

LRG launches Latin American GIST initiative

A Call to Action: New Group Initiates Cancer Awareness Campaign in Latin America

November 23, 2009— The LRG announced the foundation of the Latin American GIST Coalition, a partnership of patient advocates starting with ten Latin American countries who have convened to create the Latin American GIST Initiative for the GIST community.

Unfortunately, there are no statistics about the incidence of GIST in Latin America; however, research is underway to investigate the rates of this disease in the region. The LRG has identified a need to close the information gap in Latin America among GIST patients, caregivers, and their healthcare professionals. The Latin American GIST Initiative aims to improve the survival rate of GIST patients with current treatment options, close the gap between scientific knowledge and clinical treatment of GIST, identify and reach more patients

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Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

December 2009 In memory of Neva Hageman, Linda Chuyko, Herbert Moses, Selena Hudson, Anja Long, Brad Clark & Jack Harrison Vol 10, No. 9

IGF-1R: A novel GIST therapeutic target

By Dr. Michael Heinrich
Oregon Health & Science
University & LRG Research Team

The vast majority of GISTs arising in adult patients have activating mutations of the KIT or PDGFRA genes (80-90%). GISTs lacking activating KIT or PDGFRA mutations are commonly referred to as wild-type GIST. Despite intensive research, the molecular abnormalities giving rise to wild-type GISTs remain unknown. Compared to the common exon 11-mutant GISTs, wild-type GISTs have lower rates of objective response to imatinib. In addition, the pro-

gression free and overall survival of patients with wild-type GIST is reduced compared to that of patients with KIT exon 11-mutant GIST. In pediatric GIST, the kinase mutational frequency is reversed, with more than 90 percent of pediatric GIST having a wild-type genotype. Notably, the effectiveness of imatinib against wild-type pediatric GIST is often reduced compared with its activity against adult wild-type GIST.



HEINRICH

Given the limitations of imatinib for treating wild-type GIST, numerous investigators have sought to identify other biologic abnormalities that could be used to de-

A glossary of terms for this article is available on page 8.

See HEINRICH, Page 7

Vettel lives life with her future in mind

By Paula Vettel
LRG Science Team member

When you start the morning by throwing up blood, you know it's not going to be a good day.

Thus began my history with GIST in October 1989. A quick trip to the emergency room led me to a gastroenterologist's office. An endoscopy revealed a "muscle tumor" at the top of my stomach, which was removed surgically. When pathology reported the tumor as benign, my GI doctor seemed more sur-



VETTEL

prised than happy. I suppose that should have set off a few warning bells. But hey, when the lab says it isn't cancer, you give thanks to God and don't ask too many questions

(Keep in mind that this took place before

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There was just so much big news this issue, we thought it best to help you out with a list of some of the big topics.

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More highlights from Life Fest 2010, plus how you can pick Clinician of the Year!

Plans for Life Fest 2010, and especially the gala event Friday night, *GIST 2010: A Decade of Difference*, are moving quite rapidly here. Below are a few additions to the weekend.



VASELLA



DEMETRI

• **Humanitarian of the Decade:** The last ten years of GIST progress would not have been possible without Dr. Dan Vasella and Dr. George Demetri, two extraordinary men whose contributions to GIST have saved countless lives.

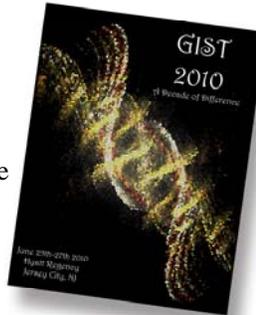
• **GIST Hall of Fame:** GIST champions from the scientific, medical, pharmaceutical and patient communities will be honored for their contributions.

• **10 Year Commemorative Program:** Profiles of the honorees and a history of GIST scientific and medical advancements including profiles of those fighting GIST on the front lines.

• **GIST: Personally Speaking** – A video documentary featuring scientists, clinicians and patients—their GIST journeys in their own words.

• **Volunteer of the Year:** The LRG recognizes one volunteer for outstanding service.

• **The Beacon of Hope Award:** Honoring innovation in GIST drug development.



The **GIST Clinician of the Year** award will be presented to a physician or nurse who demonstrates a level of skill and dedication in caring for GIST patients that exceeds expectation.

GIST patients & caregivers will have an opportunity to submit a nomination form for their doctor. A panel of GISTers will review all the nominees and choose a winner. The award will be presented in person at Life Fest 2010. The person who submits the winning entry will present the award to their clinician in person and will also receive: **round-trip airfare** (up to \$500), a **complimentary stay** at the Grand Hyatt and **free registration** to Life Fest 2010. *Emails will be sent out soon with nominations forms but you can also email us at liferaft@liferaftgroup.org and request one.*

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 or by sending a **check** to:

The Life Raft Group
40 Galesi Dr., Suite 19
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 of any errors.

Rhode Island GISTers meet!



On Saturday, October 17th, the New England GIST group gathered for its second annual luncheon at Susan Farmer's house in Providence. Nine GISTers and caregivers assembled from Rhode Island, Massachusetts, Connecticut, New Hampshire, as well as Jerry Call from Colorado. "Organ recitals" were held, as well as traded information on side-effects management, amidst much laughter and joy at the time shared together.

Standing, left to right: Dwight Simpson, Julie Thompson, Bob Coffey, Louise Ladd, John Sewell. Seated: Susan Farmer, Maura Cesarini. Margot Chevers was also present, but had to leave early.

GIST Research: LRG Articles on the Science of GIST

CTOS 2009 Reports: Adult GIST

By Jim Hughes

LRG Clinical Trials Coordinator

Imatinib plasma levels correlate with response

This presentation at the 2009 Connective Tissue Oncology Society meeting by Dr. Jonathan Trent offered several new observations for patients on imatinib. One hundred forty-two GIST patients underwent therapeutic drug monitoring from May 2008 to September 2009 at MD Anderson Cancer Center. Imatinib blood plasma levels were measured and minimum concentration or trough levels were calculated. Patient response was also tracked as part of this retrospective, observational study, which included both those with advanced GIST and

those receiving adjuvant imatinib (approx. 20%).

Patients were ranked by imatinib plasma trough level and divided into four groups or quartiles labeled Q1 to Q4. Q1 patients had the lowest measurements, Q4 the highest. The upper cutoff for the lower quarter in this study was 910 ng/mL. It was noted that this level was lower than the earlier study of patients in the 2000-2001 Phase 2 STI-571 (Gleevec) trial. That study introduced the much discussed 1,100 ng/mL boundary. Reasons for the difference may include the larger size of the MD Anderson patient group and differences in the patient populations.

Note: It is perhaps also significant that this boundary number increased from 851 ng/mL in the earlier abstract to 910 ng/mL (+7%) in the actual presentation

due to later data including just two more patients in this lower quartile and six more patients overall.

Patients who responded to imatinib therapy as measured by the Choi criteria had a significantly higher imatinib trough plasma level. Imatinib plasma level correlated with Choi response.

Higher doses and dose escalation resulted in higher imatinib levels. An imatinib dose escalation of 100 mg resulted in an average 296 ng/mL plasma level increase.

In this study imatinib trough plasma levels correlated with age, gender and dose, but did not correlate with race, body surface area, duration of imatinib treatment, or whether a patient had a gastrectomy, either partial or complete.

Patients with KIT exon 9 mutation

See ADULT CTOS, Page 9

CTOS 2009 Reports: Pediatric GIST

By Jerry Call

LRG Science Coordinator

At the 2009 Connective Tissue Oncology Society (CTOS) meeting there were several posters/presentations about pediatric GIST. One of the posters was from the NIH Pediatric & Wildtype GIST clinic and there was a presentation and a poster about the expression of two important proteins in pediatric GIST. The Consortium for Pediatric and GIST Research (CPGR) presented a poster of results from the first 39 patients to enter the National Institute of Health (NIH) clinic. This clinic is held twice a year and is a collaborative effort between clinicians, researchers, support groups and patients. All pediatric and wildtype GIST patients from any country are eligible to attend. Patients who wish to register for subsequent clinics should

contact ncipediaticgist@nih.mail.gov.

Among the findings of the NIH clinic were that 7 of 39 (18%) of the patients had germline mutations in one of the genes that make up the succinate dehydrogenase complex (SDHA, SDHB, SDHC and SDHD). There were 4 patients with mutations in SDHB, 1 patient with a SDHC mutation and 2 patients with a SDHD mutation. Mutations in the succinate dehydrogenase (SDH) complex had already been reported by Dr. P. Aidan Carney, a retired pathologist at the Mayo Clinic and Dr. Constantine Stratakis, a pediatric endocrinologist at the NIH. The mutations previously reported by Carney and Stratakis were found in families of the syndrome. In the patients seen at the NIH clinic, only one family had a complex family history. Although longer

follow-up is probably needed, this suggests that perhaps not all family members that have the mutation will develop clinical disease (penetrance may be incomplete). SDHB, SDHC and SDHD are known to be tumor suppressor genes. Mutations in these genes can cause several different types of cancer including GIST, paragangliomas and less frequently, renal cell carcinoma.

Other findings of the NIH clinic included an average age at diagnosis of 25.1 years, and average duration since diagnosis of 5.5 years and an average current age of 31.1 years. Females accounted for 79% of the clinic participants. Although tyrosine kinase inhibitors (TKIs) had limited effect in these patients (19% response rate), the majority of patients were doing well (95% overall survival rate and 23% in first remission) according to the authors.

Dr. Katherine Janeway, a pediatric



JANEWAY

See PED CTOS, Page 11

Big surprises and bigger hearts prevailed at this year's annual NYC poker tournament

By **Tricia McAleer**
LRG Program Director

The Sixth Annual New York City Poker Tournament, held on November 19 at the Midtown Loft and hosted by Board President Jerry Cudzil, was a tremendous success thanks to all of our supporters who came out to play for a cure.

The tournament has been a significant fundraiser for the Life Raft Group since 2004, when Jerry first began hosting the event, this year raising over \$70,000!

Jerry's father-in-law, Bill Roth was a long-time GISTer who sadly lost his battle in October of last year (you can read an article about Bill's life at www.liferaftgroup.org/in_memoriam/roth.html.)

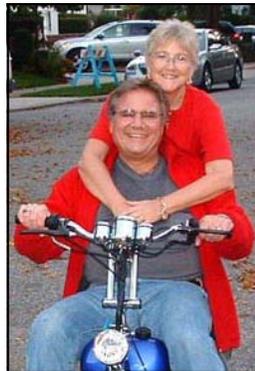
Jerry's continued commitment to the LRG carries on Bill's legacy—to find a cure for GIST.

Despite the overall decline in charitable giving and general uneasiness felt by most during these tough economic times, droves of people came out to support Jerry and the LRG. Well, there was also the poker.

Chips and cards were flying as round after round of elimination left us with one final table. Last year's first place

winner, Joe Bonavita, was once again one of the last men sitting. With over one hundred competitive players this year, the intensity could be felt by all who were present. Poker faces began to fade quickly as some of the best players lost all their chips.

With only five players left, Kurt Lichtman was not only the first to gracefully bow out, but he also donated his prize of two Yankee tickets back to the LRG.



Bill, with wife, Francis.



Jerry (standing 2nd from right, his wife Lorie (standing 2nd from left), "super-dealer" Terry (far left) and members of the LRG staff stop for a picture after a very long but exciting night.



Nothing beats making it to the final table at our poker tournament!

Allen Oppici was next to fold, and walked away with dinner for four at The Palm, which was donated by LRG supporter Nick Chiara.

Now, only three players remained, including Bonavita. Could he win two years in a row? The hands on the clock were ticking and the hands at the table were getting tougher. Stephen Czick was the next to go broke, but won an impressive tailored suit and tailored shirts from Shaban Alam.

The final two remained, Bonavita and Derek Smith, neither of whom were strangers to the final table. Smith was definitely a good match, but Bonavita's chips were piled high and there was no

defeating him. All was not lost, Smith also walked away with a tailored suit and shirts to match.

Against all odds, Bonavita took the grand prize for the second year in a row—a \$10,000 seat at the World Series of Poker Main Event in Las Vegas, Nev.

On another note, we held a 50/50 raffle again this year (50/50 is a raffle in which people buy tickets and the proceeds from the ticket sales are split up with one half of the sum being awarded to the winner) and raised an impressive \$1,100! This year's winner, Tim Turpin, donated his half of the winnings back to the LRG. Thanks Tim!

As always, a thank you must go to Long Island Poker & Casino for their help year after year.

A very special thank you must also go to Cricket Hill Brewery for donating delicious micro-brews for our players to enjoy and Kim Tallau of Innovative Images, for her talent and time photographing the event. Photos can be viewed on Facebook at: www.facebook.com/lrgpokertournament.

Although there could only be five winners that night, we believe that everyone who supported the event that night went all-in for a cure for GIST.

We can't wait to see you all next year!

LRG uses registry & “GISTory” to help patients in a new way

By **Roberto Pazmino**, LRG Database Administrator & **Magda Sarnas**, Patient Registry Supervisor

What is a GISTory?

Many of you who participate in the Life Raft Group’s Patient Registry may have received our monthly plea to help us update our records. Those who received this plea in November also received an additional surprise: We included a PDF document that consolidated your medical history of GIST, aka your GISTory. We did this for a few reasons. We wanted to verify the information you have provided to us over the years, as well as provide you with a summary that will help you better track your diagnosis, treatment and scans.

For those of you have not seen the form, we made an easy-to-follow diagram (pictured right).

How do we use this information?

We utilize the data from this registry to identify critical areas not being covered in a timely way by clinical trials or by the traditional cancer research community, including understanding the non-toxic but life-altering side-effects of cancer drugs and the implications of changes in drug levels after a clinical trial has started.

How do I keep it accurate and up-to-date?

We can provide your Gistory by email, mail, or fax. All you have to do is provide us your current contact information so we can assure that you will get your personal copy.

Once you receive it, **please review the entire contents of the document.** From your initial diagnosis to your latest scan, we would like make sure we have your

See GISTORY, Page 14

This box contains basic diagnosis information like age at diagnosis, mitotic rate, ckit test results, a misdiagnosis, mutation and what type of tumor was found.



GISTORY

Patient : Patient, Blank

* Basic information like name, age, GIST type & doctor are also listed for your convenience.

Current Age: 43	Gender: M	Gist Type: GIST	Pediatric: <input type="checkbox"/>
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Diagnosis		Tumor Locations		
GIST Diag Date: 5/13/2002		Event	Tumor Type	TumorLocation
Age @ Diag: 18		Diagnosis	Primary Tumor	Stomach
Mitotic Rate: 10		Evaluation	Mets	Stomach
CKIT Positive: <input checked="" type="checkbox"/>		Evaluation	Mets	Liver
Misdiagnosed: <input checked="" type="checkbox"/>		Diagnosis		
2/15/2001 LMS				
1st. Mutation: Exon/Kit 11				

Tumor @ Diagnosis	<input type="checkbox"/> PT <input checked="" type="checkbox"/> Multi	Current Doctor/Oncologist	Facility:
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History		
Date	Event	Comments
01/01/01	Eval – Scan-UltraSound->Abnormal	Originally Doctor or
02/14/01	Eval – Biopsy-Biopsy->Gist -	
02/15/01	Misdiagnosed LMS	Originally thought to be ulcers, further examination prompted due to fainting and anemia.
02/15/02	Treat - Surgery Primary Tumor - Clear Margins - Place: Christies Hospital,	Laparoscopic Surgery preformed.
05/13/02	Diag @ Age of 17.78 /PT/ Ckit +	Originally thought to be ulcers, further examination prompted due to fainting and anemia.
05/14/02	Eval – Biopsy-Biopsy->10/50 hpf	
05/14/02	Eval – Biopsy-Biopsy->GIST +	Taken during endoscopy. Diagnosis
05/15/02	Treat - Gleevec @ 400-mg - Place: Christies Hospital, Manchester, UK	
07/16/02	Eval – Scan-CT->Ned	Cold
	Eval – Scan-CT->Ned	NED
	Eval – Scan-MRI->Ned	NED
	Eval – Plasma Test-Plasma Test->10001	
03/14/03	Eval – Scan-CT->New Tumors - Mets	Dr found lesions on Liver.
06/04/03	Eval – Scan-CT->Ned	shadow on previous surgery site. NED
02/03/04	Treat - Surgery METs - Place: Christies Hospital, Manchester, UK	
02/04/04	Treat - Ablation LA - Place: Christies Hospital, Manchester, UK	Since clear margins could not be achieved, LA was done ensure that all tumors were removed.
03/15/04	Treat - Gleevec @ 600-mg - Place: Christies Hospital, Manchester, UK	After healing from surgery, the patient waited to start taking gleevec.
05/18/04	Eval – Scan-PET->Cold	Cold

Your history is listed in chronological order by date, event (diagnosis, evaluation and treatment), and any additional comments that you provided.

This box details all tumor locations and whether found at diagnosis or evaluation.

All treatments, such as surgery & medication, are bolded so you can find them easily.

Evaluations are listed chronologically by type of test and result.

What are the benefits of a GISTory?

Our new electronic medical record system gives you more flexibility and more direct access to your health information than ever before.

- View your health summary, current health conditions and health history
- View evaluation results
- View current and previous medications
- Identify patterns that may be relevant to your own health
- GISTORY can help your doctor interpret the history of disease
- Greatly help you in understanding and gaining control of your health
- Help present and future practitioners treat you much more effectively

GIST Research: LRG Articles on the Science of GIST

A spotlight on trials for adjuvant GIST

By Jim Hughes

LRG Clinical Trials Coordinator

Adjuvant trials don't always get the same attention as second and third line trials for advanced GIST patients. They can also take up to seven years to get results. But when they do get reported the news can be earth moving. In late 2008, the Food & Drug Administration approved imatinib for adjuvant use in patients whose GIST has been completely removed. The European Medicines Agency (EMA) followed with a recommendation for approval in March 2009, but the phase III trial that produced the results supporting those decisions started in June 2002. It was halted early in April 2007 because a clear advantage was seen in recurrence-free survival for patients in the active

imatinib arm. Patients on imatinib had less than half the risk of recurrence compared to patients on placebo. That trial had been studying imatinib versus placebo for one year after surgery with over 700 patients participating in the United States. Although the results were significant, the question remains about what to do after that first year. How long should patients stay on imatinib?

In a parallel phase II adjuvant trial of imatinib alone in high-risk GIST patients (tumors greater than 10 cm) researchers found a similar response pattern over the one year of the trial treatment period. They also found that when adjuvant treatment was stopped there was a significant increase in the rate of recurrence beginning six months after treatment was discontinued.

See ADJUVANT, Page 14

Table: United States Adjuvant Trials

TITLE	IMATINIB IN TREATING PATIENTS WITH COMPLETELY RESECTED GISTS	IMATINIB IN TREATING PATIENTS WITH COMPLETELY RESECTED PRIMARY GISTS	5-YEAR ADJUVANT IMATINIB IN GISTS
PHASE	2	3	2
START YEAR	September 2001	June 2002	June 2002
ACCRUING	107	708	133
STATUS	Ongoing-Not Recruiting	Ongoing-Not Recruiting	Recruiting
SPONSOR	ACOSOG, NCI	ACOSOG, NCI, NCIC, CALGB, SWOG	Novartis
ARM 1	Imatinib (400) daily/1 year	Imatinib (400) daily/1 year	Imatinib (400) daily/5 years
ARM 2	None	Placebo daily for 1 year	None
INCLUSION CRITERIA	Kit+tumor≥10cm or hemorrhage or multifocal and completely resected w/i 70 days	Kit+tumor≥3cm completely resected w/i 70 days	Kit+tumor≥2cm and with mitotic rate ≥ 5/50 HPF, completely resected w/i 84 days
REGULATORY ACTION?	None to date	FDA approved (08), European Commission approved (09)	None to date

December 2009 clinical trials update

By Jim Hughes

LRG Clinical Trials Coordinator

United States

RAD001 in combination with CP-751,871 in patients with advanced sarcomas and other malignant neoplasms (NCT00927966)

An mTOR inhibitor (RAD001) and an IGF-1R inhibitor (CP-751,871) are combined in this phase I trial, which is now recruiting at Dana-Farber Cancer Institute (DFCI).

The entry criteria allow GIST and state that patients "...on approved tyrosine kinase inhibitors must be off therapy two weeks prior to study entry."

This trial is for age 18 and over and might be a good option for wild-type GIST patients whose tumors test for higher levels of IGF-1R and who have exhausted other options. RAD001 (Everolimus, Afinitor) has previously been used off label and in trials for GIST. The Principal Investigator is Dr. Suzanne George.

Contact: Suzanne George at 617-632-5204, or Dr. Richard Quek at richard_quek@dfci.harvard.edu.

Imatinib and sunitinib in treating GIST patients (NCT00573404)

This phase I trial in resistant GIST at Vanderbilt University is now ongoing and no longer recruiting.

International

Nilotinib 800 Mg and imatinib 800 Mg for The treatment of GIST patients refractory to imatinib 400 Mg (LANGIST) (NCT00751036)

Seventeen new sites have been added to this phase III trial comparing imatinib and nilotinib in resistant GIST patients. The new sites are now recruiting in Latin America, the Republic of Korea and Thailand.

Dasatinib as first-line therapy in treating GIST patients (NCT00568750)

This phase II trial for newly diagnosed GIST patients has added 17 sites and contacts in Finland, France, Germany and Switzerland.

HEINRICH

From Page 1

vised novel therapeutic strategies. Recently, Tarn et al. identified the Insulin-like growth factor 1 receptor (IGF-1R) as a potential therapeutic target in GIST. IGF-1R is a tyrosine kinase receptor that binds either IGF1 or IGF2. After ligand binding, the tyrosine kinase domain is

activated and stimulates the intracellular signaling pathways that control the proliferation rate and apoptosis. Similar to KIT and PDGFRA, two key IGF-1R signal transduction networks have been identified: the GPTase Ras-Raf-ERK/MAPK and PI3K-AKT/mTOR. The IGF/IGF-1R system plays a key role in the biology of normal cells and tissues. Aberrations of this molecular pathway such as over-expression of IGF-1R, or elevated plasma levels of IGF1, or genetic polymorphisms of the gene encoding IGF1 have been found in association with a variety of cancers including sarcoma. Because over-expression of IGF-1R has been identified in several

tumor types and because of its role in cellular metabolism, which potentially has relevance to the survival of malignant cells, IGF-1R has become a target for anticancer therapy. Notably, both monoclonal antibodies and small molecule tyrosine kinase inhibitors that block IGF-1R activation are undergoing clinical development.

In their original publication, Tarn and colleagues use immunoblotting studies to show that IGF-1R was expressed and activated in 17 GIST tumor samples.[1] IGF-1R was markedly over-expressed (10-30 fold) in wild-type GIST (3 cases) compared with mutant GIST (14 cases). Using KIT-mutant GIST cell lines, these investigators showed that a small mole-

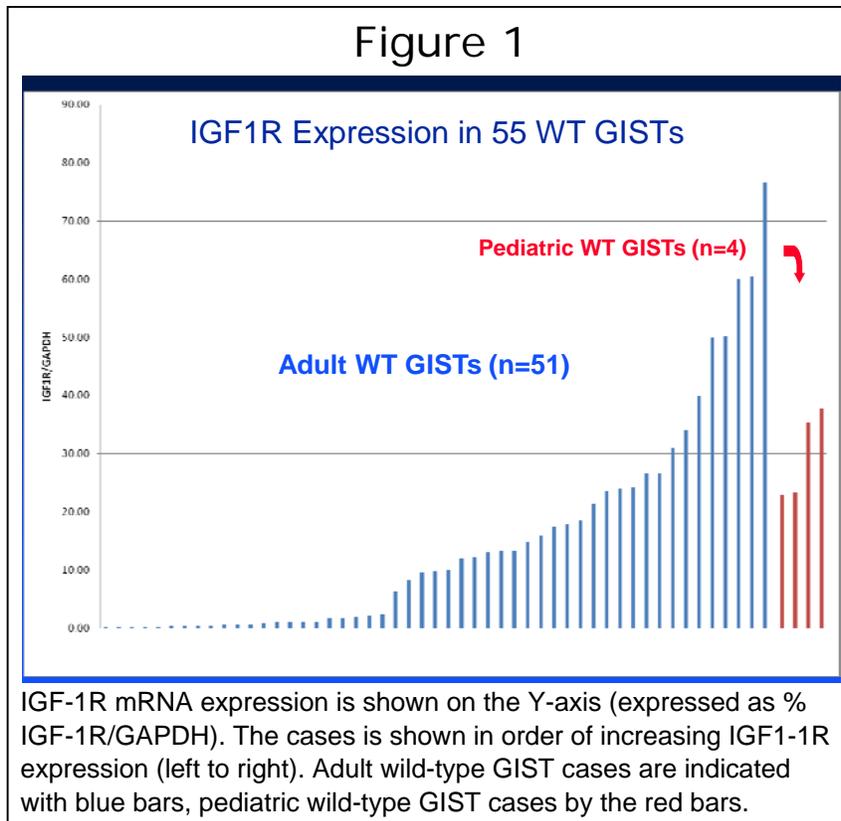
cule IGF-1R kinase inhibitor (NVP-AEW541) reduced cellular proliferation and induced apoptosis. In addition, combining imatinib and NVP-AEW541 resulted in more effective cell killing than either drug alone. Dr. Cristina Antonescu's research group at Memorial Sloan-Kettering Cancer Center has also reported that pediatric GIST have much higher levels of IGF-1R expression than adult wild-type GIST and show distinct

levels of IGF-1R expression that were similar to kinase mutant GIST. In contrast, the other 60 percent of adult wild-type GIST had IGF-1R levels that were ten to 100 times higher (Figure 1) than KIT-mutant GIST. Our series also included four cases of pediatric wild-type GIST, these cases all had high level expression of IGF-1R in a range that overlapped with adult wild-type GISTs with high level IGF-1R expression. Using our

data, Drs. Rob West and Matt van de Rijn (Stanford University School of Medicine) were able to perform a tree analysis of KIT, PDGFRA, and IGF-1R expression versus tumor genotype (Figure 2, page 8). Notably, PDGFRA expression was strongly clustered with cases of PDGFRA-mutant GIST, high-level IGF-1R expression was restricted to a subset of wild-type GISTs (including all four cases of pediatric GIST). KIT expression was variable amongst our cases and was not strongly associated with any particular tumor genotype.

Our data indicate that significant biological

heterogeneity exists amongst wild-type GIST and that IGF-1R might allow molecular sub-classification of wild-type GIST (along with other markers). These results also have implications for trials of IGF-1R inhibitors, as it would be predicted that clinical response might correlate with the level of IGF-1R expression. This would suggest that the most favorable responses would be seen in the 60 percent of cases of wild-type GIST with high-level IGF-1R expression. However, it remains to be seen if this prediction is borne out by the results of clinical studies and whether there will be a threshold level of IGF-1R expression that is required for a therapeutic response. In ad-



patterns of gene expression compared with adult wild-type GIST.[2]

To further assess the biology of IGF-1R expression in GIST, we developed quantitative real time PCR assays for IGF-1R, KIT and PDGFRA. We prepared RNA from a series of 117 previously genotyped GIST and quantified expression of the IGF-1R, KIT and PDGFRA mRNA using a control gene (GAPDH) to normalize for differences related to variations in the quality of specimen RNA. Using this approach we found that GISTs with mutation of KIT or PDGFRA had very low levels of IGF-1R expression. In the case of 51 wild-type GISTs that we tested, approximately 40 percent of these cases had low

What Does a Cure Mean For You?

a cure for cancer is in our reach



Spoiling our grandchildren for many more years.



Playing in the leaves next fall...

As most Life Rafterers and our friends know, we do a yearly fundraising campaign to support our research project – *Pathway to a Cure*.

In years past, GIST survivors and their loved ones sent out note cards, letters and emails asking their friends and their family for their support.

Last year, we tried something new and asked everyone to get involved. Because cancer affects all of us.

We asked the questions, “What does a cure for cancer mean to you?” and in-

vited the world to join the GIST community in our quest for the cure. Thanks to our donors and supporters, we raised over \$60,000 and people from all over the world told us what a cure meant to them (You can view these pictures and upload your own at www.ACureIsInOurReach.org).

With the holiday season nipping at our heels, we are once again asking everyone to donate to the LRG GIST Research team and be a part of the cure.

The proceeds of this campaign coupled with our Board and corporate fundrais-

ing have enabled the LRG to contribute over \$5 million to propel *Pathway to a Cure*, founded in 2006.

We won’t just wait for a cure. We have to make it happen. Join us.

Fundraising materials for this year’s holiday campaign should be arriving in your mail within the next few weeks.

Please email us at liferaft@liferaftgroup.org or call us at (973) 837-9092 if you have any questions or comments.

For information on our Pathway to a Cure research effort go to www.liferaftgroup.org/research.html.

IGF-1R Article Glossary (page 1)



Tyrosine kinase inhibitors (TKI)- Targeted cancer drugs that block specific signaling pathways.

Progression-free survival- the length of time during and after medication or treatment during which the disease being treated (usually cancer) does not get worse.

Overall survival- Overall survival refers to time a patient survives (usually given in

months or years).

Signaling pathway-molecular interactions that enable communication in or between cells.

Polymorphisms- A common variation of a gene.

Monoclonal- a group of cells produced from a single ancestral cell by repeated cellular replication.

Immunoblotting- a technique for, or the blot resulting from, analyzing or identifying proteins via antigen-antibody specific reactions, as in Western blot technique.

mRNA-a molecule of RNA encoding a

chemical "blueprint" for a protein product.

Genotype- In GIST, genotype usually refers to the type and general location of mutation within a tumor, e.g., KIT exon 11.

Heterogeneity- means that something (an object or system) consists of a diverse range of different items.

Immunohistochemistry- A method for staining cells.

Interstitial cells of Cajal- specialized cells, found throughout the gastrointestinal tract that are essential for normal gastrointestinal motility; these are the cells from which GISTs arise.

ADULT CTOS

From Page 3

were treated with higher doses of imatinib, had higher plasma levels and had progression-free survival similar to that of patients with exon 11 mutation.

Dr. Trent also presented a protocol outline for a future clinical trial to study imatinib plasma levels under the sponsorship of the Sarcoma Alliance for Research through Collaboration (SARC019). Preliminary designs show recently diagnosed GIST patients are randomized to cohorts that do and do not adjust dose based on imatinib trough plasma level measurements. SARC019 design will explore the best Cmin (minimum concentration) for eventual use in the clinic.

Rechallenge with imatinib reported as possibility for patients without options

Clinical trial options may be limited when patients face resistance to standard GIST therapies. In this poster the authors ask if returning to imatinib after other options have failed has an active effect. They conclude that rechallenge with imatinib is feasible and can display some anti-tumor activity in patients with GIST resistant to standard and investigational therapies who lack alternatives. Seventeen resistant GIST patients in Italy were given imatinib (12 at 800 mg and 5 at lower doses). Two patients achieved partial response and five had stable disease. Four patients are alive and still on treatment. Median duration of imatinib rechallenge treatment for all patients was 105 days. Thirteen of the 17 were male. Mutation status was not reported and may have had some bearing on the result. (Abstract 39404 Rechallenge with imatinib in GIST patients resistant to second or third line therapy.)

GIST bone mets reported as rare but underestimated

A group of 288 advanced/metastatic GIST patients treated in Italy with tyrosine kinase inhibitors over seven years were reviewed. Fourteen patients (5%) developed bone lesions at a median 35

months after primary GIST diagnosis. In roughly half the patients bone mets were associated with other unusual metastatic sites (lung, soft tissue, spleen and parotid gland). The most frequent bone met sites were spine and pelvis. Four patients received radiation therapy and had subsequent pain relief. "In nine patients, tyrosine kinase inhibitors obtained a stabilization of bone disease with a metabolic response." GIST bone mets are rare but more frequent in this study than previously reported. (Abstract 39410 Bone metastases in GIST: an underestimated occurrence.)

Possible new pathway targets modeled in vitro

This interesting presentation comes from the lab of Dr. Anette Duensing, an LRG Research Team member at the University of Pittsburgh Cancer Center. Dr. Duensing's team has been exploring the signaling pathways that allow some GIST cells to survive imatinib therapy. Her team has explored cell defense mechanisms by which some GIST cells become dormant or "quiescent," thereby avoiding exposure to apoptotic effects of imatinib treatment in the natural cell division and growth cycle. These discoveries may lead to new targets in the lab and approaches that seek to eradicate all viable remnants of GIST. Proteins identified in human GIST cell lines include SKP2, p27(Kip1) and the human DREAM complex involving B-MYB, p130 and LIN37. (Abstract 39394 Imatinib modulates regulators of tumor cell quiescence in GIST cells.)

Bortezomib shown to kill resistant GIST cells in vitro

This presentation reported the work of three LRG-funded

research team members, Dr. Sebastian Bauer of West German Cancer Center, Dr. Jonathan Fletcher of Brigham and Women's Hospital in Boston, and Dr. Anette Duensing of the University of Pittsburgh Cancer Institute. At CTOS 2008, Dr. Duensing presented data demonstrating the role of the proteasome in GIST resistance. The proteasome is a special protein that recycles other proteins into their component parts. In GIST, the proteasome mechanism lowers levels of a protein, H2AX, that is involved in GIST cell death (apoptosis). Inhibiting the proteasome could therefore lead to GIST cell death. In this presentation, data is presented showing the effect of proteasome inhibitor bortezomib on resistant GIST cell lines. The report concludes, "Collectively our results show that inhibition of the proteasome using bortezomib can effectively kill imatinib-sensitive and imatinib-resistant GIST cells in vitro and provide a rationale to test the efficacy of bortezomib in GIST patients."

So far, anecdotal reports of bortezomib use in GIST have not shown any breakthroughs. (Abstract 39457 Pro-apoptotic activity of bortezomib in GIST cells.)

For more presentations on ASCO 2009, go to www.liferaftgroup.org/news_sci_articles/ctos2009.html.

Pennsylvania GISTers meet!



A note from PA Group leader, Kim Trout: "Pennsylvania GISTers gathered for lunch on November 14, at The Cheesecake Factory in King of Prussia. One new person joined the group, Linda Volkening, who was able to meet others, for the first time, who could empathize with what she has been going through for many years. Also in attendance were (left to right) Rachel Glass (my future mother-in-law), Esther Trout (my mom), me, Kim Hoffman (wife of GISTer, Mike Hoffman), and Linda Volkening. We had a fantastic lunch and had a great time getting to know each other. We hope to meet again soon! We only wish more people would take advantage of meeting others and receiving support from others who know a lot about what they are going through."

VETTEL

From Page 1

CT scans were available).

I went home happy. Every year for five years we repeated the endoscopy, but nothing ever showed up. After five years I was pronounced cured, and didn't give the episode another thought.

Fast-forward to the summer of 2001 when I started having strange symptoms. I was out of breath constantly; brushing my teeth would leave me gasping. I went right to the doctor, but not for a second did I connect these symptoms to my ordeal of 12 years ago. The blood work came back okay, so we focused on allergy and breathing problems. Eventually the internist repeated the blood work, which showed elevated counts of white blood cells and liver enzymes. He ordered a CT scan.

At this point I was more confused than worried. I figured they'd find the problem, fix it, and that would be that.

Late that night I woke up with sharp pains. By morning, the pain had gotten so strong that I couldn't stand up, let alone walk. I don't remember how my husband got me off the bathroom floor, into the car, and into the emergency room.

Once in the ER, they performed the CT scan that I was scheduled to receive anyway. We were still in the emergency room when a nurse came in and started talking matter-of-factly about "the growth". I asked her what she was talking about. She looked uncomfortable. "Hasn't a doctor been in here yet?" she asked. When we told her no, she took a deep breath and told us what a doctor should have: There were two small masses and a large mass – 15 x 9 cm – sited on my liver.

My first reaction was, well, now I know why I've been out of breath. The largest tumor was pressing into my right lung, which was partially collapsed. But now the tumors were in full revolt. My entire abdomen swelled up. I had quarts of liquid removed from my abdomen and chest cavity, but the extreme swelling remained. My shoes didn't fit. Hell, my hospital gown barely fit. I couldn't

even roll onto my side in bed.

The surgeon who performed the original stomach surgery – the guy everyone in the hospital assured me was the best

around – told me that the tumor was cancerous and that surgery was not an option. It wasn't so much what he said as how he said it. It was clear from his facial expression, the slow and deliberate way he was speaking, that he was delivering very bad news.

And yet, I didn't panic. No one told me I was going to die. (One doctor did tell my husband that I was going to die. But he didn't pass that bit of happy news along.) I was in an amazing state of denial. Yes, of course, I knew that having cancer was bad. Yet I assumed that I would get out of this fix somehow.

I didn't see the oncologist for several days. After his examination, he told me that there was a medicine that could help me, maybe even cure me, but I needed a test to see if I qualified. I lay in bed wondering if this was the miracle I was waiting for. I prayed and pleaded with God to give me my old life back. After three long days, the oncologist came back with the news that I was loaded with the desired receptors (c-kit). My husband and I wept with joy.

I received my first 400 mg dose of Gleevec that evening. When I woke up the next morning, I felt vaguely better. Soon I was able to roll in bed. That afternoon I got out of bed for the first time in eight days. The second dose of Gleevec was taken on an empty stomach. That was the first and last time I tried ingesting Gleevec without a full meal (What a waste of expensive medicine).

The swelling continued to subside. I was released from the

hospital the next evening. Gradually my strength increased, and I returned to work and activities with my family. As life returned to normal, I refused to think about the possibility that I would not be cured. I was afraid to do any research on Gleevec because I didn't want to read any bad news.



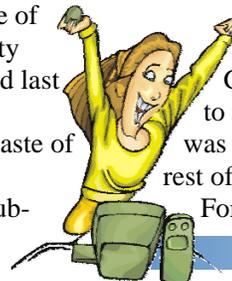
Paula with her sons, Ed (left) and Chris (right) in Ireland.

Two months later, the swelling was gone from the liver, but the tumors remained substantial. Five months later, the largest tumor had shrunk to 11 x 8 cm. By this time I had recovered completely from the swelling and symptoms. The smaller tumors shrank from 4 x 3 cm to 3 x 2.3 cm and 5.7 x 3.5 cm to 4.6 x 2.9 cm. I was tolerating Gleevec so well, the oncologist increased my dose to 600 mg.

The next CT scan showed no more shrinkage. When I heard this I panicked, convinced that tumor regrowth would inevitably follow. My oncologist tried to assure me that everything was okay, but I didn't believe him. I was angry that I would be cheated out of seeing my boys grow up and get married. Phil and I would not have the long happy life to which we looked forward.

Finally, I began searching the internet for more information, and found the Life Raft Group. I soon learned that my experience was typical for GIST and Gleevec. I finally began to relax and accept the fact that I was going to live with cancer for the rest of my life.

Fortunately, this has been relatively



Chuyko passes with love at her side

Linda D. Chuyko, 59, of South Whitehall Township, NJ, passed away Tuesday, September 29, 2009 in the Lehigh Valley Hospital, Salisbury Township. She was the wife of Harry Chuyko, Jr. They celebrated their 40th wedding anniversary in May 2009. Born in Allentown, she was a daughter of the late Richard Burke and the late Florence E. (Kerschner) Alberth. Linda was the owner of Westgate Electronics for 25 years. Previously, she was a manager for Westgate Florists and then Stahleys Landscaping. Linda was a graduate of Allentown High School. She was of the Christian faith. Linda enjoyed baking, cooking and spending time at home with her pets. An angel to many, Luber, you were the wind beneath my wings. Mom, thank you for all the good memories that fill my heart. You were my support, my friend and now my angel. Survivors: Husband; son, Jason; sister, Pat; granddaughter, Cristian and her husband Pat; great-grandson Van; special friends, LeeZa and Linnie May; nephews and nieces. Services: A memorial gathering will be held at her residence on Sunday from 2-4 p.m. Arrangements by Stephens Funeral Home, Inc. www.stephensfuneral.com.



VETTEL

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easy. My side effects from the 600 mg Gleevec are very manageable. I have no nausea as long as I eat enough food to keep my stomach from being empty. I have no diarrhea, or fatigue. At first I took diuretic pills to control the edema in the eyes and feet along with extra potassium, magnesium, and calcium to counteract the diuretic. My hemoglobin

PED CTOS

From Page 3

oncologist at Dana-Farber Cancer Institute, also gave a very interesting presentation on SDHB expression. Dr. Janeway and her colleagues looked at 15 KIT mutant GISTs (adult GISTs), 5 NF-1 GISTs and up to 14 pediatric wildtype GISTs (they ran some through more tests than others). They found that the pediatric GIST tumors had a complete loss of SDHB expression (stained negative for SDHB). The adult GISTs stained positive for SDHB. They also found that the pediatric GIST samples tested had lost the function of complex II of the respiratory chain (in the mitochondria). This is interesting because it is what might be expected from the patients that had known SDHB mutations (Carney-Stratakis Syndrome), but would not be expected in pediatric patients that did not have that mutation.

Dr. Stratakis and Dr. Carney have previously reported that patients with Carney's Triad might have a loss of one of the two copies of the SDHC genes. As noted previously, Stratakis and Carney and the NIH clinic participants have also found mutations in 3 of the genes that code for the SDH complex in patients with Carney-Stratakis Syndrome. However, loss of SDHB expression in Carney's Triad and other forms of pediatric GIST is not due to mutations or deletions of SDBH, SDHC or SDHD. Instead, Dr. Janeway's group is looking at the possibility of a different mechanism that might account for the loss of SDHB in other pediatric GIST patients. While

is always good. And I **never** skip a dose of Gleevec.

I was able to go back to my job as a lubricant research chemist. I continue to work full time now as a consultant. I travel, garden, exercise, and enjoy dining out with my husband Phil. His job as Restaurant Critic for the *Chicago Tribune* gives us many opportunities to try delicious and interesting food and wine. Our sons are grown now, and we have enjoyed watching their high school and college activities.

Mark your calendars!

- New Jersey GISTers will be meeting **January 16** at Gilda's Club in Hackensack. Please email the LRG at lifteraft@lifteraftgroup.org for information.

- The 2nd Annual GIST Benefit Ball will be held on **January 30** at the Mansion in Voorhees, NJ. Go to www.gitsbenefitball.org for details.



the cause of SDHB loss remains unclear, their current hypothesis (work in progress) is that loss of SDHB is related to an epigenetic event. The authors concluded that "... these findings indicate that SDHB loss and defective cellular respiration may be central mediators of oncogenesis in pediatric GISTs lacking receptor tyrosine kinase mutations."

Note: For more information on SDH mutations and Carney-Stratakis Syndrome, see the October 2007 edition of the Life Raft Group newsletter.

Dr. Janeway and her colleagues at Dana-Farber also presented another poster about the overexpression IGF1R in pediatric GIST. This report of 9 pediatric GIST patients confirms previous reports of overexpression of IGF1R in pediatric GIST. The authors noted, "Clinical study of IGF1R-directed therapies in pediatric wildtype GIST is warranted." *For a detailed description of IGF1R in pediatric and wildtype GIST, see the article by Dr. Michael Heinrich on page 1.*

I have been to many Life Raft meetings, both locally in the Chicago area and at the biannual LifeFest, and I am a member of the LRG Science Team. I recently succeeded Dick Kinzig as coordinator of the Chicago chapter. I continue to monitor the tumors by CT scan every six months. I know that this will never change, but with the support of my family and friends, I will be hanging onto our "life raft" till the end. I've learned to live for today. But I still plan for the future.

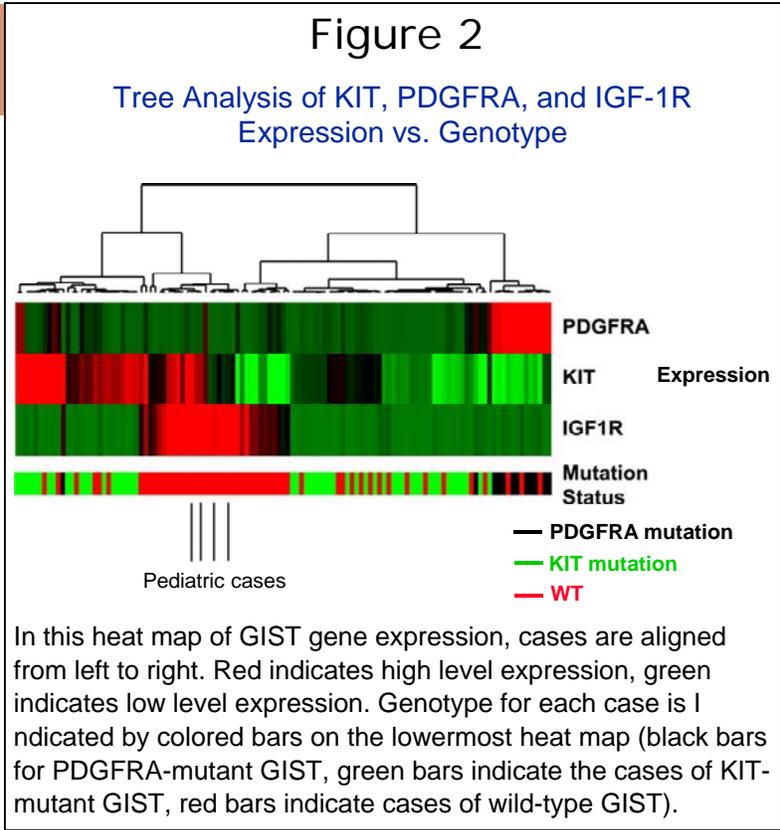
HEINRICH

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dition, methods for detection of IGF-1R expression by GIST need to be optimized (immunoblotting vs. immunohistochemistry vs. RNA-based detection methods). As a cautionary note, we need to remember that cellular expression does not always correlate with biological importance of a pathway. Therefore, the mere fact that IGF-1R is highly expressed by certain cases of GIST does not necessarily mean that clinically inhibiting this protein will cause GIST cells to stop growing or die.

It is believed that GIST arises from, or shares a common developmental pathway with, the interstitial cells of Cajal (ICC). Notably, immature ICC express IGF-1R protein, whereas mature

IGF-1R do not. In contrast, very immature ICC express KIT at much lower levels than committed ICC progenitors



or mature ICC. Therefore, IGF1-1R expression by GIST may be an indicator of the differentiation state of these tumors and may be a surrogate marker for the underlying biology of these tumors. The use of this marker in studying ICC development, especially in existing mouse models of GIST, may provide important insights into GIST biology and yield clues to new therapeutic strategies for this disease).

Reference List

- [1] Tarn C, Rink L, Merkel E, et al. Insulin-like growth factor 1 receptor is a potential therapeutic target for gastrointestinal stromal tumors. Proc Natl Acad Sci U S A 2008;105:8387-92.
- [2] Agaram NP, LaQuaglia MP, Ustun B, et al. Molecular characterization of pediatric gastrointestinal stromal tumors. Clin Cancer Res 2008;14:3204-15.

LA

From Page 1

and key medical professionals, and empower patients to take charge of their own care.

The founding members of the LRG's Latin American GIST Coalition include: Sandra Mesri of Argentina, Vicky Ossio of Bolivia, Dr. Alexandre Sakano of Brazil, Piga Fernandez Kaempffer of Chile, Dr. Rafael Vega of Colombia, Dr. Michael Josephy of Costa Rica, Alejandro Miranda of Dominican Republic, Rodrigo Salas of Mexico, Fabrizio Martilotta of Uruguay, Maria Isabel Gomez de Soriano of Venezuela, and Pat Garcia-Gonzalez of The Max Foundation.

Working together, this group has the potential to enable thousands of patients to become experts at navigating their care for this rare cancer, as well as to engage and mobilize the medical community to improve the management of



GIST.

In most Latin American countries, cancer patients do not participate in cancer support organizations for reasons such as cultural factors, lack of information or lack of interest. "It is a challenge to identify and reach GIST patients to share more information about their disease. With the LRG's help, we need to find and empower patients and caregivers to stand up for their rights and participate in the decision-making process for their treatment plan. We cannot let patients die due to lack of information on their part or their physicians' part," says Vicky Ossio, the Latin American Coordinator and Facilitator of the Latin American GIST E-mail Community.

Unlike having the National Institutes of Health in the United States, most of the countries in Latin America do not have a centralized system of care to track statistics and management of cancer cases, nor sufficient treatment options. "Latin American countries are behind in the clinical trial process, making it difficult to extend the lives of many of these patients. We need to collaborate with the teaching and medical institutions in each country to spread awareness about this problem and get diseases such as GIST on the radar screen," says Rodrigo Salas of Mexico, who has already started working with Monterrey Institute of Technology to begin such a collaborative effort.

With the LRG's experience of being a world-renown patient advocacy group, the Latin American GIST Coalition has the right tools to carry out its strategic plan to provide information, education, and new treatment horizons to the Latin American community.

Supporters ‘Show The Love’ for Texas Marathoner

By Belinda Ehrlich
LRG Program Associate

“**S**how the love!” Kate Poss emphatically writes on her website. “The generosity continues!

We hit \$5,000 in less than three weeks!”

Kate will be running the 26-mile Austin Marathon on February 14, 2010, with all donations going to the Life Raft Group.

Kate’s father John, who was diagnosed with GIST in May 2000, is a member of the LRG Board of Directors.

On October 6, Kate began a fundraising campaign challenging herself to raise \$2,620 or \$100 for every mile she ran, “plus an extra \$20 for that pesky last .2 mile,” she noted. Little did she know the amazing response she would receive. Kate met her \$2,620 goal in less than six hours.

“Unbelievable!,” Kate posted on the



Kate (pictured left) at the 2009 Austin Marathon.

site. “Your generosity is overwhelming. It seriously brings tears to my eyes.” After increasing the goal to \$5,000, Kate was ecstatic to find it was reached in less than three weeks. She has now set a new

target at \$6,500 — a goal that surely seems within reach. So far, Kate has raised \$5,926.20.

Kate noted the importance of showing support for LRG through fundraisers such as hers. “By understanding and finding a cure for one cancer, we are one step closer to finding a cure for all cancers.”

John had surgery to remove a canta-

loupe-size tumor from his stomach, along with two-thirds of his stomach, spleen, a section of his diaphragm and 40 percent of his liver.

“At the time of his diagnosis, my dad was told by his doctors to go home and enjoy what little time he had left,” Kate writes. “No one with cancer, not my dad, not your dad, no one should be told to go home and die, for there is nothing left to do. Help us find a cure and support those already diagnosed with this rare form of cancer.”

After John began Gleevec, the remaining tumors shrank in size and he continues on Gleevec to this day with no progression.

Many donors to Kate’s marathon campaign commented on her determination and spirit.

“You are amazing, girl!,” writes one such supporter. “Good luck! Do it for our daddies and all the others out there!”

You can visit Kate’s fundraising website at www.firstgiving.com/kateposs.

Hague runs with friendship in her heart

By Belinda Ehrlich
LRG Program Associate

In memory of her friend Bill Roth, Wendy Hague completed a half-marathon — 13.1 miles — October 4 in Portland, Maine and raised \$1,800 for the Life Raft Group.

“It was a great day, and I couldn’t have done it without the support and motivation from all of you!,” Wendy wrote in a letter to her family and friends.

As a runner, Wendy thought a marathon was the perfect way to honor Bill’s memory.

“Bill Roth was a friend of mine for a long time,” she said. “He kept me motivated in spirit during my run.”

Bill’s son-in-law, Jerry Cudzil, is President of the LRG Board of Directors. Bill battled GIST for more than five years and passed away October 15, 2008 (You can read an article about Bill’s life



HAGUE

at www.liferaftgroup.org/in_memoriam/roth.html and see pictures of Bill & Jerry in the article on page 4).

Wendy had worked with Bill in New York more than 15 years ago, but the

two kept in touch after her move to Maine. She was always glad to see him at a trade show each year.

“It was a long friendship,” Wendy said. “He was a really nice man with a wonderful family. It was very hard this year not to see him.”

Wendy was thrilled that her fundraising efforts could benefit research through LRG. She said the LRG website was extremely helpful in educating her supporters about GIST.

“Not a lot of people know about GIST,” she said. “I notified all my friends and family and described all the good work the Life Raft Group does.”

Wendy hopes her fundraising efforts will encourage others to do the same.

“There are things out there a lot bigger than yourself,” she said. “It’s always good to pay it forward. Even small deeds go a long way.”



Hamilton lived his life serving others

Our loving husband, father, grandfather, brother and uncle, Joseph Glenn Hamilton, born March 29, 1949, in Mobile, AL, passed away October 4, 2009, after a long and tough battle with GIST, a rare form of cancer. He retired from the U.S. Marine Corps in 1993 after 26 years of dedicated service. He took part in the Persian Gulf War and Peacekeeping mission in Somalia. After his retirement, he joined American Red Cross San Diego/Imperial Counties Chapter as a Program



continued to serve the military community for seven years. He loved to travel, go to the Padres games, and to play golf with his friends. He was Secretary of the Board of Southern California Mexican American Golf Association (S.C.M.A.G.A.) and President of S.C.M.A.G.A. Carlsbad Chapter. He enjoyed taking part in planning the association's annual golf tournament. He will be greatly missed by family, friends, and



countless others whose lives were touched by him. He is survived by his wife, Takako; daughter and son-in-law, Lisa and Fabien Savary; son, Chris; grandchildren, Kylian and Jayna; brother, James; sister, Betty; three nephews and four nieces. In lieu of flowers, it is suggested that donations be made to: The Life Raft Group, 40 Galesi Drive, Wayne, N.J. 07470 www.liferaftgroup.org

The LRG chooses to celebrate the lives of the friends we have lost and maintains an "In Memoriam" list on our website: (www.liferaftgroup.org/in_memoriam/index.html).



American Red Cross

Services Coordinator and

GISTORY

From Page 5

GISTORY correctly recorded. Remember that this tool is useful only if you keep it up to date by providing us medical updates.

To provide us with corrected and/or new information about your medical history, contact us at: email at liferaft@liferaftgroup.org, fax at 973-837-9095, call at 973-835-9092, or go online at www.liferaftgroup.org/members_medical_update.php.

How do I get a copy?

If you joined our Patient Registry and keep current contact information, you should be receiving it by email every month when your next update is due.

If you would like to get more information or join our patient registry, please call us at 973-837-9092 or join online at www.liferaftgroup.org.

We hope to provide better support and accessibility to help manage your medical records for GIST. We are currently working on online access on demand to your own medical record.

ADJUVANT

From Page 6

What's new?

Novartis has initiated a new adjuvant phase II trial: imatinib in patients who have had complete surgical removal of their GIST. Novartis plans to recruit 130 patients at over 30 sites in the United States for a five-year study of imatinib without a placebo comparison. The trial started recruiting in July, and twelve sites are currently open. Patients will receive 400 mg of imatinib daily and followed for the first five years of the study. At the end of treatment patients will be followed for another five years. Plans are to recruit patients up to December 2010.

Who should consider

Patients who have had tumors larger than two cm and with mitotic counts equal to or greater than five per 50 High Power Fields (HPF) will be eligible. Non-gastric tumors must be greater than five cm. Mitotic Index criteria for non-gastric are not given but appear to include both less than five and greater than five mitoses per HPF. By definition

these patients are at significant risk for recurrence. Patients must have a histological diagnosis of primary GIST. Tumors removed must test positive for KIT (CD117). All tumors must have been completely removed at the time of surgery (i.e. no metastatic disease on post surgery scans). Patients must enter the trial within 12 weeks of primary tumor surgery. Prior use of imatinib is restricted, and other prior therapies are excluded. There are additional criteria in the detailed PubMed listing under NCT00867113.

Novartis also has a new online form to see if you qualify at www.novartisclinicaltrials.com. Select GIST from the conditions list and then select this trial.

Questions to ask

This description for trial does not specify whether patients will receive primary mutational analysis as part of the trial. It would be advisable to have mutation analysis done as part of the initial diagnosis process before considering this trial. Patients who are wild type, exon 9, or PDGFRA mutation D842V do not always get optimal response to imatinib 400 mg daily. As always, you should consult your oncologist when considering a clinical trial.

Father, grandpa & friend says goodbye

Herbert Dewayne Moses, age 54, of Corbin, Ky. passed away on Friday, Oct. 9, 2009, at Baptist Regional Medical Center in Corbin. He is survived by his wife, Diane Moses; parents, Elmer and Flora Lee Moses; three daughters, Jessica Moses and her fiancé Donnie Allen, Olivia Moses and fiancé Tyler Troglin, and Jennifer Bryant and husband Travis; brother, Jeff Moses; two sisters, Judy Price and husband Chris, and Deb Kersey and husband Carl; his expectant grandson, Donovan Dewayne Allen; and by several nieces, nephews, cousins, family, and friends who will mourn his passing.

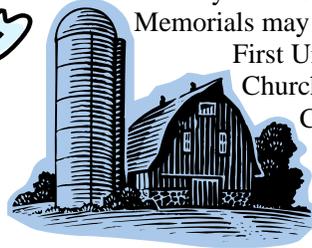
Messages of condolence may be written to the family by logging on to vankirkgrisellfuneralhome.com.



Cherished mother & farm girl passes away

Neva Hatten Hageman, passed away Wednesday (08/12/09) at The Ambassador in Nebraska City. She was born to George and Ruth (Kempf) Calkins, at home on the family farm, Northwest of McCook, in Hayes County.

Those left to cherish Neva's memory include sons, Michael Hatten, West Des Moines, Iowa; and Gregg Hatten, Bonita Springs, Fla.; step-daughters, Debra Concannon, Shawnee, Kan.; Sharon Reddy, Albuquerque, N.M.; six grandchildren; four great grandchildren; several nieces and nephews; other family and many friends.

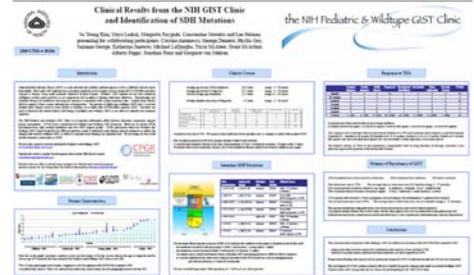


Memorials may be given to the First United Methodist Church, American Cancer Society or Nebraska City Volunteer Fire Dept.

LRG in the News: Poster & Abstracts, oh my!



The LRG keeps popping up in the science community. Recently, the National Institutes of Health (NIH) as part of the Consortium for Pediatric & GIST Research (of which, LRG is a part) submitted a poster from the NIH Pediatric GIST & Wildtype Clinic with Tricia McAleer, Program Director of the LRG listed as one of its authors. Congrats, Trish!



Go to the Pediatric Library at www.pediatricgist.org to see the full poster.

The LRG also received great news when we learned our paper, "Evaluation of Self-Reported Progression and Correlation of Imatinib Dose to Survival in Patients with Metastatic Gastrointestinal Stromal Tumors: An Open Cohort Study" has been published in the *Journal of Gastrointestinal Cancer*. You can go to [www.ncbi.nlm.nih.gov/pubmed/19946763?log\\$=activity](http://www.ncbi.nlm.nih.gov/pubmed/19946763?log$=activity) to read the full article.

Cross-continental fun at the LRG office!

Estelle Lecointe, French cancer advocacy poster girl, founder of Ensemble Contre le GIST, and all-around pretty groovy person stopped by LRG headquarters in October and had a fun day seeing the New York sites with Trish and then enjoying (a shockingly large) dinner with Trish, Norman & Erin. It was widely speculated in the LRG offices that she left New Jersey just a little bit cooler than when she came.



Did you Know?

The Holidays are here! Why don't you get your holiday shopping done and support the LRG? Go to www.goodsearch.com/goodshop.aspx and type the **Life Raft Group**. Then start shopping! You can also support the LRG just by searching the internet. Go to www.goodsearch.com and type in the **Life Raft Group**. Click verify and you're done; every search you do through Goodsearch (powered by Yahoo) will donate money to your cause. Dr. Brian J. Druker, whose research led to the development of Gleevec, has been the prestigious Lasker-DeBakey Award, regarded by many to be the America Nobel Prize. Go to www.nytimes.com/2009/11/03/science/03conv.html?_r=1 to read an interview with Druker on this topic.

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