

# Rants and raves from a 'GISTwife'

It's a long, winding road to an accurate diagnosis

By Sarah Buch

March 2001 began with another bout of Bob's on-again, off-again "down with his back" syndrome. Bob's biggest problem in this area is that he never stays "down" with his back problem! After a few visits to the chiropractor, an emergency visit to the doctor's house, and finally a visit with his primary doctor, Bob received an order for an X-ray and a prescription for an anti-inflammatory called Naproxin.

Still in major discomfort the weekend of the NCAA championships, I insisted that he lay flat on the floor for the entire day. I pointed out he could still watch basketball and offered to hang around as opposed to abandoning him for the mall. I will admit I had the keys in my hand and my hand on the doorknob when I sensed I should not leave him.

Around 7 p.m., he asked permission to get up and use the bathroom! Since this was a fairly reasonable request, I agreed. He was halfway across the hardwood floor when "BAM!" — he had collapsed.

Not yet frightened, I ran over to him and asked, "Are you alright?" He said he didn't know. I asked if I should call



Bob Buch

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Battling GIST with Gleevec (STI571)



## LIFE RAFT GROUP

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## Researchers: Protein defect linked to GIST

### Scientists find potential target for 'smart bomb' cancer treatments

PORTLAND, Ore. — In a study published Jan. 9 on the journal Science Web site, researchers say they've discovered a protein defect that triggers some cases of a deadly gastrointestinal cancer.

The defective protein, a mutated form of the enzyme platelet-derived growth factor receptor alpha (PDGFRA), may serve as a target for

new "smart-bomb" therapies against gastrointestinal stromal tumors (GIST).

"PDGFRA is found in many body tissues, so it also will be important to determine whether mutations in this enzyme might play a role in other cancers," said author Dr. Michael Heinrich, associate professor of medicine at the Portland VA Medical Center and Oregon Health & Science University Cancer Institute. Heinrich is the study's co-principal investigator

See GIST link, Page 4

## U.S. bill would let Medicare cover oral cancer medication

### Pryce Introduces Access to Cancer Therapies Act

Washington, D.C. — House Republican Conference Chairman Deborah Pryce (R-Ohio) on March 13 introduced the Access to Cancer Therapies Act (H. R. 1288), which will ensure patients have access to quality cancer care by updating Medicare to cover innovative oral anti-cancer drugs.

During the 107th Congress, this legislation garnered the extraordinary support of 327 members of Congress.

"Advancements in research are constantly improving medicines and treatments for cancer that provide new hope to those who suffer with this disease," said Pryce.

"Despite these innovations, access to newly-developed oral cancer therapies for patients covered under Medicare is non-existent."

See Cancer bill, Page 5

## GISTwife

From Page 1

911, and he said, “Yes.”

I calmly told the dispatcher that maybe he was just dizzy from abruptly rising after being down all day. That was when I heard another loud THUMP! He’d made it to the bath but had passed out in the floor. Now I was just short of hysterical.

The dispatcher asked me to describe his color, breathing, etc. When I stepped in the bathroom to assess all that, I saw the toilet full of blood. Bob was almost clear in color, though semiconscious. I should mention that my husband does not even get the common cold.

Police and firefighters arrived before the ambulance. They weren’t very kind, apparently suspected I might have shot Bob or something! I guess they never know. Nonetheless, I ranted about why the ambulance was taking so long while a few neighbors congregated out front. When the paramedics arrived, I informed them about the back pain and Naproxin. Would you believe we live just F-O-U-R miles from the hospital but the ambulance driver asked if he could follow me? I am sure the \$1,004 bill allowed for that!

The triage nurse quickly surmised that Naproxin causes stomach bleeding. Whew! What a relief. Stop the medicine, stop the bleeding. However, Bob had lost a third of his blood, and was immediately asked to sign for transfusions. I spoke right up, asking questions like, “Is the blood safe? Has it been tested?” — you know, being in charge and all. The nurse sharply replied, “He doesn’t have a choice.” Gulp. I sank low into the chair. Then I got the lecture on how I should go home and get some rest!

The following morning, I found Bob with a red bag hanging next to a clear bag and the tubes running straight to his veins. A lot of fuss for a backache, I thought. Fear was settling in.



**Sarah and Bob Buch pose with a feline pal at their neighbor's house last summer.**

Family members said, “Money is no object! Get a specialist!” Friends said, “That hospital is no good! Move him!” Doctors said, “Just go home and get some rest! We’ll take good care of him!” I know all the advice was well intentioned, but how do you get a specialist for lower back pain/bleeding? What category does that fall under? If I am to move him, where? Whose care do I transfer him to? How can I go home and rest? How can I trust the hospital when most of the time doctors aren’t around, only on call?

Bob continued to lose blood over the next three days. He was given seven transfusions and multiple Pepcid shots. He’d cry from the back pain. I cried for him. I lost my temper with various staff for letting him suffer and not identifying the problem. They did blood tests, X-rays, colonoscopies, MRIs, nuclear something-or-others, and decided it was an ulcer that would not appear on the films.

This is where I want to bang my head against a wall for being so stupid! Why did I not insist on a CAT

scan? What was I thinking? I was thinking they must know what they are doing. I certainly wasn’t thinking about insurance — we’re covered! We have a great insurance policy!!

That afternoon a surgeon came to introduce himself, “just in case.” I looked right in his eyes and said, “Open him up and find out where all this bleeding is coming from.” The surgeon replied, “I cannot open him up without knowing where I am going. It could risk further bleeding.”

The gastro doc pretty much told me in no uncertain terms that he was not going to discuss Bob’s back pain with me anymore. They prescribed all the popular painkillers. They gave him ice packs, but we were no longer allowed to talk about it. Hmmpf.

Now, Bob wasn’t feeling bad other than the back. My boss, Don, visited every day and Bob was always cheery and upbeat. I remember thinking, “Don is not going to understand why I am not at work because Bob does not seem sick!”

**See GISTwife II, Page 6**

## Letters to the editor



### Why more GIST research is needed

**M**y name is Stephen Larsen and I just wanted to thank you for putting your newsletter on the Internet for everyone to read. It was one of the few places where I could find any information on my wife Kerrie's cancer and what was being done to fight it. It was also encouraging to read the stories of those who were beating it. We were going to join your group but didn't have all the answers for the application and we could never remember to take it to our doctor.

Below is her battle with GIST for anyone interested.

My wife passed away on Feb. 28, 2003. She found out that she had the disease on her 22nd birthday in 1997, four months after we were married. She was diagnosed with leiomyosarcoma, and later the doctors called it a GIST. They removed the small tumor that they found by accident while removing an ovarian cyst. She then started seeing an oncologist, Dr. Patrick Travis of Highlands Oncology in Bentonville, Arkansas, U.S.A.

All was going well and there was no sign of the tumor for the longest time. We asked the doctor if it was OK to have children and he said that he thought it would be fine. We had our son, William-Grant Alexander Larsen, on April 5, 2001.

Shortly after having Alex, Kerrie went in for what we thought would be the last CT scan for a very long time. We were expecting the usual "everything looks OK," but it didn't turn out that way. They found a very



large tumor by her uterus. Dr. Travis immediately started working on getting us to Boston to see Dr. George Demetri.

We started on the trial for Gleevec (800 mg) and went home hoping for the best. Her tumor growth slowed, but was still growing. She was also having some minor problems from Gleevec (rash, stomach problems, hair loss, etc). We went back to Boston in November and scheduled a surgery with Dr. Samuel Singer in December. She had the tumor removed, which had grown to about the size of a football.

Everything was fine for a while and she had healed well from the surgery. Then we got the results back from a new CT showing small tumors in five or six different places. Dr. Travis put her back on Gleevec and we waited.

She went for another CT and the tumors were growing, fairly aggressively. We went back to Boston, hoping to be placed on the Sugem trial in late 2002. We came back home and Kerrie began experiencing some pretty severe pain. Dr. Travis called Boston. A spot on the trial somehow opened early and we left immediately without even time to go home and pack. Everything was on track and we were so hopeful that this would be the answer. We only had a few more tests and everything would be set.

Kerrie went in for the MUGA scan and the doctors didn't like what they were seeing on the left ventricle of her heart. They ordered an echo and at first told us that her left ventricle was operating at about 55 percent.

This was what we were praying for, anything over 50 percent (the trial cut-off)! They asked us what we were so excited about and we were explaining it to them, when about that time someone from the cardiologist's came out and said the ventricle was only operating at 30 percent. We went back to talk to Dr. Susan George and she gave us the bad news: Kerrie couldn't participate on the trial.

We were crushed and all we could do was look at our near 18-month-old son playing in the floor and cry. Dr. George did her best to reassure us and we flew home, hoping for another chance of some kind.

We tried the Gleevec combined with Gemzar. By now it was December of 2002 and Kerrie was back in the

**See Kerrie's story, Page 8**

## GIST link

From Page 1

with Dr. Christopher Corless of the Portland VA and OHSU Cancer Institute, and Dr. Jonathan Fletcher of Harvard Medical School.

Researchers previously had reported that an abnormal form of the enzyme KIT triggered about 85 percent of GISTs, but the cause in other cases remained unclear. Using a novel molecular technology, Heinrich and his colleagues found that 14 of 40 (35 percent) GIST tumors lacking KIT mutations instead had mutations in the related receptor tyrosine kinase, PDGFRA. Tumors expressing abnormal KIT or PDGFRA proteins were indistinguishable in cellular changes that drove tumor growth.

These findings not only show that two separate mutant proteins apparently can trigger the same cancer, Heinrich said, but validate that the technology used to detect them — or related methods — can be used to find additional targets for a whole new generation of cancer treatments.

“We think the future of cancer treatment is targeted therapy that impacts cancer cells and not normal cells,” said Heinrich. “First, however, we have to identify these targets, and in most cancers we don’t yet know what they are.”

Each year, 5,000 to 10,000 Americans are stricken with GISTs, which invade the organs or linings of the gastrointestinal tract. Once these tumors spread, they prove unresponsive to conventional treatments and are al-

## Quote:

**“We think the future of cancer treatment is targeted therapy that impacts cancer cells and not normal cells.”**

— Dr. Michael Heinrich, associate professor of medicine, Portland VA Medical Center/Oregon Health & Science University



ways fatal, Heinrich noted.

Heinrich and his colleagues had been studying KIT receptor tyrosine kinase for years when they became interested in a new drug that was producing astounding remissions in clinical trials with patients suffering from chronic myelogenous leukemia, a blood cancer. The drug Gleevec had been developed by Novartis in collaboration with OHSU researcher Dr. Brian Druker. It targeted a mutated enzyme driving the uncontrolled growth of white blood cells. Because this enzyme is structurally similar to KIT, Heinrich’s team speculated that Gleevec might also inhibit the KIT enzyme.

After successful tests in the laboratory, Heinrich and OHSU/VA investi-

gator Dr. Charles Blanke led a multicenter study that found a majority of patients with GISTs responded well to Gleevec.

Still, researchers are puzzled by the molecular defect causing some GISTs to resist Gleevec, Heinrich noted. A new OHSU/VA study is near completion to determine Gleevec’s effectiveness against GISTs caused by abnormal PDGFRA rather than KIT. In the laboratory, Heinrich and colleagues also are exploring other protein defects that may cause some GIST cases, potential new drugs to target the PDGFRA mutation and the possible role of abnormal PDGFRA in other cancers.

In addition to Heinrich, Corless and Fletcher, co-authors of the Science report include Laura McGreevey, Diana Griffith, Andrea Haley and Ajia Town of the Portland VAMC/OHSU; Dr. George Demetri of the Dana-Farber Cancer Institute and Harvard Medical School; Dr. Samuel Singer of the Memorial Sloan Kettering Cancer Institute; and Dr. Anette Duensing, Chang-Jie Chen, Ph.D., and Dr. Christopher D.M. Fletcher, of Brigham and Women’s Hospital and Harvard Medical School. Jonathan Fletcher also is affiliated with Dana-Farber and Brigham and Women’s Hospital.

The research was supported by the U.S. Department of Veterans Affairs and the Janice and Michael Burke Leiomyosarcoma Research Fund.

## Life Raft Group launches survey on GIST treatment relapse

The Life Raft Group is completing an intensive investigation of patients with metastatic disease who have been on Gleevec for over a year, had a positive initial response, but subsequently relapsed.

The study is being carried out under the direction of Norman Scherzer, Life Raft Group executive director and a

former assistant commissioner of health for New York city, and is based upon data submitted by Life Raft Group patient members. The intent is to see if there’s any pattern to such relapses, such as drug dosage level. The results will be reported in the next issue of the newsletter and posted to the Life Raft Group Web site: [www.liferaftgroup.org](http://www.liferaftgroup.org).

[liferaftgroup.org](http://www.liferaftgroup.org).

In addition, the Life Raft is in the process of gathering interesting case histories that can be shared with other patients and with treating physicians. As is the case with all Life Raft Group data, all information is first cleansed of any identifying information before it is published or shared in any way.

## Grand view, courtesy Gleevec



**Gleevec patient Marina Symcox and her husband, Keith, pause atop the continental divide while on a March ski trip to Colorado. Three years ago this month, Marina was on oxygen while in hospice, waiting to die. Unbeknownst to her, a GIST patient in Finland began the first Gleevec-for-GIST treatments. Marina still can't ski well, but cancer has taught her to no longer worry about such trivialities. Marina invites all to check out a new online mail list, GIST Support International at [www.gistsupport.org](http://www.gistsupport.org). Membership is open to all interested in GIST.**

## Cancer bill: Medicare would cover oral medications

From Page 1

When science first brought treatments for cancer such as radiation and chemotherapy, these therapies were covered under Medicare Part B because they were administered in a hospital or outpatient care setting. In 1993, as research yielded new self-administered (oral) delivery methods for many of these treatments, Congress updated Medicare to include coverage for self-administered therapies as long as they were also available in an injectable form. This expansion ensured patients continued access to the latest cancer treatments.

Added Pryce: "In 2003, the vast public investment in cancer research has yielded new and better treatments for various types of cancer. Many of these



**U.S. Rep. Pryce**

therapies are available only in oral form, as this delivery device is often more effective with fewer side effects than an injectable. However, because they are administered solely in oral form, Medicare does not cover these life-saving treatments.

"Lack of coverage often means that any beneficiary without an alternative method of payment must default to older, often less effective treatments in order to obtain coverage through Medicare. The devastating impact of this

coverage shortfall becomes clear when one understands that more than half of all cancer diagnoses are within the Medicare population and that 20 percent of all Medicare beneficiaries have at least one cancer diagnosis."

Today Medicare covers about 95 percent of cancer therapy, but over the next decade as much as 25 percent of cancer drugs will be oral. Not only will these oral drugs be more targeted, less toxic and ones patients can safely take in the comfort of their own homes, these new drugs will be more cost-effective in comparison with the currently covered alternative treatments.

"It is time to update Medicare to provide patients with the best anti-cancer treatments available," concluded Pryce.

## GISTwife II

From Page 2

I was escorting Don out of ICU when all of a sudden there was a “CODE BLUE ROOM 201” over the intercom. I thought, “It’s not Bob, I just left him 20 seconds ago, and we are on the FIRST floor!” You can imagine the feeling when the loud-speaker came on again and said the correct room number was 101 — Bob’s room. First floor, first bed, ICU. I froze.

An older nurse came out of ICU running for more blood. Then the hospital pastor showed up. He did not identify himself but just stood there next to me wearing his chaplain badge. This was too much for me to handle. For goodness sake, we were dealing with back pain and an ulcer! Bob was all but dancing with my boss seconds earlier!

Bob had lost all his vitals and collapsed while trying to get to the porta potty. He lost so much blood they called the surgeon, and ran — and I mean ran — him to the operating room.

In the operating room they gave him an angiogram or something similar right in the stomach. It lit up a baseball-sized tumor. It glowed, surrounded by hundreds of “feeder veins” as I call them. It was those feeder thingies that were bursting and causing the bleeding.

In an hour and a half the surgery was complete. I was relieved. OK, so it was a tumor, but no one said cancer. Cancer did not occur to me in my fragile, sleep-deprived state. But ... what about the back pain? This tumor was in the jejunum, the small intestine.

The following day a surgeon from the group came to visit. He suggested it was leiomyosarcoma and to see an oncologist. Another doctor ordered a testicular cancer test.

I thought the worst was over. I didn’t know how good I had it with “back pain and ulcers.” Oh, by the way, the MRI had discovered a herniated disc



**Sarah and Bob Buch pause for a photograph just before taking a helicopter tour of the Denver Glacier outside of Skagway, Alaska, last June. Atop the glacier, they further explored the icy environment via dogsled.**

in his back. Poor Bob, they just finished cutting him up the front, and he was petrified that they were going to turn him over and cut him up the back!

The recovery period was tough on his digestive system. After 11 days in the hospital he was ready for dinner. Yet, like I couldn’t keep him down with his back, I could not convince him to stick with baby food for a day or two! He came home and ate things like steak and chili. Hardheaded ... anyone got one of those? Naturally, the effects of these poor choices did not occur until the middle of the night!! Sometimes we were sent back to the emergency room; sometimes I was heading to the 24-hour Walgreen’s. Soon after he was unable to keep anything down — but kept that fact hidden. He wasn’t telling anyone for fear of having to go back to the hospital. But when he lost 10 pounds and nearly ran out of potassium, he was rushed back for treatment.

Bob’s oncologist has little experience in GIST. He painted a rosy picture and prescribed CAT scans every

six months. We went home feeling great.

In June of 2001 I learned of the Life Raft Group. My naivety in regard to GIST was soon shattered. I am a proactive person, so I took action. I composed a letter to 12 specialists worldwide consisting of a summary of Bob’s path report, and a dozen or so questions. I was thrilled and surprised when five of the 12 either e-mailed me or personally called me at home.

One of the specialists who called asked if Bob was c-kit positive. He said, “There is no reason for us to discuss anything further unless he is c-kit positive,” he said. “You cannot call a GIST a GIST without a positive c-kit.” Well, according to the Mayo Clinic, he was positive.

Since then I have read and saved every e-mail from the LRG. This group is so important to the caregivers as well as the patients. I have been reading, mostly in silence, for over a year. I feel like I know you though.

**See GISTwife III, Page 7**

## Fund-raising fun, Roaring '20s style



**R**aising money for the Life Raft Group can be a ton of fun. Just ask Michael and Mia Byrne.

Last December, Mia says, her boss hosted the annual office holiday party, a “Roaring ’20s” theme casino night fund-raiser. “Our office was to choose a charity that our casino winnings would be donated to by he and his wife,” Mia said. “My co-workers chose The Life Raft Group in support of Michael.

“Well, we dressed as flappers and gangsters and together won \$961 for the Life Raft. Since our office is so small (three of us plus spouses) compared to the other business that participated, my boss said he will add another \$1,000 to make his total contribution \$1,961.

“Michael and I had a great time. Just remember, don’t ever bet with me at roulette or craps. I was not a big winner, but my co-workers came through.

“Just thought I would share that with the group. Maybe our photo will make it in a future newsletter.”

And here it is.

## GISTwife III

From Page 6

I cannot tell you how many caring people ask, “What’s it called again?” No one quite understands like all of you. In our case, Bob does not know all of you. He knows of you through siphoned information. Do not take offense. Until recently, he was not ready to hear ALL the nitty gritty. After all, he has not recurred. Although he is not in denial, he is in a peaceful state of mind. Bob is smart, positive, outgoing, and a huge sports enthusiast. (Go, ’Cuse! Go, Braves! Go, Avalanche! ...

go figure!)

So, I am the worrier. I am the information searcher. I have the specialists in mind. I have you all to count on. I have you to introduce to him “if and when.” I have a plan prepared ... just in case. These are the positives.

In closing, I would like to share that the insurance company would have paid for the initial CAT scan. The doctor told me, “They just rather you run the less expensive tests first.” I am sure they ended up spending MORE

money — on cheaper tests, added days in ICU, and extra blood transfusions. They lost in that way — but it could have been our loss ultimately. It could have cost Bob’s life. My frustration stems from the fact that I was not given the option up front to pay for the CAT scan if the insurance company refused. I now walk into doctors’ offices proclaiming, “Money is no object” in hopes we will be given all options.

Best wishes to all of you.

## Kerrie's story

From Page 3

hospital for severe pain and uncontrolled nausea. I knew it was bad but I didn't really know the extent of it because Kerrie was the type of person who didn't want to know or talk about it. Dr. Travis told us that he didn't know if she would make it to Christmas. We were told that there really weren't any more options and surgery was out because there was no place to start or stop.

She courageously fought on and would hear nothing about giving up or dying. She told the doctors she was

continuing with treatments and was going to beat this. With a lot of praying and fighting, she left the hospital a couple of days before Christmas feeling much better. She was doing pretty good until the end of January. Around the first of February we went back to the hospital. I thank the good Lord for that good month she had at home.

She had another CT and the GIST had grown even more. The doctors said that you should see a lot of black area on the scan and there was none. He told us that she had a couple of weeks. She still wasn't feeling real good, but at the two-week mark, we went home. We had a good few days before one morning when I was unable to get her up

from the couch. I called Dr. Travis and he told me to call an ambulance and get her to the hospital. That was Wednesday morning and she never regained consciousness. She passed away early Friday morning. She was the strongest, most relentless fighter I have ever known.

Kerrie's favorite verse:

"I shall not die, but live, and declare the works of the Lord." — Psalms 118:17

Again, I want to thank you all for your newsletter and everything you are doing to fight this terrible, unforgiving, indiscriminating disease.

**Stephen Larsen**  
Colcord, Oklahoma

## Family of Abdul Hai is grateful for the Life Raft

Dear Mr. Scherzer,

I am emailing you regarding my father, Abdul Hai, a resident of Karachi, Pakistan, and a member of the Life Raft Group, with whom you were occasionally in contact regarding Gleevec.

I am sorry to have to tell you that my father passed away a couple of weeks ago, on Feb. 26.

Our family is immensely grateful to you for acting on my dad's behalf to have Gleevec be available to him free of charge. In fact, just two days before he died, the Novartis representatives informed us that they would henceforth regularly provide us with a week's supply of Gleevec.

My dad had requested me to e-mail you and thank you again for your ef-

fort. I know that his continued contact with the members of Life Raft was a source of great comfort and emotional support to him.

I am very sorry to have to ask you to remove his name from the mailing list. Thank you again for all you have done.

Sincerely,  
**Mehreen Hai**

## In Memoriam

There have been 25 deaths in the Life Raft Group to date:

**Debbie Nance**, 38, Oct. 2, 2000, wife to Eddie, mother of Chris.

**Jim Ackerman**, 49, Jan. 16, 2001, husband to Betsy, father of Jill and Tom.

**Jim Perham**, 63, May 2001, husband to Karen, father of Craig, Kathy, Jennifer.

**Amy Barney**, 25, June 10, 2001, wife to Reed, mother of Joshua.

**Jeff Prichard**, 52, July 11, 2001, husband to Joyce, father of Gregory and Scott.

**Ron Martinez**, 60, July 25, 2001, husband to Jo Ann, father of Ron, Wendy, Natalie.

**Ehud Nehemya**, Aug. 7, 2001, father to Einat Zelinger, father-in-law of Ophir Zelinger, Hadar Nir.

**Bruce Gunn**, 43, Nov. 8, 2001, husband to

Roisin, father of Seamus, Liam, Brendan and Aislinn.

**Robert Carr**, Dec. 30, 2001, father of Robert, Steven, Scott and Melissa.

**Jonathan Montague**, 23, Jan. 19, 2002, son of Ray and Sheila Montague, brother to Jamie, Adam, Meghan.

**Robert Lecca**, 49, Jan. 28, 2002, husband to Diane.

**Jacob Winfield Waller III**, 67, March 31, 2002, husband to Jerry, father to Rita, Richard

**Mary Golnik**, 50, April 18, 2002, wife to Gary, mother to Timothy

**Ana Maria Baldor-Bunn**, 30, April 19, 2002, wife to Stan, mother to William.

**Stewart "George" Wolf**, 51, April 19, 2002, husband to Maggy, father to Thomas.

**Michael Cornwell**, April 19, 2002, husband to Cathy.

**Jerry Pat Rylant**, 61, May 5, 2002, husband to Pamela, father of four, grandfather to 10.

**Jill B. Meyer**, 53, June 9, 2002, mother of Aliza.

**Todd Hendrickson**, 44, June 29, 2002, husband to Janet, father to Max, Tyler and T.J.

**Chet Duszak**, 79, Oct. 5, 2002, husband to Kay, father to Lori.

**Nora Shaulis**, 42, Nov. 4, 2002, wife to David, mother to Griffin.

**Howard Delapenha**, 41, Dec. 14, 2002, husband to Sandra, father to Joshua and Hannah.

**Kathy Colwell**, 45, Jan. 5, 2003, wife to Tom, mother of Katherine, Mary and Tom.

**Cynthia G. Whitson**, 64, Jan. 19, 2003, wife to Jerry, mother to Steve, Jill, Randy and Donna.

**Abdul Hai**, 76, Feb. 26, 2003.



# THE LIFE RAFT GROUP

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## Who are we and what do we do?

The Life Raft Group is an international, Internet-based, non-profit organization providing support through education and research to patients with a rare cancer called GIST (gastrointestinal stromal tumor). The Association of Cancer Online Resources provides the group with several listservs that permit members to communicate via secure e-mail. Most members are being successfully treated with an oral cancer drug Gleevec (Glivec outside the U.S.A.). This molecularly targeted therapy inhibits the growth of cancer cells in a majority of patients. It represents a new category of drugs known as signal transduction inhibitors and has been described by the scientific community as the medical model for the treatment of cancer.

## How to join

GIST patients and their caregivers may apply for membership free of charge at the Life Raft Group's Web site, [www.liferaftgroup.org](http://www.liferaftgroup.org) or by contacting our office directly.

## Privacy

Privacy is of paramount concern, and we try to err on the side of privacy. We do not send information that might be considered private to anyone outside the group, including medical professionals. However, this newsletter serves as an outreach and is widely distributed. Hence, all newsletter items are edited to maintain the anonymity of members unless they have granted publication of more information.

## How to help

Donations to The Life Raft Group, which is incorporated in New Jersey,

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