

New trial combines Gleevec, surgery

Study looks at surgery to remove tumor, the drug to keep it at bay

A phase II clinical trial combining Gleevec with surgery for people with gastrointestinal stromal tumor (GIST) is seeking patients.

The purpose of the trial is to study the effectiveness of Gleevec (previously called STI571, also known as imatinib mesylate) before and after surgery for either original or recurrent GIST.

Patients will take Gleevec for eight weeks so long as their cancer doesn't progress. Patients with disease progression will immediately undergo surgery. Otherwise, after eight weeks, patients will undergo complete surgical resection of their tumor. Two to four weeks after surgery, patients will begin receiving Gleevec. Patients will be evaluated every three months for two years, and then every six months for three years.

The objectives of the study:

- To determine the disease-free survival of patients with primary or recurrent resectable GIST treated with neoadjuvant and adjuvant Gleevec.
- To determine the objective response rate of patients treated with this drug.
- To determine the safety of this drug in these patients.

The trial will accept patients with

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Battling GIST with Gleevec (STI571)



LIFE RAFT GROUP

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In memory of Ana Baldor-Bunn, Mary Golnik, Jacob Waller, George Wolf

Early testing begins for new GIST drug

It's for people who can't tolerate Gleevec or had cancer growth on Gleevec

Early human testing has begun on a new drug to see if it can be effective against GIST in patients who couldn't tolerate Gleevec or had cancer growth while on Gleevec.

SU011248, like Gleevec, is a signal transduction inhibitor and comes in capsule form. It is made by Sugen, based in San Francisco, California. Sugen was acquired in August 1999 by Pharmacia Corporation, one of the world's largest multinational pharmaceutical companies.

According to the draft trial protocol, SU011248 was first given to test subjects who didn't have GIST to begin determining the most appropriate and tolerable dose. The phase I (earliest phase of human testing) clinical trial will help determine the best dose for GIST patients, see how GIST responds to SU011248, and what are the side effects.

According to its Web site (www.sugen.com), Sugen has focused on investigating signal transduction pathways that transmit messages into a cell and its nucleus. These pathways are key to the normal functioning of virtually every type of cell.

Normal cells don't proliferate unless

See Sugen drug, Page 2

Boston gathering is almost here

The Life Raft Group will hold its first meeting May 3-4 at the Radisson Cambridge Hotel in Cambridge, Massachusetts.

Never before have so many cancer patients who were on the brink of death come together to celebrate their survival and to honor their rescuers.

About 100 patients with a rare can-

cer called GIST, and their families, will be meeting each other for the first time. Many have already become old friends, having shared their most intimate thoughts with each other over the internet.

The meeting will bring together patients, their families, and a number of

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Sugen drug

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they are signaled to do so by other nearby cells. This ensures that cell and tissue growth is done in an orderly, interdependent manner. Accurate and timely cell signaling — called signal transduction — is key to a healthy balance of cell growth and metabolism.

Many cancers happen, researchers believe, when the cell signaling pathway breaks down, and the cells begin proliferating in an uncontrolled manner.

Of the many cancer-related genes (oncogenes) identified to date, says Sugen's Web site, many appear to be abnormal versions of signaling pathway components, such as tyrosine kinases (TKs), which are enzymes that function as signaling molecules. Other oncogenes include serine-threonine kinases (STKs), the most abundant molecules found in cells, responsible for controlling the cell cycle, a cell's response to stress, the development of certain cells and tissues, and more.

The close tie between cell signaling aberrations and cancer has led many researchers, including those at Sugen, to think that certain cancers could be classified more effectively by their signaling pathway defects than their mere physical location (e.g., TK or STK rather than breast or lung).

Using this approach, Sugen's Web site says, a suspected cancer might be diagnosed by first sending a tissue sample to a pathology lab. If cancerous, gene or protein expression profiling could be done. If overexpression of a particular TK was found, the doctor could treat the cancer with the appropriate target-specific signal transduction inhibitor.

SU11248 is a small molecule drug — small molecule, because they more easily penetrate cell membranes and the blood-brain barrier, and they

Professor George Wolf, 51

Stewart "George" Wolf, a linguistics scholar and professor of French at the University of New Orleans, Louisiana, U.S., died April 19, 2002, of cancer at Memorial Medical Center. He was 51.

A new Life Raft member, he was born in New York City and lived in New Orleans for the past 15 years. He graduated from Phillips Academy and received a master's degree in French from Columbia University and a master's degree and a doctorate in modern languages from Oxford University.

He taught at the College of William and Mary and was an acting principal of the high school at St. Hilda's and St. Hugh's School in New York.

Wolf was widely published, having edited or translated several books, including "Integrational Linguistics: A First Reader," which he co-edited with Roy Harris, and "Linguistics Inside Out: Roy Harris and his Critics," co-edited with Nigel Love.



He also wrote numerous articles and reviews in scholarly publications and contributed chapters to a number of books on linguistics.

Wolf organized the conference for the International Association for

the Integrational Study of Language and Communication held in New Orleans in March, where he presented a paper titled "The Pre-history of Grammar." Long before he embarked upon his career, one of the landmarks in his life was attending Woodstock. A year later, when he met his wife-to-be Maggy,

they saw the movie "Woodstock" on their first date. It was the beginning of a romance that would last some 32 years.

He was a board member of Carrollton Soccer Association and a member of Trinity Episcopal Church, where a memorial service was held April 24.

Survivors include his wife, Maggy Sawin Wolf; a son, Thomas Wolf, 10; a brother, Thomas Wolf; a sister, Angeline Gloria, and his father, Stewart Wolf.

can be delivered orally or intravenously. These molecules also tend to be cheaper to make.

Initial results of animal studies for this SU11248 indicate potential activity against some forms of cancer by inhibiting the tumor's blood supply, thereby inhibiting tumor growth and survival.

Sugen's draft trial protocol and Web site emphasize it is not clear whether this drug will be effective in treating cancer in people.

Future phase II trials, which will

look at the efficacy of SU11248, are planned. When these trials are started, they will be listed at ClinicalTrials.gov Web site.

Several Life Raft group members learned about SU11248 at a mid-March meeting with Dr. Robert G. Maki of Memorial Sloan-Kettering Cancer Center in New York City.

Attending the meeting were Norman Scherzer, Tania and Robert Stutman, Dan C., Joan A., Ana Baldor-Bunn's

See More Sugen, Page 4

From 'rock bottom' to happiness

Editor's note: Life Rafter Laura Cooley posted the following message to the Life Raft Group on April 4. It is published with permission.

I can hardly believe it, but today is the one-year anniversary of my diagnosis. I sent the following e-mail to my family and friends earlier today as a reflection on the last year. I haven't gone through nearly as much hardship as a lot of other Rafterers, but thought I'd share this anyway. I knew this group could relate to how I feel this day.

One year ago right now, I was waking up in a hotel room in middle-of-nowhere Rochester, Minnesota, getting ready for my appointment at the World Famous Mayo Clinic. I was feeling a little better after having received five units of blood during the previous weeks.

When I had first gone to the doctor in late February, my blood count was so low they couldn't figure out how I drove myself there, much less how I was managing to work full time and take care of a 10-month old!

But, I was counting on the World Famous Mayo Clinic to tell me how to get rid of these pesky benign tumors that had popped up in my stomach and liver.

Little did I know that in a few short hours, my life was going to be changed forever.

As we all know by now, it turned out that I didn't have pesky benign tumors. I had Cancer. And ironically, it turned out that the World Famous Mayo Clinic gave me the worst advice of my life!

After the doctor came in and started talking about the options I had for treating my cancer, I stopped him and said, "excuse me?!?!" They had forgotten to TELL me I had cancer before they started spelling out treatment options. So much for bedside manner!

Anyway, long story short, under the



The Cooley family: Laura, Ben, and their son, Jacob, at home in Columbus, Ohio, U.S.A.

care of their (world famous) Mayo Clinic advice, I was not to have surgery to remove the large bleeding tumor, I would just start chemo and cross my fingers. THAT was rock bottom.

Today is one year after that Worst Day of My Life. I got myself some much better advice after that horrible day, and today I feel great, my blood counts are great, my cancer appears to be stable, and I have returned to a lot of things that make me happy. Time with family and friends is right at the top of the list, which is why I have chosen to philosophize to all of you at 5:30 in the morning. (Sorry about your luck ...)

Sure, I've lost a couple of major organs in the process (I have yet to figure out what my now-missing gall bladder's function actually was?). But after almost a year without a stomach, I eat very well (as my mother and husband can tell you) and have very few problems. I encountered other bad advice along the way, but now after some false starts and a LOT of traveling, I have an oncology team that I think is the closest thing to heaven here on earth. (If you are interested in knowing

more about Dr. George Demetri, he has his own Web site at www.sarcoma.net). I truly owe my life to Dr. Demetri and, of course, to Gleevec.

My mom wondered why I considered today to be my big turning point, rather than April 30th (surgery day). I pointed out that surgery day was a much bigger deal for her than me — I was blissfully "asleep" the whole day. (The things a toddler's mom will do to get some rest ...!) Seriously though, April 4th is the day that will always stick out in my head. It was the day my world changed forever. And it is the day I will pause every year to admire how far I have come since Rock Bottom.

I apologize for taking up your time this beautiful morning, but I woke up today so happy to be alive and so grateful for all of the support I have gotten from all of you over the last year. I couldn't have done it without you! I love you all!!!!

You may now return to your regularly scheduled day ...

All my love,
Laura Cooley,
Columbus, Ohio

Gathering

From Page 1

key medical researchers and clinicians from the Dana-Farber Cancer Institute and from Novartis, the pharmaceutical company that makes Gleevec, the targeted cancer drug responsible for saving the lives of so many GIST patients.

The meeting will be opened by Life Raft Group Coordinator Norman Scherzer, a former disease management specialist for the Centers for Disease Control and assistant commis-

sioner of health for New York city.

Friday night, the Life Raft Group will present its first Humanitarian Award to Dr. Daniel Vasella, the CEO of Novartis.

Saturday, the group will present its second Humanitarian Award to Dr. George Demetri, director of the Center for Sarcoma and Bone Oncology at Dana-Farber.

Special recognition awards will also

be given to the Dana-Farber Cancer Institute, and accepted by its President Dr. Edward Benz, and to the president of the Association of Cancer Online Resources, Gilles Frydman.

The meeting will feature a series of unprecedented interactive sessions between patients/caregivers and research clinicians sitting down together and exploring treatment effectiveness and side effects, and sharing information.

More Sugen

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aunt Teresita and her son.

“Dr. Maki showed us slides,” said Robert Stutman, “showing us what GIST looks like and how Gleevec works. He explained everything as he went along so even a layman could understand.”

Dr. Maki also talked about a phase II trial of a drug by Millennium Pharmaceuticals called PS-341 for patients with advanced or metastatic sarcoma (though not specifically GIST).

Right now there are only two places where the trials are being held, said Robert: Dana-Farber Cancer Institute in Boston, Mass., and Memorial Sloan-Kettering. The trials are starting with just a handful of patients.

“Let us hope that these drugs are as successful or more successful than Gleevec,” said Joan.

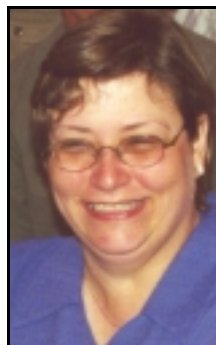
Mary St. Martin Golnik

30 August 1951- 18 April 2002

“I still love you”

Mary St. Martin Golnik, 50, of Old Bare Hill Rd., Boxford, Massachusetts, U.S.A., artist and wife of Gary Golnik, died April 18, at home after a long illness.

Born in Northbridge, Mass., daughter of the late Romeo and Cora St. Martin, she was a graduate of the School of the Worcester Art Museum and The University of Massachusetts, Amherst. An illustrator, art teacher and tole painter, she enjoyed her art and her friends.



In addition to her husband with whom she shared 27 years of married life, she is survived by her dearest son, Timothy Golnik of Boxford; a sister, Doris St. Martin of Northbridge, Mass., and a brother, Edward St. Martin of Libertyville, IL.

Mary has requested that there be no services. Memorial contributions in her name may be made to The Life Raft Group, c/o John Poss, 8507 Forest Hills Blvd., Dallas, TX 75218.

Gleevec & surgery

From Page 1

measurable disease that has not spread from its original site.

Patients must not have had chemotherapy, radiation therapy or biological therapy within four weeks of starting the trial.

The trial is being sponsored by the National Cancer Institute, and 63 pa-

tients are being sought for the trial.

For patients seeking more information, the clinical trial protocol identification numbers are ACRIN-6665, RTOG-DEV-1055, RTOG-S-0132.

Principal investigators are Dr. Annick D. Van den Abbeele of the American College of Radiology Imag-

ing Network, Boston, phone 617-632-3223, and Burton L. Eisenberg of Fox Chase Cancer Center in Philadelphia, phone 215-728-3096, e-mail BL_Eisenberg@fccc.edu

More information is also available at the National Cancer Institute Web site, www.cancer.gov

A Life Rafter's trip from hospice to hope

Editor's note: Life Raft member Marina Symcox posted this to the list March 6 after she'd returned home to Bristow, Okla., from seeing Dr. Charles Blanke at Oregon Health Sciences University in Portland. The occasion was Marina's 16-months-on-Gleevec visit. Marina's post is published here with permission.

By Marina Symcox

I have returned from the Land of Gleevec, a.k.a Pendleton, Utopia. First, I must give you the headline news. Dr. Blanke said to me, "I don't think your GIST will kill you any time soon." It was a most stunning announcement. It even topped the very bold statement he made to me in October 2000, when I first appeared on his doorstep in a dire situation.

Back then he said, "I can't promise you anything, but most people feel better on the drug" (referring to the first GIST patients who were two to three months ahead of me in the trial). At the time, I was shocked that any sarcoma doctor would say something so boldly optimistic to me. Any kind of hope was stunning to hear, after three years of intense physical decline, a watermelon-sized mass of GIST, and all the grim prognoses from the world's best sarcoma doctors, George Demetri included. The October 2000 statement was eloquent in that it proved to be such an understatement. Poetry to me.

A formidable enemy

My GIST tumors are innumerable in my liver, and surgery is impossible. I greet each day with faith that Dr. Blanke has a good crystal ball. Nevertheless, I've been around the block enough times to realize that cancer is a formidable enemy. I take nothing at face value. Norman once said something about the process of "learning to live with hope again." This is a task I tackle with one eye on the moon and

another viewing my old footpath in hospice. To ever find enough peace to relish each day, a person has to embrace death. "Dying today is OK." I know that much from hospice. But for today, I am one lucky lab rat. Modern medicine has pulled off a most amazing accomplishment. For those who continue to struggle against GIST, and for our ACOR friends with leiomyosarcoma ... do something in their honor that is within your power. Write your legislator about the Medicare/oral cancer drug bill.

My tumors continue to shrink very slightly. Dr. Blanke's eye, (better than most fine analytical instruments) determined 73 percent shrinkage at 16

Quote:

"I am one lucky lab rat. Modern medicine has pulled off a most amazing accomplishment."

months. This is the latest installment in an amazing series of measurements: 70 percent at 12 months, 68 percent at nine months, 65 percent at 6 months, 62 percent at 3 months ... For those of you with experience in basic laboratory measurements, you appreciate this exquisite degree of precision and accuracy, especially given what a CT image looks like, and the slicing variability.

Dr. Blanke was very familiar with the joint pain I described (arthralgia). I suppose they are seeing it in CML patients also. Lora Wilson was unfamiliar with Dr. Demetri's comments that Gleevec might lead to ovarian cysts. I didn't get around to discussing Demetri's observation with Dr. Blanke. At any rate, I must have a follow up visit with a GYN for the three large

ovarian cysts evident on the CT scan. I would hate to push back the GIST, and have another disease take me out.

Resistance problem small but real

Dr. Blanke claims that the resistance problem is small, but real. So the old schedule from Novartis allowing six months between scans is headed for the paper shredder. He said that 80 percent of patients continue to benefit from Gleevec. I didn't ask him to define what he meant by 80 percent exactly ... anyone who ever started the trial, or perhaps 80 percent of those who experienced a response in the first three months, or what? You can see there is ambiguity about the definition of 80 percent.

The evening of Feb 28th, the CBS affiliate in Portland, (oops — Pendleton, Utopia) had a 30-minute special about Oregon Health Sciences University. Dr. Brian Druker, Dr. Blanke, a CML patient whom I did not know, and our own Trudy Webb were the stars. Trudy looked and sounded wonderful, and received many minutes of air time. The research-level cancer center at OHSU is only a few years old, according to the television show. The accomplishment of a quickly developed major drug is unprecedented for a new-ish research center. The show implied that many Pendleton residents aren't aware about the medical milestone that had happened "on the hill" in their city. For those of you have been to the behemoth M.D. Anderson Cancer Center in Houston, OHSU stands in stark contrast. Just consider the directory of names by the elevator ... what is noteworthy is that there are so few doctor's names listed for the entire oncology/hematology clinic.

Looking for instant friends

After my meeting with Dr. Blanke, I stepped outside of the beige brick Phy-

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Ana Maria Baldor-Bunn, 30

Ana Maria Baldor-Bunn of Tampa, Florida, U.S.A., died peacefully at her home Friday evening, April 19, surrounded by family and friends. She was 30.

The St. Petersburg, Florida, Times profiled Ana in an article last November, relating the remarkable spirit of a young mother who endured five major surgeries and an experimental treatment over an 18-month period, while raising a newborn and bringing her entrepreneurial dream from concept to concrete.

Ana discovered she had GIST in May 2000 while she was pregnant with her first child, William. She had her first surgery the day he was born.

Here's what she told the Times:

"They found it at 8:30 the night before I was going to have this baby," said the Tampa native whose family emigrated from Cuba in 1961. "The next morning I went in for a C-section and laparoscopic removal of two tumors that were found to be malignant."

She went on to endure five major surgeries, the Gleevec clinical trial for two months in Houston, and traveled to Boston to meet with an oncol-

ogy expert.

Despite the medical regimen, Ana remained committed to opening her own store in an upscale shopping center, working up to 20 hours a day to prepare Mi Bebe for its grand opening. The store features fashions and children's decor, from fine confirmation dresses to custom cribs.

Each corner of the store features different products and is labeled with the names of Ana's nieces and nephews. For instance, "Nicholas' and Javi's Rodeo" is named after two nephews. It's family, she said, that has helped her get this far.

"It's been a long road, but I've had a wonderfully supporting family," the Times quoted Ana as saying. "I wouldn't have gotten through this without my husband, my family and my faith."

Ana graduated from the University of Tampa where she was president of Delta Gamma sorority, and a graduate of the Academy of the Holy Names. Before opening her business, she was an integral part of BST Consultants serving as the visual/marketing designer. She was a parishioner of St. Lawrence Catholic Church.

She is survived by her husband, Stanley R. Bunn, and their 2-year-old son, William H. Bunn. She was the only daughter of Carlos and Liana Baldor, the sister of Javier (Cindy) Baldor and Carlos (Maria) Baldor Jr., and aunt to Sophia, Nicholas, Javier, Cristina and Victoria.

Ana Maria gave strength, inspiration and courage to those around her while living out her many dreams and aspirations. She had boundless energy and zeal that, coupled with her compassion and kindness, showed in all of her efforts and accomplishments. She had remarkable creative and design talents that were widely appreciated and respected. Each person she touched carries a host of moments and gifts that will forever remind them of how special and unique she was.

Services were held April 21 in Higgins Hall, St. Lawrence Catholic Church. In lieu of flowers, the family asks that contributions in her memory be made to assist those that are still battling this deadly illness: American Cancer Online Resources, Re: Gastrointestinal Stromal Tumor (GIST) Research, 173 Duane St., Suite 3A, New York, NY, 10013-3334

Marina's story

From Page 5

sician's Pavilion at OHSU. I was looking for a gray Volvo station wagon belonging to Dick and Regina Whiting from the LMS list. I was looking for ACOR souls, whom I knew would be instant friends though I had never seen them before.

For those who have never had the experience of meeting listmates, it is unlike any other. For months or years, you share names, words, writings, inner thoughts, troubles and matters as

serious as death. You get to know someone's soul, pure and simple — minus the distractions of appearance, voice, and clothes. When you get to meet the physical body, it is an instant friendship. In this world, we usually discover a person's exterior first, and then later unravel their character. With ACOR you do it from the inside out. It is delightful beyond belief.

And my instant friends were looking for me. Dick told me on the phone to

look for a guy with a beard and a funny hat. I told Dick to look for a pale Okie, puffy from Gleevec, black jeans and a magenta jacket. I stepped out of the building into the sun. For all the talk of rain in Pendleton, I've only seen sunshine during my six trips.

I negotiated the cascade of steps, and I spotted the Volvo approaching. The driver sported a funny lumberjack sort of hat with a flare of the Northwest, a

See Marina, Page 7

In Memoriam

There have been 14 deaths of Life Raft members 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 2, 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.

Robert Lecca, 49, Jan. 28, 2002, husband to Diane, father to son.

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.

Jacob Waller, 67, lifelong resident of Alabama

Jacob Winfield Waller III, 67, battled GIST until his death Easter Sunday, March 31, 2002.

He was born in Falkville, Alabama, U.S.A. and lived in Birmingham until moving to Vincent, Alabama in 1972. Mr. Waller studied electrical engineering at the University of Alabama, Tuscaloosa, before beginning his career with the Bell System.

An installer with Western Electric, he didn't want to leave his family behind in Birmingham so he bought a house trailer and pulled them everywhere with him. His daughter Rita recalls living in 17 different places before she was 6 years old.

One of the biggest joys of his life was working with the Sara Lee Classic LPGA Golf Tournament at the Hermitage Golf Course in Nashville. He loved the game and the lady golfers and he loved working the event every year for 13 years. A plane full of people from Nashville flew in for his funeral.

He retired from BellSouth's Engineering and Network Services Divi-

sion in 1987 after 35 years of service. During retirement he enjoyed traveling in his recreational vehicle, visiting almost every state in the U.S. and portions of Canada.

The friend who delivered his eulogy said that he never knew anyone who wanted more to live but was more prepared to die.

He was a member of Shades Mountain Baptist Church and the Truth Seekers Sunday School Class. He was also a member of the Telephone Pioneers of America and the Heart of Dixie Bells Camping Group.

He is survived by his wife of 47 years, Jerry Waller; daughter, Rita (David) Grub of Loachapoka, Alabama; son, Richard Allen (Barbara) Waller of Helena, Alabama; grandchildren, Richard Austin, Mason Scott, Logan Jacob and Cristina Kate Waller of Helena, Alabama; brother, Richard Lee Waller of Huntsville, Alabama; mother, Leannora V. Waller of Birmingham; and many nieces and nephews.

He was preceded in death by his father, Jacob W. Waller Jr.

Marina

From Page 6

plaid shirt that might have been off a Pendleton Woolen Mill loom, a huge brown beard, a bigger-than-huge smile, a hand energetically waving hello, and bright kind eyes. I climbed into the back seat. To people whom I had never seen before, I started the update about ovarian cysts. The ACOR bond so unique ... we were in the middle of yesterday's conversation, only we had switched from cyberspace to 3-D space.

The best part of the visit was meeting Dick and Regina. They are beautiful people. They live in the countryside. Their neighbor runs a bed-and-breakfast. So guess where I am staying when I return in May? Also they offered the use of their Mercedes diesel. Goodbye, downtown Doubletree. (The rest of you might want to drift over to the LMS list and introduce yourself to Dick and Regina, knowing them is not only enjoyable, but it has perks.)

Dick commented that Portland is one of the prettiest cities on earth. I looked at the two people in the seat in front of me, and I thought to myself, this city is gorgeous, but it ain't because of the mountains and trees. This fair city of the Pacific Northwest is not my home, but it is the stage of some personal miracles. It is perhaps the dearest city on earth to me ... probably Bristow America included in that rank. Perhaps we should call it Eden.

THE LIFE RAFT GROUP

<http://www.liferaftgroup.org>

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Who are we and what do we do?

We started in July of 2000 as GIST patients and caregivers in the Gleevec (STI571) clinical trials, and have since extended membership to all GIST patients. We share our experiences and support each other. We focus on symptoms, side effects and other drug-related issues. Members correspond privately to each other and to the group as appropriate. If you are interested in joining, contact membership coordinator Penny Duke at liferaft@cfl.rr.com, or download an application at www.liferaftgroup.org.

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. To assist in that goal, the secure e-mail listserv does not include professional members of the various

study sites. However, this newsletter does serve as an outreach and is widely distributed. Hence, all items in the newsletter are edited to maintain the anonymity of members, unless members have granted publication of more detailed information.

Method: Our primary means of communication is through a confidential, secure listserv operated by the Association of Cancer Online Resources, ACOR (www.acor.org).

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

Newsletter note: 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 you may find.

Some facts about Novartis

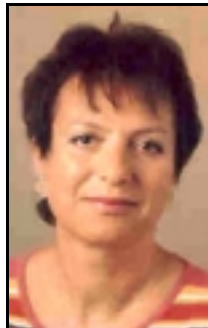
Novartis AG is one of the largest health care businesses in the world, with core businesses in pharmaceuticals, consumer health, generics, eye care and animal health.

In 2000, Novartis businesses had collective sales of \$17.2 billion and a net income of \$3.9 billion. The businesses invested approximately \$2.4 billion in research and development.

Novartis is headquartered in Basel, Switzerland. Novartis companies employ about 70,000 people in more than 140 countries.

Novartis maintains a hotline for U.S. residents with questions about Gleevec and clinical trials. Call 877-453-3832, 8:30 a.m. to 5:30 p.m. weekdays, Eastern Standard Time.

Who's new in the Life Raft Group



the clinical trial in Naperville, Illinois, U.S.A.

Barbara Smith, a GIST patient from the United Kingdom.

David and Peggy Wicker, David is on the trial at Duke University Medical Center, Durham, N. Carolina, U.S.A.

David Shaulis and Nora Parker Shaulis, Washington state, U.S.A.; Nora by prescription

Toni Young and her daughter, **Ashley**, who is on Gleevec though Dana-Farber Cancer Institute in Boston, Mass., U.S.A.

Carolien and Hans Verhoogt, The Netherlands. Carolien is a GIST patient (not using Gleevec).

Their photos were omitted last month when the editor ran out of space, so here once again, in living color, are **Ulrich and Helga Schnorf** of Zug, Switzerland. Ulrich on the trial at the Centre Hospitalier Universitaire Vaudois in Lausanne, Switzerland.

Louise Ladd, a GIST patient from Connecticut, U.S.A.

Robin Jaruszewski of California for her brother **Phillip**, who's on