Battling GIST with Gleevec (STI571)

LIFE RAFT GROUP

December 2002 In memory of Howard Delapenha Vol. 3, No. 11

Irmgard and Mel Heller hike up a hill last August with their lovely Chesapeake shore in the background.

Mel Heller is 'stubbornly optimistic' at eight decades

Psychiatrist deals with loss of hearing, GIST, but remains positive

By Mel Heller

The following e-mail arrived Nov. 8:

"Hey Mel, Tell us your story. From the bits I know, it is great. Marina."

How can one say "no" to our brave and sparky Marina? Especially when her request was furthered by Cynthia, who wrote, "...When you get time, I wish you would post your GIST story or something about yourself …"

I hope that Marina and Cynthia won't be sorry that they asked for this. Let me start with my GIST story, and

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Sugen drug 'surprisingly effective' in early trials

European study finds it works in about 25 percent of patients

The new cancer drug from Sugen has proven surprisingly effective in early clinical trials, dramatically shrinking tumors in 25 percent of patients.

Preliminary results from a phase I trial at France's biggest cancer center, Institut Gustave Roussy in Villejuif, were presented at the 14th EORTC-NCI-AACR cancer symposium held Nov. 19-22 in Frankfurt, Germany. The symposium was jointly sponsored by the European Organization for Research and Treatment of Cancer, the U.S. National Cancer Institute and the American Association for Cancer Research.

The oral cancer drug SU011248, which is given in capsule form, is a signal transduction inhibitor designed to act against several abnormally behaving enzymes along the cellular signaling pathway. SU011248 was developed by Sugen, a California-based company that was acquired in 1999 by Pharmacia.

Patients in the study had a range of advanced cancers, including renal, non small-cell lung, neuro-endocrine, uterine, angiosarcoma, mesothelioma,

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Researchers find GIST more common than once thought

Study finds GIST occurs three times more often than previously believed

Gastrointestinal stromal tumor — isn't quite as rare as previously believed.

A study presented at the 27th annual European Society of Medical Oncology Congress held in Nice, France, in October found that GIST arises three times more often than doctors believed.

Swedish researchers calculated that the incidence of GIST is 16 cases per 1 million people annually. Their study was the first population-based examination of the incidence of GIST.

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Sugen

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pancreatic, breast, colorectal and nasopharyngeal. Patients had failed to respond to all other therapies: in many cases at least three different types of treatment had been tried.

"Any activity in this situation is very promising since everything else has failed," said lead researcher Dr. Eric Raymond. "But we did not expect to see such a high number of responses in a range of cancers." A response was defined as a tumor reduction of more than 50 percent as measured by CT scan.

The goal of any phase I trial is to determine drug safety, not to measure the effectiveness of the drug. That patients responded well, Raymond said, "was huge. You are expecting in a phase I trial less than 5 percent response."

The drug is well tolerated by most patients. The dosage was increased for some patients, and patients became more fatigued the greater the dose.

The drug also drained the color from patients' hair, and some patients' skin turned a "tanned gold" from the drug. This effect wore off within a week of stopping treatment.

Raymond said that the phase I study would continue for the next six months or so. Phase II and III studies would start immediately afterwards and would include a formal analysis of the response rate — an analysis that was inappropriate for the phase I study, which began with very low doses of the drug.

Jerry McMahon, president of Sugen, said there were a half dozen phase I trials underway and all are producing similar results — including patients with GIST, gastrointestinal stromal tumor. More data will be presented at the American Society for Clinical Oncology conference next year.

The drug is a newcomer in the field of anti-angiogenics — drugs designed to damage tumors by attacking the blood vessels that feed them. Although it has been a major research field over the last decade or more, angiogenesis has not so far lived up clinically to its early research promise. But, the response in this study provides evidence that anti-angiogenics may yet have a future.

Added Raymond: "Initially we thought that the drug would be an angiostatic agent that stabilises tumors, rather than an angiotoxic agent that actively shrinks tumors. Angiostatic compounds were associated with a low level of response, but angiotoxics are much more promising in inducing responses.

"We were happily surprised right from the first patient response — a reduction of more than 50 percent in the tumor for six months in someone with a renal cancer that had recurred and who also had adrenal and lung secondaries that had not responded to immunotherapy."

Dr. Jaap Verweij, chairman of the meeting's scientific committee, noted that he's "seen a lot of phase I trials in my life," and called the results "fascinating. And the toxicity we will learn how to handle that, I am sure."

Raymond said that a lot more work needed to be done on dosing and on toxicity as the drug affected normal blood vessels as well as tumor vessels. It was also vital to get information on toxicity after repeated treatment cycles to avoid discovering late delayed cumulative side effects.

He concluded that if the drug's activity holds up in further trials, it has the potential to be a potent new weapon.

"It is one of the first angiotoxic drugs with anti-tumor effects. In fact, we had too much effect in higher doses in some patients resulting in tumor necrosis that required surgery. So this drug is teaching us a lot about the potential efficacy and, just as important, about the adverse effects of new anti-angiogenic agents."

From the ECORT Web site, Reuters Health News and MW Communications.

Heller

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then, I caution impatient readers, I will go on for a bit. So, here is something about who I am. What I am, I'm still not so sure.

First, let me say that I am, despite GIST, a reasonably healthy, married 80-year-old with a stubbornly optimistic outlook and a strong, enduring faith for the future of your and our loved ones. I retired in 1990 as clinical professor of psychiatry at Temple University Medical Center in Philadelphia, but have remained active in part-time practice, and continue to study, teach and learn.

I thought I might have some wisdom when I reached 80, but sometimes I'm not so smart at all. For example, despite having been a medical doctor for more than 50 years, I completely missed my own diagnosis.

Not only had I missed the diagnosis, but I hadn't even considered the possibility. "What would you expect from a psychiatrist?" you might ask. Hopefully a lot, at least diagnostically. Considering that I had spent a couple of years in a surgical internship and residency program before I got interested in psychiatry, I certainly knew how to diagnose a surgical abdomen. Understand that the knack of diagnosing a surgical belly, like that of riding a bike, is little different today than it was 50 years ago. Some things, like the signs and symptoms of peritoneal irritation or inflammation, don't change.

I'm telling you this because a number of us Life Rafters began our GIST adventures with a missed diagnosis. In my case it began the night of Oct. 20, 2001, following a sumptuous Sunday supper prepared by my good wife, Irmgard. Having had my gall bladder out the year before, I confidently assured her that I had probably eaten too much, and that it was merely a case of indigestion.

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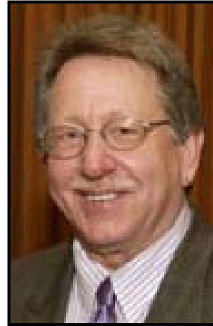
The Life Raft Group needs your help

$50,000 will secure a matching grant from Novartis Pharmaceuticals

The Life Raft Group remains a work in progress. Starting with a handful of members, the Life Raft Group began in the summer of 2000 as an informal group of GIST patients who were part of the first clinical trial for Gleevec. Gradually, we expanded our membership criteria to all GIST patients, regardless of treatment status. In June of 2002, we were formally incorporated in the United States as a 501-C-3 non-profit organization. Since then we have rented a small office, hired a full time executive director, a part-time administrative assistant and a very part-time IT director. Our key volunteers have also been expanded and now include a newsletter editor, Web master, list manager, science team leader, medical librarian, chief financial officer, accountant, general counsel, area coordinators in Los Angeles and Chicago, and country representatives in the U.K. and France. We have grown to more than 225 members in 18 countries and continue to expand on an ongoing basis.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We remain committed to providing support to GIST patients and their families, to providing information and education to doctors and other medical professionals, and to reaching GIST patients not yet properly diagnosed and/or treated. This mission continues to grow around the world and it continues to focus on ensuring the survival and well being of GIST patients, with a clear priority to addressing the causes of drug resistance.

Although when we met as a group in May 2002, we voted to ask each of our members to pay dues, we have not yet decided to implement such a policy. We have been fortunate to receive a generous start-up contribution from Novartis Pharmaceuticals and from several of our members. We need to raise $50,000 towards the portion of the Novartis grant requiring such a match in 2003. In addition, we need to expand our capability to reach a growing number of patients and doctors and to address the growing number of GIST patients resistant to existent treatments.

We are asking you, your family and your friends, to contribute what they can during this holiday season and as we enter the new year. Contributions are fully tax deductible in the United States.

Contributions should be payable to The Life Raft Group, and sent to John Poss, Chief Financial Officer, The Life Raft Group, 8507 Forest Hills Blvd., Dallas, TX 75218

International Contributions can be sent via the Bank of America directly to the checking account maintained by John. If you wish to do this, please e-mail Trish McAleer, administrative assistant, for the instructions at tmcaleer@liferaftgroup.org.

Norman J. Scherzer
Executive Director
Stan Bunn
President, Board of Directors

Heller 2: GIST proves humbling for this doctor

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A few hours later, my wife said I looked pale. Leave me alone, I insisted. Thankfully, she did not, and I got my come-uppance – this overly confident doctor fainted from internal blood loss and came to as a humbled patient, properly laid low in an ambulance, on the way to the hospital. Live and learn. Who needed to learn about this? Apparently I did, because it has been a powerful learning experience, especially for a doctor.

Well, you GIST'ers know the rest of the story. Like you, I had never heard of a gastrointestinal stromal tumor when my surgeon told me that the 12- to 15-centimeter tumor was malignant, and had ruptured into my peritoneal cavity where it had deposited two and a half liters of blood.

"So, we did a subtotal gastrectomy. Had to take a bit more than half of your stomach, and by the way, we did a splenectomy because your spleen was in the way."

So there went my perfectly good spleen, and half my stomach, so shortly after losing my gall bladder. How easy it is lose things as one gets old, I reflected. But by then, my busy and good surgeon was quickly displaying for me an emesis basin with bits and pieces of a gray and bloody tumor (mine), covered with damp gauze (theirs). Then, on his way, he added somberly and hopefully, "I think we got it all, but you know it was ruptured, and so we have to hope for the best." I liked him then, all business-like, and still do.

You know, when doctors become pa-

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Heller 3: Irony of a psychiatrist who goes deaf

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tients, especially in a situation like ours with a sarcoma like GIST, it is, to put it mildly, an "interesting" experience. (Did you know, by the way, that the Chinese allegedly have a curse that goes something like, "May you have an interesting life!")

In addition to all of the emotional aspects of encountering a major illness, we doctors tend to think of all the worst-case possibilities, perhaps like an experienced auto mechanic when he hears grinding noises in the engine or transmission of his own aging car. And so, weak and laid low, I attempted to sort out some of that, and its sober implications, as I tried to stay alive during the next several days in intensive care.

Finally, on the 10th day post-op, indeed grateful for the care but so very weary of the hospital impedimenta or "baggage" and routine, I prayed (yes, I prayed) that my peritoneal drainage tubes could be removed and that I might be sent home. And on that last morning, a very young man whom I had not seen before woke me at 5 a.m. and, sitting on the edge of my bed, told me he was an oncologist, asked me a few questions, and wondered if I had any for him. "No," I told him (I was hardly awake). He said that, unfortunately, there was no adjuvant therapy for GIST, left me his card, and suggested that I call his office in about a month. Well, good for him.

Now, let me tell you some other interesting news. My son-in-law happens to be a highly regarded and accomplished oncologist nearby, in the D.C. area. He is the father of my three granddaughters and married to my only daughter, Joan, who is in her third year of remission from acute myelocytic leukemia after three horrendous bouts of chemotherapy, and for whose continued remission and well-being I pray far more ardently each day than for any other of my heart's wishes.

Ironic, it seems, that "my son, the oncologist," has a wife and father-in-law, both of whom have cancer concerns.

Well, Marina and Cynthia, since you asked, I'll add another couple of dimensions to this story:

GIST is not my first battle with cancer. In 1989, following a routine chest film, I underwent a left lower lobectomy for bronchio-alveolar carcinoma, and growing quite strong again, have lived to tell the tale. I'm not bragging mind you, merely telling the tale. What has this got to do with the price of beans, as we asked in New England where I grew up so long ago but seemingly yesterday? Well, just this: my middle granddaughter, 14, looked at me a few weeks ago with her blue eyes and her therapeutic, youthful sincerity, and said, "Grandpa, you'll be fine. I don't worry about you. I kind of think of you as a tree, tall and strong, like an old oak." From her lips..., as the saying goes.

> Quote:
>
> **"Grandpa, you'll be find. I don't worry about you. I kind of think of you as a tree, tall and strong, like an old oak."**
>
> — Mel Heller's middle granddaughter, age 14

So, I'm perhaps not as scared of cancer, for myself that is, as I should be. And as you can see, like the rest of you perhaps, I indulge in a bit of magical thinking now and then. It comforts me, but I don't fool myself.

I'll give you one other item in this script. Beginning about age 50, I began to experience hearing loss, first only in one ear, and then alarming in the other. I eventually became quite hard of hearing — a lousy and ironic plot development in the life of a shrink. A psychiatrist who goes deaf seems almost as tear-jerking a story line as a surgeon who goes blind — not to mention deafened Beethoven who could no longer fully hear the splendid music he continued to create inwardly.

Well, I use a TTY and relay operator (711) to phone, and I do a lot of lip-reading, and found there is indeed life after deaf, even for a psychiatrist. After retiring from Temple, I could have sent myself out to the green but challenging and eventually humbling pastures of golf, or fished and sailed full-time on the beckoning waters nearby. But I still wanted to practice my profession, and so, about 10 years ago, I began to learn sign language, and worked with children, their counselors and teachers at several nearby schools for the deaf.

Life, I think, is a lesson too often learned the hard way. I became hearing impaired and learned about the world of the deaf. I got GIST, and learned more about the world of cancer — things we do not learn in medical school. I hope and pray, however, that I shall not be exposed to more such lessons first hand.

Why have I told you all this? Much of it follows Marina's exquisite examples of intimate human sharing with us all. And Cynthia's request for something of "my story." But it really follows upon a warm greeting I received from Richard Palmer a few days after I first climbed aboard our LRG:

Richard wrote: "… While we can't do much about our GIST, we can control how we react to it emotionally. … Nonetheless, CT scan time puts everyone on edge, even veterans who've

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Heller 4

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Mel and Irmgard Heller, enjoying a quiet moment.

been dealing with the disease for several years. I've collected some of the comments made by Life Rafters that have resonated with me.

"Marina: 'Norman called the scans "Quarterly Installments of Terror." Ditto for me.'"

"Pat: 'One cancer patient said to me after his three-month check up, "Another three months of parole."'"

"Beverly: 'For me, the three-month scan thing is a reminder to appreciate life. It's like every three months, go see if you will live or die ... More than most, we three-month people are forced to appreciate the time we have.'"

"Tim: 'I am always on edge on scan day. I am a runner and my resting pulse is usually under 60. On my last scan I was at 100. Sitting in that examining room, staring at the door, waiting for the doctor to come in is pure agony.'"

Continued Richard: "I include such things in the newsletter to put a 'face' on the disease for researchers and the drug companies …anything to encourage extra effort to find the answers to resistance and recurrence, since we know Gleevec controls but does not cure our GIST."

So, responding to Richard's wish that the newsletter could somehow "put a face" on us, I quickly sent back some thoughts, including the following:

"It seems to me that we are sitting, standing or lying together, with some of us dying sooner and some later — but all of us eventually of one thing or another, not necessarily from GIST. Perhaps this business of facing one's pending mortality is an integral, if not the central and most significant ingredient, not only of the GIST and Life Raft experience, but of the so-called human condition.

"… I think we can perhaps do more for each other and the researchers if we might even develop and discretely and responsibly share a sort of profile of the kinds of people who have been hit by GIST, our specific encounter with cancer, and how we are handling it inside.

"… Richard, your brief notes about how some of our members have expressed the anxieties that hover over this Raft put me on to this. It gave me the thought that perhaps we might find ways of collecting meaningful input about who we are, and how we are being impacted by this specific type of cancer, and our adaptations to its anxieties, pitfalls and prospects."

So, dear Rafters, this letter was kind of brewing. Enough for now. Maybe too much. I hope not. Perhaps some of you, emboldened by the example of Marina and others of our crew, can respond to Richard's wish, which I echo and endorse, that we "put a face" on the story of our battles with GIST.

As I say, I'm trying to dip my paddle in and add momentum to our endeavor, somehow, somewhere — and hopefully without splashing on too many others.

GIST: Less than a third are initially diagnosed as GIST

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The researchers analyzed medical records and pathology reports of 1,500 people with abdominal tumors from 1983 to 2000. They found 400 cases of true GIST in that group. However, only 28 percent of the 400 received a GIST diagnosis originally.

In their study, the researchers used a special staining kit to identify GIST cases. This new form of immunohistochemistry makes it easier to identify GIST.

The researchers say being able to more accurately diagnose GIST is important because there is now an effective treatment for it — imatinib, better known as Gleevec. GIST is resistant to chemotherapy and radiation.

SOURCE: Swedish Research Council, news release, Oct. 22, 2002

Howard Delapenha loved helping others

Services for Howard Delapenha, 41, were held Dec. 19 in Rosedale, Queens, New York, U.S.A.

Howard Delapenha was a native of Brooklyn, New York, but his parents returned to Kingston, Jamaica, when he was an infant. He was raised there, and returned to the United States when he was 16 with his sister and mother, who was battling cancer.

Howard Delapenha attended St. John's University. His career centered on helping others as a social worker in job development, assisting those on welfare, youth and adults in job training & placement.

Besides is family, Howard had several other loves. He loved helping people, and made a career of it. He loved animals. He once saved a dog that had been hit by a car and brought it home. He was the only kid in his town in Jamaica who had a horse.

He loved to sing, and sang to Sandra on their wedding day. He loved to cook, and would say "cooking is therapeutic." He loved to make soup that he ate most every day.

Sandra says Howard, as evidenced by his recent e-mails, was "strong until the end" and fought a good fight.

Howard is survived by his wife, Sandra, of Rosedale and their two children, Joshua, 14, and Hannah, 12. He is also survived by his best friend and sister, Dianne.

In Memoriam

There have been 21 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 Betsye, 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, 2001, 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.

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, husband to David, mother to Griffin.

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

Area meetings coming in Michigan, Illinois

Area meetings of Life Rafters will be held in January in Michigan and Illinois.

The Michigan Life Raft Group will hold its first meeting at noon Saturday, Jan. 4, at Gilda's Club. "Gilda's Club is a wonderful non-profit group dedicated to assisting individuals and other groups with cancer," reports meeting organizer Allan Tobes. Gilda's Club is located at 3517 Rochester, Royal Oak, Michigan. For details, contact Allan at atobes@comcast.net

Following a successful inaugural meeting of the Illinois chapter of Life Raft Group in September, the second meeting is happening Jan. 11, 2003. All Life Raft Group members from the surrounding area are invited to attend.

The meeting will be held on a Saturday this time to accommodate those who are working and had trouble taking the time off for the first meeting, reports area coordinator Dick Kinzig. The meeting will be from 10 a.m. to 2 p.m. at "The Wellness Place," a cancer support center with a homelike atmosphere located in Inverness, Illinois.

Those interested should contact Dick Kinzig as soon as possible either via e-mail at rjkinz@aol.com, or by phone at 1-847-359-3626 to learn more about the meeting and how to get there.

All new members from Illinois are especially invited to attend.

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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), most of whom 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 at the Life Raft Group's Web site, 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, U.S.A., as a 501-c-3 nonprofit organization, are tax deductible in the United States.

Donations, payable to The Life Raft Group, should be mailed to:
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Disclaimer

We are patients and caregivers, not doctors. Any information shared should be used with caution, and is not a substitute for careful discussion with your doctor.

As for this newsletter: read at your own risk! Every effort to achieve accuracy is made, but we are human and errors occur. Please advise the newsletter editor of any errors.

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