (10)**
12:30 – 14:00	**NETWORKING LUNCH (90 minutes)**

DAY 1 – THURSDAY May 19, 2016 – Part 2

14:00 – 15:30 (90)	**GIST 3: Following the research journey in GIST** *PA-Chair: Norman Scherzer / Sara Rothschild* **Interesting targets in GIST & selected current / upcoming clinical trials in GIST…** *Breelyn Wilky, Team Jonathan Trent, Miami (USA)* **Additional questions from the auditorium**
15:30 – 16:00	**TEA / COFFEE BREAK (30 minutes)**
16:00 – 17:15 (75)	**EDUCATION: The MITIGATE project** *PA-Chair: Markus Wartenberg* **New strategies and protocols for diagnosis and treatment of GIST** *Stefan Schönberg, Mannheim (DE)*
17:15 – 18:00 (45)	**SPECIAL LECTURE: The Indian Experience…** ● Challenges of rare cancer patients in low income countries ● First examples to achieve changes in India ● Programmes, giving patients access to innovations *Viji Venkatesh, Region Head (India & South Asia), The Max Foundation*
18:00 – 19:30	**BREAK BEFORE DINNER (90 minutes)**
19:30	**Internal Dinner (Meliá Hotel)**

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

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

DAY 3 – SATURDAY May 21, 2016

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

5. Participants

COUNTRY	NAME	GIST-ORG./-GROUP	SC-MEMBER	EMAI-ADDRESS
Argentina	Mesri Florinda Sandra	AGA (Asociación GIST Argentina)		sandramesri@hotmail.com
Austria	Bruno-Lindner Amy	GIST-Support Austria		amy.bruno-lindner@univie.ac.at
	Bruno Martin	GIST-Support Austria		
Bolivia	Ossio Vicky	Alianza GIST	SC	vossiop@gmail.com
Bulgaria	Popova Yuliana	GIST Alliance for Patients-Bulgaria		info@gist-bg.com
Canada	Josephy David	Life Raft Group Canada	SC	djosephy@uoguelph.ca
	Tam Laetitia	Life Raft Group Canada		laetitia.tam@gmail.com
Chile	Fernandez Piga	Alianza GIST / Fundación GIST Chile		pfernandez@liferaftgroup.org, pfernandez@gistchile.cl
China	Liu Xian	Shanghai Roots & Shoots		liuxian25@gmail.com
	Yu Xia	Shanghai Roots & Shoots		yuxiam@hotmail.com
Colombia	Becerra Jairo	Fundacion GIST Colombia		becerrajairo@hotmail.com
Finland	Väisänen Marjo	Finnish GIST Patients Network		vaisa.marjo@gmail.com
Germany	Wartenberg Markus	Das Lebenshaus e.V.	SC	markus.wartenberg@daswissenshaus.de
	Pilgermann Kai	Das Lebenshaus e.V.		kaipilgermann@yahoo.de
Greece	Visvardis Evangelos Efstathios	University of Athens		evangelos.visvardis@gmail.com
Guatemala	Castillo de Armas Silvia	Asoc. de Pacientes con LMC ASOPALEU		sirecaa@gmail.com
Hungary	Szekfü András	Association of CML-GIST Patients		andras.szekfu@gmail.com
India	Guhagarkar Nikhil	The Friends of Max		gdental99@gmail.com
	Venkatesh Viji	The Max Foundation		vvenkatesh@themaxfoundation.org
Israel	Moshe Gideon	Israeli GIST Group		bgm.mng@gmail.com
	Moshe Bracha	Israeli GIST Group		
Italy	Tedone Gabriella	A.I.G. Associazione Italiana GIST	SC	g_tedone@hotmail.com
	Tamagni Barbara	A.I.G. Associazione Italiana GIST		barbaratamagni@yahoo.it
Kenya	Mwangura Ferdinand	Henzo Kenya		chairman@henzokenya.or.ke
Macedonia	Dimitrovski Toni	gist-macedonia		centarcom@yahoo.com
	Dimitrovska Meri	gist-macedonia		
Mexico	Salas Rodrigo	Fundacion GIST Mexico		rodrigo.salas@fundaciongist.org
Netherlands	van Oortmerssen Gerard	Contactgroep GIST Nederland/België		gerard.vanoortmerssen@gmail.com
Netherlands	Jansen Ton	Stichting Contactgroep-GIST		hellouw36@hetnet.nl
Poland	Fonrobert Piotr	Polish GIST Patients Support Assoc.		pfonrobert@gmail.com, piotr.fonrobert@pkopo.pl
Spain	Herrero Luis	GIST Espana		luis.herrero.fuente@uva.es
	Mejías García Dora	GIST Espana		domeg1@hotmail.com
	Alabau Calvet Xantal	GIST Espana		
Switzerland	Wettstein Martin	GIST-Gruppe Schweiz	SC	m.wettstein@wp-ing.ch
	Meier-Schnorf Helga	GIST-Gruppe Schweiz		helga.meier@bluewin.ch
UK	Bressington Jayne	PAWS-GIST (SDH deficient GISTs)		jayneandkim@aol.com
UK	Falconer David	GIST Support UK		david.falconer48@gmail.com
	Falconer Doris Blair	GIST Support UK		
USA	Scherzer Norman	The Life Raft Group	SC	nscherzer@liferaftgroup.org
	Rothschild Sara	The Life Raft Group		srothschild@liferaftgroup.org
USA	Sawyer Ginger	GIST-Support International	SC	grsawyer@icloud.com

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
maria.debiec-rychter@med.kuleuven.be

Bernd Kasper
Sarkom Zentrum, Interdisziplinäres Tumorzentrum Mannheim (ITM)
Bernd.Kasper@medma.uni-heidelberg.de

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
srossi@ulss.tv.it

Piotr Rutkowski
Sklodowska-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

NEW HORIZONS GIST

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

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