

# In your eyes, I am complete

By Erin Kristoff  
LRG Newsletter Editor

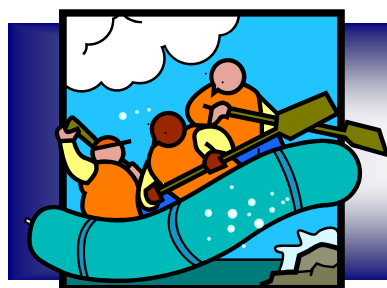
Since joining the Life Raft Group in January 2007, Janeen Ryan, caregiver to her husband, Larry, has acted as a jester, a confidante and a supportive shoulder to many in the LRG email community. Usually a ray of sunshine (but occasionally a bolt of lightning), Janeen is equally at home making suggestions about speaking with your doctor or inventing new written ways to express frustration with a medical blunder. In each post, she signs off with a snippet from her daily life. Signed once as Janeen Ryan, "Wife of Larry (I can't fish in the rain!) Ryan", another as



Janeen & Larry Ryan

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## Battling gastrointestinal stromal tumor



## LIFE RAFT GROUP

April 2009

In memory of Dr. Ulrich Schnorf & Fatima Quassini

Vol 10, No. 4

## GIST diagnosis: The pathologist's perspective

By Dr. Chris Corless  
Oregon Health & Science  
University, LRG Research Team

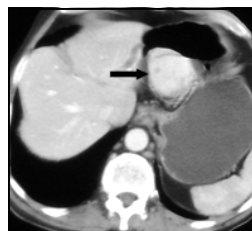
For a patient suddenly faced with a cancer diagnosis, the process by which the diagnosis was made may seem of little interest. It is only the result – traumatic, life-altering – that matters. But there is in fact a well defined pathway by which the initial discovery of a suspicious mass is turned into a final diagnosis of GI stromal tumor (GIST).

This article reviews the events that lead to a diagnosis and emphasizes the importance of teamwork and experience that are necessary to ensure that this diagnosis is accurate. Of



CORLESS

define the size of the lesion and its anatomic location, which in the case of GIST is usually within the wall of the stomach or intestine. As there are well over 250 different types of recognized human tumors, many of which can occur in the abdomen, information from imaging studies is important in narrowing



A GIST tumor as seen on a CT film.

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## LRG Research Team holds 2nd in-person meeting: new tissue banking initiative born

By Marisa Bolognese  
LRG Director of Planning & Development

On March 6 and 7, the LRG Research Team met for the second in-person meeting at Brigham & Women's Hospital in Boston, Mass. The Team had previously met in Portland, Oregon



Brigham & Women's Hospital

at Oregon Health & Science University (OHSU) in October 2008. The two-day meeting brought together the LRG-funded scientists, all world-renowned GIST researchers: Jonathan Fletcher, Brigham & Women's Hospital; Cristina Antonescu, Memorial Sloan-Kettering Cancer Center; Sebastian Bauer, West German Cancer Center, Essen, Ger-

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**Help support GIST Research! See page 11.**

# Community hospitals vs. cancer centers: should the patient be informed of the risks?

By Erin Kristoff  
LRG Newsletter Editor

In a January *New York Times* article, “Should Patients Be Told of Better Care Elsewhere,” the author, Denise Grady, discusses a friend who was diagnosed with rectal cancer and needed surgery, radiation and chemotherapy. The friend consulted a surgeon at a local community hospital who was pleasant and very direct. Because of the tumor size, it was doubtful he could save the sphincter muscles; she would most likely require the use of a colostomy bag for the rest of her life.

The friend weighed her options, a doctor close to home seemed so convenient, especially because shopping around for doctors while she so ill seemed a daunting task. However, the threat of the colostomy bag outweighed the other concerns and she made the two hour hike to a cancer center where they saw people like her all the time.

He was able to save the sphincter muscles and there was no need for a bag.

This issue comes up again and again with cancer patients, including those with GIST. Will a patient receive the same level of skill and care at a community hospital as they would at a cancer center which specializes in these types of patients?

Grady cites an article published in the

online journal, *PLoS Medicine*, which is a peer-reviewed, open-access journal published by the Public Library of Science. In this article, authors argued that doctors have an “ethical duty” to inform patients whether they are more likely to receive better treatment at another hospital that deals with a higher volume of cancer patients.

According to the *Times* article studies have proven the “common-sense notion that practice makes perfect.” Dr. Leonidas G. Koniaris, a cancer surgeon at the Miller School of Medicine at the University of Miami and one author of the *PLoS* article, feels that it is not just the doctor’s skill level that is greater, but also the level of expertise in other post-surgery areas such as nursing, intensive care and rehabilitation.

The *PLoS* article also pointed out a few cases in the United States and Australia, in which courts have ruled that doctors who had operated on people with poor results should have informed the patients that more experienced surgeons were available. In one Wisconsin Supreme Court case, the court decided that “information on the availability of other centers and physicians better able to perform that procedure would have facilitated the plaintiff’s awareness of ‘all of the viable alternatives’ and her ability to make an informed choice,”

**Should doctors inform patients they are more likely to receive better treatment at another hospital that deals with a higher volume of cancer patients?**



according to Koniaris’s article. In the same *PLoS* article, Dr. Robert J. Weil, a neurosurgeon at the Cleveland Clinic, argues that Koniaris’s viewpoint “faces a number of logistic

## 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  
40 Galesi Dr., Suite 19  
Wayne, NJ 07470

### Disclaimer

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

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

hurdles”. Weil raises a number of questions and concerns such as, “Which hospitals should be chosen for comparison? “ This question is further complicated by the possibility that one surgeon

may have good surgical outcomes but practice at a hospital with a poor overall outcome. Another concern of Weil’s is whether surgeons will “do less radical...operations that may have little effect on cancer outcome but improve complication rates substantially.” In this case, a surgeon may only take low-risk or “simple” surgeries in order to have a good outcome.

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# April 2009 US clinical trials update

**By Jim Hughes**  
**LRG Clinical Trials Coordinator**

## United States

### **Bevacizumab plus Imatinib Phase 3:**

This trial continues at over 200 regional cancer centers across the United States. Recently added were major GIST trial sites including Fox Chase Cancer Center, Oregon Health & Science University and the University of Chicago. This first line trial is for patients recently diagnosed with unresectable GIST. The trial exclusion criteria include “No prior imatinib mesylate, Bevacizumab, or other agents targeting KIT, vascular endothelial growth factor (VEGF), VEGF receptor, or platelet-derived growth factor receptor (PDGFR) for advanced disease. These agents may have been used in the adjuvant setting provided no recurrence for  $\geq 12$  months after completion of therapy.” Bevacizumab is an anti-VEGF agent intended to reduce the ability of the tumor to grow new blood vessels. The trial is intended to answer the question of whether the addition of Bevacizumab to Imatinib will lead to longer progression-free survival. Half the patients will receive Bevacizumab, which is administered intravenously once every three weeks. All patients will receive Imatinib.

## US and International

**Sunitinib or Imatinib Phase 3:** New sites have opened in Michigan, Nevada, Ohio, Wisconsin, Germany, the United Kingdom and the Republic of Korea. This trial is for patients having progression while on Imatinib at 400 mg. Patients are randomly assigned to receive either 800 mg Imatinib or 37.5 mg Sunitinib daily.

## International

**IPI-504 Phase 3:** This trial is for patients failing both Imatinib and Sunitinib. It now has multiple new sites in Australia, Belgium, France, Germany, Sweden and the Republic of Korea. IPI-

504 is a HSP-90 inhibitor administered intravenously. Patients are randomized to receive either IPI-504 or a placebo.

### **Nilotinib Versus Imatinib Phase 3:**

This trial for first line patients is now recruiting at two sites in Canada, and one each in Austria and Spain. In the US 19 sites, 11 states are listed in [clinicaltrials.gov](http://clinicaltrials.gov) along with detailed contact information. All are listed as ‘Not yet recruiting’. That could change quickly.

This phase 3 trial will test whether nilotinib (also known as AMN107 and Tasigna) given as initial treatment for metastatic GIST is better than the current initial therapy, imatinib (Gleevec). Nilotinib is a more powerful inhibitor of KIT and PDGFRA than Gleevec. Lab tests also show it is more effective than imatinib against both wild-type GIST and the exon 13 mutant GIST. Nilotinib also showed higher concentrations levels inside GIST tumor cells in the lab.

Patients entering the trial will be randomized to receive either imatinib or nilotinib. Estimated enrollment for the trial will be 736 patients.

#### *Inclusion Criteria include:*

1. Histologically confirmed diagnosis of GIST which is unresectable and/or

metastatic and either:

- No prior therapy with imatinib or any investigational therapies (e.g. sunitinib). Note: newly diagnosed patients may have received up to 14 days imatinib treatment for disease management while awaiting study start.

- Recurrent GIST after stopping adjuvant treatment with imatinib and no subsequent treatment with any other investigational therapies (for example sunitinib).

2. At least one measurable site of disease on CT/MRI scan

3. Performance status  $\leq 2$  (capable of self-care but unable to carry out any work)

4. Normal organ, electrolyte and marrow function

#### *Exclusion Criteria include:*

1. Prior treatment with nilotinib or any other drug in this class or other targeted therapy agents with the exception of adjuvant imatinib.

2. Disease progression during adjuvant therapy with imatinib

3. Prior or concomitant malignancy that is currently clinically significant or currently requires active intervention.

4. Impaired cardiac function

Other protocol-defined inclusion/exclusion criteria may apply



Because the size of the Clinical Trials Table has grown so large, we have decided it warrants its own publication. You can still find trial updates here, but the trial listing will now be a “Clinical Trials Bulletin” sent separately each month. You can find this bulletin at:

<http://www.liferaftgroup.org/docs/ClinicalTrials/April2009.pdf>

If you have any questions, please email us at  
[liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org).

**Don't forget to go to [www.liferaftgroup.org/newsletters.html](http://www.liferaftgroup.org/newsletters.html) and fill out our newsletter survey!**



# Life Raft members share medical solutions

**By Jerry Call**  
**LRG Science Coordinator**

*Elevated liver enzymes are a rare side effect of Gleevec and can occur in CML and GIST patients. Auto-immune hepatitis appears to be one cause of elevated liver enzymes in some patients where the body's own immune system begins to attack the liver. The cause is not always known, but sometimes it can be drug induced. This condition appears to be treatable in the small set of patients reported here and the reintroduction of Gleevec was successful. This article was originally published in the September-October 2005 issue of our newsletter. Since it has been a constant source of information, we thought reprinting it here might be helpful to other GISTers to read.*

**A**fter taking the standard 400 mg dose of Gleevec for nine months, Life Raft Group member Vadim Schukin be-

gan having problems. A blood test found elevated levels of liver enzymes ALT and AST. Elevated levels of these two enzymes usually mean that damage is occurring to the liver. Schukin's doctor had him stop taking Gleevec after which his liver enzymes returned to normal; but when Vadim tried to restart Gleevec at 200, then 100, and finally at 50 mg, his liver enzymes started to rise again. After nine months of on and off low dose Gleevec, his ALT and AST were still above normal.

For most of Schukin's doctors, untangling the mystery of his elevated liver enzymes was difficult. That's when he started his own search for answers.

With the help of the American Society of Clinical Oncology (ASCO) website, he found an interesting report of a GIST patient from a group of Italian doctors (S. Aliberti et al). This patient's story was similar to Vadim's case. After a good response at 400 mg, the patient's



Vadim Schukin and his family

AST and ALT levels began to rise. After ruling out other problems, the doctors found the presence of autoantibodies in the blood. After a liver biopsy, the diagnosis was autoimmune hepatitis. The patient was successfully treated with prednisone which caused a decrease in ALT from 1056 U/L to a normal value.

Armed with this new information, Vadim's doctors performed additional tests and found a slight elevation in

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## RYAN

From Page 1

"Wife of Larry (whipped cream on my cocoa please) Ryan", each time Janeen leaves us with a snapshot of a life untouched by cancer. A life she and Larry have created for themselves despite all the odds.

When Janeen walked into Larry Ryan's office for an interview at sundown, with her bright red hair, he thought it was a "bright, glowing angel" standing in the doorway. "He kicked the guy who was with him out of the office. He didn't even know why I was there!" says Janeen. The pair spent the next two and a half hours talking about life, kids, hobbies and love—everything but a job. Larry had four kids, Janeen had two.

It didn't take long for the couple to fall in love and get married. But the beginning was difficult for both sides. Larry had been married to his late wife, Eileen,

for almost 25 years before she died of cancer. The children harbored resentments toward their father for remarrying, which put a strain on the relationship. But then Larry got sick.

He had had a lot of back pain over the years. Doctors had mostly attributed it to arthritis or "getting old". One particular day in December 2006, Larry was bent over in pain and Janeen knew something was wrong. That day, Larry was admitted to the hospital and a CT scan was taken.

The next morning a group of doctors stood in Larry's room and said they were operating the next day; they thought it was diverticulitis. Another doctor interrupted and demanded to speak to the others, "I just thought, 'Oh, they have the CT results,'" remembers Janeen. Her intuition had been right, a mass the size of an orange was attached to the duodenum, and there were metastases throughout his GI tract. During surgery, Larry's tumor burst, flooding

his abdomen. Despite the setback, they cleaned out the fluid and biopsied the tumor.

"A few days later, they said it was GIST and he had three months to live."

Thankfully, this was just another assumption that Larry overcame. He was put on Gleevec, which worked for 18 months. After experiencing progression, he upped his dosage. Eventually, at the suggestion of Dr. Mike Heinrich at Oregon Health & Science University, following a mutational test that revealed an exon 9 mutation, Larry was switched to Sutent in September 2008. Despite dosage issues, Larry has been stable since.

"In the beginning, [Larry] thought he was dying. He didn't want to talk to other sick people or do anything. But when his tumors started to shrink, hope was alive again. Now he's taken up hobbies like fishing and target practice."

His illness has also brought the family back together, "There was a lot of heal-

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# Janz, 65, left behind a devoted family

**D**ennis Desmond Janz, 65, of Jefferson, died peacefully on Friday, February 6, 2009, at his home in Jefferson surrounded by his family after a long fight with GIST cancer.

He was born on Oct. 21, 1943 on the family farm in the Town of Seneca, Green Lake Co., Wis., the son of the late Ervin and Lucille (Verch) Janz.

He graduated from Berlin High School in 1961. Dennis served in the U.S. Air Force from 1964-1968. Dennis graduated from UW-River Falls with a bachelor's degree in agricultural engineering in 1972. Dennis and Diane were married on June 23, 1973 at St. Peter's Lutheran Church in Sturgeon Bay, Wis.

They started their family while living



Janz, pictured with his daughter, Melissa.

in Fort Atkinson where Dennis worked as a technical service representative for Butler Manufacturing. In September 1987 he started as one of the first thirteen employees hired at Perry Printing, now Multicolor in Watertown, retiring in September 2008.

He was a member of Bethany Lutheran

Church in Fort Atkinson. He served on the 4-H Leaders Board, operated the Janz Strawberry Farm in the summer, and sold pumpkins in the fall. He is survived by his wife, Diane of Jefferson; one daughter, Melissa (Joseph) Barbey of River Falls; three sons, Aaron (Leah) Janz of North St. Paul, Minn., Matthew (Kelly) Janz of Jefferson, and Michael, at home; and one granddaughter, Johanna Barbey; one sister Carol (William) Romundson of Stevens Point.

Those wishing to express sympathy through memorials may direct them to The Life Raft Group, Rainbow Hospice, or Bethany Lutheran Church. You can also view Dennis's Caringbridge page at [www.caringbridge.org/visit/dennisjanz](http://www.caringbridge.org/visit/dennisjanz)

# Schnorf fully enjoyed life in spite of GIST

By Helga Schnorf

**N**o one can predict how one will react when confronted with a cancer diagnosis. Dr. Ulrich Schnorf (Ueli) was, during his lifetime and shall continue to be, an inspiration to many. Sadly, Ueli passed away on March 15, 2009 from diffuse large B-cell non-Hodgkin lymphoma. He was successfully battling GIST since his initial diagnosis in 2000 with surgery, Gleevec (600mg.), and most significantly, with incredible optimism and courage. Two years ago Ueli also survived a lung cancer operation that was accompanied by several complications.

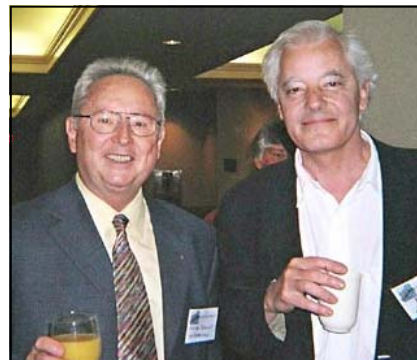
Ueli was focused and disciplined in all aspects of his life. He applied these skills to develop a successful business and again when confronted with GIST.

Soon after his diagnosis, Ueli realized that Switzerland had very little organized support to offer individuals with GIST. He made it his mission to create the Swiss GIST patient support group liaising with The Life Raft Group in the United States and Das Lebenshaus in

Germany. The subsequent website and annual GIST conference in Zurich (the sixth conference will be held on April 24, 2009) are a credit to Ueli's hard work and determination. Ueli may have retired professionally, but his wholehearted involvement with his GIST activities became a time-

consuming part-time job. He did not see it as a burden, but rather as an opportunity to help others during his lifetime and as a chance to establish his legacy.

Ueli and his wife Helga did not let GIST define the course of their life together. They shared many diverse interests and activities. Since 2001, Ueli and Helga have completed three voyages around the world, visiting numerous countries for months at a time. Ueli, true to form, did his homework thoroughly before each trip, learning about the culture and history of the various places on their itinerary. He possessed a keen in-



Schnorf (left), pictured with French GISTER, Bertrand de la Comble

terest in trying to understand people and came to their assistance when needed by sharing part of his story with them. Ueli was passionate about music; he regularly attended classical music concerts in Luzern and Zurich. Actively hiking in the hills and mountains near his home or a stroll by the lake were

daily pleasures. Spending time with his large circle of family and friends was another favorite pastime and provided much amusement, excellent food, wine and numerous cherished memories for all.

It was easy to forget that Ueli had been battling GIST for nine years. He packed a multitude of activities into a day, a week, a month and always looked forward to the next trip, concert, or friendly gathering. Ueli is going to be missed by many while his "joie de vivre" (enjoyment of life) will continue to inspire us all.

## ENZYMES

From Page 4

ANA, an antibody that is often elevated in autoimmune hepatitis. Ten days after starting prednisone, Schukin's liver enzymes drastically improved and neared normal levels. With this new information, the physicians gradually increased the dose of Gleevec while decreasing the prednisone. Schukin's liver enzymes remained low and he eventually increased his dose back to a "standard" dose of 400 mg without any problems. For the last month, Vadim has been taking 800 mg of Gleevec and his liver enzymes are within a normal range.

After finding the "cure" for his liver problems, Vadim shared his newfound information with several other Life Raft Group members with similar problems. Two members, Jani DeHart and Ginger Sawyer, worked with their doctors to begin the "prednisone treatment." Both met much success.

Jani DeHart's story is representative. In October 2004, Jani began having upper quadrant pain and generally did not feel well after 10 months of treatment on Gleevec. Blood tests at the doctor's office revealed elevated AST and ALT levels (in the 700 and 400 range respectively).

After consulting with other doctors, the conclusion was that Gleevec probably caused the elevated liver enzymes. The doctors told Jani that she would have to stop the Gleevec. This was "devastating news" according to Jani. The Gleevec had been keeping her GIST under control.

Jani stopped Gleevec in early November and a subsequent CT scan showed some progression. Her liver enzymes were checked a week later and were slightly higher than when she stopped Gleevec. This was about the time that

Jani heard from fellow GIST patient Vadim Schukin. He described his case to Jani. She forwarded the information to her doctor who ran blood tests and ordered a liver biopsy to check for signs of auto-immune hepatitis. The liver biopsy came back as normal, but the blood tests showed slightly elevated level of ANA.

DeHart's doctors prescribed prednisone and Imuran (an anti-rejection drug) to treat the suspected auto-immune hepatitis. Within 5 days, her liver enzymes had dropped by half. She restarted the Gleevec at a higher dose (800 mg) in mid-November 2004 and her liver enzymes continued to drop even though she was now on double the dose of Gleevec. By early December her liver enzymes were back to normal.

DeHart saw a liver specialist during this period. The physician believed that another drug, Aldactone, a diuretic that she had started in mid-September, may have contributed to the auto-immune hepatitis. His opinion was that there are just so many different drug combinations that it is impossible to predict how specific combinations will affect different people.

DeHart continued the prednisone until mid-February and the Imuran for another month past that. Her liver enzymes continue to be normal and she remains stable on 800 mg of Gleevec.

Life Raft Group member Ginger Sawyer began having problems with elevated

liver enzymes within 2 months of starting Gleevec. Her ALT and AST levels were above 2400. Gingers' doctors at M.D. Anderson Cancer Center suspected that the problem might be auto-immune hepatitis and recommended prednisone. While this seemed to help, it did not seem to be the total answer. Her GIST specialist at M.D. Anderson then collaborated with a liver specialist near Ginger's home.

Gingers' doctors felt that she needed to stop the Gleevec until they got the auto-immune hepatitis under control. She

began this treatment with prednisone, then added Imuran and finally Entocort. With each addition, there seemed to be more improvement, until finally her liver enzymes were back under control. She has successfully resumed Gleevec at 300 mg (she started at 400 mg).

A "Pubmed" search of medical literature found several reports that mention both hepatitis and Gleevec. One of these reports by S. Kikuchi et al, concluded that "These results suggest that both hepatitis and molecular response were associated with the (high) serum STI571 concentration (in this patient)."

*Vadim Schukin wanted to share his experience in the hope that he might be able to help other patients taking Gleevec who are having similar problems. In sharing his experience, Vadim helped Jani DeHart and Ginger Sawyer with their liver problems, just as he was helped by an Italian doctor whom he never met. Jani and Ginger also agreed to share their stories in the hope that others might benefit from them.*

*On September 16, 2006, Jani DeHart passed away. We honor her life here and the contribution she made to help her fellow survivors.*



LRG members DeHart and Sawyer seek out solutions to their liver enzyme count

### Check out our new Familial GIST pamphlet!

*The LRG has just published a Familial GIST pamphlet which will help answer some commonly asked questions about the hereditary form of GIST. Below is a brief snippet of information from the pamphlet, which can be ordered or downloaded at [www.liferaftgroup.org/pamph\\_order.php](http://www.liferaftgroup.org/pamph_order.php)*

Some of the features seen in familial GIST cases are:

- ☒ Multiple family members with GIST
- ☒ More than one generation with GIST
- ☒ Specific skin findings: areas with more or less pigmentation, certain types of moles, a specific rash called urticaria and swallowing disorders





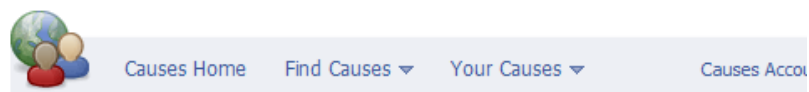
# Are you on Facebook or Myspace? Check us out and join our cause!

The impact of social networking sites has grown exponentially in the past few years. What used to be a high school and college-age “playground” has now become something much more important.

The LRG constantly strives to serve our members and the GIST community as best we can. Our Facebook and Myspace pages enable users to more easily share breaking GIST news and interesting LRG happenings with their caregivers, family and friends. We post announcements weekly about new websites, newsletters and local group meetings.

If you are a Facebook or Myspace user, please join our cause and encourage your friends and family to do the same. It is LRG policy never to contact the people on your Friends List, we leave all invitations up to your discretion.

Facebook membership has already reached 389 members in the last few months and continues to climb each day. Please remember that the greater our membership gets, the more awareness we raise for GIST.



## The Life Raft Group

Ensuring that no one has to face GIST alone.

Beneficiary:

Donations to the cause benefit:

**LIFE RAFT GROUP INC**

A 501(c)(3) nonprofit

Positions:

The mission of the Life Raft Group (LRG) is to ensure the survival of GIST patients while maintaining the quality of their lives.

▼ See Extended Info



To join our Facebook community:

[www.causes.com/liferaftgroup](http://www.causes.com/liferaftgroup)

To join our Myspace community:

[www.myspace.com/liferaftgroup](http://www.myspace.com/liferaftgroup)

## ELSEWHERE

From Page 2

Kaniaris suggests that perhaps, instead of an obligation by physicians, “it should just be up to the patient.”

However, the *Times* article raises the issue that although patients can ask for comparative information, “Many patients would fear giving offense.”

The LRG has faced this particular hurdle many times. There are many reasons why a patient will not ask their oncologist or surgeon for a second opinion or recommendation, many of which stem from the fear that by doing so, they are in fact questioning their doctor’s compe-

tency. For many patients, doctors are seen as somehow better or smarter than the average person.

When discussing medical care with a GIST survivor, the LRG maintains that it is beneficial to consult with a GIST specialist. GIST research is a very fast-paced and quick-changing field. Each month, the LRG publishes articles about new signaling pathways found and new trials opened. When selecting a doctor, you should make sure s/he is keeping current with the latest treatments and developments. A good doctor should be

more concerned with their patient’s care than their own ego.

If you would like to search the LRG GIST Specialist Directory, go to [www.liferaftgroup.org/gist\\_directory.php](http://www.liferaftgroup.org/gist_directory.php)

To find out how a specific hospital performs in treating certain illnesses go to [www.hospitalcompare.hhs.gov](http://www.hospitalcompare.hhs.gov). You can also go to [www.hospitalinfection.org](http://www.hospitalinfection.org) to view the infection rates of some hospitals

## RYAN

From Page 4

ing. It has actually been the happiest two and a half years of our marriage. Nothing else matters but being together and forging forward.”

Larry’s & Janeen’s children started to come over often and chip in with mundane chores like mowing the lawn, slowly bridging the gap between family members. This also helped Janeen considerably since Larry’s illness had begun to take a toll on *her* health.

“When he first got sick, I didn’t leave him for 63 days straight; I set up a baby monitor in the bedroom to listen to every breath he took.”

Janeen began having thyroid problems and was forced to call Larry’s daughter to stay with him while she went to a doctor’s appointment. Because of this she began to ask for more help and has learned a lot from the experience, “When somebody offers help, take it! Don’t be shy about saying, ‘Can you stop at the grocery store for me or the mailbox?’ You have got to take care of yourself!”

At one point, Janeen sought counseling, though not for the reasons one would think. Janeen was involved in an armed robbery at a credit union, which acted as a catalyst for her to seek professional help. Those sessions helped her open up about her emotional burdens as a caregiver. “For the first appointment we talked about the robbery, and then we never talked about it again.”

Janeen also found genuine support in an unexpected place. Several years ago, she found a chat room online about finance and investing which ended up becoming a kind of second family when she was in crisis.

In that virtual place, Janeen was able to share in a way she had not been able to before. “We talk about everything. On the internet you can open up your innermost thoughts and feelings. You can tell them, ‘I just want to hit something!’ and they talk to you and tell you it’s okay to feel this way and you don’t have to be the ‘iron maiden’ all the time.”

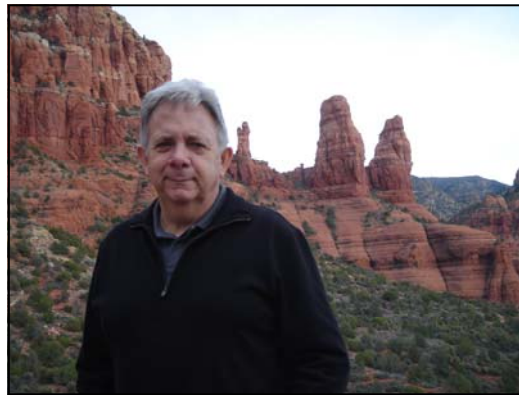
At one point Janeen actually got on a plane to San Francisco and joined all of her friends for a face-to-face meet-up. “We ended up staying for three days and had a blast.”

Of course, there were other places that she found solace. Janeen takes great comfort in her gardening and now boasts an organic vegetable garden complete with tomatoes, onions, beets, leeks, cabbage, lettuce, broccoli, brussel sprouts and various herbs. This has also brought surprising benefit to Larry who has lost much of his taste, “Even with Sutent, where he can’t taste chicken, he can taste broccoli out of our garden.”

Janeen loves to feel connected to the earth, so when she was in need of extra money, she thought of an old hobby of hers: creating jewelry out of completely natural substances like crystal and glass made from sand.

“I thought to myself, ‘Now what do I know how to do?’”

Janeen made a few bracelets here and there, which she sold at work and pretty



Larry enjoying some time outdoors.

soon, a following emerged. “One friend said that I should sell my jewelry on the internet, but I didn’t know what to do.”

Fortunately, Janeen was told of a website, Etsy.com, which sells handmade items, and even got some photography pointers from one of her chat room friends. Business has been doing well; she will soon begin having jewelry parties and is having business cards made up.

It is Janeen’s dream to one day give up her job as an auto broker and make a living by selling jewelry, so that she can spend all of her time with her husband.



Two pieces found in Janeen’s jewelry collection.

But the recent economy has prevented that dream for now, “The auto industry has been hit really hard. I can’t do that yet.”

Because of this situation, the Ryans were recently unable to keep up their car payments. But as usual, they were blessed with great people around them to offer help where needed. A friend took the car and continued the payments, and Larry’s son dropped by with a replacement. “Now Larry can have independence and go to the lake by himself.”

Throughout their battle with GIST and indeed their entire marriage, Janeen has kept one thing in her heart that she keeps reminding herself, “Don’t pretend that everything’s okay, everything’s not okay, everything’s changed. It’s okay to cry and feel weak. It doesn’t mean you are weak; it just means you’re having a bad day.”

Janeen holds on to those good days, when she sells a lot of jewelry or gets a car from her son-in-law, and lets them carry her through the rougher ones. She knows she is blessed and doesn’t take any moment for granted.

“We have more good days than bad. And there was a point when we thought that would never come”

*To check out Janeen’s jewelry collection, go to [www.TCscustomdesigns.com](http://www.TCscustomdesigns.com)*

Because Janeen & Larry’s article is such a love story, I thought it appropriate to use classic romantic lyrics as the headline. Did you recognize the song? Email us at [liferaft@liferaftgroup.org](mailto:liferaft@liferaftgroup.org) with the correct answer and win an LRG T-shirt!



## PATHOLOGY

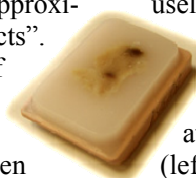
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the long list of possibilities to approximately one dozen “likely suspects”. Depending on the experience of the radiologist, gastroenterologist or surgeon reviewing the imaging studies, the list may even be shortened a bit, and GIST may become the prime suspect.

The final diagnosis of a tumor, however, requires examination of the lesion under the microscope. For more than 130 years, the microscope has been the mainstay of cancer diagnosis. Studious examination of various tumors by generations of pathologists, in collaboration with surgeons, oncologists, gastroenterologists and basic science researchers, has defined the current “dictionary” of diagnoses that serves us today. GIST is a rather late entry into this dictionary; up until the 1990’s GISTs were commonly lumped together with other, similar tumors. We now have a better understanding of what distinguishes GISTs from other cancers, so that the diagnosis can be made more accurately than ever.

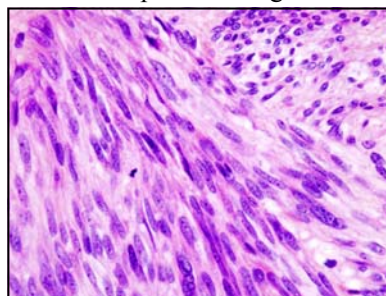
The process by which a sample of a newly discovered tumor makes it onto a pathologist’s microscope is largely unknown to most patients, as it is carried out behind the scenes in the hospital laboratory. The first step is to obtain a piece of the tumor. This may happen through an endoscopic biopsy, where small snippets of the tumor are removed through a gastroenterologist’s scope, or through an image-guided needle biopsy. The amount of tumor from such biopsies is generally quite small (pieces measuring 1/8 of an inch or less), but they are generally sufficient to make the diagnosis of GIST with a high degree of confidence. Occasionally, an entire tumor is removed by a surgeon before it has been formally diagnosed. Diagnosis in such cases is straightforward.

Whatever the method by which it is obtained, the fresh tumor tissue must first be immersed into formaldehyde in order to preserve it. This is necessary because any tissue removed from the body can quickly dry out rendering it



useless for diagnosis (think of a piece of chicken left for too long on a cutting board). The next step is to embed the tissue into wax to create a so-called “paraffin block” (left). This process, invented well over one hundred years ago, requires that water in the tissue be slowly replaced by soaking the tissue in alcohol and then transferring it into an organic solution called xylene, which is somewhat similar to gasoline. This is necessary as water and wax naturally repel one another, whereas organic solutions can mix with hot wax and allow the tissue to be fully embedded in it. The purpose of embedding the tissue into a paraffin block is that it provides a mold that can be mounted on a device called a microtome (right) – which is essentially a sophisticated pastrami slicer. It has a fixed, rather than rotating blade, and can create very thin sections of the tissue measuring only five micrometers (5 x one millionth of a meter) in thickness. Such sections must be handled carefully as they are laid out on the glass slide that will end up on the pathologist’s microscope. The final step is to stain the tissue with special dyes that allow the cellular detail in the tumor to be visualized on the microscope.

It must be emphasized that key steps in the paraffin embedding and slicing of tumor are performed entirely by hand, and that the skills of the technicians performing this work are critical in the preparation of the glass slide that is examined by a pathologist. Wrinkles, tears or uneven thicknesses in the sections can make interpretation on the microscope very challenging, which is why laboratory technicians are an essential part of the team that supports accurate



GIST cells under a microscope.

cancer diagnosis.

Review of the microscopic section from a tumor is generally performed by a pathologist sitting in a quiet office. S/he may know the patient’s age and that the tumor is from the stomach, the intestine or liver, but little more information is required as it is important that the pathologist keep an open mind as to all the possible diagnoses that could fit with the microscopic features of the tumor. In the case of GIST, there are a number of other tumors, both benign and malignant, that can have a similar appearance, including fibromatosis, leiomyosarcoma, schwannoma, and solitary fibrous tumor, among others. An experienced pathologist may determine that GIST is at the top of the list, but there is another important step in arriving at a final diagnosis: the use of special, immunohistochemical stains that will turn positive or negative depending on whether GIST is, in fact, the correct diagnosis. These stains were first developed in the 1970s and have become a bastion of modern pathology. They make use of commercially prepared antibodies (usually purified from rabbits or mice) that act as specific “tags” for proteins present in a tumor. A large pathology laboratory generally has over 150 of these antibodies available to help distinguish different tumors. One of the most important antibodies for GIST is CD117, as this marker is positive in 96 percent of all cases and is negative in other tumors that may resemble GIST under the microscope. CD117 is an alternative name for KIT, which is the target for imatinib therapy.

As has been reviewed in many other articles in the LRG newsletter, mutations in the KIT gene are commonly present in GIST tumors, and testing for these mutations has become common in the initial evaluation of a GIST. Confusion may arise, however, between whether a tumor is CD117-positive (as determined by the special antibody stain) and whether it contains a KIT

## BOSTON

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many; Peter Besmer, Memorial Sloan Kettering Cancer Center; Chris Corless, OHSU (also representing Mike Heinrich of OHSU); Anette Duensing, University of Pittsburgh Cancer Center; Maria Debiec-Rychter, Catholic University of Leuven, Belgium; Brian Rubin, The Cleveland Clinic; and Rob West, Stanford University Cancer Center (filling in for Matt van de Rijn). The Life Raft Group was represented by Norman Scherzer, Executive Director, Jim Hughes, Clinical Trials Coordinator, and Marisa Bolognese, Director of Planning & Development.

Team meetings are critical to the research process funded by the LRG, which is built on a foundation of collaboration and cooperation. These meetings help accelerate the research process by minimizing duplicative efforts and maximizing team work. The impressive



Clockwise: Drs. Cristina Antonescu, Brian Rubin and Maria Debiec-Rychter, Marisa Bolognese, Norman Scherzer, Drs. Chris Corless & Anette Duensing.

brain power of the team provides for a creative meeting environment where researchers share ideas and work together to identify new areas of investigation and help each other interpret research findings. In fact, progress on a number of collaborative projects, identified only four months ago at the Portland meeting, was reported in Boston, demonstrating how important is in to have regular in-person meetings where true cross-fertilization of ideas can occur.

A number of interesting findings were presented by the research team. Tumors

range from simple gain/loss by chromosome profile to highly complex in GIST. Some chromosomal losses produce highly aggressive tumors. Other genomic data was presented including amplification regions (genes that might make too much of a particular protein) and deleted regions (tumor suppressor genes that are missing/non-functional).

Drug testing in cell lines and mouse models is progressing. Of note, some of the newer HSP90 inhibitors, such as 17AAG, are significantly more potent than earlier inhibitors. Several new drug combinations appear to be headed towards phase I clinical trials.

### A problem is posed

One of the most urgent ongoing needs expressed by the team was for GIST tissue samples. Even more vital was that these tissue samples be tied to a patient's clinical history. Unfortunately, when researchers are able to acquire tissue, HIPAA patient privacy regulations make it virtually impossible for researchers to have the patient's complete clinical history. It is also uncommon for researchers

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## PATHOLOGY

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gene mutation. CD117 staining of GISTs is quite routine and is available in almost all pathology laboratories in the country. Adoption of this staining has greatly increased the accuracy of GIST diagnosis over the past decade. In contrast, assessing a GIST for a KIT gene mutation is a much more complicated process that requires purification and analysis of tumor DNA. This type of testing is available from only a few dozen specialized laboratories worldwide.

At the time when imatinib treatment was first being tested in clinical trials and CD117 staining was rather new, a GIST diagnosis was not being made reliably in all pathology laboratories. Today, virtually all pathologists are aware of the importance of correctly identifying GISTs so that patients can get the right therapy, and the diagnosis is being made with much greater accuracy throughout the world.

## WEBSITE OF WORTH



Explore the extraordinary power of tiny actions

Occasionally the LRG likes to feature a website we think could be of benefit to GISTers and caregivers. The Ripples Project is a website that offers one thing, inspirational quotes, and let's face it: everyone needs a little inspiration now and then.

Each Monday morning the Ripples Project sends an email message containing a quick splash of inspiration to all Ripples Project Members. It takes 60 seconds or less to read and contains the following:

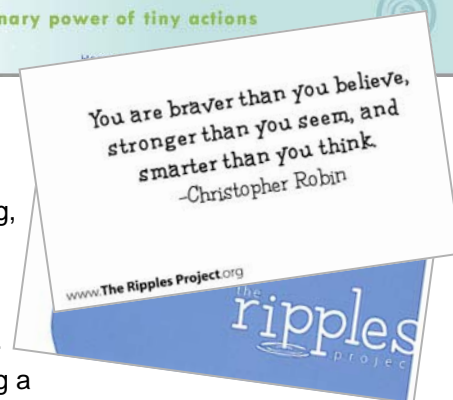
PEBBLE: brief, inspirational quote

BOULDER: poem, song, or longer quote

PONDER: short piece by Paul, Ripples editor

The site's founder, Paul, is also a motivational speaker, who passes out cards with inspirational messages on them and encourages people to do the same and create a "ripple of kindness".

You can find your dose of inspiration at [www.theripplesproject.org](http://www.theripplesproject.org)



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from different institutions to share results of experiments conducted on these tissues. In Portland we began exploring ways to solve these problems. At the Boston meeting we were able to finalize a process to accomplish both goals: provide ongoing GIST tissue linked to clinical histories and find a way to share research results.

### Solution: a collaborative tissue bank

Since its inception, the LRG has been maintaining an extensive GIST patient registry which cuts across institutional and geographical boundaries by collecting information from patients. Today, with over 1,000 GIST patient clinical histories, it is the largest database of its kind in the world. Working together with our research team, the LRG devised a system to integrate this patient-based registry with our lab-based research efforts. The key is patient submission of paraffin tissue blocks. These tissue samples are on file in the pathology labs where patients had their surgeries and they remain archived by law. Tissues are typically required to be held for five to six years, but this varies by state. By having patients send their paraffin tissue blocks to the LRG, who in turn will send it to the research team (without personal

information to comply with research privacy regulation), researchers will have GIST tissue linked to patient clinical histories for the very first time. This unique project will allow researchers to analyze tissues in ways that have never been possible before. For example, scientists will be able to compare primary tumor tissue and metastasized tumor tissue from individual patients and then look for genetic similarities in other patients. All samples will be shared with Dr. Chris Corless for mutational testing (To learn more about how tissue is processed in a lab, read Dr. Corless's article on page 1).

Finally, the LRG and Stanford University have begun working on a shared data system so that results of this and other projects can be accessed by the entire research team via the Stanford Tissue Microarray online database, creating a truly integrated research effort. We are exploring ways to provide web access to this database so that patients and other GIST researchers from all over the world can see firsthand the results of hundreds of experiments.

### Pilot program underway

As a result of the two team meetings and the collaborative efforts of the LRG Research Team members, a pilot program has begun. In the next few months the program will be open to all GIST patients who would like to donate tissue.



Clockwise: Drs. Chris Corless (facing way from camera), Jonathan Fletcher, Sebastian Bauer, Peter Besmer, Cristina Antonescu.

### What's ahead

The Research Team is excited about the new projects that have come about from the collaborative and in-person meeting process. Over the next several months the Team will be continuing their investigations into the mechanisms of resistance and understanding how best they can promote apoptosis or the death of all GIST cancer cells. Areas of investigation include more potent inhibitors, stem cell markers, cellular adhesion, alternate activation pathways, genomic progression, new drug combinations and more.

One of the needs of the team is tissue from long-term responders to Gleevec. By analyzing the differences between long-term responders and patients that progress, researchers hope to increase their understanding of progression and how to prevent or overcome it. Tissue from long-term responders is particularly hard to come by because these patients seldom need surgery.

## Help fund the LRG Dream Team!

Now more than ever, the LRG needs your help to fight GIST. We are asking everyone to donate to the LRG's "Pathway to a Cure" research effort and bring us closer to finding the cure.

We have built a new research paradigm that will produce **better and faster research results** for those living with GIST and, ultimately, other cancers. Instead of handing over money to cancer research and just waiting for answers, the LRG opted to direct a more focused approach on areas that are crucial to **fast track a cure**. With this

Donate now to LRG research at <https://acureisinourreach.org/investinthecure.aspx> OR mail a check to:

The Life Raft Group  
Attn: Research  
40 Galesi Dr., Ste 19  
Wayne, NJ 07470

approach, we have entered into a successful partnership with the research community because they see the value that patients bring to the decision-making table. The LRG has funded the top GIST scientists in the world, which we call the "**LRG Dream Team**" to **collaborate and coordinate** their efforts to bring us to a cure. You can read more about LRG Research at our "What Does a Cure Mean For You?" site: <http://acureisinourreach.org/TheProject.aspx>.

## Mark your calendars!

- The GIST Cancer Research Fund has begun its annual check presentations.

**April 8:** Fox Chase Cancer Center

**April 14 & 15:** Oregon Health & Science University

**April 28:** Dana Farber Cancer Institute

**May 4:** University of Pittsburgh

Please see [www.gistinfo.org](http://www.gistinfo.org) for more information on speakers, tours and locations.

- CancerCare is holding a workshop, "Living With, Through & Beyond Cancer" on **April 14**. Go to [www.cancercare.org](http://www.cancercare.org) for details.



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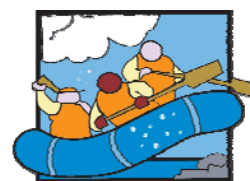
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