



# **NEW HORIZONS** **GIST**

**2015 New Horizons GIST Meeting**  
**“Celebrating 15 Years of GIST Treatment”**

**Hampton Inn & Suites**  
**Miami Brickell Downtown**  
**50 SW 12th Street**  
**Miami, FL 33130**

## ACKNOWLEDGEMENTS

The New Horizons GIST Steering Committee would like to give a special thank-you to **NOVARTIS ONCOLOGY** for its historic and unwavering support to New Horizons over the years that have allowed the birth and constant development of a highly knowledgeable and global community of GIST patients.



The New Horizons GIST Steering Committee would also like to thank **PFIZER** and **BAYER** – for their confidence, support and involvement in the New Horizons GIST conference.



May this partnership continue as a major contribution towards a better future for every GIST patient worldwide.

Dear New Horizons GIST Attendees,

On behalf of the New Horizons GIST Steering Committee, welcome to the “2015 New Horizons GIST” meeting!

First and foremost, I would like to thank all of you for your time and efforts to participate in this year’s New Horizons GIST conference – all of you who represent the global GIST patient community - whether you are a participant, speaker or support staff member. There is one ultimate goal that unites us all - to ensure the survival of GIST patients and maximize the quality of their lives, and we will work together for the next few days to do our very best to represent their needs and interests.



The topic of this conference is “Celebrating 15 Years of GIST Treatment: GIST Therapies on the Horizon” as it continues to examine the treatment of GIST as observed by the patient, caregiver, medical expert and pharmaceutical communities. The goal of this conference is to open up a discussion, and make changes and improvements. We will define common global strategies and set-up collaborative initiatives with experts and the pharmaceutical industry that will have positive impact on the management of GIST patients’ treatment and quality of life.

We will have an opportunity to hear from several experts, analyze and address the unmet medical needs and inequalities in GIST worldwide. We will look to understand our global landscape to support local member organizations and formulate ways we will expand our reach to each other through a communication and educational virtual platform.

The Steering Committee and I wish you a very productive meeting, enjoyable social networking as well as a memorable experience in sunny Miami!

Warmest regards,  
Diana Nieves, 2015 New Horizons GIST Administrator

2015 New Horizons GIST Steering Committee:

- Gabriella Tedone, A.I.G. Associazione Italiana GIST Onlus (Italy)
- David Josephy, GIST Sarcoma 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)

## LOGISTICAL INFORMATION

### CONFERENCE VENUE

#### Hampton Inn & Suites

Miami Brickell Downtown  
50 SW 12<sup>th</sup> Street  
Miami, FL 33130  
Tel: 305-377-9400

### CHECK IN/CHECK OUT

Check-in time: 3:00 PM  
Check-out time: 12:00 PM

### MEETING REGISTRATION

Registration begins on Friday, May 15th at 4:00pm in the **Bluebird Room**

### WELCOME DINNER

Welcome dinner will be held on Friday, May 15th at Perricone's Restaurant  
15 SE 10th Street, Miami, FL 33131, Tel: 305 374 9449.

### PROGRAM AGENDA

The conference will be held from Friday, May 15th to Sunday, May 17th, 2015

Friday, May 15th: 4:00pm-6:30pm Registration/ 7:00pm Welcome Dinner

Saturday, May 16th: 8:00am - 5:30pm in the **IBIS I Room**

Sunday, May 17th: 8:00am – 5:30pm in the **IBIS I Room**

### DINNERS

**Friday, May 15<sup>th</sup>:** We will meet in the Hampton Inn and Suites lobby at 6:45pm to walk over to Perricone's Restaurant, 15 SE 10th Street, Miami, FL 33131, Tel: 305 374 9449.

**Saturday, May 16<sup>th</sup>:** We will meet in the Hampton Inn and Suites lobby at 6:30pm to take a shuttle to Casa Juancho, 2436 S.W. 8<sup>th</sup> Street, Miami, FL 33135, Tel: 305 642 2452

**Sunday, May 17<sup>th</sup>:** you are free to explore Miami.

### DRESS CODE

Light clothing (business casual)

### CONTACTS

If you need assistance while you are in Miami, FL please contact:

**On-site Logistics Assistant:** Matt Mattioli, Cell: 973-330-6601

**New Horizons GIST Administrator:** Diana Nieves, Cell: 646-554-7121

## 2015 AGENDA

### Day 1: Friday, May 15th

4:00 PM Registration in **Bluebird Room**

7:00 PM **Dinner at Perricone's Restaurant**  
15 SE 10<sup>th</sup> Street, Miami, FL 33131, Tel: 305 374 9449

### Day 2: Saturday, May 16<sup>th</sup>

**IBIS I Room**

08:00 – 8:45 AM Breakfast

08:45 AM Opening Remarks

09:00 – 10:30 AM **Celebrating 15 Years of GIST Treatment: GIST Therapies on the Horizon**  
Dr. Jonathan Trent, Dr. Peter Reichardt, Dr. Matias Chacon

10:30 – 10:45 AM Coffee/Snack Break

10:45- 11:30 AM **The Era of Personalized Medicine: A Focus on Mutational Testing** Dr. Pablo Bejarano, Pathologist, Cleveland Clinic Florida

11:30 – 12:15 PM **Surgical Management of GIST: Focusing on Different Stages of Disease** Dr. Alan Livingstone, Surgeon, Sylvester Comprehensive Cancer Center

12:15 – 12:30 PM Question & Answers

12:30 – 1:30 PM Lunch

01:30 – 3:00 PM **Issues that Impact GIST Survival: Discussion**

3:00 – 3:15 PM Coffee/Snack Break

3:15 – 5:00 PM **Addressing the Unmet Medical Needs and Inequalities in GIST Worldwide**  
Discussion

7:00 PM **Dinner at Casa Juancho**  
2436 S.W. 8<sup>th</sup> Street, Miami, FL Tel: 305 642 2452

## Day 3: Sunday, May 17<sup>th</sup>

IBIS I Room

08:00 – 9:00 AM	Breakfast
09:00 – 9:45 AM	<b>Patient Group Involvement in the Clinical Trial Process</b> Bray Patrick-Lake, Clinical Trials Transformation Initiative
9:45 – 10:30 AM	<b>Bringing Research to the Patients</b> Steven Young, Addario Lung Cancer Medical Institute
10:30 – 11:00 AM	Coffee/Snack Break
11:00 – 11:45 AM	<b>Collaborative Initiatives in Europe</b> Markus Wartenberg, SPAEN
11:45 – 12:30 PM	<b>Closing the Gap: Understanding the Global Landscape to Support Local Member Organizations:</b> Karen van Rassel, Lymphoma Coalition
12:30 – 1:30 PM	Lunch
01:30 – 3:00 PM	<b>Upgrading New Horizons GIST to a Global GIST Patient Information, Communication and Education Platform</b> Norman J. Scherzer & Markus Wartenberg
3:00 – 3:15 PM	Coffee/Snack Break
3:15 – 4:30 PM	<b>Round Robin Discussions:</b> Working towards a Resolution
4:30 – 5:00 PM	<b>Closing Remarks &amp; Vision for Future Discussions</b>
7:00 PM	Dinner on your own to explore Miami, FL

## PARTICIPANT LIST

<b>First Name</b>	<b>Last Name</b>	<b>Organization</b>	<b>Country</b>	<b>Email Address</b>
Christine	Battistini	Alianza GIST	Brazil	cjtb@espacodevida.org.br
Jairo	Becerra	FundaciónGIST Colombia	Colombia	becerrajairo@hotmail.com
Dr. Pablo	Bejarano	Cleveland Clinic Florida	USA	bejarap@ccf.org
Jayne	Bressington	PAWS-GIST + GIST-Support UK + Sarcoma UK = GIST-Patients in the UK	United Kingdom	jayneandkim@aol.com
Lynn	Burrows	Life Raft Group Canada	Canada	blbcounselling@msn.com
Silvia	Castillo De Armas	ASOPALEU	Guatemala	asopaleu@hotmail.com
Dr. Matias	Chacon	Alexander Fleming Institute	Argentina	matiemi@yahoo.com
Gissoo	Decotiis	Bayer Pharmaceuticals	USA	Gissoo.decotiis@bayer.com
Margalit	Edelman	Pfizer Pharmaceuticals	USA	Margalit.Edelman@pfizer.com
Piga	Fernandez Kaempffer	Life Raft Group	Chile	pfernandez@gistchile.cl
Piotr	Fonrobert	Polish GIST Patients Support Assoc.	Poland	pfonrobert@gmail.com
Bracha	Gideon	Israeli GIST Group	Israel	bracha.mng@gmail.com
Moshe	Gideon	Israeli GIST Group	Israel	bgm.mng@gmail.com
Maria Isabel	Gomez de Soriano	Asociación de Ayuda a Pacientes Hemato-oncológicos	Venezuela	asaphevenezuela@gmail.com
Nikhil Suresh	Guhagarkar	The Friends of Max	India	gdental99@gmail.com
Margie	Hickey	Novartis Pharmaceuticals	USA	Margie.Hickey@Novartis.com
David	Josephy	Life Raft Group Canada	Canada	djosephy@uoguelph.ca
Michael	Josephy	Alianza GIST	Costa Rica	mjosephy@hotmail.com
Estelle	Lecoite	Association Française des Patients du GIST	France	estelle.lecoite@laposte.net
Dr. Alan	Livingstone	University of Miami Miller School of Medicine	USA	alivings@med.miami.edu

## PARTICIPANT LIST (continued)

<b>First Name</b>	<b>Last Name</b>	<b>Organization</b>	<b>Country</b>	<b>Email Address</b>
Maria Paz	Mastretta	Fundación GIST México	Mexico	mmastretta@fundaciongist.org
Helga	Meier-Schnorf	GIST-Gruppe Schweiz	Switzerland	helga.meier@bluewin.ch
Florinda Sandra	Mesri	AGA	Argentina	sandramesri@hotmail.com
Ferdinand Mwangura	Micho	Henzo Kenya	Kenya	chairman@henzokenya.or.ke
Alejandro	Miranda	Un Paso Max	Dominican Republic	alex3@sbt.com.do
Christopher	Ngai	Bayer Pharmaceuticals	USA	christopher.ngai@bayer.com
Vicky (Virginia)	Ossio	Alianza GIST	Bolivia	vossiop@gmail.com
Bray	Patrick-Lake	Clinical Trials Transformation Initiative	USA	Bray.Patrick-Lake@duke.edu
Kai	Pilgermann	Das Lebenshaus e.V. GIST/Sarcomas	Germany	kaipilgermann@yahoo.de
Al	Riberio	Pfizer Pharmaceuticals	USA	
Dr. Peter	Reichardt	HELIOS Klinikum Berlin- Buch	Germany	peter.reichardt@helios-kliniken.de
Sara	Rothschild	The Life Raft Group	USA	srothschild@liferaftgroup.org
Rodrigo	Salas	Fundación GIST México	Mexico	rodrigo.salas@fundaciongist.org
Ginger	Sawyer	GSI GIST Support International	USA	grsawyer@icloud.com
Norman	Scherzer	Life Raft Group USA	USA	nscherzer@liferaftgroup.org
Gunnar	Schroefel	Bayer Pharmaceuticals	Germany	Gunnar.schroefel@bayer.com
Erin	Schwartz	The Max Foundation	Global	erin.schwartz@themaxfoundation.org
Dr. Jonathan	Trent	University of Miami Sylvester Comprehensive Cancer Center (USA)	USA	JTrent@med.miami.edu
Gerard	van Oortmerssen	Contactgroep GIST Nederland/België	Netherlands	gerard.vanoortmerssen@gmail.com
Karen	Van Rassel	Lymphoma Coalition	USA	karen@lymphomacoalition.org
Markus	Wartenberg	Das Lebenshaus e.V. GIST/Sarcomas	Germany	markus.wartenberg@daswissenshaus.de
Steven	Young	Addario Lung Cancer Medical Institute	USA	syong@alcmi.net



## STEERING COMMITTEE

### **DAVID JOSEPHY, President of GIST Sarcoma Life Raft Group (Canada)**



David Josephy is President of GIST Sarcoma Life Raft Group, Canada, and a member of the Life Raft Group (USA) "Science Team". David has a dual perspective - both personal and scientific - on GIST. His sister-in-law has been living with GIST since 2000. David teaches biochemistry at the University of Guelph, and his research interests are in pharmacology, toxicology, and cancer research. During a sabbatical leave, 2010-11, David worked in the GIST research laboratory of Dr. Jonathan Fletcher at Harvard Medical School. Life Raft Group, Canada was incorporated in 2008 and obtained charitable status in 2012. We have held patient-and-caregiver meetings across the country; met with many doctors, government officials, and pharmaceutical industry representatives; established a web page, internet chat room, and toll-free telephone support line; presented well-attended "GIST Day of Learning" sessions each year since 2012; and, in 2015, we are sponsoring a position for a summer student in a Canadian GIST research lab. A priority for our group is to help GIST patients navigate through the maze of Canadian provincial health-care systems and to ensure that best diagnosis and treatment practices are available to all Canadian GIST patients.



### **VICKY OSSIO, Coordinator of Alianza GIST (Bolivia)**

I am a caregiver from Bolivia in South America. My daughter Carolina Ponce Williams was diagnosed with GIST in January 2006 at the age of 27. As a desperate mother, I seek for support and information everywhere possible. I found out in this process that most patients in Spanish speaking countries die because of lack of treatment and information. Together with two GIST patients from Columbia, Rafael Vega and Rafael Becerra, we decided to organize ourselves to help patients in our region, and created Alianza GIST with the support of The Life Raft Group.



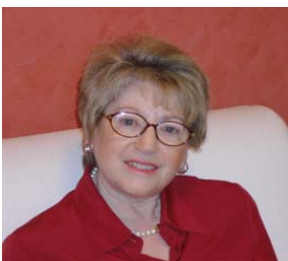
### **GINGER SAWYER, Board Treasurer of GIST Support International (USA)**

Ginger Sawyer is a nine-year GIST patient, having survived a small bowel GIST rupture in 2003. Ginger lives in Baton Rouge, Louisiana, and has retired after working for the state chamber of commerce for 32 years. She continues to do part-time contract research. She currently serves on the board of GIST Support International and is treasurer of that organization. One of her primary roles for GSI is to work with new GIST patients who are seeking financial assistance for second opinions and/or travel assistance to major cancer institutions for GIST-specific treatment.



### **NORMAN SCHERZER, Executive Director of The Life Raft Group (USA)**

Norman J. Scherzer is executive director of The Life Raft Group, an international, non-profit organization supporting people with GIST. Norman Scherzer began a career in public health at the Centers for Disease Control before moving on to the New York City Department of Health as Assistant Commission of Public Health. His wife, Anita, was misdiagnosed with LMS in 1994; treatments offered little assistance and in 2000, they celebrated their 39th wedding anniversary, since she would not make it to their 40th. Gleevec, thankfully, would be Anita's saving grace. When she entered the first clinical trial for GIST, she flourished and Norman helped found The Life Raft Group, utilizing his vast public health experience.



### **GABRIELLA TEDONE, Board Member of Associazione Italiana GIST Onlus (Italy)**

I am a GIST patient, diagnosed with GIST in August 2002; since then I was on neo adjuvant Gleevec until February 2011, when I underwent surgery of my primary tumor and I stopped taking Gleevec. I am a retired teacher and I live in Messina, in Sicily, with my family. I am Vice President of *A.I.G. Associazione Italiana GIST Onlus*. Along with other volunteers. I provide information and support to GIST patients, their families and caregivers in Italy, to promote awareness of this disease, to protect the rights of Italian GIST patients, to allow them access to the best treatments and innovative drugs I enjoy my life, my family, and I want to help other people to fight GIST. I hope that a cure for GIST will soon be possible!



### **MARKUS WARTENBERG, Executive Director/Spokesperson of Das Lebenshaus (Germany)**

Markus is a honorary Senior Manager of the charitable patient advocacy organization Das Lebenshaus e.V. (House of Life) This is a German non-profit organization - supporting patients with rare solid tumors: GIST, Sarcomas, Kidney Cancer. He is responsible for conceiving and organizing all community activities in GIST/Sarcomas 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 communication. After 10 years with his business, he left the agency in 2003 to start a more meaningful life in founding and managing the charitable patient association Das Lebenshaus e.V. (House of Life) and the non-profit-company Das Wissenshaus GmbH (House of Knowledge). Markus maintains extensive collaborations with leading Sarcoma experts (centers), industry and other important stakeholders to improve the situation of sarcoma- and GIST-patients in Germany and other European countries. This includes e.g. early involvement in clinical trials, timely and correct diagnosis, access to qualified treatment, monitoring, guidelines, centers of excellence, generating more/better evidence/data and HTA-processes.



**MARTIN WETTSTEIN, President of the Swiss GIST Group (Switzerland)**

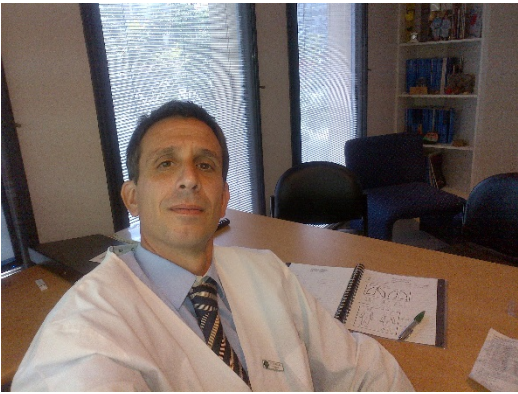
Martin Wettstein, father of 3 grown up children and engineer in his profession received his diagnosis of Exon 9 GIST in the fall of 2007. After one year of 800 mg neoadjuvant Gleevec treatment his surgery on the small intestine was successfully performed and he terminated his adjuvant Imatinib medication 4 months after the surgery. The biyearly and now yearly 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 was 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 a 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 together with Helga into a stable and long lasting PAG the way Dr. Schnorf intended the group to be.

## SPEAKERS



### **Dr. Pablo Bejarano, M.D.**

Dr. Pablo Bejarano, M.D. is board certified in Anatomic Pathology. He has special expertise in 3 Areas, including Adenoma Warthin's tumor, Glandular Cancer Adenocarcinoma, and Multiple Primary Cancer.



### **Dr. Matias Chacon, Medical Oncologist**

Internal medicine and medical oncology fellowship in Buenos Aires Argentina (1993-1998). Visiting fellowship at MD Anderson, Memorial Sloan Kettering and Lee Moffit Cancer center (1999). Member of American Society of Clinical Oncology since 2004. Member of the Argentinean Association of Clinical Oncology since 1998. Chief of department of melanoma, sarcoma and gastrointestinal tumors at the Alexander Fleming Institute. President of the GATE-D (Argentinean Group of Digestive Stromal Tumors) since 2003. Principal investigator in more than 30 clinical trials focus in sarcoma, GIST, gastrointestinal tumors. Several ASCO poster presentations since 1998. Dr. Chacon has participated in: 1994 –

2014 - Working groups of the Argentinean Association of Oncology, 1994 – 2014 – Argentinean Oncology Congress, and

2000 – 2014 – American Congress of Clinical Oncology.



### **Dr. Alan Livingstone M.D. Lucille and DeWitt Daughtry Professor and Chairman, DeWitt Daughtry Family Department of Surgery, University of Miami Miller School of Medicine**

Dr. Livingstone trained at McGill University in Montreal where he earned his BSc, MSc (Experimental Surgery), and MD degrees. Upon completion of his Surgical Residency at the Montreal General Hospital, he was recruited to the University of Miami Miller School of Medicine. Having distinguished himself as an educator, surgeon, and researcher, he was made Interim Chairman of Surgery in 1997 and then the Lucille and DeWitt Daughtry Professor and Chairman of the DeWitt Daughtry Family Department of Surgery at the University of Miami Miller School of Medicine in 2000.

He maintains a busy surgical practice treating esophageal, liver and pancreatic cancer patients. He is the Chief of Surgical Services at Jackson Memorial Hospital and has served as the Chief of the Division of Surgical Oncology for 2 decades. His Division of Surgical Oncology is actively involved in translational research for esophageal, breast, colon, and liver cancer, has an accredited Fellowship Program in Surgical

Oncology which is highly sought after, and has a research section of Molecular Oncology with significant NIH funding. Educating medical students and residents is a prime interest, and he has received the Chief Residents' Award for "Leadership and Excellence", as well as the "Outstanding Teacher of the Year Award".

The Department of Surgery has grown substantially under Dr. Livingstone's leadership. It is recognized nationally for its clinical excellence in the fields of Transplantation, Burns, Trauma, and Cardiac Surgery, and is one of the three busiest solid organ transplant programs in the United States. It is the world leader in pancreatic islet cell transplantation to cure diabetes. Recruiting researchers and expanding laboratory investigation has been a priority, and the Department of Surgery is in the top quartile for NIH funded research.

Dr. Livingstone is a Fellow of the American College of Surgeons and a Fellow of the Royal College of Surgeons of Canada. He is a member of 30 professional organizations. He is the author of numerous books and book chapters and over 200 peer reviewed articles, and has been invited to give 600 presentations at national and international venues. In October 2002 his contributions to medicine were recognized with an *Honoris Doctor Causa* Award from the Universidad de Moron, Buenos Aires, Argentina, and the Robert Zeppa, M.D. Award of Excellence. In 2014, he was inducted into the Brazil National Academy of Medicine.

Dr. Livingstone has served many extra departmental roles at the medical center including Associate Vice President of Medical Affairs at the University of Miami, Medical Director of the University of Miami Medical Group, Executive Dean for Clinical Affairs/University of Miami Miller School of Medicine, and Chief Executive for UHealth Clinical Affairs



**Bray Patrick-Lake, MFS, Duke CTSA, Director of Patient Engagement, and Clinical Trials Transformation Initiative (CTTI), Director of Stakeholder Engagement**

Ms. Patrick-Lake supports efforts to actively engage participant partners in Duke research programs, as well as patient advocacy organizations and other stakeholders in CTTI efforts to improve clinical trials. She implements strategies to enhance awareness of Duke CTSA and CTTI's work, particularly with patient advocates, and extend its impact by working in partnership with the patient advocacy community on research design and conduct and improvement of the

clinical trial enterprise.

In 2010, Ms. Patrick-Lake founded the PFO Research Foundation in response to the lack of definitive scientific information regarding the condition of patent foramen ovale (PFO) after being a patient in an aborted clinical trial. Ms. Patrick-Lake has served as a patient representative at the FDA on a variety of advisory committees and panels, in workgroups for EMA and NIH, as a guest lecturer and an external reviewer for IOM, and as a patient stakeholder or co-investigator for AHRQ and PCORI grants. She is a member of the PCORnet Coordinating Center's Executive Leadership Committee where she develops patient engagement strategies, MDEpiNet's National Medical Device Registry Task Force, MDIC's Patient-centered Benefit-Risk Steering Committee, ACC Foundation's Patient-centered Care (PC3) Shared Decision Making Workgroup, DIA's Patient Fellowship Selection Committee, TVT Registry Stakeholder Advisory Committee, and is a board member for the Alliance for Headache Disorders Advocacy.



**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.



**Jonathan Trent – Medical Oncologist; Director, Sarcoma Medical Research Program**

Jonathan Trent, MD, PhD is the Co-Director of the Musculoskeletal Center, Director of the Sarcoma Medical Research Program and professor of medicine at the University of Miami Sylvester Comprehensive Cancer Center. Dr. Trent transferred to Miami after leaving his position as an assistant professor of medicine in the Department of Sarcoma Medical Oncology at The University of Texas, MD Anderson Cancer Center in Houston, Texas. He is the chief editor of the sarcoma section of Current Opinions in Oncology and on the editorial board of The Chinese Journal of Clinical Oncology, Rare Tumors, and Translational Medicine. His clinical interests focus on GIST patient care, clinical trials and translational research. The excellence of his GIST clinical team led to his recognition as the 2010 GIST Physician of the Year by the Life Raft Group. He is the principal investigator, as well as a collaborator, on several ongoing clinical trials that are examining the use of kinase inhibitors alone and in combination with novel drugs in patients with primary and metastatic GIST. He is a principle investigator of the ongoing GIST registry and is credited with several breakthroughs in GIST that stemmed from his 5-year NIH K-23 GIST research grant. Dr. Trent earned his MD and PhD in cancer biology from The University of Texas Health Science Center. He completed an internship and residency in internal medicine at The University of Texas Health Science Center, and a fellowship in medical oncology at The University of Texas, MD Anderson Cancer Center while serving as chief fellow. Dr. Trent is board certified in internal medicine and medical oncology.



**Karen Van Rassel, Executive Director, Lymphoma Coalition**

Karen began her role as Executive Director (ED) of Lymphoma Coalition in late 2009 and prior to that was ED of Lymphoma Foundation Canada (LFC) since 2002. Before joining LFC, she was involved in a number of children's charities in various roles, holding a board position as well as working as Director of Corporate and Business Development bringing to these charities 20 years' experience from the Marketing and Advertising industry. As a founding member of the Lymphoma Coalition, she has taken special interest in LC's growth and membership support since its inception.



**Steven W. Young, President & Chief Operating Officer of the Addario Lung Cancer Medical Institute**

Steven W. Young serves as the President & Chief Operating Officer of the Addario Lung Cancer Medical Institute, a patient-founded/-focused non-profit research consortium directly linking more than 21 academic and community centers via shared infrastructures (biorepository, data system) and centrally managed intramural translational projects in the United States, France, Italy and Spain. After transitioning from the clinical research information technology industry, Mr. Young had played a central role in the development and early evolution of the Multiple Myeloma Research Consortium as its Executive Director from 2003 through 2008. Earlier still, he served as Director of the National Institutes of Health-funded

General Clinical Research Center at Mount Sinai School of Medicine and the Pediatric Clinical Research Center at Cornell University College of Medicine, both in New York City. Mr. Young resides in Weston, Connecticut with his wife and two sons.