



LIFE RAFT GROUP

January 2002

Volume 3, Number 1



Photo courtesy Kay Banker

Carl Banker of Southern California, U.S.A., holds the Olympic torch as he prepares to carry the flame through San Diego on its way to Salt Lake City, Utah.

Life Raft's Carl Banker carries Olympic flame

By Kay Banker with Richard Palmer

Carl Banker is supposed to be dead. That's what the doctors told him in January 2001. Despite surgery, despite harsh chemotherapy, the cancer had come back. He was given six months to a year.

This month, the Banker family and friends gathered in San Diego — but not for a funeral. They came to watch Carl carrying the Olympic flame through the streets of San Diego, on a sunny day, the 14th of January, 2002.

After his turn at carrying the torch, Susan Taylor interviewed Carl "live" on NBC news that evening. Carl told

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Gleevec on way to being No. 1 treatment for CML

Our 'cancer cousins' can opt for Gleevec when standard treatment fails

Editor's note: As Life Rafters await U.S. approval of Gleevec for treating GIST, there's good news for our cancer "cousins" who take Gleevec for chronic myeloid leukemia (CML). Most of the following was taken from a Novartis press release earlier this month.

For years, interferon-alpha injections with cytarabine has been the standard treatment for newly diagnosed chronic myeloid leukemia (CML) patients. Recent clinical trial results could lead to a change in that approach.

An ongoing phase III study comparing Gleevec to the interferon-alpha plus cytarabine treatment showed that Gleevec resulted in a substantially higher response. Based on this finding, the independent data monitoring board (independent hematologists and a clinical statistician tracking the trial) recommended a change: CML patients on the trial who don't have significant response to the standard therapy will be told of the better results with Gleevec, and given the option to switch.

The changes to the clinical trial protocol have been communicated to investigators and patients this month. These changes allow patients who have not achieved a major "cytogenetic response" (the disappearance or reduction in the number of cancerous cells) after one year of treatment with interferon-alpha and cytarabine to switch to Gleevec. Patient consent forms will be changed to inform patients of the new data, and to urge them to speak with their physicians.

Called the IRIS study — International Randomized study of Interferon vs. STI571 (the original name for Gleevec) — this large, international multicenter Phase III trial is evaluating Gleevec versus the combination of standard interferon and cytarabine as first line therapy in patients with chronic myeloid leukemia. Between June 2000 and January 2001, the ongoing study enrolled 1,106 patients in 177 centers across 16 countries. The study was designed to help determine the long-term outcome (including survival) of patients with newly diagnosed CML treated with Gleevec in comparison to the combination of interferon-alpha and cytarabine.

The independent data monitoring board further recommended that a for-

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CML

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mal, peer-reviewed presentation of the 12-month data results be made to the scientific community at the earliest possible opportunity.

Preliminary results from a different study of 47 newly diagnosed patients with early chronic phase CML showed that after three months of treatment, 77 percent (36 patients) had achieved complete or major cytogenetic responses. By comparison, previous studies of similar patients on interferon-alpha alone and interferon-alpha with cytarabine revealed just 24 percent of patients achieved complete or major cytogenetic responses after three months.

As with GIST patients on Gleevec, CML patients did suffer some side effects, most deemed mild to moderate. Treatment was discontinued due to adverse side effects in only in 1 percent of patients in chronic phase. The most common side effects: nausea, fluid retention, vomiting, diarrhea, hemorrhage, muscle cramps, skin rash, fatigue, headache, dyspepsia and dyspnoea.

Olympic

From the front page

TV viewers about GIST and the clinical study he was in at UCLA, the University of California, Los Angeles. A friend of the Bankers who lives in Memphis later told them that he'd seen Carl on the news there.

Kay, Carl's wife and caregiver, relates Carl's story. Many fellow Life Rafters will nod their heads when reading his experiences, for they've been there:

Carl began seeing spots and feeling fatigued in July 2000. His family doctor gave him an antibiotic and told him to get his eyes checked. Two weeks later he still felt bad, and this time they drew blood.

Later that day, the doctor called and said they wanted immediately because he was severely anemic. They suspected Carl was bleeding internally, and a few days later he was admitted to the hospital for a colonoscopy and endoscopy.

The endoscopy showed a very large tumor in his stomach. "When I asked the doctor about the size of it, he used his hands and made a baseball," Kay says. More tests and a CT scan were done, and when the surgeon came in, he said the tumor was the size of a volleyball.

The surgeon, Dr. Terry Mayers, said they wanted to try to shrink the tumor with chemotherapy. But at a follow-up visit to the oncologist, the Bankers learned Carl had gastrointestinal stromal tumor that would not respond to chemotherapy, and that the only thing they could do was to remove his stomach, part of his liver, his spleen and possibly his pancreas.

Dr. Mayers pulled no punches with the seriousness of the surgery Carl would undergo. All four of the Bankers' children flew in from their respective states for the surgery, done Sept. 11, 2000.

Carl lost 75 percent of his stomach, part of his liver, his spleen, and a mass on the pancreas.

His primary tumor weighed 8 pounds!

Carl made a very fast recovery from surgery but had trouble, of course eating. At first it would take him an hour to eat part of a sandwich.

In October, his oncologist suggested chemotherapy of adriamycin, ifosfomide, and mesna. Chemo was started in October — four hospital stays of almost a week each, finishing up on Dec. 24th — Carl's 52nd birthday. He'd lost all his hair, was extremely weak, and could barely eat ("Thank God for the feeding tube," says Kay).

The January 2001 scan showed new tumors in his liver. "At that point we were told there was nothing more they could do, and suggested we try and find a clinical study," says Kay. "The doctor gave him six months to a year to live."

At the oncologist's suggestion, the Bankers called UCLA. That was where they learned about STI571. Fortunately, Carl's tumor was highly positive for the c-Kit and was admitted into the study under Dr. Peter Rosen at UCLA. Carl began taking 800 mg of STI571 a day on March 11, 2001.

The STI571 gave him a light rash, which cleared up with Fluocinolonone

Who's new in the Life Raft Group

Gretie Hegge from Holland, the Netherlands.

Abraham, by prescription from doctors at the University of Southern California/Norris Comprehensive Cancer Center, Los Angeles.

Silvia Williams of Winnipeg, Manitoba, Canada, on the list for her mother, Jeanne, by prescription from the University of Minnesota.

Laura C. of Columbus, Ohio, U.S.A., by prescription at Dana Farber Cancer Institute.

Carol Berres of Milwaukee, Wisconsin, U.S.A., on the trial at University of Wisconsin Comprehensive Cancer Center.

Jim and Lisa Barth of Asheville, North Carolina, U.S.A., Jim on Gleevec by prescription.

Leonie Cousins, Toronto, Canada, GIST survivor since 1993.

Developer of Gleevec carries Olympic flame

Dr. Brian Druker was nominated by dozens of CML, GIST patients

PORTLAND, Ore. — Oregon Health & Science University researcher Dr. Brian Druker, M.D., lead developer of Gleevec, carried the Olympic torch through Portland on Tuesday evening, Jan. 22.

Druker carried the torch through part of the downtown area starting around 6 p.m.

He was one of 54 runners carrying the torch through the Columbia River region on its way to the Winter Games in Salt Lake City.

Residents of areas where the torch run traveled were asked to nominate someone they found inspirational to carry the flame. The Portland Torch Committee says Druker received dozens of nominations, mostly from grateful leukemia patients.

"This is an honor unlike any other I've received," said Druker, an avid runner and cyclist.

Druker, director of the OHSU Cancer Institute's Leukemia Center, worked in close collaboration with pharmaceutical company Novartis to develop Gleevec, a targeted treatment for chronic myelogenous leukemia (CML). The drug has been so effective and non-toxic in treating CML that it was approved by the FDA last May in



Photo courtesy Martin Munguia

Dr. Brian Druker, principal developer of Gleevec, carried the Olympic flame through Portland the evening of Jan. 22.

the fastest time ever for a cancer therapy. Druker led the CML clinical trials of the drug and has treated more than 250 patients with Gleevec.

As Life Rafter's well know, Gleevec also has been shown to work against gastrointestinal stromal tumors and is being tested on a variety of other cancers.

Druker was one of two OHSU physicians to carry the flame Tuesday. Dr. Craig Nichols, associate director of the OHSU Cancer Institute, carried the torch shortly after Druker. Nichols was nominated by none other than three-

time Tour de France winner Lance Armstrong, whom Nichols successfully treated for testicular cancer in 1996.

Peter Fish carries flame

Earlier in the torch run Peter Fish, the father of GIST patient Katie, carried the flame on a leg through southern Oregon. Running is nothing new for Fish, who ran from Kansas City to Washington, D.C. last summer to raise awareness for sarcoma and ACOR.

Fish had to meet the check-in point at 3 a.m. He was the seventh runner out of 25 that day, and wore a tag with the number 007, "earning me innumerable references to James Bond," Fish said.

"We had been told before the start that each of us was the only one in the world with the flame at that point," said Fish, "and I was quite moved at the thought of being a meaningful part of something much larger."

Nationwide, 11,500 torchbearers will carry the Olympic flame through 46 states. Official torchbearers were nominated by family, friends and colleagues who wrote 50- to 100-word essays explaining how the nominees "embodied the Olympic spirit and provided inspiration to their communities."

Each local organizing committee waded through the 210,000 total nominations to choose the several dozen or so who will carry the torch in their areas.

More Olympic

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0.025PC cream. However, it was an interaction of Reglan (for an upset stomach) and STI that caused him to lose muscle control in his face — on the freeways of Southern California.

"We were driving up to UCLA for our monthly visit, when I looked over at Carl and said 'your face doesn't look

right'," recalls Kay. "That's when he told me he couldn't close his mouth.

"Minute to minute his facial features changed; he developed his very strange grin that he could not control," Kay says. "He kept on driving on the freeway while I urged him to pull over because I thought he might be having a

stroke. He kept saying he was OK but I was so frightened, I thought I was going to throw up. All this was going on as seven lanes of cars are flying by at 75 miles an hour.

"Anyway, we made it to UCLA and

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Carl's Olympics

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after checking him over they gave him a Benedryl and said he was OK! By the time we arrived home, his face was back to normal. Other than that, he has had no other side affects."

All of Carl's follow-up CT scans has showed "no progression" of disease. The latest CT scan done was Jan. 21 and they finally measured his tumors for the first time. One lesion shrunk from 3.0 to 2.2 and the other one from 2.9 to a 2.2 -- shrinkage!

"That is sooooo good to hear," says Kay. "All these months we've been wondering what was going on with his tumors. We just never knew until now."

Carl has worked for General Motors for 26 years, and is presently an area sales manager. After his surgery and chemo he was back on the job but unable to work full-time at first because he was too weak. He was told that he HAD to take a medical retirement.

"That was NOT agreeable to Carl as he loves his work and he told his boss he was not going to take retirement," says Kay. "I don't think his boss knew how to handle this because he told Carl OK, continue on -- then a few days later, he told Carl he was out of a job because they already had someone to replace him."

All this was going on while Carl was trying to get into the clinical trial at UCLA. "This was probably the worst time for both of us," recalls Kay.

Carl finally went over his boss's head. He was told to get a letter from our doctor saying he was capable of resuming work. That's what he did. Carl was given the go-ahead to resume work.

"At one point the company offered him a "special assignment." He would still get a paycheck and company car, but someone else would do his work.

"This was done with kind intent because they thought he had just six months to a year to live.



Photo courtesy Kay Banker
Carl Banker runs up a hill carrying the Olympic flame in San Diego, California, with an escort of motorcycle police officers.

Quote:

"I am married to a wonderful and remarkable man. I truly am. Carl is a gift to me from God. Never have I met anyone as kind as he ... he is admired by his co-workers and everyone that knows him thinks highly of him. I believe this is why Carl was nominated to carry the Olympic torch."

— Kay Banker, wife and caregiver

"They were trying to do something nice for him but that is not the way Carl wanted to go out," Kay says. "He wanted to work!"

"I believe Carl was nominated to carry torch for his dedication to his job and company. He was unwilling to stop living or give in to this disease.

Kay adds: "I am married to wonderful and remarkable man. I truly am. Carl is a gift to me from God. Never have I met anyone as kind as he.

"When I met Carl I was a divorcee with three children. Carl adopted my children as his own and we had one more child together. He has been the best father any child could ask for. My youngest daughter recently said he was her hero. They all feel that way.

"He is admired by his co-workers and everyone that knows him thinks highly of him. I believe this is why Carl was nominated to carry the Olympic torch. We still don't know who nominated him, but I believe it was people he works with.

"One more thing, the whole time Carl went through the surgery and chemotherapy, not once did he ever complain about how bad he felt or why it happened to him.

"I know I would not have had the grace he displayed throughout his ordeal."



Life Rafter Laura C. and her son, Jacob, of Columbus, Ohio, U.S.A. The photo was taken last October when Jacob was 17 months old. The two were playing in the fall leaves — a brand new experience for Jacob.

Life Rafterers on the go

Life Rafter Rob Ryninger and his then-15-month-old daughter, Hannah Noelle, are shown in this picture taken by wife and mom Vonna last Halloween while the family was on their way to the church fall festival. The Ryningers live in Wilmington, North Carolina, U.S.A.



The events of September 11 have made the background of this photo all the more notable. The Byrne family — Life Rafter Michael, 6-year-old Matthew, and Mia — took a week-long trip to New York City last June, and while there posed for this photo with the New York City skyline behind them. Right behind Michael's head are the Twin Towers of the World Trade Center.

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Who are we and what do we do? We started as GIST patients and caregivers (spouses and others) in the Gleevec (STI571) clinical trials, and have since extended membership to all GIST patients on Gleevec/Glivec. We come together to 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.

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 out-

reach 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.

In Memoriam

There have been eight 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, 16, and Scott, 9.
- **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.

Life Rafterers in Boston



Penny Duke, membership coordinator of the Life Raft Group, left, got to meet with Life Rafter Elsie Hernandez and husband Michael Josephy in Boston on Jan. 7 at the hotel where Penny and her mom were staying next to Dana Farber Cancer Center. "We spoke about the medical situation, Gleevec, side effects, etcetera — what you'd expect," said Michael. He and Elsie were in Boston to see Michael's brother, David, who was giving a talk at Harvard. "Penny has studied the literature far more than us," relates Michael. "A couple of days ago she sent me the URL of a mathematical model of tumor growth!"