

# Three ways to help find a cure for GIST

An Important Message from Norman Scherzer, LRG Executive Director

Many people ask the question "Isn't it depressing to work with cancer?"

While sometimes it is, we have witnessed countless joys and triumphs along the way making it all worthwhile. If my experience at the LRG has taught me anything, it is that we can't choose how long we want to live, but we can choose how we want to live.

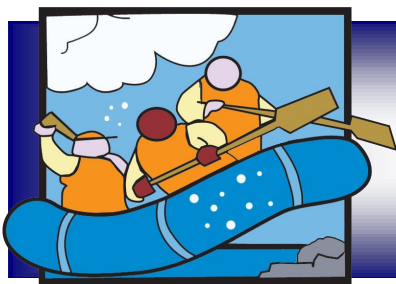
I have had the privilege of witnessing so many survivors look cancer in the face with more dignity and courage than I thought possible. This is what inspires me to work harder and push the envelope. But finding a cure for GIST is not a one-man job.

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SCHERZER

## Battling gastrointestinal stromal tumor



## LIFE RAFT GROUP

October 2011

In memory of Richard Palmer, Sandra Krizan, Stephen Walker, Deborah Reney, Jonathan Wilson, Vicky Zuber, Mervin Gangstead, Kitty Cartwright, Jonathan West & Dan Cunningham

Vol 12, No. 5

## TDM extends BLT deadline: LRG urges GISTers to take advantage

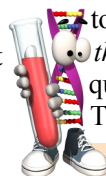
By LRG Staffers

Many of us have been lucky enough to have reached a plateau of successful treatment, and in reaching this level, we may have become complacent about our care; but it is important to be proactive to ensure that we are receiving proper treatment.

Some simple ways to stay vigilant about your care include finding the

right doctor, getting side-effects under control so that you can take your medicine regularly, and having a mutational test to identify what type of GIST you have (such as pediatric, adult, exon 11, exon 9, etc.). In addition, for Gleevec-sensitive GIST patients with manageable side-effects, *the most important thing* that you can do is to maintain adequate levels of Gleevec in your body.

The only way to know if you have



See BLT Page 11

# Aloha, our dearest friend, Richard Palmer

By Erin Kristoff  
LRG Newsletter Editor

Here in New Jersey, home to the Life Raft Group HQ, we've had a strange run of bad luck. First, there was an earthquake, quickly followed by Hurricane Irene.

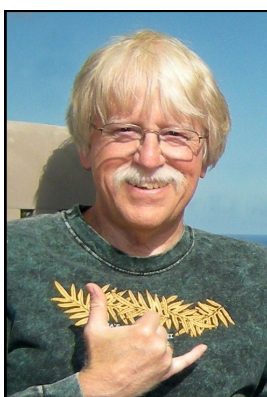
We boarded our windows, emptied our yards, stocked up on water and ice and prepared for the worst.

I, for one, was not prepared when the worst came, not in the form of property damage, but in the loss of a friend.

Like many others, I sat at my computer in the midst of a storm, deaf to the world around me. Richard Palmer was not just a member of the LRG; he was a mentor and a friend.

This is not an obituary you'll be reading because I believe that Richard will

never truly leave us. This is a celebration of his life, which lives on in the memories of his family and friends, done the



PALMER

best way I know to honor him—on paper.

Richard was a newspaper man and bounced around his home state of California writing for papers like the San Luis Obispo County-serving *Tribune & El Morro's Sun Bulletin*.

He met and married his wife, his "bride", Linda in 1976 and within three years, they had welcomed Rebecca & Matt.

But soon the surf called to him. Richard had longed to go to Hawaii since the 80s but his home and his life was in California.

"He said that the only way he would ever leave [the Sun Bulletin] was for 'more money and Hawaii,'" said longtime GISTER and fellow LRG member, Tom Overley, "Then, one day he got the call...the rest is GISTory."

Richard knew a woman who worked at the *Hawaii Tribune Herald* on the Hilo side of the Big Island and told her if ever a spot were to open up, he'd be ready. Wasn't he surprised when she called and said he could have her job? With Rebecca recently married and Matt off on his own, it was perfect timing.

"It was a courageous move," says Tom, "but Richard and Linda were courageous people."

See ALOHA Page 6

# LRG to make its mark on CTOS

**By Jerry Call**  
LRG Science Director

**T**his year's Connective Tissue Oncology Society (CTOS) conference held in Chicago on October 26-29 will not only feature presentations on GIST, but some of those presentations will be given by LRG Researchers and staff members.

CTOS is an international group of physicians and scientists with primary interest in the tumors of connective tissues including sarcomas and GISTs. The goal of the society is to advance the care of patients with these tumors and to increase knowledge of all aspects of the biology of these tumors, including basic and clinical research.

Presentations this year will include several by Life Raft Group Research Team members including:

- Long-term follow-up of patients with GIST undergoing metastasectomy in the era of Gleevec – An EORTC-STBSG collaborative analysis of prognostic factors, by Dr. Sebastian Bauer and colleagues.
- Gleevec-induced quiescence and the DREAM complex in GIST: Searching for novel therapeutic targets, by Dr. Anette Duensing and colleagues.

Long-term follow up data will be presented for the SWOG S0033 randomized phase III Gleevec for metastatic GIST trial (presented by Dr. Laurence Baker of the University of Michigan). **In addition, long-term follow-up data from a group of 169 Life Raft Group patients will be presented by Executive Director, Norman Scherzer.**

The objective of the Life Raft Group study was to assess the influence of Gleevec dose on metastatic GIST patients and to evaluate the difference of using starting dose of Gleevec versus the last reported dose of Gleevec. Although not a randomized trial, this study has raised the issue of whether or not there is a different way of looking at dose/

Gleevec response.

Initial results of the LRG study were reported at the 2004 CTOS meeting in Montreal and subsequently updated in



The site of CTOS 2011.

December 2007 (published in Journal of Gastrointestinal Cancer in 2009). This report provides long-term follow-up of these patients through May 2011.

When analyzed by starting dose, the LRG results were similar to randomized trial results and did not show any

difference in overall survival between higher doses and standard dose Gleevec. However, when analyzed by last reported dose overall survival was significantly longer in the higher dose group (most of whom were on 600 mg of Gleevec).

**The Life Raft Group will also have a poster of the demographics and survival reported by LRG members.** As of October 2010, 23.5 percent of LRG members in the registry reported having metastatic disease at diagnosis. Of those that did not have metastatic disease at diagnosis, 501 (41.2%) later had a recurrence. Overall, 65 percent of members in the registry had metastatic disease (785 of 1215) as of October 2010. Significant differences were noted in gender distribution with females diagnosed more commonly up to age 35 and males more commonly after age 35. In different age groups, significant differences in survival, types of mutations, median age at diagnosis and primary tumor location were also noted.

Other GIST presenters will include, Dr. Peter Hohenberger, Dr. Piotr Rutkowski, David Reynoso, Dr. Duffaud Florence, Dr. Anthony Conley and Dr. Suzanne George.

## The Life Raft Group

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

**The Life Raft Group (LRG) directs research to find a cure for a rare cancer and help those affected through support and advocacy until we do.**

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

### How to help

Donations to The Life Raft Group, a 501(c)(3) nonprofit organization, are tax deductible in the United States.

You can donate by **credit card** at [www.liferaftgroup.org/donate.htm](http://www.liferaftgroup.org/donate.htm) or by sending a **check** to:

The Life Raft Group  
155 US Highway 46, Suite 202  
Wayne, NJ 07470

### Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor.

Please advise Erin Kristoff, the Newsletter Editor, at [ekristoff@liferaftgroup.org](mailto:ekristoff@liferaftgroup.org) of any errors.

## Did you Hear?

As reported in our last issue, Dr. Jonathan Trent has left MD Anderson and is now practicing at Sylvester Cancer Center in Miami. Dr. Trent was kind enough to provide us with his new information, which we have listed below:

The University of Miami,  
Sylvester Cancer Center  
Sarcoma Multidisciplinary Program, Rm #C-050  
1475 NW 12th Ave, Ste 3513  
Miami, FL 33136  
Email: [jtrent@med.miami.edu](mailto:jtrent@med.miami.edu)  
Clinic Appointment email: [askforana@med.miami.edu](mailto:askforana@med.miami.edu)  
Appointment line: 305-243-5302 or 1-800-545-2292.  
Monday through Friday from 8:30 to 5PM  
Fax # 305-243-7781



# Eighth Annual LRG Poker Tournament raises over \$110K!

By **Christine Schaumburg**  
LRG Director of Development

**T**he Eighth Annual New York City Poker Tournament to benefit GIST research, held on September 22<sup>nd</sup> at the Midtown Loft and hosted by Board President Jerry Cudzil, was once again a tremendous success thanks to all of our supporters who came out to play for a cure.

Jerry first began hosting the event in 2004, when his father-in-law and friend, Bill Roth, was battling GIST. Sadly, Bill lost his battle with GIST in 2008, but Jerry continues the fight and carries on Bill's legacy – to find a cure.

“Each year, I am overwhelmed by the outpouring of support that LRG receives from our poker players. But this year, even in this economy, they outdid them-

selves. There may be only one first place winner in the tournament, but each of them contributed to breaking our record by raising over \$110,000 to fund research to cure this terrible disease!”

Over 175 players and spectators, another record number, came out this year for an exciting evening of competition in support of a great cause. But only three players remained at the final table when midnight came.



No, you're not seeing double. That is Board President & Poker Tournament founder, Jerry Cudzil's (far right) twin brother Michael, our 3rd place winner on the left. Decked out in their own bling are 1st place winner Patrick Moore (right of Michael) and Charles Sorrentino (left of Jerry). Congratulations to all of this year's winners!

**See POKER, Page 9**

## LRG launches mutational & plasma level testing survey project

By **Pete Knox**  
LRG Special Projects Coordinator

**R**ecently, the Life Raft Group began work on a survey project sponsored by Novartis Pharmaceuticals designed to assess knowledge and practices among patients and physicians regarding mutational analysis and plasma level testing.

The project, which will also incorporate focus groups and expert panel interviews, is an attempt to assess the behaviors and rationales that motivate GIST patients and physicians to either have or not have these tests performed and identify any obstacles that may exist. Once these obstacles have been identified, the Life Raft Group will then be able to more clearly develop strategies to overcome them, with the ultimate goal being

an increase in the availability of these tests for GIST patients. In addition, past and present clinical trials will be studied to see whether mutational analysis and plasma level testing were included in the trial protocol, and a number of principal investigators from these trials will be interviewed to help better understand the reasoning behind the exclusion or inclusion of these tests. In addition to the survey and interviews, the LRG GIST Patient Registry will be examined to see if pa-

### Did you Know?

**Mutational testing** determines whether you have a mutation present in your tumor, and what genotype it is. Examples include Exon 11 or 9 (for KIT positive tumors), Platelet Driven Growth Factor Receptor Alpha (PDGFRA), or “Wild Type” (no mutation). As different mutations respond to different drugs, and different doses of those drugs, knowing if a specific mutation is present can help your doctor determine the best type of treatment for your individual situation.

**Plasma/Blood Level Testing (BLT)** is a pharmacokinetic method of determining how much imatinib (Gleevec) is present in a patient's blood at a specific time. Typically, the minimum concentration (known as a trough level or Cmin) is measured right before taking the next dose of Gleevec (ideally 22-24 hours after taking the last dose). By measuring this level doctors can see if a patient is taking their Gleevec as prescribed.



**See SURVEY, Page 10**

## Pediatric GISTer will test his mettle in Marine Corps Marathon

By Jason DeLorenzo  
LRG Member

**M**y name is Jason DeLorenzo and my experience with GIST has given me a new lease on life. I feel like I have a second chance, and that has inspired me to do two things with my life. The first is to become the best person I can be, which means to treat others with charity and grow in virtue so that I can share the gifts and talents I was given with the world. The second is to never waste another day. I was fortunate enough to come face to face with my



DELORENZO

mortality early in my life, and because of the efforts of all the research towards GIST, Gleevec, and the knowledge of exactly what I have, I am healthy enough that I can do all the things people wish they did when they got old. One of those things is to run a marathon. At the Battle of Marathon, the legend of the runner Pheidippides was born, as his running from Marathon to Athens declaring "We are victorious" and dying of exhaustion immediately. It was hailed as the far-

thest a man could run before he died. Since then I've learned this never happened, but nonetheless, it is still the gold standard of distance running.

Once they learned of my goal, many had doubts that I would follow through. Honestly, I couldn't blame them since the most I ran before training was a 5K (3.2 miles), and I was exhausted. But I've been training since February for the Marine Corps Marathon on October 30, 2011, and feel that I can finish.

I don't plan on breaking world records, and I don't know if I would run another, but I feel like finishing just one is an accomplishment in itself.



## Social Security's Compassionate Allowances explained

By Diana Nieves  
LRG Program Associate

**T**he United States Social Security Administration (SSA) pays disability benefits to people who cannot work because they have a medical condition that is expected to last at least one year or result in death. Federal law requires this very strict definition of disability. While some programs give money to people with partial disability or short-term disability, Social Security does not.

Applicants whose medical conditions are so serious that their conditions obviously meet disability standards are considered Compassionate Allowances (CAL). CALs are a quick way for SSA to identify disabled individuals who most obviously qualify for allowances based on objective medical information. CAL cases will receive expedited processing within the context

of the existing disability determination process. CAL cases are similar to Terminal Illness claims, although not all CAL cases involve terminal illness. For example, a person with a spinal cord injury could qualify as a compassionate allowance – even if he or she is expected to live for many years.

CAL conditions are developed as a result of:

- Information received from public outreach hearings,
- Comments received from the Social Security and Disability Determination Service communities,
- Counsel from medical and scientific experts, and
- SSA's research with the National Institutes of Health (NIH).

New conditions are evaluated at Compassionate Allowances public outreach hearings; the total number to date of Compassionate Allowances conditions is 100. GIST specifically is not currently on the

list. However, cancers located in the esophageal, large intestine, liver, small intestine and stomach are CAL conditions.

To view the complete list of Compassionate Allowances Conditions, visit: [www.ssa.gov/compassionateallowances/conditions.htm](http://www.ssa.gov/compassionateallowances/conditions.htm)

The two ways you can apply for disability benefits are to:

**Apply at**

[www.socialsecurity.gov/disability](http://www.socialsecurity.gov/disability) online

**OR**

**Call** the toll-free number, 1-800-772-1213, to make an appointment to file a disability claim at your local Social Security office or to set up an appointment for someone to take your claim over the telephone. The disability claims interview lasts about one hour. If you are deaf or hard of hearing, you may call the toll-free TTY number, 1-800-325-0778, between 7 a.m. and 7 p.m. on business days. If you schedule an appointment, we will send you a Disability Starter Kit to help you get ready for your disability claims interview. The Disability Starter Kit also is available online at [www.socialsecurity.gov/disability](http://www.socialsecurity.gov/disability).





# Dutch GISTers share laughter, tears & hugs

**By Ellen van Arem de Haas**  
Editor in Chief  
Contactgroep GIST

**I**t was a foggy autumn Saturday morning, September 24th, 2011, when my husband and I drove to the annual GIST Contact Day. From all parts of our country as well as from Belgium, and countries like Germany and Portugal, Dutch speaking members were on their way to celebrate life with each other.

This year, we experienced loads of grief, as 16 members (and more non-members) have passed away, all because of GIST. We remembered those special people as our chairman of the board, Jack Asselbergs, mentioned their names with honor. We swallowed our tears, and we felt deeply grateful as we have had the opportunity, though sometimes only for a short time, to get to know those unfortunate members a little bit.

Jack presented our freshly printed new GIST brochure, a general outline of

what you need to know, what you must ask at your doctor's, and what you have to do if he or she appears not to be a GIST-expert. We're sending it to all (new) members. Even more, we're sending it to all hospitals in The Netherlands, as well as the Flemish ones in Belgium, and hope they want to display our important message in their waiting rooms. Fingers crossed! Too many patients do not get the best treatment, and this has to change.

Sonja Adriaansz from the newly founded charity, 'Een Gift voor GIST' (a gift for GIST), told the story of her beloved partner who passed away a year ago. He had a dream to make public funding possible for GIST studies, as this is not custom in The Netherlands. The first project they tackled is research conducted by Professor Hans Gelderblom, from LUMC (the Leids University Medical Centre). He was the guest speaker of the day, actually for the third time! His speech about GIST yesterday, today, and heading tomorrow, was swift and clear, as was his skilled leadership

of the medical panel of the day. The audience heard their previously emailed questions answered, and raised their hands to ask new ones.

Laughter roared when Gleevec was mentioned as being a big profit winner for years for Novartis, of course being a profit winner for most of our patients as well.

In the afternoon our guests had a few choices, a workshop on the psychosocial problems resulting from receiving a GIST diagnosis, or having a long walk in the woods surrounding the conference building, and an old renovated cow house on an ancient estate. Afterwards, we had a few drinks to clear our throats from loads of laughter and dust and then we enjoyed our dinner together.

Tidying up the old barn, as we were part of the organization of the day, Helmer and I were cheerful because of all the happy faces saying goodbye, the heartfelt hugs, and the pecks on the cheek. Later on, we headed home in the warm rays of the descending summery autumn sun.



GISTers from all over the Netherlands & Belgium (and even some from Germany & Portugal) gathered together.

## Sign our petition: Safe medicines save lives!

**E**veryone has been touched by cancer. One in three people will be affected by cancer at some stage in their life.

The hope is to have access to the best treatment available to conquer the disease. For some, that is not so easy.

Many cancer patients around the world have poor access to cancer therapy, especially in parts of Latin America. For those who cannot afford or access the original branded medicine, they are left with alternative options. Those medicines may be less safe, of lesser quality,

or not produce the desired therapeutic effect as the original counterpart. Thus, patients' lives are at risk. The Life Raft Group is:

- Committed to keeping people safe and helping them to receive safe medicines.
- Insists all patients be made aware of the type of drugs they are being given, whether original or non-original and potential risks or side effects.
- Urges everyone to take a stand in ensuring higher quality medicines are available in Latin America.

**By signing our petition**, you are helping to raise awareness about this issue and the concern of the growing threat of poor quality medicines available for cancer patients.

It should be everyone's right to have safe medicines regardless of whether he/she can afford it or not.

**Sign our petition at**  
<http://alianzagist.blogspot.com/>.

Learn more about this issue at:  
[www.liferaftgroup.org/docs/AlianzaGIST.pdf](http://www.liferaftgroup.org/docs/AlianzaGIST.pdf)



## ALOHA

From Page 1

"We had a good run in Hawaii," muses his beautiful bride, Linda.

Indeed, Hawaii seemed to love Richard and Richard loved Hawaii. In fact, he treated it as a tool for healing.

After one of Tom's GIST-related surgeries, Richard wrote to him and said, "I know just the beach where the trade winds off the Pacific cool

the tropical temperature, and the Wahine practice the hula while the boys surf and the snorkelers ogle at brightly colored fish and coral inside the reef. We'll get you one of those umbrella drinks and filter that into your bladder, buddy bag."

Richard was like that. He used his gifts for writing and humor to engage and support his friends and loved ones.

"He was so easy to talk to and so funny," recalls Linda.

Friend and colleague, Bill Morem, of *The Tribune* noted in a recent article about Richard, "Those who were fortunate enough to have come within his orbit — whether through friendship, family, church or journalism — were rewarded with a generosity of humor and spirit tempered by an unerring moral compass that he used wisely and well in comforting the afflicted and afflicting the comfortable."

When Richard was diagnosed with GIST (then LMS) in 2000, he quickly hooked up with a group of people in the early STI-571 trials on an email list hosted by the Association of Cancer



Richard (in his famous Hawaiian print, with his "bride", Linda.)

Online Resources (ACOR). This group would later become the Life Raft Group, and Richard its newsletter editor.

The early years of GIST and Gleevec were scary and unpredictable times. Everything was new and changing. You would think that being diagnosed with GIST in 2000 would steal some of Richard's humor and light away, but it didn't.

He summed up his philosophy of living with cancer once when he told Tom, "Sounds like life is good if you just ignore the cancer part. So focus on the good, and keep the bad in perspective."

Richard tried to spread this philosophy to everyone he came in contact with.

Linda was quick to point out, "Everybody who ever met Richard loved him."

Bill's theory on Richard's enthusiasm and impact on the world is laid firmly at his family's doorstep, "His life and the exuberance of that life, even during his cancer battle, was most likely formed and burnished by the love of his wife,

life."

Richard always believed that it was hard to feel down on yourself and life when you had such a wonderful "bride" and caregiver in your life, as he had with Linda.

Married for 35 years, Linda & Richard's love never wavered, "It just got better and better over the years. I hope other people can find what he had."

In recent days, that is what Linda holds onto the most, the love...and the laughter.

"His goal, every day, was to make me laugh," she says.

And anyone who knew Richard knows that the man with the smiling face and quirky sense of humor never had any trouble with that.

In his article, Bill wrote, "Richard was the kind of person who was so full of life, integrity and well-honed professional skills that, regardless of the situation, when he showed up on the scene, people would think or say: All right, Richard's here."

"What can I say of this man whose path ran parallel with mine?" Tom asks, "We shared a disease, a drive, a love for and respect of life. We shared friends. We said good bye to long time GISTers and we sat before the same candles but 4,500 miles apart."

"He was the Kahoona," he declares, "A tremendous friend who I never had the pleasure to meet in person but with whom I felt a certain brotherhood."

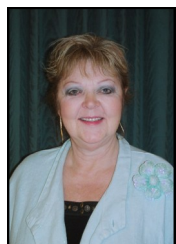
Bill is wistful, "Richard...as long as those who knew you draw a breath, your life and story will live on. And if we listen real closely in our quiet times of reflection and introspection, perhaps we'll hear those on the Other Side saying: All right, Richard's here."

As for all of us who are so much better for having Richard in our lives, Linda has this to say, "He was irreplaceable and we'll miss him forever, but please keep Richard in your hearts."

*Please go to page 8 for an homage to Richard from his email buddies.*

*If you would like to read the rest of Bill Morem's tribute to Richard go to <http://www.sanluisobispo.com/2011/08/30/1736323/richard-you-will-be-sorely-missed.html>*

## Please welcome new Texas rep, Dee Hawkins!



**HAWKINS**

I think it's important to give back and hopefully as a Texas Rep. for GIST I'll be able to help others. When I was first diagnosed with GIST, it was the most stressful period in my life. I truly am so thankful for the GIST Listserv and all the people who shared with me then to give me hope for survival. I can only hope to repay them even a portion by sharing everything I have learned and experienced with others. It's hard to "Pay it forward" but sharing is caring. We are all in this together.

Linda, and his two children, Becky and Matt. His grandchildren — Camden, Logan and Luke — only deepened his embrace of



## 3 WAYS

From Page 1

I need your help in continuing the fight against this terrible cancer. I decided to compile three simple ways that you can help us find a cure.

### Participate in the Annual Fall Giving Campaign

In a few weeks, LRG members will receive their Fall Giving Campaign packages. It includes cards for you to send your friends, family members and co-workers, asking them to make a donation to LRG in support of research for a cure.

You've read about the incredible progress of our research team. But until we cure GIST, there is much work to be done and we are counting on your participation in this year's campaign.

Let me repeat that: We are making progress. That is the most valuable detail I can tell you. But don't just take it from me. At our 2010 Life Fest meeting, Lead LRG Researcher, Dr. Jonathan Fletcher of Brigham and Women's

Hospital and Harvard Medical School announced, "In Dallas [at Life Fest 2006], we [the LRG research team] were asked by Norman to get up on the platform in front of this incredible group and say we were going to cure GIST and I was concerned with saying this because we can't cure it...but, I am delighted to say and in a clean conscience, four years later, that our understanding of GIST has grown such in the last four years that now we can stand up on this stage and say with determination and conviction that we are going to cure GIST."



**FLETCHER**

### Send us your medical history

We need to pull together now to facili-

tate the search for a cure. In addition to the Fall Campaign, I am asking each GIST survivor who has not already done so to send us your medical history. The information will help keep patients alive in the absence of a cure and will provide vital help to our researchers to fuel the search for a cure.

The Life Raft Group maintains the largest active patient registry for GIST in the world. It is driven by data provided by patients which enables us to cross institutional and national boundaries. Over 1300 patients from 57 countries currently participate and the highest standards of confidentiality are maintained.

**Although no patient registry is a substitute for formal, randomized clinical trials, the reality is that many GIST patients do not have enough time to wait for such trials to provide the information they need to stay alive today.** On top of monitoring those on clinical trials, the LRG patient registry monitors the efficacy and side-effects of the off-label treatments and other interventions outside of clinical trials that a growing number of patients have to rely upon when they become resistant to Gleevec and Sutent, the only two FDA-approved drugs for GIST.

The more patients who contribute and who continue to maintain their medical histories, the better the life saving advice others may receive.

Yes, our Patient Registry helps us provide patients and their oncologists with timely information, but it also supports the vital research being done by key GIST pathologists working on a cure for GIST, including the distinguished mem-

bers of the LRG research team.

Dr. Daniel Vasella, Chairman and former CEO of Novartis Pharmaceuticals, once said of our Registry, "The Life Raft Group has provided various people, patients, doctors, and investigators, with a unique kind of data bank that cannot be replicated anywhere else, not even in patient trials".



**VASELLA**

### Send us your tissue

The LRG maintains the only patient-driven comprehensive GIST tissue bank in the world.

At the GIST Collaborative Tissue Bank, housed at Stanford University and created by Dr. Matt van de Rijn, tissue is sent by the patient through the LRG; so that the LRG can provide the medical history of the tissue but remove the patient's identifying information. Dr. van de Rijn creates Tissue Microarrays, which not only analyze large amounts of tissue at a time, but are also able to be shared with other researchers. We also send the tissue to Dr. Chris Corless at Oregon Health & Science University (OHSU), who does a free mu-



**"The support by Life Raft enables our laboratory to study GIST with the goal of finding novel diagnostic markers and potential therapeutic targets. Perhaps as importantly, Life Raft has brought together a group of researchers that share the goal of curing GIST and who have been exchanging information on pre-publication data for the past 5 years, allowing for a rapid dissemination of ideas."**

**-Dr. Matt van de Rijn  
LRG Research Team member**

tational test and sends the results to the patient's doctor and, with consent, to the LRG for entry into our patient registry.

#### What does this mean to you?

- The patient and his/her doctor receive a free mutational analysis, which can aid in GIST treatment.
- The researchers at Stanford and

# Richard Wayne Palmer 1948-2011

"I once told Richard I thought of him as a big brother, although he was probably younger than I, because he helped pave the paths, the meandering, winding stones through the jungles of GIST treatments. But he did so much more too..."

-Louise Ladd

"To me Richard was "one of the voices" of our group, always ready to give advice and support. I will greatly miss his insight into this battle and kind words so often spoken."

-Judie Bouldry

"He was an ebullient and energetic presence. Richard will be hugely missed by everyone in the GISTer community."

-David Josephy

"So, to a friend I could always chat with,  
but see only so seldom,  
I must bid a long, a last, farewell.  
He is at rest from his labors  
.....may it be in peace.  
Some day, I, too,  
must follow, in similar fashion.  
I hope we meet again  
.....'cause I don't remember  
ever hugging him."

-Pat George

"There aren't enough candles to properly honor Richard. What a fabulous soldier he was, and how fortunate we were to have known him, even if just online."

-Susan Farmer

"Richard was indeed something special. I will mourn his loss; celebrate his life, and remember him always."

-Jerry Call

"I shared Richard passing with my husband this evening, as well the outpouring of grief expressed here. He said, 'Now, that's how you leave a legacy behind.' Indeed."

-Jennifer Draper

"Richard's loving and compassionate spirit with which he lived his life will continue to encourage us all."

-Rick Ware

"Richard, I will always light a candle for you anytime, anywhere. You were my inspiration and still are."

-Maria Lagaluga

"When our daughter Nancy died in 2005 Richard wrote to us: 'Hilo is known as the city where rain reigns, and tonight the rain masks the tears I feel in my heart for your family.' Tonight, it is raining in our hearts."

-Jim & Margi Hughes

"1000 candles are not enough."

-Gail & Tim Mansfield

"For those who did not know him, you missed something really special."

-Norman Scherzer

"Richard always had a helpful, informed and optimistic response to our rafters. We've been in the Life Raft family together for 10 years and I'm heartbroken to lose him."

-John Stinson

"No matter how bad things were he always made us laugh. Richard never saw the clouds just the sun shining through it."

-Tania Stutman



## POKER

From Page 3

We know our first place winner, Patrick Moore, will make us proud when he competes in the World Series of Poker in Las Vegas, Nevada this summer. Charles Sorrentino was a formidable opponent and earned a respectable second place title while Jerry's brother, Mike, made the Cudzil family proud in earning third place.

Congratulations to this year's winners!

The LRG extends a special thank you to our tournament sponsors. Our Diamond Sponsor, Pfizer, donated \$10,000 toward a cure, while Clubs Sponsor, the Phoenix Foundation, donated \$5,000 on behalf of Phoenix Partners Group and



Jerry Cudzil and his wife look as the playing field dwindles.

Hearts Sponsor, Investors Bank, contributed \$1,000. In addition, we thank beverage sponsor, Robert Spellman and Kim Tallau of Innovative Images who annually donates her time and talent as our profes-

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

Once again, our players went all-in for a cure!

For pictures and information on ordering, visit [www.fb.com/lrgpokertournament](http://www.fb.com/lrgpokertournament).



"Poker face" is the name of the game at this poker tournament. But as the night wears on tension runs high.



The terrace was open for this year's poker tournament so guests and players took full advantage of the fresh night air, including one of our previous third-place winners, Lyon Carter III (third from right).

## Join us in welcoming LRG's new SoCal Representative



**WILEY**

Shortly after being diagnosed with GIST in 2003, Dina Wiley was referred to the Life Raft Group, where she found essential support and vital information. Once she was put in touch with Floyd Pothoven, LRG's former representative, she began attending support group meetings that he hosted. Those meetings were significant, because as the members shared their experiences she realized that she was no longer alone. She saw this meeting as a pivotal point in her fight against GIST. Dina's desire is to keep the flame burning by providing opportunities for others with GIST to be informed and share their stories while they offer and receive support.

Now a retired psychologist, Dina is involved in civic endeavors, and looks forward to having an opportunity to serve as the LRG's So. California Representative. She shares a home in Redondo Beach with her husband, Sam, and their feline "baby," JazzCat. \* The LRG would like to extend a special thank you to Floyd Pothoven for many years of dedication in supporting others living with GIST.



## Gangstead was 61

**M**ervin L. Gangstead, 61, of Garland passed away on September 14, 2011

after a lengthy battle with GIST. He is survived by his mother, Ruth Gangstead; his sister, Vivian Nore; his devoted wife of 38 years, Carol; his beloved daughter, Stacey, son-in-law, Kyle Richardson, their two sons, Grant and Hayes; his beloved son, Steven, and daughter-in-law Alex. His father, Lloyd Gangstead, preceded him in death.

Mr. Gangstead was born in Ft. Dodge, Iowa on September 4, 1950 and grew up on the family farm in Badger. He loved life, his family, his work, his friends and his country. He graduated from Humboldt High School in 1967 and received his B.S. from Arizona State in 1973. He served in the USAF from 1970-1978 and was stationed most of this time at Edwards AFB as an engineer for the Rocket Propulsion Laboratory. He was an engineer for Raytheon for over 31 years. He had a keen mind and enjoyed solving challenging technical problems and learning new things. His ever expanding variety of interests included computers, optics, photography, flying, water skiing, scuba diving, motor homes, car repair, and home remodeling projects. He was a wise and loving husband, father, and friend.



## Zuber remembered as loving wife, mother & grandmother

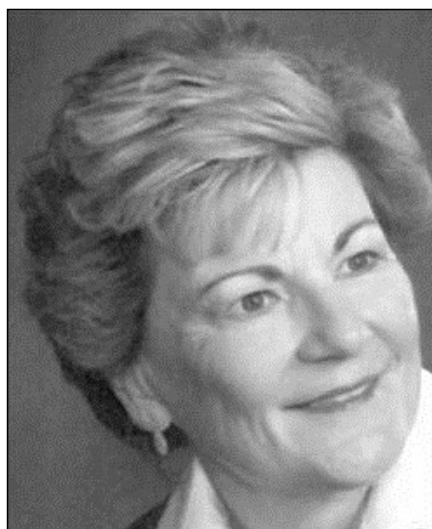
**V**ictoria S. Zuber, 62, entered into rest on September 12, 2011 at her home in Ripon. She was born December 3, 1948 in Alameda, CA to Silvio and Marie Simi.

Victoria leaves behind her beloved husband of 42 years, Leo M. Zuber as well as her daughters, Randi Polanich and husband Jon of Glen Mills, PA and Robyn Udavi and husband Richard of



Ripon. Victoria was blessed with five grandchildren, Ethan and Owen Polanich and Jazmin, Stephanie and Martin Udavi. She was a loving sister to Michael Simi and wife Cathy.

Victoria worked as an educator for the most part of her



life. She was a teacher in Manteca and a school administrator in Oakdale and Livingston. Victoria went on to become principal and superintendent for Shiloh school district. Victoria was an avid golfer and was a member at Spring Creek Golf and Country Club in Ripon

and an active member of the 18 Hole Ladies. Victoria loved her family dearly, they were her pride and joy. She will be remembered as a loving wife, mother and grandmother.

For condolences to the family please visit [www.plfryandson.com](http://www.plfryandson.com). (search obituaries).

In lieu of flowers, donations may be made to Community Hospice, 4368 Spyres Way, Modesto, CA.

## SURVEY

From Page 3

**Read more about BLT and its importance on page 1!**

tients who have had mutational analysis and/or plasma level testing have better overall survival than those that did not.

The LRG believes that the information garnered from these tests is potentially crucial information for both doctors and patients and thus these tests should be made more readily available. One of the issues that has hindered the availability of these tests is a lack of data regarding how often they are performed and their impact on patient survivability. Thus this survey is a very important step towards making more data available, and ultimately, helping to make it easier for patients to get the tests.

**GISTers who participate in our patient registry, as well as doctors who have supplied us with a valid email address, will soon receive an email asking them to participate in our survey. Be sure your email address is current, and if not, please contact us to have it updated at [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org). Then watch for it in your inbox, and let your voice be heard!**

## Alianza GIST & GGN

add new **Alianza GIST** reps



**Guatemala**  
**Silvia Castillo de Armas**  
[asopaleu@hotmail.com](mailto:asopaleu@hotmail.com)



**Honduras**  
**Xiomara Barrientos**  
[xlizethb@hotmail.com](mailto:xlizethb@hotmail.com)



**Peru**  
**Eva Maria Ruiz de Castilla Yabar**  
[evamaria@esperantra.org](mailto:evamaria@esperantra.org)



## BLT

From Page 1

**Check out the launch of our new Mutational & BLT survey on page 3!**

enough Gleevec in your body is have a plasma or blood level test (BLT).

"I do not believe that you can play "catch-up" when it comes to Gleevec," says LRG Science Director, Jerry Call, "You can't take a marginal dose for two years, become resistant, then raise your dose and get the same response as if you had been on an adequate dose the whole time."

### Argentina GIST.org is official!

We are proud to inform you that Asociación GIST Argentina (AGA) is finally an official, legal organization, which allows us to receive funds to run the association. This is crucial for AGA's future because it will allow us to grow quicker and accomplish more activities. We are grateful to those who have agreed to support us financially, which will allow us to do things that we were not able to do without funding.

This support will help us organize a meeting with GIST patients in Buenos Aires. AGA finally has the tools needed to grow and to have an important role in the treatment of GIST in Argentina.

**Melisa Biman**  
President of AGA

[www.gistargentina.com.ar/](http://www.gistargentina.com.ar/)



Data from the Life Raft Group registry suggests that over 60% of patients on 400 mg of Gleevec

checking their Gleevec plasma levels for the first time will be less than 1100 ng/mL (the standard reference number currently used to determine a therapeutic dose of Gleevec).

"If this reference level ultimately is proven correct this means that over half of the patients taking Gleevec may be taking too low a dose," adds Jerry.

Yes, there's still room for debate. We are not yet sure that 1100 ng/mL is the right reference number and there are valid questions about the precise applicability for plasma level testing in the management of Gleevec.

Despite that, given that the test is free and requires only a blood test within a specific time frame, we believe that plasma level testing is something that every Gleevec-sensitive GIST survivor should have.

A compelling reason to have plasma testing done now is that the opportunity for such testing may be running out. TDM Pharmaceutical Research, LLC has partnered with The LRG to make this testing available for free because TDM laboratory shares our point of view on the potential value in using this test to help GIST patients survive!

**This free period of testing was originally scheduled to end November 2011 but TDM has granted us an extension until January 31, 2012.** However, this program may be suspended if we do not get enough numbers of patients taking advantage of this free tool!

To get this free testing done, please contact:

TDM Pharmaceutical Research, LLC  
100 Biddle Ave Suite 202  
Newark, DE 19702  
1-866-990-0007  
[support@tdmrxresearch.com](mailto:support@tdmrxresearch.com)

## Mark your calendars!

• Susan Farmer will be hosting a local group luncheon on **October 15**, please email her at [sfarmer10@cox.net](mailto:sfarmer10@cox.net) for information.

• The first patient meeting at Cook County Hospital in Chicago will be on **October 22** at 1 pm.

• CTOS is hitting Chicago October 26-29 (See page 2).

• Jason DeLorenzo's marathon (See Page 4 for how you can support him) will be on **October 30**.

• Ensemble Contre Le GIST (AFPG) is meeting **November 26**. Email Estelle at [ensemblecontrelegist@yahoo.fr](mailto:ensemblecontrelegist@yahoo.fr) for details.

• GISTers in Texas will be meeting on **December 10**, so email new local group leader, Dee Hawkins for more info at [dee@abetteranswer.com](mailto:dee@abetteranswer.com)



## 3 WAYS

From Page 1

elsewhere are able to correlate their laboratory work with the patient's clinical history.

- The LRG is able to do the same.
- The patient's tissue, which is often sitting in a file cabinet at the hospital where surgery was performed, is put to good use. After all the testing is completed the unused tissue (many core samples can be obtained from one block) can be returned to the hospital.

I can't stress the importance of this tissue bank enough;



**CORLESS**

recently Dr. Corless stated, "This ... project is essential to building the number of samples that we can genomically analyze using the latest next-generation sequencing technology. Only through analysis of several dozen samples can we begin to define patterns of mutations that contribute to GIST growth and drug resistance."

For more information about the Patient Registry or the GIST Collaborative Tissue Bank please contact Magda Sarnas at [msarnas@liferaftgroup.org](mailto:msarnas@liferaftgroup.org) or call her at 973.837.9092, Ext. 114. The LRG is working hard each and every day find the cure for GIST while helping those living with it until then. Be a part of the fight—a part of the cure. Support our efforts today.

## Fall is here!



# THE LIFE RAFT GROUP

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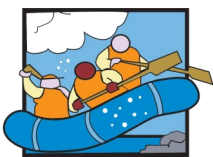
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E-mail: [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org)

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