

# GISTer's legacy launches new support program

By **Tricia McAleer**  
LRG Program Director

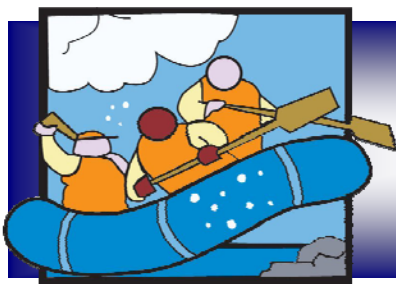
**T**he Bill Buchanan Life Raft GIST Support Group held its first meeting on Saturday, October 22 at the John Stroger Hospital of Cook County located in Chicago. This program was mentored by the LRG and made possible by the wishes of the late Bill Buchanan. Bill was an active member of the Chicago-area GIST patient group who kept in touch with other Life Rafters and also volunteered his time. Concerned that some people who were facing GIST did not have the same opportunity for support that he did, he wanted to establish this group at Cook County Hospital to serve that need. Bill had expressed his wishes to the LRG and to his wife Maureen. His



**BUCHANAN**

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## Battling gastrointestinal stromal tumor



## LIFE RAFT GROUP

December 2011

In memory of John Smith, Lynette Ferguson, Mark Walker, Bob Tikkanen, Goetz Wochinger, Rene Cordell, Preston Ford & Rafael Becerra

Vol 12, No. 6

## CTOS wrap-up: LRG among key presenters

By **Jim Hughes**,  
LRG Clinical Trials Coordinator,  
and **Pete Knox**, LRG Special  
Projects Coordinator

**T**he 2011 Connective Tissue Oncology Society (CTOS) conference was held in late October this year in Chicago.

If the meeting had a GIST theme it would have been "imatinib and surgery." The LRG was honored to both present a poster and conduct a presentation, both of which were very well received.

Three GIST authors discussed the benefits of neo-adjuvant imatinib therapy. In neo-adjuvant therapy, newly diagnosed patients take imatinib (Gleevec) before surgery in order to shrink tumors prior to surgery and to determine whether the tumors are responsive to imatinib.

In some cases neo-adjuvant imatinib therapy can make surgery possible when it was impractical at initial diagnosis.

A French team led by Dr. Florence Duffaud showed that primary tumors in the duodenum (between the stomach and small intestine) can be removed with a number of procedures and that patients have a reasonably favorable prognosis (64.6% event-free survival at four years). Neo-adjuvant imatinib is also recommended to shrink duodenal GISTs and reduce the need for a Whipple, the most complex procedure, which affects multiple organs including the stomach, duodenum, gall bladder and pancreas.

Another team from the Netherlands showed that neo-adjuvant imatinib seems to improve the chance of sphincter preserving resection (55% with neo-adjuvant versus 33% without) and dis-

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## Alianza GIST update: CME & access discussed

By **Piga Fernández**  
Chile Alianza GIST  
Representative

**O**n November 16, representatives of 10 countries, and Susana Sarabia from The Max Foundation, got together in a teleconference conducted by Vicky Ossio, Alianza GIST Coordinator, and Sara Rothschild, LRG Global Relations Director. Despite the difference in hours, all participated with great enthusi-



ics were discussed. Melisa Biman from Asociación GIST

Argentina spoke at the event in Argentina. In both countries, doctors participated with great interest.

Of great importance was an update from Rodrigo Salas, President of Fundación GIST México and director on the LRG Board. He gave an update about the online GIST course by *Instituto Tecnológico de Monterrey* (TEC) that gives CME credit to doctors (CME credit refers to a specific form of continuing education that helps those in the medical

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# Swiss GIST group's film wins silver Edi in Zurich!

By **Helga Meier Schnorf**  
GIST-Gruppe Schweiz

**O**n November 3, 2011, the twelfth Edi film prize for the best advertising, industrial and corporate films was awarded in the Schiffbauhalle in Zurich. Our film, "Life with GIST" won a Silver Edi in the "Corporate: Internal Communication & Training" section.

The aim of this film was to introduce GIST and the exemplary treatment successes to the public at large. The documentary shows the route from correct diagnosis to treatment and dealing with this cancer, with the aid of case histories. It examines the worldwide networking of patients and physicians, and the collaboration between different medical disciplines and research. The focus of all these endeavors is the patient. Three patients talked about their experiences, their lives and their cancer histories, and provided audiences with room for hope.

## About the Edi

**Edi is the official prize for Swiss quality films**



All who participated in the making of "Life with GIST" took to the stage to accept their Edi.

Edi is the Swiss prize awarded to advertising, industrial and corporate films. The competition is operated under the patronage of the Swiss Federal Department of Home Affairs and organized and executed by the SWISSFILM ASSOCIATION.

The industry association for Swiss contract film productions aims to use the Edi to publicize and honor outstanding Swiss productions. The award stands for

### The jury's summary:

**"This film achieves a confident balance between emotion and information and centers on the message of a difficult subject. It neither tugs at the heart strings nor loses its way amid technical details. The film succeeds in keeping this quality for 50 minutes."**

high quality in film production. It achieves an artistic entity that serves the imparted content well, and carries the instruction of the client at a high conceptual and filmic level of production quality.

### Assessment criteria

A winning film must demonstrate absolute top-level performance in every film discipline.\*

- Overall impression: The work is assessed as an entity
- Concept/Script/Idea: These are evaluated within the context of the communication task
- Direction (and/or creative direction): Here, the evaluation rests upon the

performance of the direction, the dramatic execution of the story, guidance of the actors and the use of image and sound

- Camera: Assessing the photographic quality, comprising design, lighting and dramatic composition
- Production De-

## The Life Raft Group

Who are we, what do we do?

**The Life Raft Group (LRG) directs research to find a cure for a rare cancer and help those affected through support and advocacy until we do.** The LRG provides support, information and assistance to patients and families with a rare cancer called Gastrointestinal Stromal Tumor (GIST). The LRG achieves this by providing an online community for patients and caregivers, supporting local in-person meetings, patient education through monthly newsletters and webcasts, one-on-one patient consultations, and most importantly, managing a major research project to find the cure for GIST.

### 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.htm](http://www.liferaftgroup.org/donate.htm) 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 Newsletter Editor, at [ekristoff@liferaftgroup.org](mailto:ekristoff@liferaftgroup.org) of any errors.

sign: Assessing the styling, make-up, scenery and design

- Editing (and/or technical execution): Assessing the quality of the editing and the montage, as well as the dramatic composition of image and sound
- Post-production visual effects: Assessing visual effects such as 2D- and 3D-animations, compositing, graphics and title
- Post-production music & sound design: Assessing the music and sound design, the quality of composition, the use of sounds and effects and the interplay between them

*\*Information taken from the [www.edinet.ch](http://www.edinet.ch) website*

# Deck the halls with boughs of jewelry!

By William Sumas  
LRG Program Associate

**A**re you tired of long lines and seemingly endless mall traffic? This holiday season avoid the tomfoolery and come buy some jewelry!

The Life Raft Group is hosting an online shopping event in collaboration with our dedicated volunteer photographer Kim Tallau and Touchstone Crystals Jewelry (a member of the Swarovski Group). You can shop their online store from now until December 20 with 15 percent of all sales going towards helping the LRG achieve its goal of curing GIST and to helping those living with it until then.

Everyone who makes a purchase will also automatically be included in a raffle

to win the eloquent *Inspire* necklace (pictured right). All items will be delivered within a few days of purchase (They will be immediately shipped from Rhode Island, so while most orders will arrive in 2 days, orders from the western US may take longer).

Online instructions for this event to ensure LRG receives the contribution: 1. Go to <https://www.touchstonecrystal.com/shop-online.html>. When you are ready to purchase your items, proceed to checkout, until it asks you to register



with a log-in. You **MUST** choose the "Checkout as Guest" option under New Customers.

2. You will then be directed to a page that asks, "Invited to a party and would like to place an order?" Click "Yes, help me find my host."

3. On the following page, you **MUST** enter "Life" (First Name) and "Raft" (Last Name) as the host of the party in order

for the credit to go to this event.

4. Click "Search."

5. Check the box next to The Life Raft Group and click "Accept My Host."

6. Fill in your shipping and payment information and place your order!

This is sure to be a fun event so come out to support a great cause and add a little cheer to your holiday!

## Texas GISTers meet!

**O**n November 12, 2011, Dee Hawkins hosted her first Life Raft Group local group meeting as Local Group Leader at the Cancer Support Community Center in Dallas, Texas. An intimate group of GIST patients and supporters living in the area gathered to reconnect with and meet other GISTers and exchange each other's experiences as well as the various technological and medical advancements and options available to them.

A patient and member of the LRG shared that his doctor and surgeon had both diagnosed him with GIST immediately upon removing his tumor and started him on Gleevec, which came as overwhelming great news to the rest of the group and the GIST community. It was merely a few years ago that misdiagnosis for GIST

was fairly common and therefore, such news was received with much celebration and optimism. And since the patient has taken Gleevec, he has been stable for several years.

The Life Raft Group would like to thank Dee for hosting a successful local group meeting and for providing refreshments for all the attendees. Also, the Cancer Support Community Center, who's CEO Mirchelle Louis, staff, and volunteers showed enormous support to prepare for the meeting in numerous ways, from offering the facility to advertising the meeting in their newsletter.

The next meeting will be held in the spring and all GIST patients and advocates in the Dallas area are welcome to join. Please email Dee Hawkins for more information about the Dallas local meeting group at [dee@abetteranswer.com](mailto:dee@abetteranswer.com).



Dee Hawkins outside of the Cancer Support Community Center.



## GIST Research: Articles on the Science of GIST

# Pfizer to open clinical trial for young patients with GIST

By **Jerry Call**, LRG Science Director & **Sara Rothschild**, LRG Global Relations Director

**A** new phase I/II clinical trial will soon be opening for pediatric and young adults with GIST. This trial will be testing Sutent (sunitinib), the currently approved second-line treatment for GIST, in young patients. At the current time, the optimal dose for Sutent is not known for pediatric patients. This trial will help assess the safety and tolerability of Sutent in young patients.

Patients from age 6 to age 21 will be eligible for the trial. Patients younger than 18 years old will receive a dose based on bodyweight (15mg/m<sup>2</sup>) and patients >18 years old will receive the same dose that adults currently get, 50 mg daily. Both groups will take the drug for 4 weeks followed by a 2 week break off drug.

Due to the rarity of pediatric GIST patients, Pfizer has indicated a willingness to try to open a trial site wherever in the world that it might be needed. At



the moment, it plans to open up to 50 sites in 26 countries for 30 patients.

Although data is limited, there are some reports of some patients responding to

Sutent.

This trial may be of particular value to those patients who cannot access Sutent otherwise in their home countries.

For more information, check out <http://www.clinicaltrials.gov/ct2/show/NCT01396148> or [www.liferaftgroup.org](http://www.liferaftgroup.org) for protocol and clinical trial site information.

## DeLorenzo makes it to the finish line with a little help

By **Jason DeLorenzo**  
LRG Member

**S**ince February, I have been training for the Marine Corps Marathon on 10/30/11. I'm very happy to announce that I actually finished that thing. Can you believe it? The same person that had a hard time finishing the 3.2 miles in Sea Girt finished 26.2 miles in hilly Arlington and Washington D.C. It was a long training road filled with highs and lows, and I can't say that the marathon went completely smooth either, but I finished and got a really sweet medal for it.

There were four main motivations that had me finish the MCM. The first was my faith... I wouldn't have even started it if I didn't feel motivated to give it a go in prayer. I didn't know how hard it would be, but once the training started to

ramp up, I knew that this was a test of my faith, discipline, and my mental toughness.

Second is the Arlington Road Running group.

Without their regimen and support, I doubt I would be prepared at all for this race. The third is Jill, my girlfriend, who also ran her first marathon. While she is a much better runner than I can ever dream to be, her discipline, personal support, company, and love really kept my training on track and kept me dedicated to the cause.

And while I didn't have to raise money to run this race, I gave the LRG the opportunity to sponsor and use my training to raise money to help find a cure for



Jason & Jill flash their medals after the race.

GIST. Since many of you have donated to them in my honor, you (as well as them) were the last and definitely not least source of motivation for me to run this thing.

Initially I planned on raising around \$1,000 for the Life Raft Group, but raised that alone at my summer BBQ fundraiser.

In the end, I raised \$2,694.

I was deeply touched by that, and felt I couldn't let down all these people who decided to support the group that supports the ex-

tension of my life. So to all of you, thank you so much.

*If you would like to read more about the build up to Jason's marathon, read about it in the October 2011 newsletter issue.*

# Help the LRG keep hope alive

**By Norman Scherzer**  
LRG Executive Director

**A**s you may have noticed the cure for GIST has yet to be found but we have made many strides through our research project *Pathway to a Cure*.

The LRG remains committed, now more than ever, to find a cure for GIST. In the meantime, we will continue to provide support, advocacy and education to patients and families during their GIST journey. We need your help to

keep these efforts strong.

All of our members should have received their Holiday Fundraising Campaign packages in the mail. As you can see, this year's theme is the lighthouse, an icon that represents hope and guidance. The LRG strives to serve the same role for the GIST community. However, we depend on the support of the close-knit family of GIST survivors and loved ones to keep the LRG's light shining.

We are asking you to send out the enclosed note cards to your friends and family to support this important cause. In addition, you can send emails to co-

workers and neighbors that explain the important work of the LRG and what it means to you. Please direct them to [www.liferaftgroup.org](http://www.liferaftgroup.org) to make a donation in your honor.

With your support and the support of those close to you, we will continue to provide guidance and keep hope alive. Thanks to this support the LRG has not only been able to help patients battle this cancer but has also contributed over \$9 million to the top GIST scientists in the world focused on finding a cure.

Thank you for your participation in this year's campaign.

## LRG Canada holds third general meeting in Vancouver

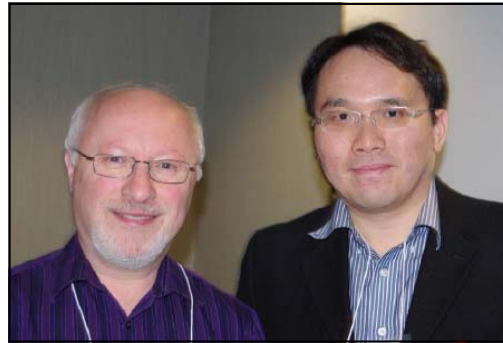
**By David Josephy**  
LRG Canada President

**L**ife Raft Group Canada held its third successful annual general meeting (AGM) on November 5 in the West Coast city of Vancouver, British Columbia.

The event began with a talk by Dr. Cheng-han Lee of the department of pathology and laboratory medicine at Vancouver General Hospital and University of British Columbia. Dr. Lee gave an excellent introduction to the state-of-the-art in GIST treatment, and explained possible new avenues for research, such as the recent work of Dr. DeMatteo and colleagues at Memorial

Sloan-Kettering Cancer Center on the interaction between imatinib and the T-cell component of the immune response. We are very grateful to Dr. Lee for his presentation and we appreciated his open and accessible approach.

The talk was followed by the AGM business meeting and the election of the Board for 2012. The meeting venue at the Coast Coal Harbour Hotel was first-



David Josephy & Dr. Cheng-han Lee.

rate, and the weather cooperated too!

Life Raft Group Canada continues to grow rapidly. We now have more than 100 members, spanning Canada from St. John's, Newfoundland, to Vancouver. Cur-

rently, a Medical Advisory Council is being established and we are working hard to advocate for improved access to treatment for GIST patients across the country.



Dr. Cheng-han Lee, speaks to the audience at the LRG Canada general meeting. Dr. Lee's presentation was entitled "Updates on gastrointestinal stromal tumors (GIST): From genetics and biology to emerging therapeutic insights".

## One of our first, one of our best: Dan Cunningham passes away

**D**aniel Cunningham of Absecon, NJ, passed away peacefully surrounded by his loving family and friends on October 2nd after a long and courageous battle with cancer at the age of 63. Born in Pottsville, PA to John and Alberta Cunningham, he joined the Air Force after high school and served in the Vietnam War. After returning home, he enrolled at Temple University where he earned his engineering degree. It was during his time at Temple that he fell in love with the Jersey Shore and one of its daughters, Martha "Mickey" Ward of

Gloucester City, NJ. Thus began a life of love, family, and the beach.

Dan was always happiest when surrounded by family – and as soon as he met you, you were family. Those lucky enough to have met him can attest to his inclusivity and kindness. Those who knew him will always remember his strength, honesty, and courage. Those blessed enough to have loved him will forever re-

gale each other with memories of those days on the beach at Brigantine, summer nights (and mornings) at Maloneys, family vacations, weddings, graduations, and countless moves, renovations, and late night chauffeuring. He strove to improve our lives. He was always there for you

– for everybody – for anything. There will forever be a hole in our lives; but in knowing that someone as strong and altruistic as he existed, we will always fight to be better people, friends, family.

Dan was a long time employee of Atlantic City Electric Company, and most recently, PSE&G. Dan is survived by his loving wife, Mickey; daughters Marissa (Nicolas) Castellano and Danielle (Michael) McNulty. His brothers and sisters: Jean (Elmer) Freeze, Marie (Frank) Walsh, Dorothy (James) Kase, John (Martha) Cunningham, Patricia Lowthert, David

*My son, Jonathan was diagnosed with GIST in 2002. Weeks before he passed away, I was referred to Dan by a business associate. He responded to me as if we were long-time friends or family, even though we had never met. His caring way was a comfort during a very difficult time, and he will always be in my heart. His connection led me to the LRG, and I am now the Treasurer on the Board of Directors. I did finally get to meet Dan years later, and we became instant friends. Those few sincere moments on his part changed my life and fostered my commitment to finding a cure for GIST.*

*-Ray Montague  
LRG Board of Directors*

*"It was about ten years ago when Dan and his daughter walked into the restaurant in Manhattan where a group of GIST patients were meeting each other for the first time. Like so many others in the room, including my wife Anita, he could not believe that so many others with such a rare cancer were in the same place.*

*"Dan broadcast a sense of good will and courage that connected instantly to everyone who met him. He went on to beat GIST by remaining stable on Gleevec but eventually developed a new cancer which caused him to lose most of his tongue but not his spirit. He showed up at our last Life Fest Meeting in New Jersey and continued to work full time dealing with environmental issues for a utility company.*

*"Because of his new surgery he was difficult to understand when he spoke but was not deterred from trying. Somehow his sign language, smile and persistence carried the day. If there was a badge for courage in the face of cancer Dan would be a Medal of Honor recipient."*

*-Norman Scherzer  
LRG Executive Director*

(Virginia) Cunningham, and Alice (Carlos) Cara; and his brothers and sisters in law, many nieces and nephews, and countless friends. He leaves behind a world that will never shine quite as bright. But when you finally get to those gates, be sure to tell them you know "Dan the Man" – he'll be there waiting, with a beer and a smile.

In lieu of flowers, please send donations in Dan's name to the Life Raft Group, a support and research group for patients fighting sarcoma (<http://www.liferaftgroup.org/donate.html>).

Arrangements entrusted to and condolences may be left for his family at: [adams-perfect.com](http://adams-perfect.com)

*For a picture tribute to Dan, please go to page 11.*



## CTOS

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ease-free survival in patients with a GIST of the rectum.

A poster by authors in Poland led by Dr. Piotr Rutkowski of Sklodowska-Curie Memorial Cancer Center and Institute of Oncology in Warsaw analyzed 46 patients who had neo-adjuvant imatinib. Five-year overall survival was significantly high (89%) in this cohort. The authors suggest that use of neo-adjuvant imatinib may avoid mutilating surgery, decrease risk of tumor rupture and decrease morbidity after surgery.

Dr. Sebastian Bauer at the University of Essen in Essen, Germany (and a member of the LRG Research Team) presented results of a review of 239 advanced GIST patients who had surgery to remove a GIST metastases (called a metastasectomy). Dr. Bauer's data showed five factors that correlated with improved survival:

- Female gender
- Shorter interval from start of neo-adjuvant imatinib therapy to surgery
- R0/R1 resection in which all visible tumor is removed (compared with incomplete resection (R2), also called debulking surgery, which does not seem to prolong survival)
- Status as stable disease or partial response prior to surgery
- Liver metastases versus other locations

The sub-set of patients who were not progressing at surgery and who had R0/R1 margins had favorable overall survival (OS). The median OS has not yet been reached.

Two other presentations on advanced GIST looked at long term imatinib therapy.

Dr. Bob Benjamin of MD Anderson reviewed data from the S0033 phase III

imatinib trial that started in 2001. Of the original 695 patients 180 have survived over eight years and of those 71 remain on imatinib. Dr. Benjamin reported that since 2001 the cost of imatinib has risen by a factor of 2.4, he also noted the hardship of patients on Medicare who are not eligible for Novartis support and who had to purchase drugs required for the trial. He questioned this practice and tasked Novartis to address the price increase.

Norman Scherzer, LRG Executive Director, presented data from the Life Raft Group Patient Registry. This was the second time this study has been updated at CTOS, and it was also the subject of an article published in the Journal of Gastrointestinal Cancer in 2009. The LRG's self-reported data continue to show both a progression-free (PFS) and

correlation of self-reported progression-free survival and overall survival with imatinib dose in patients with metastatic gastrointestinal stromal tumors." It looked specifically at the difference between starting dose and actual dose and its impact on both OS and srPFS. Most studies do not take into account the difference between actual and starting dose, and instead classify patients only by starting dose, regardless of whether they changed dose during the study.

Of the initial 169 patients in the study, 77 were female, and 92 male. Patients started taking imatinib between 2000 and 2003. The study was non-randomized and retrospective, with data coming from the LRG's Patient Registry. All patients had an initial response of tumor shrinkage while on imatinib, and all patients were on imatinib for at

least one year or more, so as to eliminate patients with primary resistance.

The study had a number of objectives:

1. to determine whether there is a correlation between imatinib dosage and the development of resistance,
2. to determine whether there is a correlation between imatinib dose and overall survival, and
3. to evaluate the difference between using starting dose vs. actual dose.

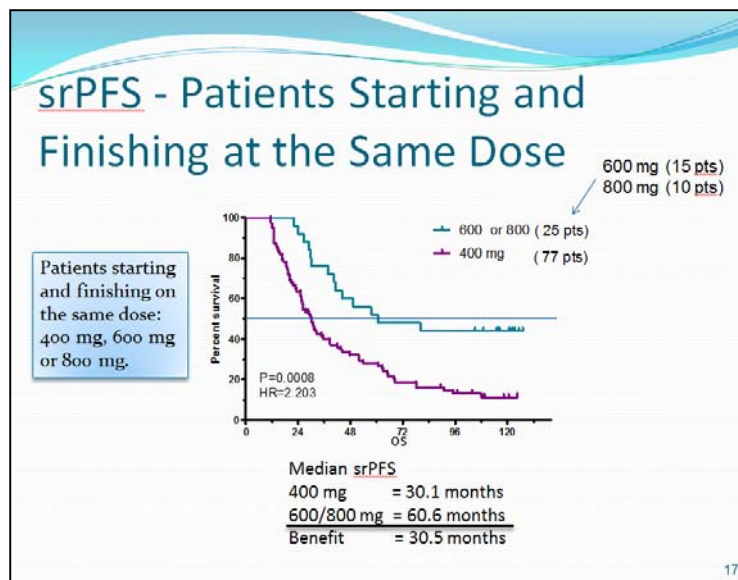
A number of conclusions were observed:

- There seems to be an increased benefit for higher doses (600 mg and above) with increased time on the drug

- Patients who are taking lower doses of imatinib (400 mg) continue to progress disproportionately beyond the five-year mark
- Patients taking higher doses (600 mg and above) have fewer long-term progressions and longer overall survival

The LRG also presented a poster highlighting survival data from its Patient Registry. The LRG Registry contains

Figure 1



OS benefit for advanced patients on higher dose (600 mg to 800 mg) of imatinib (See Figure 1). In this update self-reported Progression Free Survival (srPFS) data for patients who did not change dose also showed a highly significant advantage for patients on a 600 mg to 800 mg dose. Patients in this cohort who were on a lower 400 mg dose had 2.2 times the risk of progression. A more detailed description of the study follows.

The study was entitled, "Life Raft Group Registry – long-term (>9 years)

## New Jersey GISTers meet



We would like to thank everyone who joined us on November 12 for the NJ Chapter meeting at the Life Raft Group office.

Special gratitude goes out to Dr. William Tap (second from left) of Memorial Sloan Kettering Cancer Center who joined us and so generously gave his time and expertise.



## ALIANZA

From Page 1

field maintain competence and learn about new and developing areas of their field). He explained how well it has worked in Mexico and the great possibilities of repeating this model in other Latin American countries.

Access to treatment was also discussed in depth. This topic will be a major focus at the next Alianza GIST meeting, as well as the next New Horizons international GIST meeting. All representatives agreed on the importance of gathering information about treatment access in the different Latin American countries in order to have a clear image of the situation in each country.

Fundraising was another topic discussed. Because of the need of funds to develop our projects, all representatives

were invited to give their fundraising ideas.

As the next issue of the Alianza GIST newsletter is coming up, we expect to have interesting articles in it, and representatives have agreed to send articles on topics such as patient experiences, cases of misdiagnosis, advocacy, and access to treatment, among others.

The last topic discussed, although not the least important, was the great news of our new website which will be launched shortly.

Our next Alianza GIST meeting is going to be held March 26-28, 2012. The location has not yet been determined, but we are working to make it possible for all representatives to participate.

If you are interested in volunteering or fundraising for Alianza GIST, please contact [alianzagist@gmail.com](mailto:alianzagist@gmail.com)



## Beloved family man, Vietnam vet & 'Redcatcher' passes at 68

**S**ergeant Major Robert D. Tikkanen, 68, of Joplin, MO passed away in his wife's arms on Thursday, November 24, 2011 from GIST. He was born on May 22, 1943 in Portland, Maine to Henry J. Tikkanen and Rena St Pierre-Tikkanen of Norway, Maine.

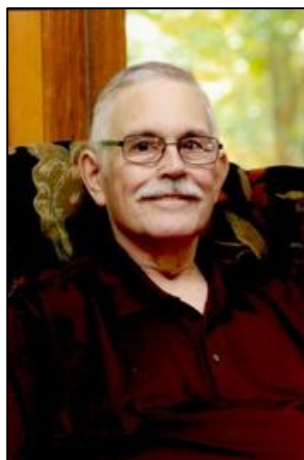
Robert was raised in Norway, Maine, graduated from Oxford Hills High School, Norway, Maine in 1962 and attended Boston University. He completed a 25 year career in the US Army and retired. Sergeant Major Tikkanen served in Vietnam with the elite 199<sup>th</sup> Light Infantry Brigade "the Redcatchers" in Long Binh and Bien Hoa, Vietnam, as well as other units in Korea, Japan, Germany, Saudi Arabia, Washington D.C. and multiple other locations in the continental US.

Robert married Patricia Louise DeGroat of Aurora, CO in Denver in 1979. They have lived in many locations around the world, as they both continued their Army careers. They moved to Joplin, MO in 1996 where Robert worked in Information Systems at Freeman Health System until his retirement in 2008. He

was an active member of Peace Lutheran Church and volunteered his time to support the House Incorporated of Joplin, MO, and was an active supporter of Alcoholics Anonymous and the Life Raft Cancer Support Group for GIST Cancers.

He was preceded in death by both his parents Henry and Rena, his step-father Osmond Towne, a brother Peter Towne and a sister Catherine Towne.

Robert is survived by his wife Pat of Joplin, MO.; his daughter Michelle Liliedahl and husband David of Essex Junction, VT; and his sons Troy Tikkanen and wife Linda of Laconia, NH; and Chris Tikkanen-Kokkola and wife Heidi of Helsinki, Finland. He leaves behind 6 beautiful and beloved grand-



children (*Morgan and Nick Liliedahl; Nicole and husband Don Levesque, Mike Tikkanen; and Hannah Kokkola*); and 1 great grand-daughter (*Liliana Lloyd-Miller*). His beloved dogs will miss him greatly (*Pele, Nani and Kiko*).

He leaves a brother Glenn Tikkanen and wife Pam of Norway, Maine; a brother-in-law Bob DeGroat and wife Susan of Clackamas, OR; and a sister-in-law Debbie Kohtz and husband Neal of Bozeman, MT.

He was blessed with 32 wonderful nieces and nephews (*Kelly Judkins, Laurie Marston; Nisa Noble, Tiffany, Wyatt, Isabel, Travis and DJ Noble; Eric and Melissa Tikkanen, Jordan, Morgan, and Alexis Tikkanen; Krista and Gary Clay, Brianna, Gary Jr. and Kobi Clay; Alyssa and Pete Morrison, Tres' and Caleb Morrison; Monica Uwajeh; Amy and Chris Washtok, Andrew and Ryan Washtok; Ben DeGroat; Fabia and Faith Kohtz; Joshua Kohtz; and Kristopher Kohtz*).

Memorial Contributions may be made to the Life Raft Group in support of GIST Cancer Research in honor of Robert Tikkanen.

### Rhode Island GISTers meet!



Rhode Island GISTers met in October at the home of Susan Farmer.

### Mark your calendars!



- The LRG Research Team will be meeting to discuss progress by teleconference on **January 10.**
- The Cook County support group will be meeting again on **January 21**, questions can be directed to Trish at [tmcaleer@liferaftgroup.org](mailto:tmcaleer@liferaftgroup.org).
- The Research Team will also be meeting in person in Leuven, Belgium in **March.**



## CTOS

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data on 1,347 GIST patients. In the poster, LRG Science Director, Jerry Call, showed how mutation profile varies with the age of on-set of GIST. Pediatric-like GIST can occur up to age 35 and, unlike adult GIST, will have a profile of wildtype and SDH genotypes.

Dr. Peter Hohenberger, from Mannheim University Medical Center in Germany, presented novel data regarding a study of imatinib levels in tumor and surrounding tissue in 24 patients undergoing surgery. At surgery, tumor and normal tissue sample were taken for analysis of imatinib and the imatinib active metabolite presence. Several studies have noted a relationship between imatinib blood levels and outcomes. In this study they did not look at outcomes but they did find a 12-fold variation in imatinib levels between normal tissue samples. The omentum showed the least (1.25 ng/ml) and the liver the most (16.6 ng/ml) with the stomach in the middle (5.25 ng/ml). Dr. Hohenberger also found only a moderate correlation between blood levels of imatinib and imatinib levels in tumor tissue. Vascularity of the tumor and surrounding tissue could explain some of the difference. He also suggested that interstitial pressure within the tumor itself might

affect imatinib levels. Dr. Hohenberger plans the future study of GIST tumor physiology looking at patterns of resistance in the tumor itself.

In an unrelated study presented by Dr. Antoine Italiano of Institut Bergonie in France, researchers showed that first-line imatinib is a feasible and effective treatment in patients with advanced GIST who are 75 years old and older. Overall survival is similar to that of younger patients. Interestingly, the authors reported that blood levels of imatinib appear to rise with age. The authors speculate that this finding may be related to decreased metabolism and to lower weight impacting the balance of imatinib in the body and in the bloodstream.

Dr. Rutkowski presented a study showing that patients taking Sutent had better outcomes when they experienced arterial hypertension (AH). Arterial hypertension (high blood pressure) is often experienced by GIST patients taking sunitinib. AH is thought to be an indicator that the drug's anti-angiogenic design is working. It was also reported that patients with wildtype and exon 9 genotypes did better on sunitinib, thus reinforcing the prognostic value of GIST genotyping.

Preliminary results of the crenolanib trial for GIST patients with the PDGFRA D842V mutation were reported in a poster by Dr. Margaret von Mehren of

## Mutational Analysis and Plasma Level Testing Survey

By the time you read this, you should have received an email from the LRG requesting that you take a short survey regarding mutational analysis and plasma level testing. If at all possible, please do so. The data we collect is anonymous, and is very useful in helping us understand when, why, and how these tests are being performed. **Thank you!**

Fox Chase Cancer Center in Philadelphia, Penn. Crenolanib is the only available tyrosine kinase inhibitor with in vitro activity against PDGFRA D842V. Toxicities have mirrored phase I experience. Preliminary metabolic response was observed in one of seven patients treated. Accrual into this trial is ongoing. Future trials are planned to optimize the dose and schedule of crenolanib in D842V patients.

All in all, a great deal of potentially useful information was presented at this year's CTOS conference, and the LRG was pleased to once again attend and present. The hope is that the research presented here will lead to further research and new treatment options, and we will be here to report on it when it does.

## COOK COUNTY

From Page 1

passing in November 2010 sparked a flurry of donations to the Life Raft Group which were provided to Cook County Hospital to support this program.

The meeting was a great success. Guest speakers included Bill's wife, Dr. Maureen Ruder, Drs. Fred Rosen, Thomas Lad, Michael Mullane and LRG's Chicago Chapter facilitator Jim Hughes. GISTers from both Cook County and the LRG's Chicago-area chapter attended, offered each other support, and had the



John Stroger Hospital formerly known as Cook County Hospital.

opportunity to learn more about their treatment and care. The next meeting is being planned for late January 2012.

Any future contributions made to the LRG in Bill's memory will be directed to support this program.

Special thanks to those who worked hard to make this meeting possible: Barbara Cleveland RN, OCN, - Coordinator; Faye Coffey, MSW - Co- Coordinator; Thomas Lad, MD, Fred Rosen, MD and Michael Mullane, MD - Medical Oncology Physician Advisors; Robert Cohen, MD and Harry Richter, MD - Surgical Physician Advisors.





*We'll miss you, Dan.* Love, Your friends at  
The Life Raft Group





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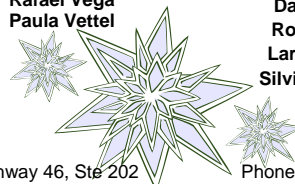


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