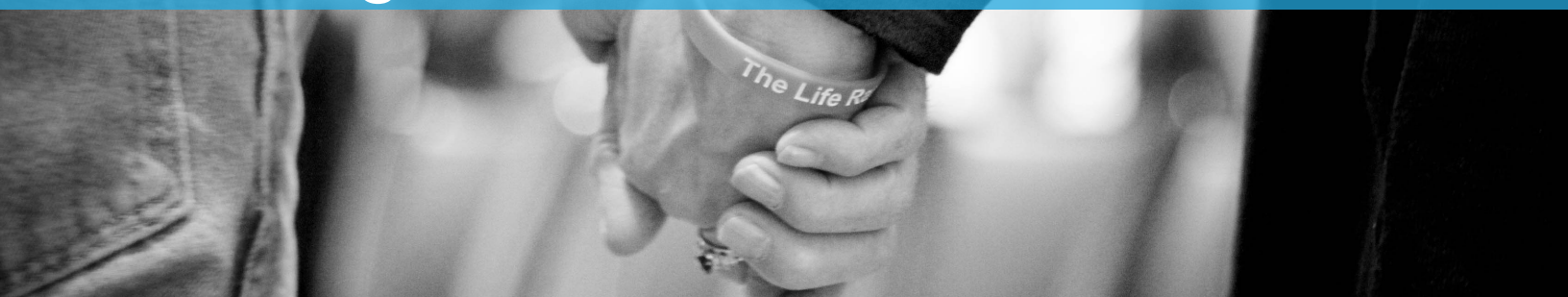


# Ensuring no one has to face GIST alone



In Loving Memory: John Clint Collins, Louis Salomons, Ian Rahimi, Gerardo Marra, Suzanne Hamm

## John Poss: Fifteen years and still kickin’

By **John Poss**, LRG Board Member

It has been a long journey since that day Melinda and I walked out of my Dallas oncologist’s office in May, 2000 knowing that I had a rare, then untreatable cancer. Now, it has been fifteen years: years that allowed me to see the birth of grandchildren, the marriage of a daughter, the incredible



**POSS**

growth and success of the Life Raft Group and to experience thousands of daily joys that enrich our lives. Thank you Gleevec, thank you George Demetri, thank you Life Raft Group and, most of all, thank you Melinda.

My story probably isn’t much different than the stories that

See **KICKIN’** on page 8

## Partnering for Cures seventh annual meeting held in NYC

By **Marisa Bolognese**,  
Deputy Executive Director

The 7th Annual Partnering for Cures meeting hosted by FasterCures was held Nov. 1-3 in NYC with more than 750 movers and shakers from patient groups, pharma, academia, government and industry. Some notable participants included: Dr. Francis Collins, NIH Director; Michael Milken, Chairman, Milken Institute; Dr. Brian Druker, OHSU Knight Cancer Center and



**FasterCures**  
A CENTER OF THE MILKEN INSTITUTE

**November 1-3, 2015**

New York City

GIST pioneer; Will Reeve, Christopher & Dana Reeve Foundation and many other cutting edge thinkers who

See **PARTNERING** on page 10

## Adjuvant imatinib study updates results

By **Pete Knox**, LRG Director of Strategic Planning

A recent study further documented the advantage of three years of adjuvant imatinib versus one year in high-risk GIST patients. The study, which is to be published in the Journal of Clinical Oncology, was authored by a number of the leading European researchers in GIST, including Heikki Joensuu of Finland,



**JOENSUU**

Kirsten Sundby Hall of Norway, Peter Reichardt and Peter Hohenberger of Germany, and Sebastian Bauer, a member of the LRG Research Team, also from Germany, among others.

The article was a follow-up to the original study that reported a significant benefit in overall survival for three years of adjuvant treatment with 400mg imatinib versus one year (see [www.liferaftgroup.org/2011/08/adjuvant-gleevec-star-of-asco/](http://www.liferaftgroup.org/2011/08/adjuvant-gleevec-star-of-asco/) for details)

See **ADJUVANT** on page 6

# Connective Tissue Oncology Society (CTOS) Annual Meeting Update

By **Mildred Menos**, Strategic Alliances Director

Today's researchers estimate that there are over 200 classified cancers today and that one out of three people will be affected by it at some stage in their life. With the extreme prevalence of cancer in today's world, it may be surprising to some that there is an entire category of cancers that is not only collectively rare but composed almost entirely of some of the rarest forms of cancer identified. As the most prevalent of



**November 4-7, 2015**

Salt Lake City, Utah

the 70 currently classified sarcoma subtypes, GIST comprises about one third of sarcoma cases diagnosed in the United States. However, these are still extremely low figures relative to the world of cancer when you consider that sarcomas only represent 1% of all cancer diagnoses.

At the 2015 Annual Meeting of the Connective Tissue Oncology Society (CTOS), sarcoma researchers, clinicians, patient advocacy groups

and the pharmaceutical industry gathered in Salt Lake City to continue the work of lifting the veil surrounding sarcomas and sarcoma research. As defined by the conference's presenters, the largest issues currently facing soft tissue sarcoma research and treatment include:

- **Rarity of population** - With the exception of major medical centers in which specialized physicians draw patients from around the country, gathering a critical mass of patients for observation and analysis is difficult. Low patient population figures make recruitment for clinical trials difficult, and if a clinical trial cannot successfully recruit it cannot advance, limiting treatment options for the patient population in question.
- **Funding for rare orphan diseases** - Along with a smaller patient base comes the corresponding challenge of raising funding for continuing research. Private donations are less plentiful because there are simply fewer people to contribute and private industry has less of a financial incentive to invest as the target consumer base is inherently smaller. These funding chal-



Alison Olig (left) with LRG's Mildred Menos at 2015 CTOS annual meeting.

lenges trickle down to rare disease researchers who struggle to keep their labs open and their work ongoing as well as impacting the number of new researchers choosing to specialize in these fields due to the lack of funding available.

- **Many distinct tumor types** - As research develops in all cancers, it is found that even though a disease may be termed with a single name (i.e. GIST), that single disease is in fact a label encompassing a host of sub-mutational types each with its own unique characteristics including progression, stability and response to treatment. In GIST alone to date

See **CTOS** on page 14

## The Life Raft Group

### Who are we, what do we do?

The LRG has a simple focus: to cure a form of cancer —gastrointestinal stromal tumors (GIST) — and to help those living with it until then. To do this, the Life Raft Group focuses on three key areas: research, patient support & education, and advocacy.

### How to help

Donations to The Life Raft Group, a 501(c)(3) nonprofit organization, are tax deductible in the United States. You can donate by credit card at [www.liferaftgroup.org/donate.html](http://www.liferaftgroup.org/donate.html) or by sending a check to: The Life Raft Group 155 US Highway 46, Suite 202 Wayne, NJ 07470

### Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor. Please advise Erin Kristoff, the Marketing Director, at [ekristoff@liferaftgroup.org](mailto:ekristoff@liferaftgroup.org) of any errors.

# Top GIST specialists present at California GDOL

By **Mildred Menos**, Strategic Alliances Director

On Sunday, November 15, the last GDOL in the 2015 series was held in Orange County, California at the Fullerton Arboretum. GDOL stands for GIST Day of Learning, a free, one-day program that provides both education and support to the GIST community. Top GIST specialists present the latest on research and treatment options as well as providing a comprehensive review of the science behind GIST. GDOLs provide an opportunity not only to meet and interact with local expert practitioners in an intimate setting, but also for patients to connect with one another in a supportive environment.

The featured speakers for this event were surgical oncologist Jason Sicklick of University of California at San Diego and medical oncologist Michael

Heinrich from Oregon Health Science University. Mildred Menos, Assistant Director of Programs at the Life Raft Group, provided an overview of the LRG's programs with a focus on the LRG Patient Registry, the impact that data donated has and the benefits its members receive. LRG Southern California state leader Dina Wiley held a support group meeting prior to the day's seminar in which patients and caregivers could come together to provide feedback, ask questions and trade experiences about their GIST journeys.



From left to right: Mildred Menos, Dr. Michael Heinrich, Dr. Jason Sicklick, and Dina Wiley.

We are currently planning the next cities for the 2016 GDOL series. Please stay tuned to the LRG website

**See GDOL on page 7**

## Society for Integrative Oncology holds 12<sup>th</sup> annual conference in Boston

By **Kathryn Troy**, Patient Registry Health Educator

The Society for Integrative Oncology (SIO) was developed to advance evidence based, comprehensive, integrative health-care to improve the lives of people affected by cancer.

The 12th Annual SIO Conference was held in Boston in November, and it provided an opportunity for attendees to both be inspired by the ongoing research to improve the quality of life for cancer patients, but also to be impressed by quantitative evidence to support the research efforts and the amount of physicians more than willing to refer their patients to integrative services. The conference consisted primarily of clinicians including oncologists, nurses, and other medical doctors, followed by educators, researchers and epidemiologists as well as integrative

specialists including yoga instructors, acupuncturists, reiki practitioners and, of course, patient advocates.

The conference exposed attendees to a wealth of therapies that are currently being used as part of integrative treatment including acupuncture, reiki, music therapy, and mind-body therapy, and more importantly, how each of these methods can be practiced by both patients and caregivers.

The focus for this author during the three-day conference was to learn applicable resources for GIST patients. Among the diverse research, Mind-body Therapy was of particular interest. As defined by the National Institute of Health (NIH), "Mind-body medicine focuses on the interactions among the brain,



**November 14-16, 2015**  
Boston, Massachusetts

the rest of the body, the mind, and behavior as well as the ways in which emotional, mental, social, spiritual, experimental, and behavioral factors that can directly affect health." SIO speaker Dr. Gary Deng, Ph.D., Interim Chief, Integrative Medicine Service at Memorial Sloan Kettering Cancer Center further elaborated that chang-

**See SIO on page 11**



# Genetic Alliance event invites collaboration

By **Pete Knox**, Strategic Planning Director

**G**enetic Alliance recently held an event in Chapel Hill, N.C. that brought together patient advocates, scientists and representatives from the pharmaceutical industry in a unique “speed-dating” format. Disease advocacy organiza-

approach development of therapies for them. This event was an interesting micro-cosm of the rare disease community with a variety of perspectives represented. Ample opportunity was provided to speak with advocates representing a broad spectrum of diseases such as Huntington’s Disease, Angioma, Adenoid Cystic Carcinoma, Autism, and others. The diseases

may be disparate, but the challenges faced by rare disease advocacy organizations are similar.

Adding to this was the scientific perspective provided by the Structural Genomics Consortium, a forward-thinking research institute based out of Oxford University in the UK, Frankfurt, Germany, and UNC- Chapel Hill, N.C. Scientists at SGC-UNC are building a functional map of the



**LRG’s Pete Knox with Sharon Terry, President of Genetic Alliance at the recently held event in Chapel Hill.**



**October 14, 2015**

Chapel Hill, N.C.

tions were invited to present briefly on their opportunities for scientific collaboration, and the roadblocks to accomplishing their goals. The focus was on rare diseases and how best to

See **ALLIANCE** on page 13

# On the road with the LRG patient registry

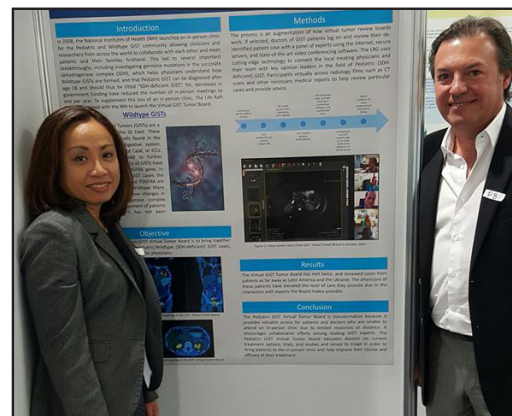
By **Michelle Durborow**, Patient Registry Director

**T**he tenth annual ICORD meeting was held in Mexico City on October 13-14 with the theme “A Decade of Discoveries and Current Challenges in the World of Rare Diseases and Orphan Drugs.” The meeting was part of the “Global Rare

Diseases Week, Mexico 2015” and was back-to-back with the fourth Latin American meeting of Rare Diseases on October 12.

About 200 delegates from all continents and representing many different stakeholders such as patients, patient support groups, healthcare professionals, researchers, industry representatives, politicians, regulatory and health authorities came to take part in an inspiring program, to network and to share their experiences in the field of rare diseases and orphan drugs.

Michelle Durborow, LRG Director of Patient Registry presented in the session on Development and Accessibility to International Registries and Biobanks, on the importance of



**Michelle Durborow with Rodrigo Salas, LRG board member, at tenth annual ICORD meeting.**

building a global GIST registry and tissue bank. The goal of this presen-

See **ROAD** on page 12



**October 13-14, 2015**

Mexico City, Mexico

# Encouraging rare disease connections at the NORD Conference

By **Erin Kristoff**, Marketing Director

The National Organization for Rare Diseases (NORD) held its 2015 Breakthrough Summit

October 21-22 in Arlington, Virginia. This year's event convened top leaders from the FDA, NIH, Industry, Patient Groups, Payers and Research Institutions to address the progress of rare disease diag-

nosis, genomics, drug development, patient engagement, patient-centered research models, product approvals, FDA oversight and market access to orphan products.



**Mildred Menos networks with rare disease patient advocates.**

LRG staffers Erin Kristoff and Mildred Menos were in attendance and were able to listen and engage with

presenters at this innovative conference, which kicked off with an inspiring keynote address by Treacher-Collins patient advocate, Jono Lancaster.

Inspiring speeches were given by key NIH and FDA representatives including Director for the National Center for Advancing Translational Sciences (NCATS), Chris Austin and FDA's Center for Drug Evaluation and Research Director, Janet Woodcock. Breakout sessions focused on vital

issues like fueling drug access, precision medicine and patient-centered outcomes, but one of the most benefi-



**November 21-22, 2015**

Arlington, Virginia

cial and thought-provoking aspects of the conference was the opportunity to make connections with other advocates in the rare disease community. Nothing can replace the help you are able to provide and gain from others facing similar challenges. ■

# Patient-centered care focus of Quintiles panel discussion

By **Mary Garland**, Communications Director

Executive Director, Norman Scherzer participated in a panel discussion as part of the Executive Vision Forum Series hosted by Quintiles Advisory Services on Friday, November 6 in the Alexandria Center, NYC.

The panel, entitled "Working within a patient-centered environment: Aligning perspectives and systems to deliver value" presented views from the pharmaceutical industry, healthcare and patient advocacy. The panel included Marc Boutin, JD, CEO, National Health Council, Lorraine Marchand, Director of Healthcare and Pharmaceutical Management Program, Columbia Business School, and Norman Scherzer. Norman represented the patient view, sharing the story of the Life Raft Group, and helping the audience, which was heavily attended by pharmaceutical

and healthcare industry representatives, to understand several of the key issues involved in creating more patient-centered care.

To quote Norman, "We are on the forefront of a revolution in targeted medicine, where many of the new treatments are oral drugs, versus IV chemotherapy. Compliance will play a major role in evaluating the efficacy of treatments, as it is vital to know whether or not the product is working or if the patient is not taking the medication."

Another key point made by Scherzer was that the LRG has a model for tracking patient data and the patient perspective. The LRG Patient Registry and Tissue Bank provide a blueprint for patient-centered care, and an ideal environment to recruit patients for clinical trials.



**November 6, 2015**

Alexandria Center, NYC

He also suggested that pharmaceutical companies take a lesson from the playbook of other industries and go directly to the consumer for feedback. Traditionally, input from medical professionals has taken precedence over the valuable knowledge the patient can provide.

"The patient perspective doesn't conflict with the process. It can enhance it," Scherzer added.

Follow-up meetings to share the LRG model will be forthcoming. ■

# Sebastian Bauer awarded the 2015 GIST Group Switzerland science prize

By **Heiga Meier**, LRG Contributor

**L**RG research team member, Dr. Sebastian Bauer recently received the 6th Annual Science Prize awarded by the GIST Group Switzerland on November 26, 2015 at the semi-annual meeting of the Swiss Group for Clinical Cancer Research (SAAK) in Zurich.

GIST Group Switzerland is an organization for the support of those affected by gastrointestinal stromal tumors. It supports every effort to improve the treatment of GISTs. To this end, the GIST Group awards an annual prize to organizations or individuals committed to achieving this goal. The prize is awarded for lectures, publications,

panel discussions, scientific or socially relevant projects.

Dr. Bauer was recognized for his paper, "Phase I study of panobinostat and imatinib in patients with treatment-refractory metastatic gastrointestinal stromal tumors," which was published in the British Journal of Cancer (BR J Cancer, 2014, March 4). The organization also recognized his many other publications and his commitment to patients with GIST.

The 2015 science prize, worth CHF 10,000 and donated by GIST Group Switzerland, was presented by Dr.



From left to right: Dr. Michael Montemurro, Helga Meier, and Dr. Sebastian Bauer.

Michael Montemurro, president of the SAKK project group gastrointestinal cancer, and a member of the GIST Award Committee. ■

## ADJUVANT from page 1

and ultimately led to the FDA approving three years of adjuvant imatinib for advanced GIST patients.

The initial study included 400 patients with categorized by high-risk (either one of the following):

1. Largest tumor diameter is over 10cm
  2. Mitosis count is over 10/50 high power microscopic fields (HPF)
  3. Largest tumor diameter over 5cm the mitosis count is over 5/50 HPF
- KIT-positive GIST that had successful surgery between 2004 and 2008. After surgery, patients were randomly assigned to one of two arms, and received either one year or three years of imatinib.

The follow up study, "Short (12 months) versus long (36 months)

duration of adjuvant treatment with the tyrosine kinase inhibitor imatinib mesylate of operable GIST with a high risk for recurrence," had the

**“ The ongoing trials testing the longer regimens are highly important to inform us about the optimal way to treat patients who have undergone surgery for high-risk GIST.”**

same protocol as the original study. 280 patients were reassessed to see if the survival benefit demonstrated in the previous study, persisted. It did – patients had a five-year recurrence-free survival rate of 52.3% in the one-year group vs. 71.1% in the three-year group, and an overall survival rate of 85.3% in the one- year

group vs. 91.9% in the three- year group. Both of these comparisons proved to be statistically significant ( $p < .001$  and  $p = .036$  respectively).

While confirmation of the benefits of three years of adjuvant imatinib is an important finding, a few other questions persist that may warrant further investigation. I asked the primary author of the study, Dr. Heikki Joensuu to respond to these questions.

First, this study looked exclusively at high-risk patients. What do those findings mean to those patients in an intermediate risk category? Dr. Joensuu responded by stating, "The trial was carried out in the high-risk patient population, and the results cannot be applied to lower risk GISTs. In fact, the subgroup analyses, though limited in power, suggest that patients with GIST with a high mitotic count are the ones who benefit from three-year adjuvant imatinib, whereas

See **ADJUVANT** on page 7



## ADJUVANT from page 6

the patents with a low mitotic count do not.”

Dr. Joensuu adds, “The concept of ‘intermediate risk GIST’ is poorly defined. The malignancy potential of GISTs varies from virtually benign tumors to highly malignant cancers, and it is difficult to define accurately any intermediate groups in this continuum. In practice, the criteria used in the SSGXVII/AIO trial work reasonably well in patient selection for adjuvant treatment, and the prognostic heat maps may also be helpful.” The SSGXVIII/AIO (The Scandinavian Sarcoma Group XVII/Arbeitsgemeinschaft Internistische Onkologie) trial assessed patients with resected high-risk tumors, as well as those with single metastases who received complete resection of the primary tumor and the metastases. Prognostic heat maps are contour maps that assess the risk of each tumor in which the color red means a high risk, and blue means a low risk.(see [www.liferaftgroup.org/risk-of-recurrence-details/](http://www.liferaftgroup.org/risk-of-recurrence-details/) for further details about heat maps).

Second, a number of patients have reached the three-year mark of imatinib treatment and are stable or NED, and are wondering whether to continue on the medication. When Dr. Joensuu was asked what his opinion was on patients continuing treatment for patients beyond the three-year mark, he responded, “The patient needs to have NED - being stable might indicate that overt metastases have been detected, which entails permanent tyrosine kinase inhibitor (TKI) therapy. Some patients who are estimated to have a high risk for GIST recurrence despite macroscopically complete surgery might benefit from adjuvant imatinib administered for longer than three years. This remains, however, a hypothesis with little evidence to support it. There may also

be patients who are harmed by long treatments, such as patients who are estimated to have a high risk but who were cured by surgery. Therefore, two randomized trials that compare longer than three years of adjuvant imatinib with the standard (i.e three years of imatinib) have been launched in Europe and are accruing patients.”

Dr. Joensuu concludes, “At present, the standard duration of adjuvant imatinib is three years; longer treatments than this have unproven benefit. It is likely very important to perform imaging of the abdomen and pelvis frequently after adjuvant imatinib has been discontinued to detect recurrence early should it arise. Recurrent GIST usually responds well to re-starting of imatinib, and the risk of emergence of drug resistance is likely lower the smaller the tumor bulk. The ongoing trials testing the longer regimens are highly important to inform us about the optimal way to treat patients who have undergone surgery for high-risk GIST.”

Data from the LRG patient registry reveals high-risk patients who have progressed after stopping imatinib even beyond the three-year mark. While this is a complicated question with a number of variables from patient to patient, a study looking at patients taking imatinib for longer time periods and assessing the benefit would be very useful, in that it would help patients make a more informed decision about whether to continue treatment. We will eagerly watch as the European studies Dr. Joensuu mentions progress and report results. Until that time, the LRG maintains that consulting with a GIST specialist who is familiar with your individual risk factors and keeping apprised of the latest medical research is the best way to make an informed decision before stopping Gleevec. ■

## GDOL from page 3

and our email communications for more information on these events and others.

Interested in having the LRG come to your city for our next GDOL? Email your ideas to Mildred Menos at [mmenos@liferaftgroup.org](mailto:mmenos@liferaftgroup.org). ■

## SECOND ANNUAL WATER OF LIFE CHARITY EVENT



MIDTOWN LOFT - NYC  
MAY 12<sup>th</sup> 6:00PM

The Water of Life event is an annual whisky fundraiser hosted by Dr. Matthew J Lurin (co-founder of the Whisky Nerds) to help raise money towards critical research that is dedicated to finding a cure for GIST.

Over the course of the evening, guests will have the opportunity to try over 25 whiskies out of well over 100 possibilities, accompanied by food pairings at each table, a buffet dinner and desserts.

Learn more about the event at:  
[www.lrgwateroflife.org](http://www.lrgwateroflife.org)

## KICKIN' from page 1

many of you have to tell. The only difference, perhaps, is that my story has lasted a bit longer. I was diagnosed in May, 2000 with a tumor the size of a cantaloupe sitting on top of my stomach, a tumor that had metastasized to my liver and a few other organs. The diagnosis was followed almost immediately by surgery and the absolute worst possible conversation with my oncologist: "I'm sorry John. We couldn't get it all. Your liver is riddled with GIST. You have one, maybe two years to live."

I walked out of that office determined to fight. I did my homework, and through ACOR, learned of an obscure, unpublicized Phase II Clinical Trial for STI-571 at Dana Farber Cancer Institute. I self-referred and met Dr. George Demetri for the first time in July, 2000. The drug was in very short supply, largely because of its success in treating CML, so George told me to go home and wait and pray that the drug would be available in time.

By August, my tumors were growing. By September the situation was critical. I didn't have much time remaining when I received the much awaited email from George: "John, please report to Dana Farber on October 4 to begin treatment with STI-571." I reported to DFCl as instructed, full of hope, and at the same time, anxiety. Within 30 days my tumors began to shrink. Now, here I am fifteen years later still kicking.

That's the short version of the story. The long version includes: two researchers having a beer at ASCO

in 1999 and discussing how STI-571, a drug to treat CML, might work for GIST; a patient in Helsinki, Finland (Patient Number One) refusing to give up and convincing Novartis to create a Phase I trial with one participant; George Demetri and Chris



**Water color painting titled "A Rare Bird " by wildlife artist, Sam Caldwell who went on hunting trips to West Texas with John.**

Carley (a fellow LRG board member) calling Chris's brother at the Wall Street Journal and convincing them to threaten Novartis with unfavorable publicity if more drug wasn't made available for GIST; and finally, a group of highly motivated patients and caregivers forming an email list of Clinical Trial Participants (thank you Norman) that later became the Life Raft Group.

The more important story, and question, is this: What's it been like living

with GIST and Gleevec for over fifteen years?

The first five years were the toughest. No one really knew how long STI-571, later Gleevec, would work. The mortality rate among the Phase II participants was troubling. Some didn't make it a year; others, two or three years. After five years, we had lost too many friends, too many to name but not too many to remember, especially the ones who were active in the LRG. Thus, every trip to Dana Farber was a much anticipated and much dreaded adventure. "Scanxiety" became a too frequently used word in our family vocabulary.

I remember distinctly in 2004, a little less than five years after I started taking Gleevec, learning of the death of yet another friend. The company where I worked had just been bought by a Private Equity firm and they had offered me a very good position with the new company. I looked at my options. Based on what was happening to my fellow GISTers, I had no idea how much longer the drug would work, how much longer it would be before these tumors of mine learned to resist Gleevec. Melinda and I talked about it, and I declined the job. I wanted to work less, spend more time with my family, maybe knock a few items off my bucket list and make the best of however much time I had left. Time is the only truly priceless asset. Turns out, I had a lot more time than I expected.

I also remember that first year, when everyone was concerned with side effects. I recall an LRG board meeting around 2001. We were discussing side effects such as diarrhea, nausea, fatigue, and swelling when Melinda said, "You are leaving out a very significant side effect." We all

See **KICKIN'** on page 9



## KICKIN' from page 8

looked at her expectantly, waiting to hear about this heretofore unreported condition.

She slyly smiled and said, "Gleevec must make you nice, because John sure has been easier to live with since he started taking it!"

Not so surprisingly, she was correct. Cancer, and the miraculous arrival of STI-571 just in time to save me from certain death, had changed me. I won't admit that I was suddenly nicer, but I will admit that my whole approach to life had changed, as I am sure it has changed for most of my fellow GISTers. I now take nothing for granted. I do my best to appreciate every day as a blessing, and I certainly have more empathy for others who face life threatening challenges. So, yes, I'm probably a nicer person today than I otherwise might have been. Once again, thank you Gleevec for giving me that chance.

Here's some very important advice to GISTers: show your caregiver some very deserved and hard-earned love. Frankly, I would be dead, even with Gleevec, without Melinda. I simply cannot list the innumerable times that she has spotted some aberration in my routines and said, "You don't look good, you need to go get a B-12 shot or go get a Procrit shot or slow

down and get more sleep." She also feeds me well. It is simply impossible to express too much gratitude to the loved ones that surround you and keep you going. It has always



**John and his wife Melinda with their special Disney hats at Epcot in Orlando, Florida.**

**"It is simply impossible to express too much gratitude to the loved ones that surround you and keep you going."**

been my observation that cancer is harder on loved ones than it is on the patient. Remember that.

Here's another very important piece of advice: take care of your kidneys. We already know that Gleevec is hard on our kidneys, but so are CT scans and diarrhea and the result-

ing dehydration. Even if it is your first week on Gleevec, make friends with a nephrologist. My creatinine levels had been slowly, and consistently growing higher every month since I started taking Gleevec until about a year ago when I took action. First, we eliminated contrast from my CTs. I also started making a point of staying very hydrated which is hard, because I have only half a stomach and don't really enjoy liquids (except for wine, vodka and coffee!). Finally, I started seeing the nephrologist and monitoring my blood on a monthly basis. This all led to regular Procrit shots, which mitigated my chronic anemia resulting in much higher energy levels. I was motivated to this new awareness of my kidneys because about a year ago one of my kidneys started hemorrhaging. I was hospitalized, got pneumonia and an infection and almost died. Your focus is GIST, but take good care of your organs, especially your kidneys.

Probably one of the greatest gifts that fifteen years of survival has given me is the opportunity to witness, and to some extent participate, in the unimaginable growth and success of our Life Raft Group. I remember the early days and the debate over whether we should become a 501(c)3, whether we should engage in fundraising, hire staff, sponsor research. Unfortunately, some of these debates were fought with great acrimony, but in my opinion, we have steered along the right path. Most of the credit goes to Norman – in fact, it would be impossible to overstate how much he has contributed, how much his leadership has meant to our group. Thank you, Brother. You have done well. ■

## PARTNERING from page 1

all share a common goal of bringing about cures for disease, faster and more efficiently. As summed up by Mike Milken, “The spirit of the conference is to stop talking and do something... we are all here to focus on what’s important - to eliminate life-threatening diseases for the family of mankind.”

The recurring themes of the conference were **Data Sharing, Collaboration and Patient Centeredness**. Here are some conference takeaways:

- **On Data:** “There are eight billion mobile devices in the world – more phones than people. Many countries in developing nations have gone straight to wireless, and many of them don’t have much regulation of research and healthcare. There is a revolution in patient empowerment through health data coming and mobile data will be at the center.” (Mike Milken)
- **On Sharing Data:** “There is a need for better data-sharing infrastructure – with patients and by patients. Technical barriers to data sharing are cultural, especially among academic institutions. Medicine should be at

least as good as Netflix at analyzing data for the benefit of consumers.” (Isaac Kahone)

- **On Patient Input:** “There is no substitute for patient input. It’s very different to hear from patients directly than it is to hear from translators trying to speak on their behalf. Patients must participate in all aspects of research. What we need is not just an army of patient advocates, but an army of patient scientists.” (Jeffrey Shuren)
- **On Research Collaboration:** The Precision Medicine Initiative (which will collect health data from one million participants) presents a unique opportunity, given the confluence of the genomic revolution, the growing ability to track our health, increasing public interest in participation and partnership in research and more appetite for collaboration. Francis Collins hopes the “big, hairy audacious goal” of the PMI will inspire researchers and other stakeholders to be involved. Adding that “you can’t herd cats, but you can move their food,” referring to the incentives created by new NIH funding and the requirements that will come with it.

Reminding the attendees of the role they play to question and change the status quo, the final session concluded with the inspiring words of anthropologist Margaret Mead, “Never doubt that a small group of thoughtful,



Movers and shakers at Partnering for Cures.

committed citizens can change the world: indeed, it’s the only thing that does.” Will Reeve echoed this sentiment in recalling his father’s certainty that a cure for spinal cord injuries could be found: “At first your dreams are impossible, and then they are improbable and finally, when you summon the will they become inevitable.” Words to live by and very much seconded by the Life Raft Group as we continue in our tireless search to find a cure for GIST.

To hear more from the speakers and read about all the sessions at Partnering for Cures check out these links:

See videos from all the sessions on Partnering for Cures 2015

You Tube:  
[www.youtube.com/user/FasterCures](http://www.youtube.com/user/FasterCures)

Tumblr link with recaps of all the sessions:  
[www.fastercures.tumblr.com](http://www.fastercures.tumblr.com)

Twitter link:  
[www.twitter.com/hashtag/fcp4c](http://www.twitter.com/hashtag/fcp4c)

The Power of Ideas  
[www.milkeninstitute.org/issues/power-of-ideas](http://www.milkeninstitute.org/issues/power-of-ideas)



Marisa Bolognese (left), and Sara Rothschild (right) with Dr. Brian Druker.



## SIO from page 3

ing the body from the outside (through guided therapy, breathing exercises, etc.) can stimulate cell changes, and ultimately reduce side effects such as anxiety, depression, digestive problems, health issues, and fatigue. Additionally, Dr. Deng spoke of the immense value in educating clinicians, and encouraged specialists to seek hospital based educational programs so that each oncologist can refer and practice integrative services to improve the patient's overall quality of care.

Moving forward, the SIO admitted that although they have made great progress in instituting and educating integrative practices in oncology care, there is still work to be done. They have made great headway in raising networks of integrative oncology services at cancer centers both nationally and internationally, so that outpatient clinics can provide free services to their patients affording them the

ability to conveniently engage in the best of what western and integrative medicine has to offer. Additionally, guidelines are in development to identify the ways to measure patient needs, so that they can have individualized feedback to improve their health and treatment outcomes.

Overall, it was clear the various practices of integrative oncology have an evidence-based record in reducing major side effects, and even reducing the risks of some cancers recurrence, simply through routine mindfulness. For caregivers, active mindfulness affords the ability to start each day fresh, rejuvenated, and able to prioritize their task-list. For patients, it's an opportunity to help play a role in preventative health practices, and take an active role in improving their quality of life. As the field of integrative oncology expands, it will be exciting to see specific research into the role of integrative therapies in the treatment of GIST. ■



## CALENDAR OF EVENTS

**MAY 12, 2016**

### **Water of Life 2016**

Midtown Loft, New York, New York  
5:00 PM - 11:30 PM  
[www.lrgwateroflife.org](http://www.lrgwateroflife.org)

**JANUARY 28, 2016**

### **CancerCare Workshop**

Living with Gastrointestinal  
Stromal Tumors (GIST)  
[www.liferaftgroup.org/events/cancercare-workshop](http://www.liferaftgroup.org/events/cancercare-workshop)



**JULY 15-17, 2016**

### **Life Fest 2016**

Torrance Marriott Redondo Beach  
3635 Fashion Way  
Torrance, CA 90503  
[www.liferaftgroup.org/lifest](http://www.liferaftgroup.org/lifest)

## CANCERVERSARY



## 19 YEARS

**Chuck Korte**

“It is a blessing to be alive;  
we can give thanks by  
being a blessing to others”



If you have a Cancerversary, let us know. Contact us at [info@liferaftgroup.org](mailto:info@liferaftgroup.org) and we may feature you in a future newsletter!



## ROAD from page 4



October 24, 2015

Ottawa, Ontario



From left to right: Doris McCormick, Andrea McCormick, Melissa McCormick, and Michelle Durborow

tation was to raise awareness about GIST as a rare disease, to highlight the power of patient data and tissues in the research for treatments and to demonstrate how data can fill the gaps in understanding GIST. The other speakers in this session were Yaffa Rubinstein (NIH, USA), who presented about the NIH/NCATS GRDR® Program (Global Rare Diseases Patient Registry Data Repository) who spoke about linking patient registries data to bio-specimens data and Manuel Posada (Instituto de Salud Carlos III, Spain), whose topic was medical ontologies and registering activities, what are their added values?

### GIST Day of Learning at LRG Canada

GIST Sarcoma Life Raft Group Canada held its fourth GIST Day of Learning on Oct. 24, 2015 in Ottawa, Ontario. The event brought together patients, caregivers, advocates and researchers for a day of sharing

valuable information, expertise and tools to support patients with GIST. Michelle Durborow, LRG Patient Registry Director was one of the speakers at this event, presenting about the how GIST patients, physicians and researchers can mutually benefit from the data gathered in the patient registry. The presentation entitled "The LRG Patient Registry: Research, Education and Support in Practice" illustrated the history of the registry and tissue bank and focused on practical examples of how patients can learn from the data to guide them in making informed decisions together with their physicians about their care.

### SPAEN Annual Conference

Sarcoma Patients EuroNet held its sixth Annual Conference for Organizations Representing Patients with Sarcomas, GIST and Desmoid Tumors on November 19-21, 2015

See **ROAD** on page 13

Below: SPAEN annual conference brought together an international group of sarcoma patients advocates, leading experts, and pharmaceutical representatives in Chantilly, France.



# LIFEFEST Los Angeles

## JULY 15<sup>TH</sup> - 17<sup>TH</sup> 2016

### ROAD from page 12

in Chantilly, France. The three-day conference was focused on research, treatment and access to treatment and advocacy/capacity building. Participants were sarcoma patient advocates and leading experts from different countries as well as pharmaceutical representatives who shared best practice examples, research updates and treatment options. Michelle Durborow, LRG Patient Registry Director, presented the survey tools and data collection to develop programs tailored to patients'



**Dr. Anette Duensing, Michelle Durborow, and Dr. Sebastian Bauer**

needs in terms of information on the possible impact of the generic versions of imatinib. This presentation was a follow-up from the Generic Task Force meeting that occurred in July, 2015 in Munich Germany. ■



**November 19-21, 2015**  
Chantilly, France

### ALLIANCE from page 4

understudied protein kinases in human biology and diseases through open sharing of compounds with the scientific community. They are developing a hub for kinase drug discovery.

Representatives from a number of pharmaceutical companies and patient advocacy organizations such as the LRG explored opportunities for collab-

orations which may lead to future conversations as the LRG explores avenues to aid in our research.

A number of presentations by other rare disease advocacy organizations were given at the event, with the opportunity for a presentation on how the LRG and its research team are tackling the problem of Gleevec

resistance, and the roadblocks we need to overcome to solve this.

While only a one-day event with a specific focus, the concept of creating opportunities for patient advocacy organizations, the scientific community and pharma holds promise for future innovation through collaborative efforts. ■



## CTOS from page 2

there are 14 classified mutational types, with many more still unknown and grouped together as “wildtype”. With this level of variability existing within even a single disease, tackling the complexity of sarcomas is daunting.

### Initial diagnosis and treatment -

Since sarcomas present in such a rare and varied manner, a patient’s first diagnosis and treatment will almost invariably be by a non-specialist. There are few true practicing sarcoma specialist clinicians and those in the United States tend to be clustered along the coasts making regular travel and access difficult for patients. Some GIST patients are referred to

gastrointestinal specialists instead of oncologists and not all oncologists are familiar with GIST, let alone the rarer sarcomas.

### • Treatment of metastatic disease

- For those sarcomas, like GIST, which do not manifest physical symptoms unique to one condition or if there is a delay in visible symptoms until the cancer is at an advanced stage, the incidence of metastatic disease at diagnosis is a clear danger. Greater funding for research, better physician education and awareness, and improved screening techniques can all contribute to the decrease of metastatic disease progression. However, treating metastatic disease may be inevitable in some cases leading to a difficult set of challenges. A tumor’s location, size and mutational type each inform the course of treatment. Weighing multiple sets of factors expands the decision criteria considerably and leaves the treating physician with a series of difficult decisions.

In addition to acknowledging and delving into the challenges facing the sarcoma community, CTOS also provided an opportunity to present the future goals of research in the

coming years and the direction and focus needed to improve patient outcomes:

- Better understanding of biology
- Better understanding of pathogenic mechanisms
- Larger collaborative studies of single histotypes
- Prognostic schemes of individual histotypes
- More targeted therapies
- Affordable, effective care

Although there is clearly much work still to be done, the field of GIST research and its patients have benefitted from many significant breakthroughs in the origins and understanding of GIST mutations and the treatment options these have yielded including three FDA-approved oral chemotherapies. The road for many other sarcomas has been longer and much more difficult with some still searching for answers as to the cause of their cancer. CTOS 2015 provided an opportunity for the rarest of the cancer world to unite over not only their collective challenges but also the areas in which they might collaborate to improve the lives of those with sarcoma as a whole. ■



Introducing Paddles the LRG Bear

## Gerardo “Jerry” Marra, Renaissance man, man of faith

Gerardo Jerry Marra, age 58 of Woodcliff Lake (Paramus) NJ passed away on

Thursday, November 5, 2015. Born in Italy, he was the son of Donato & Anita Marra. The beloved husband of Anna Marie (Matteo) for 36

years, he was the devoted father of Rebecca Celli & husband Thomas, Christina McElroy & husband Keith,



Jacqueline Marra-Krutak & husband John and was the loving grandfather of Jerard & Liliana McElroy. Dear brother of Carmine, Salvatore and Daniel Marra, he was also loved by numerous brothers-in law, sisters-in law, nieces and nephews.

A true Renaissance man, he was a man of many talents which served him well as a supervisor at the USPS. Through his faith as one of Jehovah’s Witnesses, he was able to endure until the very end when he passed away peacefully at home surrounded by his family.

A Memorial Talk was held on Saturday, November 14 at the Kingdom Hall of Jehovah’s Witnesses, 223 Cherry Lane, Airmont, NY 10952. ■

*Every life  
leaves something  
beautiful behind*

Contact the LRG at  
info@liferaftgroup.org for ways  
to honor your loved one.



# In Memoriam

## Ian Rahimi, beloved son and brother



### I met Ian Rahimi today.

I knew that going to his funeral would give me an opportunity to pay my respects to Ian and his family and to mourn his passing.

I knew that this would be a very emotional experience and that the fact this was a 19 year old would be particularly compelling.

I knew that the connection to GIST would add another chapter to the many



patients we have lost and whose funerals or memorials I had attended.

When Franko, Ian's father, took the podium I began to realize that up to now I had only really known about Ian the patient, a brave patient to be sure, but a struggling patient going in and out of hospitals and living for the last few months in an ICU bed in a NYC hospital. There was the extra irony that my wife Anita had just been a patient in the very same hospital separated from Ian by only a few floors.

Then Franko began to speak. About a brilliant young scientist who had one of those million-to-one brains that could figure out extraordinary complex scientific problems at the level of advanced physicists way beyond his years. About a self-effacing personality and a unique ability to put others at ease as he helped them. About a less than superb athlete who embraced soccer with a zeal to help his team and an early understanding about the brotherhood of young men.

Then brother Andrew took the podium. I learned about how Ian could never figure out how not to tell the truth and how he helped everyone solve problems, including their homework-except not his sister's. Because he realized that there was something special about her that could only be nurtured by making her figure it out on her own.

Up came Sister Rebecca who told about a practical joker whose caring for

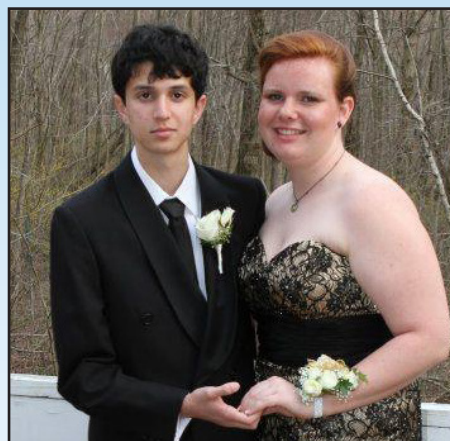
others created such affection back to him and whose brilliance of mind was tempered by not wanting people like me to talk about him.

Finally, if there was not a single emotion in my body that had not yet been stretched to the limit, up to the podium came Katie. They met years ago in school, attended each other's proms (he turned her down the first time she asked him to attend hers because he did not think she was serious; but she asked again). They became

friends. And then they fell in love. Most people spend their lives looking for their soulmate but Katie and Ian found each other when they were teenagers. Maybe this was God's way of showing them something so early because it would be cut off so soon.

I met Ian Rahimi today and I fell in love with him and everything he stood for. ■

*Norman J. Scherzer  
Executive Director  
The Life Raft Group*



Donations may be made to:

### For Ian GIST FUND

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