

A wrinkle in time: GIST marked a new beginning for LRG member

By Daniela Jorge
LRG Program Associate

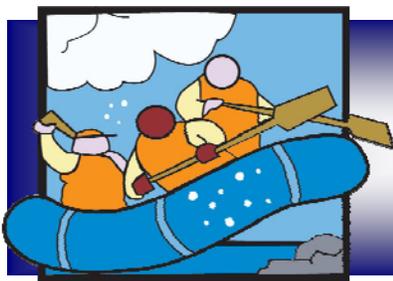
At my first glance of Anita Getler, I saw an elegant and petite woman walking toward me, shining her radiant smile in my direction. Within the first couple words we exchanged, the tone of the evening became lighter and more casual, as if we had been friends all our



Getler and her "radiant smile".

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Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

December 2010 In memory of Jay Hepner, Michael Aldridge, Linda Hampson, Vol 11, No. 4
Bill Buchanan, Jan De Kort & Lois Bond

Adjuvant Gleevec: To take or not to take?

Recent reports from trials may help in GIST patients' decisions about whether to take adjuvant Gleevec

By Jerry Call
LRG Science Coordinator



To take adjuvant Gleevec or not take adjuvant Gleevec; this is one of the most common questions that GIST patients ask. Adju-

Adjuvant therapy refers to additional treatment given after a main mode of therapy (the main treatment is usually surgery). For example: Gleevec given after surgery in hopes of preventing or delaying a recurrence is called **adjuvant Gleevec**.

vant Gleevec was approved by the Food & Drug Administration (FDA) for GIST in the United States in late 2008 with almost no restrictions. A few months later, it was approved by the European Commission (EC). Both of these approv-

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Cards, chips and laughter abound at 7th Annual LRG Poker Tournament

By Jennie Kim
LRG Program Associate

On November 18, the Life Raft Group's Board President Jerry Cudzil hosted this year's Seventh Annual Life Raft Group Poker

Tournament at the Midtown Loft in New York City. With over seventy-five guests and ninety-five players, the

evening was both sensational and incredibly successful, thanks to all the supporters who competed with each other to play a significant role in finding a cure.

The annual tournament launched in



Jerry & Lori Roth Cudzil

2004 by Cudzil and has become the organization's most anticipated event of the year. Jerry's father-in-law, Bill Roth was diagnosed with GIST in 2003 and battled it with immense strength and determination for five years before passing in October 2008 (You can read an article about Bill's life at www.liferaftgroup.org/In_memoriam/roth.html).

Undeterred, Bill's fight continues through Jerry, whose commitment to the Life Raft Group has helped to achieve tremendous milestones to find a cure for GIST.

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It's your life, shouldn't it stay in your hands?

By Erin Kristoff
LRG Newsletter Editor

This December, I will have been working with cancer patients for six years at the Life Raft Group. I have held their hands in hospital beds, coached them on how to talk with their doctors, stood by their side at the weddings of friends, walked with them through haunted houses and comforted their loved ones when they had nothing left.

I have had the privilege to meet and work for patients who have responded well to treatment; who have the good fortune to be able to treat life as a gift and go on living with the knowledge that each day is precious, and those for whom treatments come and go, never offering the relief they pledge for long; for them, hope can be both a distant illusion and their best and only friend.

I have had the blessing of working with both kinds of patients and would

not trade one second of my life, no matter how much personal pain it may have brought me.

Because of this, I have a unique perspective, shared by few, on cancer and the people it affects. In February, at age 62, my father's prostate cancer recurred in his spine. With all my prior training, I made sure he had the best doctors treating him at one of the best cancer hospitals in the area, Memorial Sloan-Kettering Cancer Center in New York City.

Despite our best efforts, his cancer spread. To date, we have had to contend with two rounds of back radiation; brain surgery, back surgery & brain radiation, all within weeks of each other; chemotherapy, chest radiation and more back radiation.

We have dealt with and discussed issues I never expected to address this early in my and my father's life. I have

witnessed the severe mental strain on my family, while we each struggle to survive in our own way. Each day, I am faced with the possibility that all of this could have been avoided or perhaps delayed had my father received proper treatment earlier on.

His original doctor was very aware of how serious his

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
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 of any errors.



Bill & Julie Kristoff on their wedding day.



Lindsey, Erin, Bill & Julie Kristoff at Julie's 60th Birthday party, less than a week after Bill's brain surgery.

cancer was when he had his first surgery and he should have immediately begun hormone treatments, but he didn't. He waited.

My father was not aware of how serious things had gotten for him until they had gotten too serious to contain.

While I cannot blame anyone for what my father's cancer has done, had he received proper treatment early on, we may not have had to face these issues this early, if at all.

During this time, and especially in light of this six year mark, I have had cause to look back and reflect on the patients and professionals I have met over the six years I have worked for the

One random act of kindness is sometimes all you need

By **Janeen Ryan**
LRG Member

Introduction by **Jennie Kim**
LRG Program Associate

In this day in age, when charitable giving is a rare thing to see during this economic strain, Janeen Ryan candidly documents her experience in which lives were transformed by a single simple yet meaningful act of kindness. Her story is one of few that epitomizes the holiday season's gift of giving and proves that when good things happen to good people, goodness is kept alive and is inevitably reciprocated and shared.

"I did have a really wonderful, heartfelt thing happen a few days ago and I would like to share it with y'all as it is proof once again that living angels walk among us.

Today has been a heavenly day but it didn't start out that way.

We began with a late start to my doctor's appointment - Larry has an odd sense of time and jumping in the shower ten minutes before we have to leave seems like a good idea to him. NOT! I

made up some time on the road so all was well when we arrived.

"After, we decided to go to get our licenses and oh, wait, I have to tell you that last night while cruising the internet I saw a KIA dealership advertising a car



Janeen & Larry Ryan

salesman position. It was right up my alley so I figured, why not? I talked to God and told him if this was the right thing then please have 'em call me in the morning. Well, while driving to the DMV I got a call. It was

Jim from KIA, we talked and he was impressed with my background so he wanted to see me the next day after I got my Massachusetts license.

"So we got to the DMV, they wanted proof of residency, and we gave them the electric notice we were sent (not a bill). The girl told us it HAD to be a bill but I didn't have a bill yet. So they went to go get the manager but there was no manager to be found. We waited and waited

and finally, the manager showed up! She looked at our documents: one was from the post office, but only our last name was on it, but she approved and signed it. Yippee!

"As an afterthought I asked her how much the license was and she said \$100.00 each. Oh no, oh no - here came the tears. I knew we didn't have that. I looked at her and thanked her for her time but we didn't have \$200.00! Maybe payday?

"I was really embarrassed. I was crying and babbling and backing away - I just wanted to get out of there, I wanted a hole to crawl into. I was still gathering my stuff and backing away from the counter apologizing and she said, "Wait! Stay right there, just wait." I was standing there feeling like a fool, thinking we should have asked about this right off the bat. A hundred dollars for a license? Oh my goodness, right? Wow.

"I felt something tugging me on my left side and I heard a voice say "Oh my, what's that in your pocket?" I looked over and she was walking away from me. I reached down and put my hand in my pocket and pull out two fifty dollar bills. Can you believe that? This DMV angel gave me \$100.00 so I could get my license and get a job. I was speechless. I couldn't even talk - nothing. Larry was still filling out his paperwork, and I was standing there shocked, staring at the money.

"Who knew God put angels at the DMV? I'll tell you what. I'm going to get that job and with my first paycheck and I'm going to send her a HUGE bunch of flowers or a cookie bouquet or something, oh, and one of my homemade necklaces, plus of course the \$100 back. Even better was the effect this had on Larry when I told him about everything. He had lost faith in humanity to an extent and this really helped to restore it.

WEBSITE OF WORTH

Are you a woman with cancer? Do you ever feel overwhelmed by or unable to complete your household duties?

The Cleaning for a Reason Foundation is a non-profit organization committed to easing the lives of women undergoing treatment for cancer by recruiting local professional housecleaning and maid services to clean the patients' homes.

The program has been rapidly growing

since its inception in 2005 and continues to reach and cover major markets across the nation. Cancer patients can register for the free service online at no cost, where Cleaning for a Reason will then connect the applicant with a local service partner to provide the free cleaning service. For more information, please subscribe to receive the foundation's news and updates or visit the website at

www.cleaningforareason.org.



We Focus On Your Home So You Can Focus On Your Health™



Do you have an interesting story you want to share? Email it to us at liferaft@liferaftgroup.org and you just might see it in the next LRG newsletter!

The giving has begun: LRG's annual holiday campaign is off to a great start

By Toni Bodrato
LRG Development Associate

The Life Raft Group's Annual Holiday Giving Campaign has been kicked off to a great start! This comes as no surprise to the LRG; our close knit group of GIST patients, families and friends are amazing people.

This year we have asked GIST survivors and families to send out note cards, letters and emails asking their friends and family for their support.

Donations to the LRG helps to support our research project, "Pathway to a Cure." We have opted, with your support, to fund the top GIST scientists in the world and focus directly on areas that are crucial to finding a cure.

Fundraising materials for this year's holiday campaign should have arrived, please let us know if you have not received yours or need more supplies. Please email us at liferaft@liferaftgroup.org or call us at (973) 837-9092 if you have any questions or comments. For information on Pathway to a Cure and our programs go to www.liferaftgroup.org

Donations this year may also support our programs. The Life Raft Group provides support, information and assistance to patients and families with this rare cancer to help keep them alive until there is a cure. The LRG achieves this by providing an online community for patients and caregivers, supporting local in-person meetings, patient education through pamphlets, monthly newsletters, webcasts, and one-on-one patient consultations.

One of the easiest and fastest ways to help support the LRG is through FirstGiving. This website allows you to create a custom fundraising page, where all donations go towards the cause of your choice.

Visit www.firstgiving.org to begin. In the donation box please search Life Raft Group; this will bring you to our page. From here simply follow the step by step instructions to create a personalized fundraising page to share with family and friends.

These few simple steps will help you



[Home](#) | [Who we are](#)

Mandy Paul's Fundraising Page

Page Creator: Mandy Paul
Event: Mandy Paul's Fundraising Page

Fundraising target: \$55,000.00
Total raised so far: \$120.00

Give now >

I want to raise money too

Spread the Word

My personal message:

Thank you for visiting my fundraising page!

As most of you know I have a very rare form of cancer. Since it is rare, fundraising and help from pharmaceutical companies is hard to get. I know many of you are generous givers every year to great organizations so please consider a donation to this organization.

This organization has hired doctors from around the world with strict guide lines to produce results quickly to help find a cure for GIST because time is of the essence. For many people this cancer comes back with a vengeance in just a few years.

Donating through this website is simple, fast and totally secure. It is also the most efficient way to support my fundraising efforts. And a great end of the year tax write off.

Many thanks for your support -- and don't forget to forward this to anyone who you think might want to donate too!

LOVE,
Mandy and Brian

Display Name	Date	Amount	Comment
Custom Home Innovations	11/22/2010	\$50.00	Cough it up kids. Its a good cause.
Hylie and Janelle Winders	11/22/2010	\$50.00	
Latte Factor: 1 week of coffee money	11/22/2010	\$20.00	For a cure...for life.

Give now >

Fill your page
Add images, your story, videos, tags, and more.

Verify Secure

If you find anything on this page offensive, please report it to us in confidence by clicking here

*Transaction fees apply to this amount.

Total raised online: \$120.00
Amount raised offline: \$0.00
Grand Total: \$120.00

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to spread the word about GIST and the Life Raft Group.

We won't just wait for a cure. We have to make it happen. Join us in the fight against GIST.

No guilt for charitable giving through iGive and Goodshop

By Jennie Kim
LRG Program Associate

This holiday season, ditch the guilt of spending and make a purchase that combines the good feelings of giving and charitable giving by shopping online through iGive.com and Goodshop.com. With partnerships from over 1,500 popular stores on both networks, funds from iGive and Goodshop

allow The Life Raft Group to continue to search for a cure for GIST.

All purchases trigger a donation towards non-profit organizations like the Life Raft Group. Remember to take note

of each site's unique features such as registration. On iGive, you must register with a username whereas on Goodshop, no personal information is needed – just enter the cause you would like to support.

Also, searching the web through goodsearch.com and isearch.igive.com, which are both powered by Yahoo, raises money for the Life Raft Group. Happy holidays and enjoy the gift of charitable giving!



Colombians gather for first time as a formal organization

By Rafael Becerra

Fundación GIST Colombia
Co-Founder

On Saturday October 23, the first regional meeting of Colombian GIST patients was held in the city of Bogotá and sponsored by Novartis-Colombia.

With the participation of 20 delegates, the attendees were instructed on the objectives of the Fundación GIST Colombia (FGC) including its mission, vision, and its alliance with Life Raft Group for its work in education, support to the GISTers of Colombia and their caregivers.

We emphasized the importance of be-



Bogota was the location for Fundacion GIST Colombia's first meeting.

longing to Alianza GIST. We delivered material about GIST survival, a break-

down of mutational testing, the Life Raft Group Collaborative GIST Tissue Bank initiative, and the first newsletter edition of the Spanish newsletter "La Voz de GIST".

The establishment of personal contact with patients is very gratifying, and we all shared our concerns, doubts and fears. Meeting our brothers and sisters living with GIST is an awakening, to know that we are not alone and that each passing day we are closer to the final cure.



The Latin American GIST Initiative now has a name...and a logo!
Alianza GIST is a partnership of patient advocates representing ten Latin American countries and aims to improve the knowledge of patients and physicians, as well as increase treatment access, support local patient organizations, and encourage collaboration and coordination amongst physicians.

Skydive for GIST is a success!

"The skydive was awesome!" says Stacey McAully. On October 24, Stacey, her sister, Sammy, and their best friend, Gemma Day skydived to raise money for The Sarcoma Trust, a UK charity which funds research into soft tissue cancers such as GISTs.

To date, the girls have raised nearly £4,000!

"Team GIST North (her nickname for the Northern UK GISTers) kicked cancers butt with a skydive in sunny Scotland!"

You can still visit Stacey's page to donate or check for updates at www.firstgiving.com/stacey-mcaully



Sammy McAully, Gemma Day & Stacey McAully proudly show off their certificates.



They're really going to do it...



...And off they go!

Safford brings together champagne, strawberries and a concert pianist for unforgettable Valentine's fundraiser

By **Tricia McAleer**
LRG Program Director

Life Rafter and GIST survivor David Safford is hosting a benefit concert on Valentine's Day to raise funds and awareness for the LRG's research project Pathway to a Cure. After being diagnosed with GIST, Dave quickly sought out information about his cancer leading him to the LRG. Shortly thereafter, he became intrigued with the LRG's research, was invited to join the board of directors and eagerly accepted.

With the help of renowned concert pianist Anthony Padilla and friends at Columbia Basin College Foundation, Dave plans to entertain guests with an evening of musical splendor. "Dave is a personal friend of mine and I am so



PADILLA

happy to support the work of the Life Raft Group and I'm very excited to help raise money to find a cure for GIST," said Padilla. Anthony Padilla, recognized internationally as a pianist of remarkable sensitivity, refined interpretation, and dazzling technique, made his debut with the Seattle Symphony at the age of sixteen. Mr. Padilla has been performing extensively ever since, as guest artist with orchestras and at concert series throughout the world. Some of his performance highlights include New York's Merkin Con-

cert Hall, the La Jolla Chamber Music Society, the Ravinia Festival, Chautauqua, Schleswig-Holstein, Holzhausen, Victoria, Sarasota, Cascade, the Bay View and San Luis Obispo Mozart Festivals, and solo and collaborative appearances throughout the United States, Germany, Italy, and China.

The event will be held at the Columbia Basin College in Pasco, Wash. on Monday, February 14th, 2011 beginning with a Champagne and Strawberry Reception in Esvelt Gallery at 7:00pm following by the concert in the Theatre beginning at 8:00 pm.

Individual tickets will be available for \$50 and there are sponsorship opportunities available. For additional information about the event or tickets, please contact: Nancy Adams, 509-542-4721 or nadams@columbiabasin.edu.

Impressive 7th meeting of the Swiss GIST group

By **Helga Meier Schnorf**
Groupe GIST Suisse

On April 23, 2010, ninety GIST patients, relatives, GIST experts, and representatives of the pharmaceutical industry attended the Seventh meeting of the Swiss GIST group.

Special guests included Anna Costato from Italy, Bertrand de la Comble from France and Candy Heberlein, President of the Swiss Foundation for the Promotion of Bone Marrow Transplantation. Representatives of Bayer Schweiz AG, Bristol-Myers Squibb SA, Novartis Pharma Schweiz AG and Pfizer AG were also present.



Martin Wettstein, President

As always, it was a unique opportunity for the participants to hear the latest findings about gastrointestinal stromal tumors and their treatment, as well as to meet and discuss directly with the experts. Markus Wartenberg of Das Lebenshaus in Germany excelled as the moderator and the presentations impressed both the participants and the organizers. Simultaneous German/French or French/German interpretation was provided throughout the event.

2010 Topics

Dr. Michael Montemurro, consultant at the Centre Hospitalier Universtaire Vaudois (CHUV) in Lausanne and medical advisor to the Swiss GIST group, gave an

extremely clear lead presentation entitled "GIST 2010: What are the Norms of Today? Which Answers Are We Still Missing?" Markus Wartenberg spoke confidently on GIST and its progression, and Amina Haouala, pharmacist at CHUV, explained the interactions of tyrosine kinase inhibitors with cardiovascular medications.

A very different approach to coping with difficult situations was taken by Dr. Oswald Oelz, mountaineer and former senior consultant at the Triemli Hospital in Zurich. In his thrilling and entertaining presentation entitled "Living and Surviving at the Limit," he drew analogies between extreme conditions in the mountains and stressful situations in the lives of patients with cancer. Monica Fliedner, an oncology nursing manager at the Inselspital in Bern, covered a current topic that excited a great deal of interest, "Compliance: Why is it so difficult to take tablets regularly? What are

ADJUVANT

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The Z9001 trial was a randomized phase III trial that recruited over 700 patients from the United States and Canada. Half of the patients received a placebo for one year and half received Gleevec for one year. This trial has a median follow-up time of 19 months.

als were based on results of the ACOSOG Z9001 phase III trial. Although the Z9001 trial is no longer recruiting patients, data from the trial continues to accumulate with longer follow-up of the patients in the trial.



CORLESS

smaller, less aggressive tumors were having surgery locally and in many cases were probably cured by the surgery. However, some cases of recurrence in “low-risk” tumors, sometimes as much as ten to 20 years after primary surgery, contributed to the reputation of GIST as an unpredictable, aggressive cancer.



DEMATTEO

In presentations at the 2010 American Society of Clinical Oncologists conference (ASCO), Dr. Ronald DeMatteo, Memorial Sloan-Kettering Cancer Center (MSKCC) and Dr. Chris Corless, Oregon Health

& Science University (OHSU), presented new data from the Z9001 adjuvant Gleevec trial. As Dr. DeMatteo noted, the presentations were geared towards answering two questions: Who should get adjuvant Gleevec and how long should they get it for? While the presentations went a long way towards answering who should get adjuvant Gleevec, there appears to be much that we do not know about how long they should get it for. Other ongoing trials may help shed more light on this question.

Who should get adjuvant Gleevec?

What’s the risk of recurrence?

Both doctors and GIST patients have developed perceptions over the years that GIST is an aggressive cancer that almost always returns. This perception was fed by early reports of the pre-Gleevec era from GIST referral centers indicating GIST as a cancer with a very high recurrence rate after surgery, poor response rate to chemotherapy and poor survival in the case of metastatic disease. We now know that these early reports were heavily influenced by referral bias; these expert centers mostly saw the most advanced cases. Patients with

A risk assessment was performed for the patients in the Z9001 trial. Patients were grouped according to their risk of recurrence according to the “AFIP-Miettinen” criteria. Perhaps the most surprising finding was that 44 percent of the patients were found to be at low risk of recurrence (see Table 1). Two years after entering the trial, only two percent of these patients had a recurrence. Not surprisingly, with this low rate of recurrence, there was no detectable difference between the placebo group and the patients that took Gleevec for a year. Although longer follow-up is needed, the early data suggests that these low-risk patients might not require Gleevec. In contrast to the low risk group, patients at moderate and high risk of recurrence clearly had a lower rate of recurrence if they took adjuvant Gleevec.

How is the risk of recurrence determined?

For the last several years there have been two commonly used criteria for estimating the risk of GIST tumors returning after surgery to remove a primary tumor. It’s important to understand that these methods estimate the risk only

for patients that do not take adjuvant Gleevec.

The first system was developed at the GIST workshop in 2002. This system uses primary tumor size and mitotic count (also called mitotic index) to estimate the risk of recurrence. This method is especially useful when the primary tumor site is unknown. The second commonly used method is the AFIP-Miettinen method. This method was de-

Table 1 – Recurrence-Free Survival by Risk Category*

2 year recurrence-free survival			
Low-Risk Tumors N=270 (44%)			
	Gleevec	98%	P=0.92
	Placebo	98%	
Moderate-Risk Tumors N=148 (24%)			
	Gleevec	98%	P=0.05
	Placebo	76%	
High-Risk Tumors N=201 (32%)			
	Gleevec	77%	P<0.0001
	Placebo	41%	
* Miettinen (Sem Diagn Pathol 2006) criteria Table adapted from 2010 GI ASCO, abstract #6 Risk assessment for tumor recurrence after surgical resection of localized primary gastrointestinal stromal tumor (GIST): North American Intergroup phase III trial ACOSOG Z9001, Blackstein et al			

veloped by Dr. Marku Miettinen and colleagues of the Armed Forces Institute of Pathology, by retrospectively analyzing several thousand cases of untreated (no Gleevec) GIST. This method adds primary tumor location to tumor size and mitotic index to determine the risk of a recurrence.

In 2009, Dr. DeMatteo and colleagues at MSKCC developed another method for determining risk of recurrence. This method is called the GIST nomogram. A

Congratulations to LRG member Kim Trout!

Kim Trout, a member of the Life Raft Group and Pennsylvania Local Group Coordinator, got married on May 8, 2010 surrounded by her beloved family and friends. "Don't let GIST stop you from doing what's important in your life," says Kim, who despite the hurdles she faces with GIST, lives a life that is overflowing with joy.



Congratulations Kim!

Just passed a GIST milestone? Have an announcement to make? Make it in the LRG newsletter! Email us at liferaft@liferaftgroup.org and you might see *your* name in print.



Congratulations Dr. Su Kim!

Dr. Su Young Kim, who runs the NIH's Wildtype & Pediatric GIST clinic, has been a little busy lately...welcoming a baby girl in to the world! Su & his wife, Yeanhee, greeted little Cara Kim, 8 lbs 3 oz, last month. Mother and child are doing just fine.

Congratulations Su & Yeanhee!

FDA official wants to prosecute pharma execs

This article is excerpted from a Bloomberg News story.

FDA to pharma: Review your marketing to make sure it's not breaking the rules, or else. In the second heads-up from an agency official since March, FDA Deputy Chief Eric Blumberg said yesterday that pharma execs may be criminally prosecuted for off-label marketing violations.

Big settlements with the Department of Justice aren't cutting it, Blumberg said. Take Pfizer--after settling claims that it had mismarketed the epilepsy drug Neurontin, the company promised



the government to stay in between the lines. Then came Bextra (and three other drugs). The company last year agreed to pay a record-setting \$2.3 billion to settle claims that it marketed the drugs for off-label uses. The settlement was so large in part because Pfizer was a repeat offender, prosecutors said at the time.

"It's clear we're not getting the job done with large, monetary settlements," Blumberg told a conference audience. "Unless the government shows more resolve to criminally charge individuals at all levels in the company, we cannot expect to make progress in deterring off-label promotion." For its part, Pfizer says it has made institutional changes designed to

make sure the whole company follows the rules.

Blumberg's comments follow FDA Commissioner Margaret Hamburg's promise that her agency would go after individual executives for marketing infractions. In a letter to Sen. Charles Grassley, whose Finance Committee has dogged the pharma industry over the last several years, Hamburg said FDA would charge company execs with misdemeanor violations of the Food, Drug and Cosmetic Act, but that hasn't happened yet.

You can read the Bloomberg story at <http://www.bloomberg.com/news/2010-10-14/drugmaker-executives-may-become-targets-of-fda-for-off-label-promotions.html>

EU Cancer Patients Concerns Heard: Cancer Patient Mobility Moves Closer to a Reality

The following article was taken from a European Cancer Patient Coalition press release.

A "yes" vote in the European Parliament's public health committee today has paved the way for cancer patients to get medical treatment anywhere in European Union.

The draft directive aims at clarifying and strengthening the rights of patients who have to seek treatment in another Member State.

Tom Hudson, ECPC President stated "We very much welcome today's vote which sends a strong signal to all Member States of a future system that would put cancer patient's needs at the center and allow them to access treatment abroad when necessary. ECPC will support the proposal which ensures our key concerns are highlighted when the vote takes place in January 2011."

There were 227 amendments to the plan, and six consolidated amendments,

but handshakes were made over the following three points:

- Patients can seek medical care in another country without prior authorization. However, for hospital stays and specialized care, patients could need pre-authorization from their national health system.
- A country could only refuse to authorize cross-border care in a very limited number of circumstances. Prior authorization systems should rely on clear and transparent criteria so as not to hamper the steps taken by patients who need to resort to healthcare treatments in another Member state
- Europeans rare cancer patients would be covered under the proposed law.

One of the key points of the ECPC's position, reflected in today's vote, was to ensure an adequate codification of the existing ECJ case law in order to avoid



any new legal uncertainty or loopholes for cancer patients, while maintaining the financial and organizational sustainability of national healthcare systems that treat cancer patients in their own Member States.

While cancer patients don't like to be cared for far from home in another member state, should they want or need to, they should be entitled to the same rights for information, treatment and reimbursement. It was also important to include mechanisms preventing, as much as possible, patients from having to pay in advance for the costs of cross-border healthcare. Information is also a key point when each Member State will be obliged to maintain national contact points to inform patients about the availability of healthcare.

For further information please contact: Denis Horgan ECPC Head of External Affairs at +32 (0) 472 535 104, or denis.horgan@ecpc-online.org

Colorado GISTers meet!



According to Colorado Coordinator, Jerry Call, "The October Colorado meeting went very well. "There was some eating and drinking and lots of laughs in addition to a few sorrows. It seems that there is a need to be able to share feelings & thoughts with each other, but also have some laughs. Can't take everything too seriously!"

Pictured from left to right: Kim Zimmer, Chris Zimmer, Marge Morgan, Mike Morgan, Stephanie Call, Bob Bridgewater, Ann Bridgewater. (Jerry took the picture on the grounds that there are plenty of pictures of him in the LRG newsletters already)

GETLER

From Page 1

lives and this was a customary event. One of the most extraordinary human beings I have ever met, Anita Getler's humbleness changed my own personal outlook on life.

Her positive attitude didn't change when she was diagnosed with cancer; instead it became a path to a new outlook on life. In February of 2006, doctors discovered a five pound GIST tumor after complaints of tiredness and a painful backache. By March of 2006, Anita had her first and only surgery. As she was exiting the hospital for the first time, she saw a blade of grass and admired it as many would a precious jewel. Her admiration for the blade of grass grew out of the new eyes she began to see the world through. It was a moment that has always stuck with her, a beginning. As even today, Anita looks at everything as if it were the first time, but without naivety.

She draws inspiration from her two

daughters, granddaughter and sister and shows genuine gratitude to the "magic pill", Gleevec, for the opportunity to be able to be part of their growth and to see them develop and embrace the different roles they will take on in life.

Anita works full-time as a receptionist in a botanical company that assists in microbiological research. In her free time she enjoys playing tennis, visiting with her daughters and granddaughter, practicing yoga (which she says helps with scanxiety, the common anxiety a patient might come to feel before going for a scan or awaiting the results), dancing and riding motorcycles.

It was a truly uplifting experience meeting Anita Getler. Her raw happiness is contagious and her motivation is fueled by the desire to continue experiencing life independently and happily, which deserves glorification and praise.

Beloved mother, Hampson passes away at age 61

Linda (nee Willert) - January 19, 1949 - October 10, 2010 (Retired from BMO, **Life Raft member**) died peacefully in her sleep on Sunday. Loving Mother of Megan Keith (John), Gran of Bronwyn and Darwin, Sister of Ken (Karen) and Larry (Triona).

Linda was one of the first members of the Canadian group. She attended several Life Fest meetings and was a founding Director of the Canadian group when incorporated in 2008.

Founding member of Life Raft Group Canada, David Josephy recalls, "[Coming back from Life Fest 2008 in a flood] we kept one another's spirits up as we tried one road after another... Linda kept her humor and perspective through that incident as she did through so many others.

Donations to Life Raft Group in lieu of flowers will be greatly appreciated.



POKER

From Page 1

The doors opened at six o'clock, where in a matter of minutes, the room quickly buzzed with eager conversations between friends, colleagues, and competitors. With the help of the Long Island Poker & Casino, the tournament began shortly after Jerry welcomed all guests and introduced Norman Scherzer, the Executive Director of Life Raft Group.

As the night progressed, the number of players decreased as each round became increasingly more competitive than the previous. Chips and cards flew around as laughter and disappointed shouts scattered throughout the room. Amongst the last remaining players was Joe Bonavita, who was the first place winner for the last two consecutive years. However hopeful, Bonavita gracefully bowed out with four players remaining.

Finally, the game had come to an unforgettable end with Cayetano Lacroze as a first-time first place winner, who took away the grand prize – a \$10,000 seat in the World Series of Poker Main Event in Las Vegas, Nevada. The second and third place winners Henji Cheung and Jonathan Rosee did not walk away empty-handed, but each with the highly coveted Apple iPads.

Raffle tickets were also sold through-



The Poker Tournament was held at the fabulous Midtown Loft for the third year in a row.



The 2010 LRG Poker Tournament winners. From left to right: Henji Cheung (2nd Place), Cayetano Lacroze (1st place) & Jonathan Rosee (3rd place). Cheung & Rosee won Apple iPads, while Lacroze won a seat at the World Series of Poker.

out the night, where eight lucky individuals won one strategic blackjack class and six individuals a 21-hour poker course, both held at and donated by the School of Cards, a professional poker school in New York. Thanks to Robert Scherzer, two Yankee tickets were also raffled off to one attendee, and a dinner for four at The Palm, one of New York City's most revered fine dining restaurants, by LRG supporter Nick Chiara.

"What a night, people were great, friendly vibe, great location – fantastic! You guys take a bow!" exclaimed Mark Green.

The tournament not only raised an astounding \$100,000 by the end of the evening, but also offered unique exposure and presented the profile of the Life Raft Group's work to those who attended. Although most participants did not have cards dealt to their favor, in this evening dedicated to

finding a cure, everyone walked away a winner.

A very special thanks must go to Kim Tallau of Innovative Images for once again donating her talent and time photographing the event. For updates and photos from the event, please check out www.facebook.com/lrgpoker tournament. Pictures should be posted soon.

The Life Raft Group is expectant and enthusiastic for the progress to come in the upcoming year and cannot wait to see everyone again at the 2011 annual poker tournament!

Have you ever thought about hosting a fundraiser of your own but you're not sure how to go about it? Just email or call us at liferaft@liferaftgroup.org or (973) 837-9092 and we can help you out!

Only one phrase could suit him, Hepner was one hell of a guy

By Erin Kristoff
LRG Newsletter Editor

He was Jumping Jack Flash. He was “Mick Swagger”. Wearing his mother’s purple leotard and tights (She was 5’5”, while he was 6’3”) and an aluminum foil lightning bolt pinned to the front, he was like a rock god.

This was the same man who spent 22 years teaching at Watkins Mill High School. The same man who coached forensics and debate for “It’s Academic”, a show similar to a college bowl.

This was also the man who played for an adult kickball league and once tried out for Saturday Night Live. His name was Jay Hepner and he was unlike anyone you’d ever met.

“He was unique,” says his sister, Shoshana Brounstein, “He marched to the beat of a different drummer.

Hepner had a zest for life and wanted to try it all, “He didn’t care about money,” recalls Shoshana, “He just wanted to live.”

Hepner *really* didn’t care about the money. A Rockville, Maryland native, he graduated from the University of Iowa and quickly got started on his life, specifically spending a few years hitch-

hiking across the country.

“He would get on a bus, subway or in a car and strike up conversations with people. But he would always come back home just before football season to watch the Redskins,” laughs Shoshana.

Jay always wanted to learn new things and people interested him, in turn, he captivated people.

“A producer [of one of the shows he worked on] said she would stop what she was doing and just watch what he was doing with kids.”

His students were equally as mesmerized, many keeping in touch long after they graduated.

Jay was also a born entertainer; besides his alter ego, Swagger, he could be found singing his own original music, like “Twinkies” and “Beer for Breakfast”.

Jay’s passion and love of life aided him when times grew hard. He was diag-



Jay and his 13 year-old daughter, Shayna.

nosed with GIST in late 2007, the same year his father died. This burden weighed heavily on Jay and he set out to learn everything he could about GIST. After a lot of research, some time on Gleeevec and four surgeries, Jay’s aggressive cancer got the best of him.

But he never stopped fighting, just 48 hours after meeting with his medical team at Johns

Hopkins about receiving Sutent, Jay quietly passed away on September 26, 2010, with his brother, girlfriend and long-time friend by his side. He was 53 years old.

Besides Shoshana, Jay left behind a daughter, Shayna Mechia; mother, Rita; brother, Allen; a loving companion, Barbara Reed Martin and nieces and nephews.

But Jay is not gone, not to Shoshana, “I learned a lot about my brother after he died.”

One thing she learned is that Jay’s voice could be heard on one of the D.C.-area’s double decker buses.

“I just need to find out which one!”

Teacher, coach, husband, father and friend, Buchanan did it all

William S. Buchanan, age 51, in Evanston, Illinois. Beloved husband of Maureen Ruder and devoted father of Nolan, Aaron, and Kyle Buchanan. Cherished brother of Alexandra (Sandy) Buchanan (William Whitney) and son of the late Rita and Stuart. Adored uncle of Elizabeth Bennets and Thomas and Robert Whitney. Dear brother-in-law of Celine Bennets and Colleen Wyse (Stephen Klasko). Son-in-law of Ge-



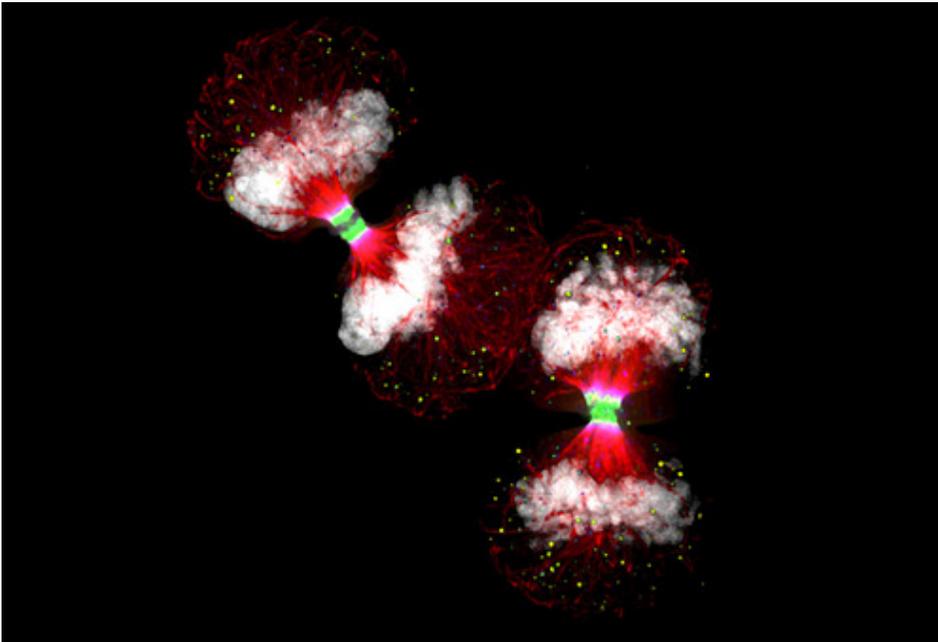
Buchanan at Life Fest 2010.

rald and Lucille Ruder. Bill will be missed dearly by a host of friends and family from throughout his wonderful life. Bill completed his undergraduate and graduate degrees at Northwestern University and served in the Illinois National Guard. A high school math and special education teacher, a baseball coach and fluent in Spanish, Bill

worked for the Chicago Board of Education for 24 years, teaching at Farragut and Foreman High Schools. He then earned his National Board for Professional Teaching Standards in Mathematics and became an Academic Coach for other math teachers throughout Chicago. Bill’s life modeled his conviction that no good person be left out or left behind. He held a firm commitment to public education and his compassion touched the lives of thousands of students. Bill Buchanan’s serious regard for his students’ futures made him highly respected by colleagues and students alike.



Have you ever thought about what your cancer looks like?



Two human cancer cells seen just before they divide into four cells, viewed at 100x magnification. From the Nikon International Small World Photomicrography Competition.

Michigan GISTers meet up!

Ellen Rosenthal, Michigan Local Group Coordinator, had this to say about their latest local group meeting, "In attendance at the September 23 Michigan LRG meeting were Abbas and Zahrina Patni, Lynne Newman, Jim Martin, Helen Snyder and her son John and myself. We welcomed new members Susan Brandt and Mandy Paul. We also discussed where we all were in our GIST journeys and shared information with Susan and Mandy. I recounted my experiences at Life Fest and encouraged contributions for our promising research."  If you're interested in attending a future meeting, email Ellen at ebrosenthal@comcast.net for details. If you're interested in contributing to the LRG Research Team, go to www.liferaftgroup.org/donate.html.

BEST EFFORTS

From Page 2

Life Raft Group and the nearly one year I have spent caring for my father... if I have anything left in me to give, it is the lesson that you should never be complacent with your health.

Educate yourself on the best practices, cutting-edge treatments and research out there. Make sure you are never ambivalent about a decision affecting your care. If you question it, interrogate your doctor until you are sure it is the right route for you. If you're still not sure, get a second opinion and continue to get opinions until you feel comfortable with this decision. Any doctor worth his/her salt will tell you the same thing. If you continue to feel uncomfortable, take a leap of faith...but a leap based not on words that you hear but on you **and** your doctor's best understanding of your disease.

A smart man dealing with his own health struggle recently said to me, "We wanted to be able to say at least we did

everything we could, at least we don't blame ourselves."

I want to be able to say that about myself, my coworkers and every patient I come into contact with. In the past six years, I have built a family at the LRG, but it wasn't until the struggle became personal that I realized how much I had invested in the lives of my friends here.

I have said it before— on the phone, in the newsletter, in person...take control of your own care and your own life. Leave nothing to the whim of others. I, and the LRG, will continue to stand by your side, but make sure your life stays in your hands and the hearts of those you love.

Programs and campaigns come and go, but some things stay the same: **the first and foremost mission of the LRG is to ensure the survival of GIST patients.**

If you have any questions or doubts about your care and want our opinion, please call or email us at (973) 837-9092 or liferaft@liferaftgroup.org.

If you do not see or consult with a GIST specialist, we strongly urge you to reach out to one. The GIST research world is ever-changing; GIST specialists are exposed to GIST trials, research findings and up-to-date GIST news on a daily basis. Specialists use this knowledge to make decisions about their patients' care. In the fight against GIST, it is just as important to find a well-educated (in GIST) doctor as to educate yourself.

You can search the LRG's GIST Specialist directory at www.liferaftgroup.org/gist_directory.php

SWISS

From Page 6

the tasks facing doctors, nurses, and patients in co-operating with treatment?”

The final presentation, accompanied by impressive illustrations, was given by Dr. Mark Anliker, consultant dermatologist at the Cantonal Hospital in St. Gallen, who spoke on skin reactions with tyrosine kinase inhibitors.

The attentive audience demonstrated their appreciation for all of the presentations with resounding applause, once more reflecting the high quality of this annual national event.

The first general meeting of the Swiss GIST group then followed, led by Dr. Urs Metzger. This association, to support those affected by GIST, was officially founded in Zug on January 14, 2010. Dr. Metzger thanked Martin Wettstein for carrying out the duties of president of the association and to great applause, Martin Wettstein then introduced himself at his first official function.

Himself a GIST patient, Martin is an engineer with his own consulting agency who lives in Meggen, Canton Luzern. He is married to Claudia, a chiropractor and they have three grown children. Claudia Wettstein is a great support to Martin in his work with GIST.

Martin then thanked Helga Meier Schnorf for her dedication and enthusiasm in promoting the lifework of the late

Dr. Ulrich Schnorf, which she does in her capacity as member of the board, coordinator, and secretary, and to Dr. Metzger for his work and his support for Helga Meier in founding the association. He also spoke of his appreciation for Dr. Metzger and Dr. Montemurro’s expertise and thanked them for acting as medical advisors to the association. Thanks were also given to Markus Wartenberg from Germany and to the four regional managers, Jürg Forster, Urs Notter, Herbert Blatter and Matthias Merki, for running the regional support groups, as well as to Vito Mediavilla for his help with the website.



WARTENBERG

Project 2010

GIST Prize for Switzerland and GIST Documentary Film

Dr. Metzger presented two further Swiss GIST group projects. The main project is the Swiss GIST prize for 2010:

The association supporting those affected by GIST encourages all efforts towards the optimal treatment of gastrointestinal stromal tumors. To promote such efforts, it sponsors an annual prize for particular merit. The prize is awarded to individuals or organizations in Switzerland who meet this aim. The prize may be awarded for a presentation, paper, podium discussion, scientifically or socially relevant project, etc. The prize money is 10,000 CHF (9,970.00 USD), a gift



Dr. Michael Montemurro & Helga Meier Schnorf

from Dr. Ulrich Schnorf, founder of the Swiss GIST group.

A further project is a documentary film by Gabriele Köstler. Ms Köstler is a film-producer and, as the wife of a general surgeon, has a genuine understanding for the subject.

Mark your calendars!

Look out for our Holiday Fundraising packages in the mail!



- The annual “Partnering for Cures” meeting is being held **December 14-15** in New York City.
- The NIH’s next Wildtype & Pediatric GIST Clinic is being held **January 19-20** at the NIH in Bethesda, Md.
- David Safford’s Piano Concert (Page 6) is set for **February 14** in Seattle, Wash.



From left to right: (first row) Anna Costato, Claudia Wettstein, Martin Wettstein, (second row) Jürg Forster and Dr. Urs Metzger.

Flu Shots

Cancer patients are considered high priority candidates for annual influenza immunizations and this certainly includes GIST patients. For those patients living in countries approaching winter (like the United States) this is the time to get your flu shot. In addition, you should talk to your doctor about getting pneumococcal vaccine.



ADJUVANT

From Page 7

nomogram is a slide rule type of estimator that assigns a point value for tumor size, tumor location and mitotic index. The points are then added to get an overall score that is used to estimate the risk of recurrence. One advantage of the GIST nomogram is that it estimates the risk at both the two-year and five-year mark. An online version of the nomogram has also been developed. This easy to use version only requires the user to input the tumor location, tumor size and check a box if the mitotic index was greater than or equal to five per 50 HPF. It will then estimate the probability of remaining recurrence-free for two years and five years. This risk is based on the patient **not taking Gleevec**.

CAUTION: *The MSKCC tool predicts recurrence-free survival (RFS), specifically, the chance a patient will survive without their cancer returning after receiving surgery alone. Recurrence-free survival as predicted by this tool has nothing to do with how long you are going to live.*

In addition to tumor size, tumor location and mitotic index, Dr. Corless presented new data from the

Z9001 trial that suggested patients with a KIT exon 11 deletion, especially a deletion involving codons 557-558, also had a higher risk of recurrence in the placebo group (Hazard Ratio 3.45 compared to wild-type GIST). At this time however, mutation type is not used in any the methods used to determine risk of recurrence. Tumor rupture (before or during surgery) and failure to obtain clear margins during surgery are other factors that will increase the risk of a recurrence.

Overall, a high mitotic index proved to be the greatest risk factor for recurrence for patients not taking Gleevec, with a hazard ratio of 11.3 for a mitotic rate

To use the GIST Nomogram, go to <http://www.mskcc.org/applications/nomograms/GastroIntestinal/GastroIntestinalStromalTumor.aspx>

equal to or greater than 5/50 hpf versus those with a mitotic rate below 5/50 hpf. Trial statisticians are examining whether or not a risk factor can be determined for other mitotic rates, so that risk might be related to a continuous scale rather than only above or below 5/50 hpf.

Is the patient likely to respond to Gleevec?

Mutational status has historically proven to be the best predictor of whether or not a patient will respond to Gleevec. Not surprisingly, mutational status also appears to be a powerful pre-

dictor of response to Gleevec for adjuvant treatment as well.

Dr. Corless reported that in the Z9001 trial, there was a recurrence-free survival benefit for patients taking Gleevec compared to placebo for:

- Patients with KIT exon mutations (including deletions)
- Patients with PDGFRA mutations, *except* those with a D842V mutation.

There was no detectable benefit from Gleevec for patients with:

- Wild-type GIST (p=0.61)

- Patients with a D842V mutation. It should be noted that patients with the D842V mutation (which is resistant to Gleevec and Sutent) had very few recurrences (only 1) in the placebo arm or the Gleevec arm. The unanswered question was whether these patients did not have a recurrence because they had low-risk characteristics (low mitotic rate, small tumor size, etc) or whether they did not have a recurrence in spite of high-risk characteristics.

Dr. Corless noted that more data about adjuvant treatment was needed for those with a KIT exon 9 mutation. While there were a number of early recurrences in the placebo group and none in the first year in the Gleevec group, there was no statistical differences between the two (p=0.84), with the survival curves crossing beyond the 18 month time point. A trial to examine whether or not higher levels of Gleevec for adjuvant treatment would produce better results for exon 9 patients is in the discussion stage.

Several trials testing a longer duration of Gleevec are in progress. These trials may help answer remaining questions about adjuvant therapy including the optimal duration of therapy and whether or not adjuvant Gleevec provides a survival benefit.

Mitotic index is a measure of how fast tumors are growing. Each dividing cell in the field of view of the microscope of a pathologist is counted. Ideally, the pathologist will count the number of dividing cells in 50 fields of view (called high powered fields or HPF) and this number will be recorded, e.g., 10/50 HPF.

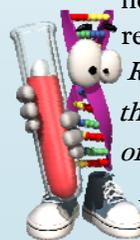
Did you Know?

If the cost of mutational testing is not covered by your insurance agency, you can have your mutational testing done for **FREE!**

You can do this by participating in the **GIST Collaborative Tissue Bank**.

The GIST Collaborative Tissue Bank is a one-of-a-kind tissue bank, where your tumor will help the world's leading GIST researchers search for the cure.

Request more information about the Tissue Bank, by contacting our office. We will send you an instructional package about the program.



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