

GIST walk set Sept. 16 in NY state

Life Raft member Tania Stutman takes cancer battle to the next level

When I first found out, I was in shock," says Robert Stutman, recalling the news that his wife, Tania, had cancer.

"I even made the doctor repeat it twice."

"Actually," interjects Tania, "six times."

"Six times," agrees Robert.

That snippet of conversation mirrors the shock everyone has felt when being told they have cancer. Since her diagnosis three years ago, Tania Stutman has shed tears, spent sleepless nights, and felt anger and resentment. But from the gantlet of cancer emotions, she's emerged with two goals: to fight the disease, and help others in their fight.

Tania's cancer was detected during an annual exam. It was during her subsequent hysterectomy that doctors discovered the tumor was not in her

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Battling GIST with Gleevec (STI571)



LIFE RAFT GROUP

September 2001 Vol. 2, No. 8 In memory of Ron Martinez, Ehud Nehemya

Side effects survey goal near as deadline looms

Life Raft Group poll has three primary goals; forms are due Saturday

By Norman J. Scherzer

Since Aug. 1, the Life Raft Group has been e-mailing, faxing and snail-mailing its new comprehensive side effects survey to members around the world. The deadline for returning the survey period is Sept. 8, to give members on summer holiday the opportunity to participate.

We expect about a 90 percent response rate, which will make the survey truly representative of the entire

Life Raft Group of GIST patients on Gleevec.

The three major objectives of the survey are:

1. To provide patients, caregivers and physicians with better information about the type and severity of side effects which GIST patients are experiencing with Gleevec.

2. To evaluate how side effects are being managed, and to improve the understanding of what works best to cope with them.

3. To continue to empower patients and their caregivers in their relationships with their physicians by making them better informed about side effects and more confident in their inter-

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'Glivec' moves closer to European approval

BASEL, Switzerland — Novartis has received a positive opinion from the Committee for Proprietary Medicinal Products (CPMP) for using Glivec (Gleevec in the U.S.) to treat people with chronic myeloid leukemia.

The European Union (EU) Commission usually grants approval of products four months after a CPMP positive opinion. Novartis' announcement was issued July 27.

"Novartis is extremely gratified that Glivec, which has already benefited thousands of CML patients worldwide, is now one step closer to becoming readily available to patients in the European Union," said David Epstein, president of Novartis Oncology.

Specifically, Novartis is seeking approval use Glivec on adults with chronic CML where interferon-alpha therapy has failed, and on adult CML patients in the accelerated phase or in

blast crisis.

To date, Novartis has received marketing clearance for Glivec in the United States, Switzerland, Argentina, Guatemala, Jordan, Korea, Mexico, Peru and Syria.

The application was based on data from more than 1,000 patients participating in Phase I and II clinical trials worldwide.

In chronic phase CML patients

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Meet GIST survivor Henry Lange Jr. of Cole Camp, Missouri



Henry Lange Jr. is pictured by his tractor and trailer on his 300 acre farm in Cole Camp, Missouri, a town of about 1,000. "One of my dad's favorite things to do is pull tractors in local tractor pulls," says daughter Nancy Balke, who represents her dad on the Life Raft Group. "He did that last month again. He enjoyed every minute of it. He collects antique tractors, fixes them up and pulls them in tractor pulls. He has one that is on steel wheels that he is so very proud of, because he pulls it out the gate every time. He has a grandson who is taking up his love of tractors and tractor pulls. It brings tears to my dad's eyes to see his grandson pull a tractor all the way out the gate. He is a Grandpa that is dearly loved and due to Gleevec is able to spend precious time with them. A few weeks ago he helped his other grandkids catch grasshoppers to go fishing with.

Survey

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actions.

The survey was designed by this author, with substantial input from the Life Raft Group Science Team and members. A draft survey was sent to a number of clinical researchers for comment, and was pre-tested by 10 Life Raft members.

The survey will attempt to review all side effects reported and to correlate them with such variables as dosage, gender, weight and marital status.

For the first time, we will be using a severity scale for side effects that was based on research of the pain management community. We will be ranking side effects over four distinct time periods: the period preceding the starting of Gleevec (our baseline); the first three months on Gleevec; the second three months on Gleevec; and the subsequent time on Gleevec. This will give us the opportunity to look at both the severity of each side effect, as ranked by the patient, and whether

they have changed over time.

We will also be looking at what makes the side effects better, from the patient's perspective, and whether any other health conditions improved — "unexpectedly positive" side effects, if you will.

We will be looking at how patients rate how their side effects have been managed, including whom they view as responsible for side effects management, whether that person is the primary source of their side effects information, and the answers to the following: "On a scale of 0 to 10, with 0 being nonexistent and 10 being extraordinary, how would you rate the care you have received from your clinical trial doctor and staff in managing your side effects?"

We will also be ranking the sources of patient information, including the clinical trial doctor, the clinical trial nurse, the local oncologist, the local primary care doctor and the Life Raft

Group itself.

Finally, we will begin exploring the issue of whether patients accurately report side effects to their physicians.

We pose two questions in our survey: 1. "Have you ever been concerned about being taken off of Gleevec because of side effects?" and, 2. "Would you consider minimizing the reporting of side effects to avoid being taken off of Gleevec?"

This inquiry will begin to open the issue of the accuracy of data collection from the perspective of the clinical research community and the patient. Although patient-driven data is hardly definitive, our analysis should serve as a potential source of quality control and should raise issues for the traditional clinical research community to consider.

Norman Scherzer is coordinator of the Life Raft Group and a former assistant commissioner of health for the city of New York.

Tania

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ovaries, but attached to the small intestine. Then she learned that her cancer was rare, not responsive to chemotherapy or radiation, and would kill her in one to five years.

She was devastated. Her biggest fear, says Robert, wasn't of dying, but that her grandchildren would forget her. Robert tried to encourage her, Tania recalls. "He'd say, 'Give it a chance, give it a chance; there'll be something out there, something coming.'"

Tania decided to make the most of whatever time she had left.

"I felt very compelled to do something," Tania said during a July radio interview with Dr. Harris Stratyner on station WFAS in Scarsdale, N.Y. "I didn't want to take this lying down ... I wanted to do something so other people will benefit from this."

Quote:

"I felt very compelled to do something. ... I wanted to do something so other people will benefit from this."

Early in her fight, Tania's regular oncologist said he couldn't help her, that he didn't have enough information about her rare cancer. So Tania set out to change that — not just with her oncologist, but with cancer professionals in general, by starting a research fund.

At first, Tania named the fund in memory of her sister, Maia, who was lead flight attendant aboard a DC-8 that crashed in 1985 near Gander, Newfoundland, killing all eight crewmembers and 248 servicemen headed home from the Middle East. The fund

was established at Memorial Sloan Kettering Cancer Center in New York with help from Dr. Ephraim Casper, chief of medical oncology. As gastrointestinal stromal tumor (GIST) became differentiated from leiomyosarcoma, the fund's official name became the GIST Cancer Research Fund.

Raising money to research an "orphan cancer" has not been easy. Most of Tania's appeals to corporations, foundations and celebrities have been largely ignored or rejected. But persistence has paid off, and to date she has raised some \$15,000 for the GIST Cancer Research Fund.

Tania plans to add to that total Sept. 16, when the first GIST Walk for a Cure is held at Rockland Lake State Park in Congers, New York. It's been largely a one-woman effort as she obtained sponsors for T-shirts and the necessary \$500,000 liability coverage.

One of the first pledges came as Tania was talking about the walk during her July radio interview. Host Dr. Stratyner, moved by Tania's story, gave \$500.

As Tania promotes the walk, raising awareness of GIST, she's been rewarded with more than pledges. At the Clarkstown, N.Y., town meeting held July 6, U.S. Rep. Ben Gilman presented her with a Certificate of Special Congressional Recognition. "You have not only chosen to fight your cancer, but to take the fight to another level by founding Maia. By doing so you have demonstrated your interest not only in self preservation, but in helping all those who now, and those who may in the future, suffer from GIST."

As for Tania's personal battle with GIST, the news is good. After nearly 10 months on Gleevec, Tania's tumor has shrunk 50 percent and is now stable. "Since she started the trial, she has hope," says Robert. "It's not a

Quote:

"I don't consider myself brave at all. Everyone deals with cancer in a different way. No one should judge anyone in the way they deal with cancer."

cure, but at least we have something to hope for and to pray for, that it will work."

Robert confesses that the crusading Tania "drives me nuts," but says it with love and pride. He is amazed that his wife, a cancer survivor and grandmother of five, is able to continue working — she's a cardiotech for five cardiologists — and devote so much time to the GIST Cancer Research Fund.

During her radio interview, Dr. Stratyner repeatedly praised her determination and courage. Tania says that's simply her way of dealing with cancer.

"I don't consider myself brave at all," she said. "Everyone deals with cancer in a different way. No one should judge anyone in the way they deal with cancer."

"I needed to do something to bring awareness to the public, to bring more awareness even to the oncologists. Unfortunately, we've lost a lot of people who have this disease who probably were treated in a different manner and died because of it."

Tania is fighting both ignorance of GIST and GIST itself. And to date, she's winning.

For details about the walk, contact Tania or Robert Stutman at (845) 634-6060, or e-mail tania5kids@aol.com. Contributions should be made to the GIST Cancer Research Fund, 55 Sawmill Rd., New City, NY 10956.

Ehud's wish: 'I want a happy funeral!'

Editor's note: In the U.S., people are accustomed to obituaries listing a person's occupation, place of birth and residence, education, occupation, memberships, etc. Such obituaries are not the custom in Israel. Instead, here are three of the many tributes offered by those close to Ehud Nehemya.

It's night, exactly 12 hours since we said farewell for the last time and closed the door on three years of continuous war over your health.

Rom is sitting besides me, refusing to sleep. He understands something terrible had happened but too small to digest it.

I am unsuccessfully trying to explain. How can you tell three little kids they will no longer see their grandpa, that grandpa will no longer talk to them the way only you did — as equals, explaining with endless patience, telling them stories in funny voices?

How can we explain it to them when we ourselves can't understand?

To the last moment, you believed you would defeat the disease. ... You wanted so much to beat it. Even when it seemed you had no strength left, you got up and went on to another battle, another trip to Belgium, another pill. And with every pill you took, a new hope was born in you and us as well.

Just half a year ago we drank to life and spoke of the future and of the creations waiting for you in your studio. ...

Twelve hours after we said farewell, you are still so much with us in the little moments ... the long talks into the night, the eyes of our kids that look for you and don't understand, and the heart of each and every one of us that will love you forever.

— *Hadar Nir, Ehud's daughter-in-law*



Not a day has passed yet we already long for you. The feeling of absence is accompanied by a strong feeling of sorrow.

Three years of war against all odds, and you, like a brave soldier, fought courageously, bravely, determined, never giving up. Standing up to harsh treatments, the surgeries, and at last the trip to Belgium, which gave you hope when hope was almost gone. ...

Your will kept you always in control all the way, from the first when you took the treatment management into your hands to the last hospitalization when you were helpless and totally dependent. Even in this situation you were a full partner in your own care and persisted on doing anything you could by yourself. But it seems there are things stronger than us and the disease had overpowered you.

You were our foundation, our pathfinder. You were a remarkable father, and everything we achieved is the outcome of years of investment. The warm, familial feeling you and Mom created granted us the sense of confidence. We knew no matter what happened, you're always there. ...

You're not with us but your presence here is powerful everywhere. The looks, the scents — you will always stay with us, be with us everywhere, in your deeds, even when we can't touch, in our many memories, in our imaginations. You will look over us, over all your loved ones, from a world we hope is all good.

— *Einat Zelinger, Ehud's daughter*

On Tuesday, August 7th, 10:30 in the morning, my mother-in-law called from hospital and told us to come quickly. Fifteen minutes later, while we're driving there, she called again, telling us what we knew would come eventually, there was no need to rush anymore. ...

Ehud's funeral was on the next day, in his Kibbutz on the northern end of Israel. Hundreds of people escorted Ehud on his final journey, many of them driving three to four hours each way, and they all wept with us. Although there were a lot of people, the ceremony was very intimate. It opened and closed with cheerful songs that he loved and personal letters and poems which we wrote him.

We tried to keep Ehud's request — "I don't want any religious ceremonies. I want a simple funeral. I ask all of you to stand up straight; I don't want any screaming or crying. I want a happy funeral!"

The ceremony was followed by a gathering in the Kibbutz social club, where we all talked and remembered him over a cup of coffee. During the next week many friends and relatives visited us.

Ehud is having his eternal rest on the place he loved so much, the most beautiful place in Israel. The Kibbutz is located on the highest cliff in the country, overlooking the beautiful Hahula valley. The small cemetery is hidden between apple plantations.

For me Ehud was much more than a father-in-law. He was a friend, a father, and an older brother all in one. He has been a guide and a mentor for all of us. He had the ability to look into everyone's soul and touch it. He could talk evenly to kids and to elders, to rich and to poor, to smart and to less smart people.

My wife lost her dad, my kids lost their grandpa and I lost my best friend.

— *Ophir Zelinger*

Jeffrey Prichard, furniture builder and craftsman

Jeffrey W. Prichard, 52, of Wayne, Pennsylvania, died July 11 at his home.

Jeff operated his own fine furniture building establishment in Strafford for more than 20 years and was widely known for his superior craftsmanship. His furniture was much sought after and clients were willing to wait for years to obtain one of his commissioned pieces. Specializing in furniture in the 18th Century style, he was also known for his careful and accurate restoration of antiques, and acted as consultant for several museums. He will be remembered for his honesty and integrity in his business.

His other interests included photography, historic preservation, sailing, wooden boat restoration and classical music. A lifelong railroad buff, he helped save and restore a number of antique trolley cars.

He was a graduate of Haverford High School and Susquehanna University. He gained an early appreciation of fine craftsmanship as a violin-maker's assistant at William Moennig & Son in Philadelphia. Prior to opening his own business, he worked as a model maker, patternmaker and as a cabinetmaker.

He is survived by his wife, Joyce Prichard; sons Gregory W. Prichard and Scott T. Prichard; parents Charlotte Schreiber Prichard and William J. Prichard of West Brandywine, Penn.; a brother, Roger T. Prichard of River-ton, New Jersey.

Contributions may be made in memory of Jeffrey W. Prichard to: Radnor High School Scholarship Fund P.O. Box 8244, Radnor, PA 19087 or to the Association of Cancer Online Resources (ACOR) 173 Duane St., Suite 3A, NY, NY 10013-3334

Ron G. Martinez, Navy veteran and commercial diver

Ronald G. Martinez of New Port Richey, Florida, died Wednesday, July 25 at his home. He was 60.

Ron came Florida in 1988 from his native Denver. He was a commercial deep sea diver and a Navy veteran (1959-1963). He was a member of the American Legion Paradise Post 79 and St. Thomas Aquinas Catholic Church, both in New Port Richey.

He and his then-wife-to-be, Jo Ann, started going together when he was 17 and she 15.

Ronald is survived by his wife, Jo Ann; a son, Ron Martin of Tampa, Florida; two daughters, Wendy Jackson of Houston, Texas, and Natalie Shahnazi of New Port Richey; his parents, John and Connie of Denver, Colorado; a sister, Linda Yoder of Concord, Georgia.; and two grandchildren.

EU approval

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who'd not responded to interferon-alpha therapy, the latest data confirm near complete, durable hematologic responses in more than 90 percent of patients, with more than half achieving a complete or near complete disappearance of the Philadelphia chromosome in the bone marrow.

Patients in the accelerated phase of the disease have continued high hematologic responses, with good cytogenetic response rates. Blast crisis patients continue to have rapid hematologic blood count responses though this was sustained in less than a third of the responders.

Glivec is one of the first oncology drugs that validates rational drug design based on the understanding of how cancer cells work.

The first submissions for marketing authorization were filed only 32 months after the first dose in man. This timeline more than halved the typical drug development timeframe of approximately six years.

In Memoriam

There have been seven deaths of Life Raft Members to date:

- **Debbie Nance**, 38, (10/9/61-10/2/00) wife of Eddie, mother of Chris.
- **Jim Ackerman**, 49, (12/29/51-1/16/01) husband to Betsy, father of Jill and Tom.
- **Jim Perham**, 63, (5/22/37-5/01) husband to Karen, father of Craig, Kathy and Jennifer.
- **Amy Barney**, 25, (10/3/75-6/10/01) wife of Reed, mother of Joshua.
- **Jeff Prichard**, 52, (5/19/49-7/11/01) husband to Joyce, father of Gregory and Scott.
- **Ron Martinez**, 60 (-7/25/01) husband to Jo Ann, father of Ron, Wendy, Natalie.
- **Ehud Nehemya**, (-8/7/01) father to Einat Zelinger, father-in-law to Hadar Nir, Ophir Zelinger.

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Who are we and what do we do? We are GIST patients and caregivers (spouses and others) in the Gleevec (STI571) clinical trials who have come together to share our experiences and support each other. Persons not in the trial are encouraged to seek support from the broader leiomyosarcoma (LMS) community. We focus on symptoms, side effects and other drug-related issues. Members correspond privately to each other and to the group as appropriate .

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 listserve 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.



Anita then ...

Anita Scherzer holds newest grandchild Katie in this photo taken June 24, 2000. The occasion was Norman and Anita's 39th wedding anniversary. They renewed wedding vows and gave their six grandchildren Hebrew names. They will find out the next day that chemotherapy has not worked, and Anita's tumors continue to grow. They are about two months away from Gleevec; the clinical trials have not yet begun.

... Norman and Anita now

At right, the Scherzers are pictured June 24, 2001 — their 40th wedding anniversary, an occasion they once thought they would not reach together. Anita has been on Gleevec about 10 months.

