

Ensuring no one has to face GIST alone



### Also in this issue

- Racing for a Cure
- All about the NIH
- What does cancer feel like?
- New Horizons
- ...and so much more

In Loving Memory: Aimee Adcock, Timothy Coughlin, Jim Dunn, Betty Gunderson, Kenneth D. Huff, Kay Jarman, Theodora Koumbouzis, Erin Malnory, Shirley Ann McIntosh, Dr. Peter Joseph Quinn and Michael Timans

# Is it time to cure GIST?

**By Dr. Brian Rubin**  
LRG Research Team  
Cleveland Clinic



I've been working on GIST most of my professional life and the initial work was both exciting and fulfilling. I remember when we confirmed the presence of KIT mutations in most GISTs in 1999. It seemed too good to believe. Then, there was the finding

that STI-571 (now known as Gleevec) could target KIT in addition to BCR-ABL. We thought it might inhibit GISTs but we had no idea it would work so well. The first clinical trials were so exciting -- dra-

matic stabilization of horrible metastatic disease in the majority of GIST patients. Then we saw the first depressing signs of resistance. Patients were progressing and many of them would go on to lose the battle against Gleevec resistant GIST, even after second line Sutent, third line Sorafenib, etc. We've learned a lot over the last 15 years but we still haven't learned how to cure GIST.

What is imminently clear to everyone in the field is that no single agent is going to cure or even control GIST indefinitely. It's just too easy to develop resistance to a single agent. That is where combinations of therapeutic compounds emerge as a strategy to treat GIST. However, more needs to be done in the way of modeling

**Research, See Page 7**

# An advocate's rewarding experience at the NIH Clinic

**By Erin MacBean**  
LRG Science Team Member

From the moment I landed at the Washington Reagan Airport to the time I took off to fly back home, the Pediatric and Wildtype GIST Clinic at the National Institutes of Health (NIH) was a whirlwind of information and memorable events. I attended the clinic with Sara Rothschild as representatives for the Life Raft Group, and it was my first time attending the GIST clinic. I was excited to get the opportunity to meet other Pediatric GIST patients.

My goal was to present a project idea to the CPGR (the Consortium for Pediatric and Wildtype GIST Research), which is a group of leading GIST experts who gather

**NIH, See Page 8**

# ASCO features many updates on GIST trials

**By Jerry Call**  
LRG Science Director



Promising results for the immunotherapy approach dominated the annual conference of the ASCO and represent one of the biggest developments in cancer research since the advent of Gleevec.

the posters relevant to GIST patients:

George Demetri (Dana-Farber) and Nikolas von Bubnoff (Freiburg University Hospital, Germany) presented extremely interesting data on the ability to detect DNA from tumors in the blood of GIST patients. Using different technology, the groups led by these two researchers showed that a recurrence of GIST is correlated with mutant free circulating tumor DNA (fc)DNA and that secondary mutations can be detected in fcDNA.

This technology could have important implications in two areas for GIST patients.

1. Rising mutant fcDNA levels could predict a recurrence earlier than a CT scan. This could allow adjuvant patients to resume Gleevec at the earliest time point of a recurrence, potentially before a tumor could grow large enough to be seen on a CT scan. Adjuvant treatment studies suggest that treating GIST as early as possible may be more effective than waiting to a later time point (this is still a debatable point). Using this technology might allow a patient to "cycle" on or off Gleevec as needed according to rising or negative fcDNA levels. If proven effective enough, this technology might even be able to

**ASCO, See Page 6**

But there was also plenty of information about GIST. Here's a review of several of

# New Horizons makes a splash in Miami



*New Horizons GIST participants in Miami, Fla.*

**By Diana Nieves**  
Project Manager

The 2013 New Horizons GIST conference was held at the Hilton Miami Downtown Hotel in Miami, Florida from Wednesday, June 5<sup>th</sup> to Friday, June 7<sup>th</sup>. The conference was chaired and planned by a steering committee of nine members. To view the list of members please check out the online version of this article on our website.

There were a total of 38 participants who included 22 patient representatives (including eight Steering Committee Members), ten speakers, four pharmaceutical representatives, and two onsite logistics staff. The conference was sponsored by Novartis, Pfizer and Bayer Pharmaceutical companies. We also received product donations from Topline Products, Udderly Smooth and Philosophy, which were distributed to the participants during the conference.

The main topic of this conference was the clinical trials process. To ensure that all conference participants had some basic knowledge of the clinical trials process, the steering committee provided a Clinical Trials 101 workshop led by Jerry Call, Science Director and Jim Hughes, Clinical Trials Coordinator, both from the Life Raft Group. Participants were sent a Clinical Trials 101 PowerPoint presentation and were then given the opportunity to login into an Adobe Connect online meeting module for a Question & Answer Session with the presenters on May 1, 2013. Participants were also sent various articles on the clinical trials process and a pre-conference homework assignment to complete on the landscape of the clinical trials process within their country.

The first day of the conference began with a welcome lunch followed by warm welcome remarks from Anna Costato, Steering

Committee member. She introduced Dr. Peter Reichardt who provided a medical presentation on current care management of GIST. All the participants were very engaged in the presentation had many questions that Dr. Reichardt was able to answer. A GIST clinical trials perspectives discussion then took place by a panel of doctors representing two pharmaceutical companies, Dr. Peter Larson of Novartis and Dr. Ewa M. Matczak of Pfizer. Steering Committee member, David Josephy, moderated the panel asking questions on various topics such as the latest developments on new drugs for GIST, the availability of generic imatinib in many countries and the impact on clinical trials, and pharmaceutical companies pro-active steps to encourage early and active participation in patient advocacy groups in the clinical trials process.

Soon after the pharmaceutical panel discussion, Louise Binder, a Clinical Trials expert from the HIV/AIDs community, also provided her perspective on the clinical trials process encouraging and empowering patient representatives on the various issues and how they can take action to create a better process. Ms. Binder focused her talk on patients creating relationships with researchers, manufacturers and prescribers in the field in order to become better educated and prepared to advocate on behalf of GIST patients with government health policy officials. The day ended with a wonderful dinner at La Loggia Restaurant in downtown Miami.

Thursday, June 6, the day began with a presentation by Dr. Jonathan Trent, who provided an overview of new GIST treatments and GIST clinical trials as they were discussed during the recent 2013 ASCO conference held in Chicago, Ill. Dr. Trent also talked about the regulatory process of clinical trials. He identified the challenges of keeping clinical trials affordable as requirements and regulatory developments

change all the time. Dr. Trent also discussed the clinical trials process study protocols, how trial sites are selected and how protocols are outlined in the operations manual. Following Dr. Trent's presentation was Jim Hughes, who also provided his wealth of knowledge and experience with the clinical trials process.

Best practices sessions were also given by Piga Fernandez of Alianza GIST, Erin Schwartz of The MAX Foundation, and Roberto Pazmino of the Life Raft Group, as well as a session on the Patient Involvement in Clinical Research led by Steering Committee member Markus Wartenberg as part of the conference. Also, Dr. Anette Duensing provided a research update to the group including some history and a summary report of the Life Raft Group's Research Team on GIST.

The rest of Thursday, June 6 and most of Friday, June 7, the participants were engaged in group exercises and discussions facilitated by Bob Chapman of American Cancer Society and Cristina Parsons Perez of Catalyst Consulting Group, on the clinical trials process from a global snapshot and worked towards common resolutions. The group created a motto: "We, New Horizons as a global GIST community, believe that: Every GIST patient, regardless of geo location, resources, has access to us."

They also identified some goals and tactics that the New Horizons GIST community could undertake in the following years and a S.W.O.T. (strengths, weaknesses, opportunities and threats) analysis that would assist them in their efforts to better engage the Global GIST community with regard to the clinical trials process.

Closing remarks were made by Anna Costato, at the end of the conference who thanked everyone for being engaged and empowered to work together.



# LRG researchers publish 'cell sleep' study

By Phil Avila  
LRG Newsletter Editor



**M**embers of the Life Raft Group Research Team continue to publish results of promising studies aimed at finding a cure for GIST. The latest reflects the collaboration that guides its efforts.

A study from Dr. Anette Duensing's lab in collaboration with Dr. Maria Debiec-Rychter that was published online in Cancer Research on June 20 describes findings that "open an opportunity for future therapeutic interventions to target the DREAM complex for more efficient imatinib responses."

The DREAM complex is a multi-subunit complex that has recently been identified as an additional regulator of cellular quiescence.

Quiescence (also called "cell sleep") is when cancer cells stop growing but remain, rather than being killed by treatment. This oftentimes happens when patients are treated with imatinib.

The researchers found that by inhibiting DREAM complex formation by targeting its regulatory kinase (called DYRK1A) they were able to enhance imatinib-induced apoptosis, or cell death. In other words, by also targeting the DYRK1A kinase, treatment with imatinib is made more effective.

Dr. Duensing is with the University of Pittsburgh Cancer Institute, and Dr. Debiec-Rychter is with the Catholic University of Leuven in Belgium.

While the research project was carried out in Duensing's lab, Debiec-Rychter gave valuable support with a xenograft study (one of her specialties). Improving response to therapy is a focus of Duensing's lab.

This highlights the cooperation among LRG Research Team members that characterizes its strategy: a team approach using each member's expertise.

"Research team collaboration is truly crucial for my lab," Duensing said. "It helps foster studies I could not have done myself."

She added, "The collaboration with Maria on the mouse studies was fundamental to prove that GISTs go into quiescence not only in the lab, but in a live organism." She also credited researchers from Dana-Farber Cancer Institute for their previous work on the DREAM complex.

The research paper, whose lead author is S. Boichuk from Duensing's lab, is titled "The DREAM complex mediates GIST cell quiescence and is a novel therapeutic target to enhance imatinib-induced apoptosis." See <http://cancerres.aacrjournals.org/content/early/2013/06/20/0008-5472.CAN-13-0579.abstract> for an abstract of the article.

## Calendar

### New Jersey Local Group Meeting

August 4th  
Contact Janeen Ryan  
jryan@liferaftgroup.org  
973-837-9092, ext. 113

### Cancer in Inner-City America Symposium

New York, NY  
August 10th-12th

### Arizona Local Group Meeting

August 24th  
Contact Janeen Ryan  
jryan@liferaftgroup.org  
973-837-9092, ext. 113

### Night to Fight Cancer

New York, NY  
September 12th

### Night to Flight Cancer - West Coast

Los Angeles, CA  
October 11th-12th

### CTOS Meeting

New York, NY  
October 30th-November 2nd

**JERRY CUZIL'S  
NIGHT  
TO  
FIGHT  
CANCER**  
BENEFITING  
THE LIFE RAFT GROUP

September 12<sup>th</sup>, 2013  
MIDTOWN LOFT IN NYC  
567 5<sup>th</sup> Avenue  
Doors Open @ 6pm

LAST ONE STANDING WINS A \$10,000  
SEAT AT THE WORLD SERIES OF POKER

PLEASE REGISTER AT:  
[www.nighttofightcancer.org](http://www.nighttofightcancer.org)

Have any questions?  
Contact Matthew Mattioli  
[mmattioli@liferaftgroup.org](mailto:mmattioli@liferaftgroup.org)  
973-837-9092 ext. 122

**10 years**

**\$500** donation to play, enjoy hors d'oeuvres, and drinks

**\$125** donation for guests who want to enjoy the evening but do not want to play

We would love to see some of our members there to experience a great evening and to spread the knowledge about the Life Raft Group. Contact Matthew Mattioli at [mmattioli@liferaftgroup.org](mailto:mmattioli@liferaftgroup.org)

# What does cancer feel like?

Dr. Moe Anderson

I've been struggling to answer that question since I was diagnosed with a rare, malignancy known as gastrointestinal stromal tumor on February 18, 2011. I cannot remember what I am wearing right now without looking down, but I recall every nanosecond of the date, place, time and, well even, the way the ER doctor lowered her eyes before informing me, "You have a mass in your abdomen."

I am writing this because my online support group asks everyone to write about their "journey" This is my story. I am a dentist and professional writer. I have been writing books, articles, speeches, poems, and songs since I learned to make my mark. Writing is my preferred form of expression, rivaled only by my ability to talk at great lengths about almost anything. (My friends are nodding and smiling here.) Word play and my sense of humor have been my crutches through 50 years of – isms: sexism, regionalism, racism. I'm not complaining. It ism what it ism. Right?

I did okay in love and life by most measures. Still, I maintain that I didn't climb a ladder to independence; I climbed a craggy range of mountains with my bare hands and feet, begging for grace every treacherous step of the way. In other words, I don't give up easily.

I only speak for me but, so far, the disease is the only thing that doesn't cause me pain. I never felt the mass growing from my stomach 10 cm into my abdomen and metastasizing to my liver. My annual physicals and blood tests did not detect it. In fact, had it not been for an episode of food poisoning, my condition likely wouldn't have been detected for a few more years.

GIST does not respond to traditional chemotherapy or radiation. I take a brown poison pill called Gleevec every day and hope they find a cure before I die. The side effects, IV's, and CT scans evoke a mile-long stream of four-letter words, but I struggle to find one adjective to describe the actual cancer despite my above average lexicon.

## It doesn't hurt

When I was around 16 years old, three masked robbers came into the fast food place where I worked. One of them held a gun to my head as he instructed me to put the contents of the cash register into a bag. He didn't say another word. He didn't have to. I knew a worker at another store had been killed in a similar situation even though she cooperated with their demands. I wondered if I would suffer the same fate. Should I disobey him and fight? Or cooperate and hope for the best? That's what cancer feels like.

## Why me?

After surgery to remove the primary tumor, I eventually went back to life as anything but usual. I now have laser-like focus on the things I am uniquely qualified to do, such as spending a lot more time with my family and friends. Every day I try very hard to do something meaningful that brings me joy--not satisfaction or praise-but measurable happiness. Every day I try to forget the specter of death pressing the barrel of an illegal assault rifle to the back of my head: an unrelenting robber of my time. Most days, I succeed for several hours until fatigue, nausea, or a friendly hug that lasts 30 seconds longer than it did a year ago becomes a whisper from this menace,

"Hey you, I'm still here. I may pull this trigger tomorrow or one-thousand tomorrows from now. Tick tock, Precious."

Not long ago, everyone diagnosed with GIST simply died. Now, we have treatments, but there is no cure. Everyone I love sees this threat and feels pity for me. I am unaccustomed to this type of attention. It is more painful than the cancer. My goal is to make my family forget what I cannot.

## "I have cancer but cancer doesn't have me."

I don't know who said it first. I only know that phrase has become my mantra. Each day I rise is a gift from God, not a pardon from death. There are many wonderful people praying for my survival. There are researchers around the world looking for a cure. Meanwhile, I take my meds and hope my best achievements help more people than my colossal failures harm. I've decided that I will not pause and wait for death: she will have to catch me. I am a realist by nature. I have planned my funeral down to the words on my tombstone but I did not die today. So I shall live.

The significance of my story for you, if any, is my plea that you do not procrastinate about that thing **you** are uniquely qualified to do: the book, the degree, the wedding, or forgiveness, because unlike my cancer, living beneath your potential and being chronically unfulfilled can be cured. I hope cancer can wait, but you cannot.

Live strong.

Monica "Dr. mOe" Anderson is a dentist, speaker, and writer in Austin, Texas. To read more of her work, visit [drmoeanderson.com](http://drmoeanderson.com)



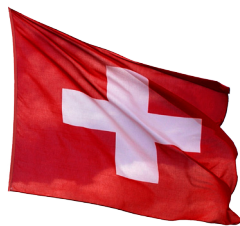
GIST Shmist. Big things are happening for our LRG members, despite living with cancer. Pediatric GISTer, Sile Bao graduated from Rutgers University in New Brunswick, NJ on May 19 and already started her first job at Princeton University in July. Fellow Pediatric GISTer, Ashley Young Vincent, gave birth to a beautiful baby girl named Lily on June 24. Ashley's first, grandma Toni said, "Ashley was in control and weathered the pain like a champ." And finally GISTer Mo Collins, of Parks & Recreation and Mad TV fame, married her devoted (and very hunky) partner, Alex Skuby on June 25 in a lovely ceremony.



# Swiss meeting marks group's 10th anniversary

By Martina Kuoni

Group Leader North-West-Switzerland



This year's Swiss GIST meeting on April 19 in Zurich was a special event. The board had started to plan early, as it wanted to offer a special program to commemorate the tenth anniversary.

The fact that Dr. Piotr Rutkowski of the Cancer Center and Institute of Oncology in Poland and Dr. Heikki Joensuu of Helsinki University Hospital in Finland had accepted the invitation of our board member, Dr. Michael Montemurro, was a great pleasure. Both guests had already lectured the evening before in the context of "Sarcoma Afternoons."

About 100 GIST patients, relatives, experts and interested professionals, as well as representatives of Swiss Group for Clinical Cancer Research (SAKK) and the pharmaceutical industry gathered at the Restaurant Au Premier at Zurich Main Station. In his welcome speech, Markus Wartenberg from Das Lebenshaus of Germany emphasized once more the value of the pharmaceutical industry's support. He extended a special welcome to the foreign guests, among others Amy Bruno-Lindner from Austria, who will launch the first GIST group in that country.

Markus Wartenberg presented a "Tour d'Horizon" on the topic of 10 years of GIST and the Swiss group. It never fails to impress how much was built up, researched, networked, exchanged and accomplished during that period. There is good reason to believe that the intensive work will be continued not only in medical research but also with regard to patient organizations.

The second speech was by Dr. Alexander Kiss of the University Hospital of Basel on the topic of "Psycho-oncology—what elements can be useful for the GIST patient?" He underscored how individual the handling and dealing with a GIST diagnosis can be.

It was fortunate that Dr. Philippe Fontaine of Satigny/Geneva agreed to contribute a second chapter on the topic "GIST—my friend." Two years ago, in a very personal account, he talked about his "friendship with GIST." Dr. Fontaine has been a GIST patient for 10 years and is a practicing physician. This time he reported on the merits of meditation, which he started after he fell ill.

Subsequently, Dr. Montemurro of RHM London/University Hospital of Zurich spoke on the topic "Treatment Standards and Perspectives in Switzerland." He mentioned that there were about 100 new cases per year in Switzerland and estimates the number of GIST patients in Switzerland at roughly 1,000. He gave an overview of the different medications currently used in the treatment of GIST and held out the

prospect of the third-line medication Regorafenib being approved this year.

The title of Dr. Rutkowski's lecture was "Role of the Surgeon 2013." He talked about different therapeutic surgical interventions in GIST, explained decision-making processes and presented actual patient cases.

Dr. Joensuu talked about "How it Began, How it Continues." He is the specialist who for the first time successfully used Gleevec on an American GIST patient. The realization that Gleevec—a medication used to treat chronic myeloid leukemia—is also effective in GIST was rather incidental, a fortunate discovery indeed. In his lecture he described the circumstances of his discovery in more detail than we know from "Living with GIST," the movie that was released nearly two years ago.

Recognition and a special thanks was given to the sponsors, Bayer AG, Novartis Pharmaceuticals, Pfizer AG and the Krebsliga Schweiz (Cancer League Switzerland.) Without their support, a meeting of such magnitude would not be possible. As usual, it was a unique opportunity for all attendees to learn the latest about GIST and relevant therapies and to meet experts in this discipline.

In a meeting preceding the Anniversary Meeting, Mrs. Helga Meier Schnorf was awarded the "Certificate of Honorary Membership of the GIST Group" in recognition of her untiring efforts on behalf of the GIST cause.

## Alianza GIST meeting to shape future

By Piga Fernandez

LRG Global Relations Coordinator

The Alianza GIST 2013 meeting in Miami marked an important milestone for GIST advocates as they embarked on a plan to build a self-sustainable organization in Latin America.

"We were energized by the meeting and now have set goals for our work in the coming year," said Piga Fernandez, Alianza GIST Coordinator. "We are heartened by our progress in bringing support to GIST patients throughout the region."

Representatives received intensive training on the latest advances in GIST research, an overview of common pitfalls in cancer screening among radiologists and pathologists, as well as an understanding of differ-

ent cancer treatments entering the market (such as generics). A six month plan was developed to focus on Alianza GIST's core mission areas: Education and Support,



Advocacy and Access, and Research and Surveillance.

Valuable tools and programs were demonstrated to help them with their advocacy and education work in Latin America such as the online GIST course prepared by the

Instituto Tecnológico de Monterrey, and the LRG's Collaborative GIST Tissue Bank and the Patient Registry.

Education, advocacy and patient-support best practices were shared by representatives from Brazil, Colombia, Chile, Mexico and Guatemala, which showed that local groups are making progress in prioritized areas this past year.

With the guidance of Bob Chapman of the American Cancer Society and Cristina Parsons-Perez from Catalyst Consulting Group, Alianza GIST representatives set benchmarks to discuss and define Alianza GIST's future working plan.

"We hope the meeting raised Alianza GIST's profile as a seasoned advocacy organization to the next level," said Sara Rothschild, the LRG's Program Director.

## ASCO, from Page 1

reduce the scan frequency of patients (reducing radiation and contrast-related negative effects on the kidney).

2. fcDNA appears to be superior to traditional biopsies at detecting secondary mutations that cause resistance to Gleevec. Up until now, treatment decisions cannot be based on secondary mutations because a biopsy may only detect one or two secondary mutations when 10 or more could exist in a resistant patient. This technology gives a much more complete picture of secondary mutations. This could eventually allow treatment to be custom tailored to each patient based on the actual secondary mutations present.

Read more about George Demetri's work on circulating tumor DNA using BEAMing technology here: <http://liferaftgroup.org/2013/04/new-blood-test-impact-gist-treatment/>

Dr. von Bubnoff's poster described preliminary results of a phase IIIb clinical trial (NCT01462994). Von Bubnoff's team collected 291 plasma samples from 38 GIST patients with known mutations in KIT or PDGFRA. In contrast to the BEAMing technology used by Dr. Demetri's team, von Bubnoff used a different method, allele-specific ligation PCR to detect fcDNA. Patients with active GIST disease had significantly higher amounts of mutant fcDNA compared to patients with no evidence of disease and the amount of mutant fcDNA correlated with disease course. A positive test result or an increase in mutant fcDNA was seen in 5 patients with progressive disease or relapse. In contrast, a decline of tumor fcDNA was seen in 5 patients responding to treatment. Von Bubnoff's conclusions were: "Our results indicate that free circulating DNA harbouring tumor specific mutations in the plasma of patients with GIST can be used as tumor-specific biomarker. The detection of resistance mutations in plasma samples might allow earlier treatment changes and obviates the need for repeated tumor biopsies." Read the von Bubnoff abstract here: <http://meetinglibrary.asco.org/content/109224-132>

The poster, presented by LRG Research Team Member, Michael Heinrich, presented in-vitro test data on ponatinib. Ponatinib is approved for use in patients with resistant forms of chronic myelogenous leukemia (CML). In CML, it is considered a third generation tyrosine kinase inhibitor (TKI). Lab data suggests that it is a very potent KIT inhibitor with widespread activity against secondary mutations, especially

those involving the activation loop (exon 17 in KIT). Activation loop mutations remain difficult to treat, although regorafenib (Stivarga) has activity against many of these mutations. The authors concluded: "PO (ponatinib) potentially inhibits the majority of clinically relevant KIT mutant kinases and has a broader spectrum of activity compared to IM (imatinib), SU (sunitinib), or RE (regorafenib). Based on these data, a phase 2 study of PO in drug-resistant GIST is being initiated." Secondary mutations are the most common cause of resistance for GIST patients with KIT or PDGFRA mutations.

The phase II trial will be starting for GIST patients in early June. The trial will initially open at the Knight Cancer Center in Portland, Oregon (Dr. Michael Heinrich) with additional sites opening later at Fox Chase Cancer Center (Dr. Margaret von Mehren) and Dana-Farber Cancer Institute (Dr. George Demetri). This trial is not yet listed on [clinicaltrials.gov](http://clinicaltrials.gov) or the LRG clinical trials database.

This study, by Dr. Myles Smith, used data from the SEER database to examine the question of whether or not GIST patients were at higher risk of developing a second different cancer in addition to GIST. Conclusions: Patients with a diagnosis of GIST have a higher incidence of second cancers when compared with standardized incidence in the general population. High-grade GISTs were associated with an additional malignancy. Both sexes were observed to have increased incidence of kidney cancer, with females at an increased risk of developing colon cancer.

As part of GIST surveillance, screening for colon cancer in females and kidney cancer in both sexes may be considered. imatinib concentrations in patients in the five-year adjuvant imatinib PERSIST-5 trial. Plasma samples were collected at 1, 4, 12 and 24 months. In this study (in contrast to other studies), imatinib plasma levels remained relatively steady over time. Inter-patient variability was 40.7-78.4 percent. Most notably, mean imatinib trough concentrations were on average ~33 percent higher in females vs males. The authors note that, "The 33% higher mean trough levels in females warrants further study for clinical decision making".

Two studies associated with neurofibromatosis were presented by Toshiro Nishida, MD, PhD, FACS.

In study # 1, the authors screened 95 adults with NF1. Six of these patients were found to also have GISTs in the small intestine with no KIT or PDGFRA mutation. In study # 2, the authors looked at 1,184 sporadic GISTs from community hospitals

in Japan and found 24 primary NF-1 GISTs. They concluded that NF-1-associated GIST is a rare entity of GIST and has distinctive features from conventional sporadic GISTs. KIT targeted TKIs appeared to be ineffective for recurrent and advanced NF1-GISTs.

Dr. Venkata R. Bulusu, MD, MSc, MRCP, FRCP presented data from the Cambridge GIST Study Group, United Kingdom.

The Cambridge GIST study group was formed in 2003. Results from 10 years of following patients (260 patients) were presented. GIST was initially suspected in 41 cases that turned out to be something besides GIST. Miettinen risk groups were: High risk = 27% Intermediate risk = 16% EGIST = 4% Low and very low risk GISTs = 57%

Conclusions: This is the first prospective regional GIST registry data from the UK. GISTs should be managed by an experienced multidisciplinary specialist team to provide a high quality patient centered service.

In a small study by Akira Sawakim M.D., Ph.D., seven Japanese patients with greater than five year's response to imatinib all had an imatinib concentration greater than 789 ng/mL. The authors also noted that small patients with a BSA <1.56, may be recommended for a lower dose of imatinib (300 mg).

Care should be used in interpreting this study due to the small size.

Data from 305 GIST patients from four trials were analyzed by Djoeko De Wit, et al to look at the influence of gastrointestinal resection on sunitinib exposure. Patients were divided into six groups according to previous GI surgery. Patients from the fourth group; with a combination of gastrectomy and small bowel resection had significantly lower sunitinib and sunitinib metabolite (SU12662) concentrations than the other five groups (one group was a control group). Concentrations were reduced by 21 percent (sunitinib) and 28 percent (SU12662) in the fourth group. Contrary to previous reports with imatinib, gastrectomy alone does not appear to influence sunitinib exposure. According to the authors, "This should be taken into consideration for the treatment of GIST patients who had a gastrectomy. In theory, such patients might have better outcomes if treated with sunitinib, given the risk of subtherapeutic exposure to imatinib."

For view all of the abstracts and posters from ASCO please check out the online version of this article on our website.



## Research, from Page 1

different drug combinations to understand how combination therapies affect GIST cells. In an effort to better understand how different therapies interact to inhibit various GIST cell models, our laboratory has been studying these combinations in dishes of GIST cells in the lab. What we've found is interesting and we believe this work has the potential to cure GIST patients.

To understand what I'm talking about, let's review basic signal transduction networks in GIST cells (see Figure 1). Think of signal transduction networks like electrical circuits. Basically, KIT is like a switch. Remember, KIT is the protein that is mutated in the majority of GISTs and since it is mutated, it is always turned "on". In normal cells, KIT is usually turned "off" and turned "on" only in special circumstances. Once KIT is "on", it needs to send a message to the nucleus of a GIST cell telling it to "divide". Cell division is how tumors grow. KIT can't communicate with the nucleus itself so it communicates with the nucleus through other proteins, which in turn talk to other proteins and eventually the message gets passed to the nucleus. You can also think of signal transduction as a weird protein-protein relay where the goal is to get the cell division message into the nucleus. These proteins form pathways / networks that we call signal transduction networks. Since KIT talks to multiple pathways, there are multiple ways to get the message into the nucleus. Combination therapy is used to inhibit KIT but to also inhibit the other protein members within the downstream pathways that talk to the nucleus. There are two major pathways downstream of KIT and also some minor pathways that we know less about. The two major pathways are the phosphatidylinositol 3 kinase (PI3K) and mitogen activated protein kinase (MAPK) pathways.

The GIST world is not alone in its realization that combination therapies are the way to go. For instance, a major oncogenic protein in melanoma is a protein known as BRAF, which is a component of the MAPK pathway. While targeting BRAF alone stabilizes tumors for only a short time, the combination of a BRAF inhibitor and a MEK inhibitor (another protein in the MAPK pathway) is more successful. Furthermore, recent collaborative work between a giant in the field of oncology, Dr. Bert Vogelstein

of Johns Hopkins University, and evolutionary mathematicians, applied mathematical models to try and understand how melanoma cells that are 'addicted' to BRAF evolve after treatment with Vemurafenib, which targets BRAF1. They found that dual

therapy (two drugs) results in long-term disease control for most patients, if there are no single mutations that cause cross-resistance to both drugs; in patients with large disease burden, triple therapy (three drugs are needed).

Because we know the major downstream pathways, we decided to work on combinations of KIT inhibitors, PI3K inhibitors and MAPK inhibitors. Other GIST researchers have of course also realized this, which is why several new clinical trials combining Gleevec with either PI3K inhibitors or with

MAPK/MEK inhibitors have been initiated.

Let's look at some results in order to get a feel for how this works (Figure 2). What you are looking at in panel 2a-e, is dishes of GIST cells that are growing in various drug combination. This GIST cell line in these dishes is known as GIST-T1-T670I. It contains a conventional KIT mutation that is controlled by Gleevec but like many GIST tumors that have been exposed to Gleevec for a while, it also contains a T670I mutation that is not controlled by Gleevec. The experiment is to treat the GIST cells for one

month and then remove drugs and see what grows. In dish "a" you can see lots of black spots, indicating that the tumors cells were unaffected by Gleevec. In dish "b" there are less black spots and they are smaller because we added two drugs in this dish, Gleevec and a PI3K inhibitor. In dish "c", Gleevec is added to a MAPK inhibitor and while there are fewer cells than in the Gleevec alone dish, the Gleevec-MAPK combination is not as good as the Gleevec-PI3K combination. That is because KIT signals largely through the PI3K pathway and to treat GIST, we must control

PI3K signaling either directly through a PI3K inhibitor or indirectly through controlling KIT as is seen in dish "b". In dish "d", there are very few and very small colonies, indicating that the combination of a PI3K inhibitor plus a MAPK inhibitor is really good at controlling these Gleevec-resistant GIST cells. However, the combination of Gleevec plus MAPK inhibitor plus PI3K inhibitor (dish "e") is even better.

When dealing with GIST cells that have become more reliant on the MAPK pathway, the difference is even more striking. In dishes "f"- "j", we have GIST-T1-10R cells which are much less reliant on KIT-PI3K signaling and more dependent on MAPK signaling. The experiment is the same as the last experiment. We treat GIST-T1-10R cells for one month and then remove the drugs and see what grows over a one to two-week period. In dish "f", the cells are treated with Gleevec alone, which does little to control the growth of these cells. In dish "g", the cells are treated with a PI3K inhibitor alone, which also does little. In dish "h", the cells are treated with a MAPK inhibitor alone. Since the cells are largely reliant on MAPK signaling their growth is greatly inhibited. In dish "i", which contains the combination of a PI3K inhibitor and a MAPK inhibitor, the results are similar to dish "h" which contained the MAPK inhibitor alone. However, in dish "j", we can see the results of the combination of Gleevec plus a PI3K inhibitor plus a MAPK inhibitor and they are dramatic. There is minimal growth and survival, especially compared with the other dishes.

We're excited about this approach because it suggests that we may be able to give therapy for a limited amount of time (e.g. one month) and that triple therapy may even cure many GIST patients. However, the down

side of triple therapy is that it is highly toxic – much worse than Gleevec alone. We're not sure if patients can tolerate these three inhibitors in combination. However, since the efficacy is so great and it treats all the mechanisms of Gleevec resistance that we've been able to model, we think this approach merits serious consideration.

### Reference

1. Bozic I, Reiter JG, Allen B et al. Evolutional dynamics of cancer in response to targeted combination therapy. *Elife*. 2013 Jun 25;2:e00747.

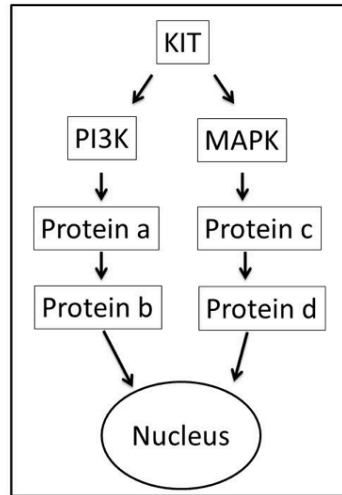


Figure 1

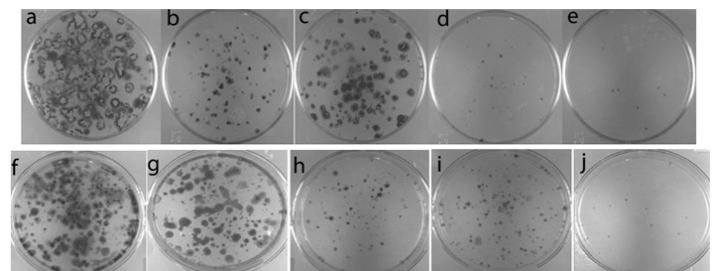


Figure 2

## NIH, from Page 1

to discuss patient data for Pediatric/Wild-type GIST. Presenting a project sounded easy on paper, but when I walked into the room and read all the doctors' nametags, something similar to a star-struck awe washed over me.

To understand me a bit more, I'm a Pediatric GIST survivor of 12 years and have been dealing with Carney Triad tumors for 14 years now. I became a full-time patient advocate in 2005. Three years ago, Jerry Call pulled me into the LRG Science Team and ever since then I have received hundreds of emails with the latest published research articles on GIST. All the doctors in the room were names I had read dozens of times in those articles. They are the superstars of the GIST world. Unfortunately, that was when I realized I would be speaking in front of all of them! Luckily, for me, I got the chance to listen to some of the research and see some of the data analysis before I had to present anything, so my nerves had a chance to calm down.

The extent of knowledge in the room was incredible. Due to recent findings in Pediatric/Wildtype GIST, the amount of hope for finding a treatment was uplifting. A highly effective treatment for our type of GIST has yet to be found, but I left the meeting feeling as if the doctors were making great

strides in gaining a better understanding on how different our tumors are, compared to the more common GIST types. It may be a small step forward but I've always lived life thinking that all great accomplishments start out as small steps before they turn into giant leaps.



*Attendees of the NIH Clinic*

I managed to present the LRG project without letting my nerves get to me, and I was deeply humbled when some of the doctors that approached me afterwards shook my hand and complimented my efforts. We didn't have much time to discuss things though, because the patients of the clinic were waiting for us to join them at the Children's Inn before dinner. It was there that Dr. Pappo explained Pediatric/Wildtype GIST to the patients and their families. I will never forget the collective gasp that filled the room when he explained that 0.06/ million people was the rarity of pediatric GIST. I think it was then that many realized having so many wonderful doctors and scientists focused on our type of GIST was

something extremely special.

The following day, I spent time with the other patient advocates. We were supposed to help patients find the locations of their appointments, but the clinic was so well planned our help wasn't all that necessary. Our task soon switched to sharing our stories and experiences while the patients waited to go to their next appointment. It was there that another shock of rarity presented itself to me.

I had the chance to meet a fellow Carney Triad patient that had all three tumors like me. There are less than 35 of us known to the world, so to be able to talk face to face with another person like me was the highlight of my visit.

The NIH Pediatric and Wildtype GIST Clinic is a one-of-a-kind special gathering. Not only does it pull together doctors and focus them on a rare cancer, it also provides patients the opportunity to meet face to face with other patients like them. After years of talking through computers and phones, I can say without a doubt, nothing beats the special connection felt when arms wrap around you in hugs of support by a fellow survivor. I hope that others will be able to experience what I have at this clinic, and I hope that the clinic will be able to continue as long as it is needed. Most importantly though, I hope that the efforts of such a clinic will pay off and that a cure will be found for us all.

## Loving father and husband passes away, 74



**D**r. Peter Joseph Quinn died on May 17, 2013, peacefully in his home in the presence of family, friends, and caregivers. He was 74.

Dr. Quinn was born in Montclair, New Jersey, the eldest son of Ellin and Peter Joseph Quinn. He graduated from St. Peter's Preparatory School and received a BS in 1960 from Notre Dame. During his junior year, Peter studied in Vienna, which inspired his lifelong appreciation of music and opera.

In 1964 Peter graduated from Georgetown School of Medicine with an MD and completed his residency training in urology at Georgetown University Hospital in Washington, DC. He was stationed in Millington as an officer in the U.S. Navy Medical Corps and stayed in Memphis, joining his future father-in-law's medical practice in 1975 and serving on the faculty of the University of Tennessee Department of Pediatric Urology.

Dr. Quinn was committed to medicine and recovery; he was a dedicated member of the recovery community in Memphis and touched many lives through sponsorship and almost daily attendance at Alcoholics Anonymous meetings.

He was a passionate man, enthusiastic

about music, opera, theater, golf, literature, fine dining, and the arts. For the last 20 years he took literature classes at Rhodes College, and actively participated in the Memphis Speakers Club, The Journal Review Club, The Memphis Wine and Food Society, and more recently attended the Amen Bible Study at Second Presbyterian Church. Peter was also a longtime member of the Memphis Country Club and The University Club.

Dr. Quinn dedicated his life to helping others and learning. He truly lived life to the fullest and defied many odds throughout his nine-year battle with cancer. Peter is survived by his wife Sheppie of Memphis, daughter Aggie of San Francisco, California, and brother Hugh, who lives in Hilton Head, South Carolina.



# Sosipatros Boikos takes helm at NIH Clinic

By Phil Avila  
LRG Newsletter Editor



Dr. Sosipatros Boikos

**D**r. Sosipatros Boikos, a graduate of University of Crete in Greece, very early and while he was a first year medical student, developed an interest in cancer genetics. After graduating from medical school, he came to the National Institutes of Health

as a Visiting Research Fellow to work on the genetics of Wildtype gastrointestinal stromal tumors—those GIST tumors without a KIT or PDGFRA mutation—under the supervision of Dr. Constantine Stratakis, the researcher who identified Carney-Stratakis Syndrome.

Now, as a medical oncology fellow at John Hopkins University and a clinical collaborator at NIH, under the supervision of Dr Lee Helman, he finds himself at the helm of the National Institutes of Health's Pediatric and Wildtype GIST Clinic, immersed in clinical and basic research that he hopes will lead to new targeted treatments for the Pediatric

and Wildtype GIST within the next four to five years.

Dr. Boikos and Mrs. Lauren Long, research nurse of the NIH clinic, organized the 10th Wildtype GIST clinic, that was held in Bethesda, Maryland, during the last week of June. Eleven patients were able to attend this clinic. **See NIH Article on Page 1**

"The clinic is unique because we can get a good sense of the natural history of the patients who participate," he said. "Wildtype GIST is a disease that appears to include distinct subgroups, based on the genetic and clinical characteristics. We wouldn't be able to identify these subgroups without a multidisciplinary approach." Patients who participated in the clinic interacted with medical oncologists, surgeons and geneticists. He said collaboration among these GIST experts is "essential" to the success of the clinic.

He said that five years ago, "We didn't know much about Wildtype GIST." But the clinic has been an excellent model for research and "it's true that we're moving faster."

Dr. Boikos said work is being done to characterize cell lines that were isolated in Wildtype and Pediatric GIST patients, which will help researchers move closer to targeted treatments. Germline mutations in succinate dehydrogenase subunits A, B, C, or D (SDHx) and absence of SDH protein expression associated with mitochondrial dysfunction have been recently described in patients with WT GIST. These SDH-de-

ficient tumors were also recently found to contain a hypermethylated phenotype. Dr. Boikos mentioned that maybe it is time for a new definition for Wildtype GIST, which would include mitochondrial dysfunction due to SDH loss of expression and hypermethylation.

## New Clinical Trials

Two trials for patients with Wildtype GIST are opening at NIH.

The first will utilize OSI-906, an insulin-like growth factor inhibitor. It has been found that Insulin-like Growth Factor Receptor 1 (IGF-1R) is highly expressed in Pediatric GIST tumors, in contrast to the mutant KIT-mutant GISTS that are sensitive to Gleevec. This study is being run by Dr. Margaret von Mehren from Fox Chase Cancer Center through the Sarcoma Research Consortium (SARC) and is available in several sarcoma centers.

The second study will utilize a drug called Vandetanib, a small molecule receptor tyrosine kinase (RTK) inhibitor which is active against VEGFR2- and EGFR- dependent signaling. It is also potent inhibitor of RET, which is frequently activated by mutation or rearrangement in medullary thyroid carcinoma (MTC). Vandetanib has shown activity in Medullary Thyroid Carcinoma while preclinical studies with a SDH-deficient renal cell carcinoma cell line have also shown activity with no significant toxicity. This study will open initially in just one location, at NIH in Bethesda.

# Erin Jean Malnory passes away, 29



**E**rin Jean Malnory, 29, of Bloomington, Minnesota, formerly of Fargo, surrendered peacefully after a short, but courageous battle against GIST

She made her journey home surrounded

by her immediate and extended family in love, prayer and song. Beloved daughter, sister, aunt, Godmother, granddaughter, niece, cousin, and friend, she was an inspiration to us all and will be greatly missed. Her memory will forever live on in our hearts.

Erin was born in Fargo on April 3, 1983. She was a 2001 graduate of Fargo South High School. Erin worked at Ameriprise Financial in Minneapolis for the past five years as a Marketing Coordinator. Erin loved to spend time with family and socialize with friends. She had a great sense of humor and a laugh that was contagious.

The blessing of close family in Minneapolis and Fargo in this time of crisis was immeasurable and a great comfort to Glenn, Bev, Erin, Megan, and Brad. She loved being an auntie to Cole who always brought her big smiles and joy.

She was survived by parents Glenn and Bev Malnory, sister Megan Fredrickson, brother-in-law Brad, nephew/Godson Cole, grandmother Margie McShane, and many aunts, uncles, cousins, and friends. She was preceded in death by grandparents William G. McShane, Arden and Dolores Malnory, uncles Tom and Patrick S. McShane.

# Scott Russell Takes the Scenic Route to Fundraising

By Gale Kenny  
LRG Development Associate

In early June, Scott Russell, husband of GISTer Carol, participated in the Fourth Annual Allegheny 100 Backpacking Challenge held by the Pennsylvania Allegheny National Forest Chapter of the North Country Trail.

This event is not a race, but an endeavor to hike 100 miles of trails in 50 consecutive hours. The trail cuts diagonally across the western corner of Pennsylvania, beginning in Marienville and extending north east to Willow Bay, close to the New York border. The North Country Trail winds along the scenic shoreline of the Allegheny Reservoir and passes through forests of 300-year-old beech, eastern hemlock and white pine.

Hikers experience the canopy of Cooks Forest State Park and the Clarion River. Completing the course is a test of stami-

na, determination and resilience, as the hikers have no access to first aid or watering stations throughout the event.

Scott not only took on the trail, but managed to rally dozens of friends and family to donate per mile, thereby motivating him to reach the 100 mile goal.

As he posted on his Facebook page, "Carol has a rare type of cancer called Gastrointestinal Stromal Tumor. GIST affects only about one percent of all cancer types, so it doesn't get much funding for research as do other types of cancers. The Life Raft Group is one of



Scott Russell hiking to raise funds for the LRG

the few organizations who pour [dollars] into GIST patients through support and research. Your support for Carol, LRG, and me is **much** appreciated."

Scott's admirable venture raised nearly \$3,000, and counting.

# Chris Skiff defies odds by running in California marathon

By Phil Avila  
Newsletter Editor



Chris Skiff at California marathon

When Chris Skiff was in elementary school, he "felt the urge to run." And he has been running ever since. Even after being diagnosed with GIST.

The 50-year-old father of five children recently completed his 10th marathon in San Luis Obispo, California, with an amazing

time of 3:59, one of his best times ever. His inspiring story attests to the value of exercise for those living with cancer.

"You don't have to be a marathon runner to get the benefit of exercise," he says. "It really does help to moderate symptoms."

Running has always been a part of Chris's daily routine. He ran competitively in high school and continued running while attending UCLA, where he graduated with honors.

Chris develops and owns Senior Assisted Living centers in California, including The Manse on Marsh in San Luis Obispo.

Before being diagnosed with GIST, he had competed in eight marathons. Then, when he was told he had cancer, his first reaction was, "Geez, I'm going to die." At the time, his wife, Laura, was expecting her third child and they had just finished adopting the second of two children from Russia.

Chris was concerned about the future of his family and thought "my running days are over."

But he was determined to move forward. "I had a lot of trouble running at first while on Gleevec, but I could tell running was helping me to have more stamina. I knew training would be long and hard," he said, but Laura gave him "the extra nudge" he needed.

He credits the support of his wife and others. "I'm thankful for the Life Raft Group (LRG) for the information they gave me and the access to professionals," he said. He said the LRG played a crucial role in "helping me ask the right questions."

His oncologist, Dr. Michael Heinrich, a member of the LRG's Research Team, surprised him one day last year by giving him the go-ahead to stop taking Gleevec. "I had been expecting to stay on Gleevec a long time," Chris said. "He reviewed the studies and said I was in good shape and that we could discontinue with strong surveillance." Chris will go for a CT Scan every six months.

He had previously done the unthinkable, running a marathon while on Gleevec. "I wanted to see if the body could take it," he said. In that marathon, he posted a time of 4:45.

He ran the same course this spring in San Luis Obispo, a year later, "to compare how I would do while off Gleevec." And he trimmed over 45 minutes from his time.

Chris stays busy operating the Assisted Living centers where, as his website says, "on any given day, you just might see (him) happily interacting with residents." But he still makes the time to be an active member of the LRG's email community, checking "on a daily basis."



## Local Group Leaders Needed!

Local group leaders are the local contact for new LRG members, they occasionally hold meetings in their home or a nearby restaurant. These gatherings are sometimes the first and only time a person in need may get any face time with others sharing their path. If you would like to volunteer as a group leader, please check the following list to see if your state is listed. Please write me at [JRyan@LifeRaftGroup.org](mailto:JRyan@LifeRaftGroup.org) if you are interested or want to know more about volunteering or call 973-837-9092 ext 113

- Arkansas
- California (Northern)
- Florida
- Hawaii
- Iowa
- Kansas
- Louisiana
- Maine
- Massachusetts
- Mississippi
- Montana
- Nebraska
- New Mexico
- New York (Upstate)
- North Dakota
- Ohio
- South Dakota
- Texas (East & West)
- Vermont
- Wyoming



*"We had a good turnout at the Michigan LRG meeting on Saturday, June 22. In attendance were Jim Mills, Diane and Dean Schmitz, Sue Severini, Susan and Ron Brandt, and new attendees Ali Tate, and Laura Boughner and her mom. Ali and Laura shared their GIST stories and we all shared our current treatment and handling of side effects. As usual, we also chatted about our lives, families and children."*

- Ellen Rosenthal

**Ellen Rosenthal is also LRG  
Local Group Leader of the Month!**



The New York Local Group Meeting gathered members from all over!

New York, Long Island, Arizona, Maryland and Micronesia were all represented at the meeting hosted by Pat Bonda Swenson at Bethpage Country Club on Long Island.

# A look at how the ASCO conference unfolds

**By Jim Hughes**

LRG Clinical Trials Coordinator

The American Society of Clinical Oncology (ASCO) conference was held again this year in Chicago. Over 32,000 medical professionals and exhibitors participated in what has become an international event. About 53 percent of attendees now come from outside the United States. It helps to know that the information presented at ASCO is not peer-reviewed as are journal articles. So the level of information is not the same. Peer review can come later as ASCO reports are submitted for publication.

However, ASCO reports are screened by a Scientific Program Committee of medical professionals familiar with each cancer type. GIST falls under the track "Sarcoma". The four doctors on the Sarcoma Program Committee have significant GIST experience. The abstracts submitted for review by the Sarcoma Program Committee are then given a place in the overall conference based on merit and likely impact. The order from higher to lower is:

- Plenary Session
- Oral Abstract
- Discussion Poster
- General Poster
- Abstract only

Most of the new information collected by the LRG comes from Oral Abstracts, Discussion Posters and General Posters.

The LRG is represented by both staff and volunteer reporters who attend the presentations and walk through the poster sessions. LRG reporters meet via teleconference before the meeting to review the GIST abstracts and plan to see important posters and presentations. At the meeting they collect paper copies and take photos of posters, talk with authors, attend oral presentations (sometimes asking questions) and interview authors and principle investigators. LRG reporters also carefully review the online video and audio archives of session material made available by ASCO for attendees. Other activities include meeting with other patient groups, attending education sessions and attending off-site meetings. The ASCO meeting usually starts on a Friday and goes through Tuesday morning. GIST oral abstracts are typically presented Monday afternoon.

To read more about ASCO check out Jerry Call's Article that starts on page 1 and read the whole version of this article in the LRG newsroom.

# THE LIFE RAFT GROUP

## LRG STAFF & CONSULTANTS

|                                       |                   |
|---------------------------------------|-------------------|
| Executive Director                    | Norman Scherzer   |
| Deputy Executive Director             | Roger Campbell    |
| Sr. Executive Assistant               | Diana Nieves      |
| Science Director                      | Jerry Call        |
| Strategic Planning Director           | Pete Knox         |
| Marketing and Communications Director | Erin Kristoff     |
| Events and Design Coordinator         | Matthew Mattioli  |
| Administrative Director               | Roberto Pazmino   |
| Program Director                      | Sara Rothschild   |
| Outreach Coordinator                  | Janeen Ryan       |
| Patient Registry Supervisor           | Magda Sarnas      |
| Newsletter Editor                     | Phil Avila        |
| Development Associate                 | Eola Bakhru       |
| Program Associate                     | Michelle Durborow |
| Global Relations Coordinator          | Piga Fernandez    |
| Bookkeeper                            | Carole Keary      |
| Development Associate                 | Gale Kenny        |
| Web Programmer                        | James Lee         |
| Websites Manager                      | Jim Napier        |

## LRG VOLUNTEERS

|                             |                 |
|-----------------------------|-----------------|
| Pediatric GIST              | Erin McBean     |
| Database Coordinator        | Steven Rigg     |
| Official Greeter            | Gail Mansfield  |
| Latin America Liason        | Vicky Ossio     |
| Clinical Trials Coordinator | Jim Hughes      |
| Photographer                | Kim Tallau      |
| Member Birthday Coordinator | Mary Kluth      |
| Special Projects Asst.      | Eileen Glasser  |
| Science Team                | Tanya DeSanto   |
|                             | Jim Hughes      |
|                             | David Josephy   |
|                             | Michael Josephy |
|                             | Rick Ware       |
|                             | Glenn Wishon    |
|                             | Paula Vettel    |

## BOARD OF DIRECTORS

|                                    |
|------------------------------------|
| Executive Committee                |
| Jerry Cudzil — President           |
| Stan Bunn — Past President         |
| Ray Montague — Secretary/Treasurer |

Mia Byrne  
Chris Carley  
Gary Glasser  
Jim Hughes  
Jerry Knapp  
Dan Miller  
John Poss  
David Safford  
Rodrigo Salas  
Larry Selkovits

Life Raft regional chapters: Find your reps info at [liferaftgroup.org/find-a-support-group/](http://liferaftgroup.org/find-a-support-group/)

|             |                  |                |                   |                |                   |
|-------------|------------------|----------------|-------------------|----------------|-------------------|
| Alabama     | Pat George       | Iowa           | Barbara Kepple    | Ohio           | Maryann Snowbrick |
| Alaska      | Jill Heinrich    | Louisiana      | Jackie Welsh      | Oklahoma       | Jane Rowan        |
| Arizona     | Janeen Ryan      | Maine          | Jodi Merry        | Oregon         | Gail Mansfield    |
| California  | Dina Wiley       | Maryland       | Bonnie Emerson    | Pennsylvania   | Jeffrey Bernstein |
|             | Martha Zielinski | Michigan       | Ellen Rosenthal   |                | Carol Heller      |
| Colorado    | Marge Morgan     | Minnesota      | Ananth Pai        | Rhode Island   | Susan Farmer      |
|             | Susy Clough      | Missouri       | Katie Bloss       | South Carolina | Paula Stover      |
| Connecticut | Pat Whitcomb     | Montana        | Dirk Niebaum      | Tennessee      | Alice Sulkowski   |
| Delaware    | Cindy Bones      | Nebraska       | Sally Norton      | Texas          | Dee Hawkins       |
| Florida     | Skip Ryan        | Nevada         | Joan Smith        | Utah           | Mike Ginsberg     |
| Georgia     | Pat Lemesha      | New Hampshire  | Julie Thorne      | Virginia       | Sally Jackson     |
| Idaho       | Janet Conley     | New Jersey     | Anita Getler      | Washington     | Deanne Snodgrass  |
| Illinois    | Jim Hughes       | New York       | Pat Bonda Swenson | Wisconsin      | Rick Ware         |
| Indiana     | Debbie Farmer    | North Carolina | Chuck Korte       |                |                   |

Life Raft country liasons: Learn more about the Global GIST Network & find contact info for your rep at [www.globalgistnetwork.com](http://www.globalgistnetwork.com)

|                |                          |             |                        |              |                       |
|----------------|--------------------------|-------------|------------------------|--------------|-----------------------|
| Argentina      | Melisa Biman             | Hungary     | Tünde Kazda            | Philippines  | Rod Padua             |
| Australia      | Roy Neil                 | India       | Paresh Majmudar        | Poland       | Piotr Fonrobert       |
| Belgium        | Kris Heyman              | Iran        | Negar Amirfarhad       | Puerto Rico  | Eileen Rolon          |
| Bolivia        | Virginia Ossio           | Ireland     | Carol Jones            | Romania      | Simona Ene            |
| Bulgaria       | Juliana Popova           | Israel      | Avi Zigdon             | Russia       | Tanya Soldak          |
| Brazil         | Valeria Hartt            | Italy       | Anna Costato           | Samoa        | John Galuvao          |
| Canada         | David Josephy            | Japan       | Sumito Nishidate       | Saudi Arabia | Mohamed-Elbagir Ahmed |
| Chile          | Piga Fernandez           | Jordan      | Mohammed Milhem        | Scotland     | Stacey McAully        |
| China          | Ruijia Mu                | Kenya       | Godsent Odero          | Singapore    | Robert Richardson     |
| Colombia       | Maria Helena Matamala    | Korea       | HyunJung Yang          | South Africa | Annette Mentasti      |
| Costa Rica     | Michael Josephy          | Macedonia   | Dejan Krstevski        | South Korea  | Hyun Jung Yang        |
| Cyprus         | George Constantinou      | Malaysia    | Choo Sian Yong         | Spain        | Luis Herrero          |
| Czech Republic | Jan Pelouchová           | Mexico      | Rodrigo Salas          | Sudan        | Mohamed-Elbagir Ahmed |
| Dominican Rep. | Alejandro Miranda        | Namibia     | Lon Garber             | Switzerland  | Helga Schnorf         |
| Finland        | Mirja Voutilainen        | Netherlands | Contactgroep GIST      | Thailand     | Kittikhun Pornpakakul |
| France         | Estelle LeCointe         | Nicaragua   | Maria Teresa Ponce     | Turkey       | Haver Tanbay          |
| Germany        | Markus Wartenberg        | Norway      | Frøde Homb             | U.K.         | Judith Robinson       |
| Greece         | Lefteris Patapis         | Pakistan    | Muhammad Shahid afique | Uruguay      | Fabrizio Martilotta   |
| Guatemala      | Silvia Castillo de Armas | Peru        | Eva Maria Ruiz         | Venezuela    | María Isabel Gómez    |
| Honduras       | Xiomara Barrientos       |             |                        |              |                       |

155 US Highway 46, Suite 202  
Wayne, NJ 07470  
p: 973-837-9092  
f: 973-837-9095  
e: [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org)  
w: [www.liferaftgroup.org](http://www.liferaftgroup.org)



Facebook  
[facebook.com/liferaftgroup](https://facebook.com/liferaftgroup)  
Twitter  
[twitter.com/liferaftgroup](https://twitter.com/liferaftgroup)  
LinkedIn  
<http://linkd.in/liferaftgroup>