



Photo by Paul Zalewski, RavenwoodPhoto.com

WINNING THE BATTLE— Bound together by their common enemy, GIST patients posed for this photo Friday, May 3 in Boston at the first ever meeting of the Life Raft Group. About 100 people — including caregivers, doctors and officials of Novartis, the maker of Gleevec, attended. One caregiver was heard to comment: “You can’t tell who the people with cancer are.” Indeed, a good looking bunch of cancer survivors.

Life Rafter's gather in Boston

First-ever meeting tops expectations, honors key players in GIST battle

Thirty-nine GIST patients, an almost equal number of caregivers, and cancer researchers, doctors and officials from the pharmaceutical giant Novartis gathered May 3-4 in Boston, Mass., for the first-ever Life Raft Group meeting.

Nearly 100 people filled the Fenway Ballroom of the Cambridge Radisson Hotel on Friday evening for a dinner that saw the presentation of the Life Raft Group's Humanitarian Award to Dr. Daniel Vasella. The chief executive officer of Novartis was acknowledged for his role in the development of Gleevec, the revolutionary oral can-

Battling GIST with Gleevec (STI571)



LIFE RAFT GROUP

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cer drug to which so many in the room owed their lives.

The meeting was opened by Gary Golnik, the Life Raft member who started making arrangements for the gathering months earlier. It was a bittersweet moment as Gary's wife, Mary, had succumbed to GIST April 18, just two weeks before the gathering. Life Raft Group Coordinator Nor-

man Scherzer dedicated the meeting to her memory.

“It is a little strange, but very delightful, to see our cyberspace community come alive,” said Scherzer, a New Jersey resident and caregiver to his wife, Anita. He spoke of the close ties the Life Raft has fostered, where people who have never met face-to-

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Gleevec's effects are lasting, researchers believe

Study results revealed May 19 at annual ASCO meeting in Florida

Most gastrointestinal stromal tumor patients who receive Gleevec have a lasting response to the drug and experience significant

tumor shrinkage, a new study shows.

The results of the study were presented May 19 at the 38th annual meeting of the American Society of Clinical Oncology. More than 23,000 cancer care professionals from around the world attended this year's meeting in Orlando, Florida, U.S.

One year after beginning treatment with Gleevec, (called Glivec, or

imatinib outside the U.S.), 63 percent saw their tumors shrink in half or more, and 20 percent had “stable” disease, meaning their tumors were unchanged or decreased by half or less.

“These responses are lasting and are in marked contrast to standard chemotherapy, which has a response rate of 5 percent,” said Dr. Margaret von Me-

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Gathering

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face become good friends, sharing inner thoughts, knowledge, troubles, even death.

Quoting Life Raft member Marina Symcox, Scherzer talked about the way online relationships develop.

“You get to know someone’s soul, pure and simple, minus the distractions of appearance, voice and clothes,” Scherzer said. “In this [real] world, we usually discover a person’s exterior first, and later unravel their character. With cyber friends, you do it from the inside out. It is delightful beyond belief.”

Noting that every member of the Life Raft Group had paid their own way to attend the meeting, traveling from as far away as Finland and Hawaii, Scherzer said they did so for five reasons: To meet one another, to learn more about their illness, to celebrate their survival, to thank their rescuers, and to commemorate the memory of the 14 Life Raft members who have died.

“The cumulative stories of the Life Raft Group members in this room are a testament to the strength of the human spirit, and to the unsung courage of those who managed to find a way to survive, sometimes for many years, until they were able to find their way to this miraculous new drug, Gleevec,” Scherzer said.

He emphasized the data-gathering efforts of the group, noting that the latest update — 16 months since starting Gleevec — shows that, “by and large, the miracle of Gleevec is lasting.”

By gathering data from patients, and publishing it in the newsletter — “heretofore the exclusive prerogative of the clinical research community” — the Life Raft Group is turning the traditional flow of clinical trial information upside down.

“For the first time in history, the clinical trial patient sees the information first, as opposed to years later,



Photo by Paul Zalewski, RavenwoodPhoto.com

MAKING A DIFFERENCE: Four people who’ve played a key role in the lives of GIST patients and Life Raft members in particular are pictured at the May 3 Life Raft Group dinner. From left, Gilles Frydman, president and founder of the Association of Cancer Online Resources; Norman Scherzer, Life Raft Group coordinator, Dr. Dan Vasella, CEO of Novartis, and Dr. George Demetri, head of sarcoma at Dana-Farber Cancer Institute.



Photo by Paul Zalewski, RavenwoodPhoto.com

Norman Scherzer of the Life Raft Group talks with Dr. Dan Vasella, CEO of Novartis, just before the May 3 dinner meeting.

when it traditionally might have been published in some peer review journal,” Scherzer said. The result, he said, “is to forever change the patient-

physician relationship.”

He also outlined three goals for the Life Raft Group:

- * To support GIST research by creating a tumor bank, and by acting as an “informed and activist broker” between pharmaceutical companies with emerging drugs and Life Rafterers who need such treatment;

- * To close the information gap among doctors and lay persons;

- * To reform Medicare in the U.S. so it covers oral cancer medications like Gleevec.

After dinner, Vasella was called to the podium — and received a standing ovation. He was then given the Life Raft Group’s Humanitarian Award — the group’s first-ever award.

Visibly touched, the Swiss doctor said his public relations firm had prepared some comments for this moment, but he’d decided to speak from his heart instead.

“I really don’t believe I deserve it,” he said of the award. “I’m standing here ... because of my colleagues in

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A CEO who can decipher tears

Editor's note: Life Rafter Marina Symcox posted the following e-mail to the Life Raft Group after the May 3-4 gathering in Boston. It is published with permission.

On May 3, I attended the Life Raft reception in Boston. I navigated a room filled with 90 unfamiliar faces. And yet, if I kept my eyes focused at name tag level — where I could read the names — then I was in a room full of good friends. I knew the people through their written words. We were Internet soul mates, bound by cancer.

At one point, Norman pulled me over and said, "I'd like you to meet Dan Vasella." I raised my eyes from name-tag level, and looked into a smiling European face. He did the head-nod-gesture that people do when they don't know exactly what to say. I did the smile-head-nod-gesture right back to him. I was uncertain if he could decipher my Oklahoma accent. My thoughts raced, *What do I say to the CEO of Novartis???* As I was shaking his hand, I blurted out the first thing that came to mind, "I was in hospice." Then my eyes filled with tears, and I was overwhelmed with emotion.

The tears came as a surprise. For months, I had been very matter-of-fact about my close call in hospice. But at that moment, I experienced a flood of gratitude for being rescued. The gratitude was mixed with anguishing memories of the time when my body had betrayed me.

The CEO of Novartis maintained eye contact and the smile. He was accustomed to his role in representing the pharmaceutical industry. But, I was not used to being a symbol for terminal cancer. I wiped away the tears, but I couldn't talk. I walked away to escape.

Later in the evening, I discovered something about the human face who



Photo by Richard Palmer

Life Rafter Marina Symcox shows "before Gleevec" photos of herself to Dr. Dan Vasella, head of Novartis, at the May 3 dinner meeting. Before starting the clinical trial, Marina had been in hospice care for eight months, and resembled a concentration camp survivor.

represented the pharmaceutical industry. He could decipher tears.

Dr. Vasella spoke to our group. Towards the end of his address he said, "I looked at one of you this evening and I saw the tears in the eyes, and it touched me very profoundly." At that moment, I stirred a little in my chair. And perhaps, so did the others who had known desperate battles against metastatic GIST in the days before Gleevec.

Then, Dr. Vasella told us about his sister who had died at a very young age from lymphoma, and how he had watched his parents mourn. He explained that lymphoma is now treatable due to advancements in chemotherapy. And so, his company remains dedicated to the development of chemotherapy.

He concluded, "I thank you for the letters. I thank you for the greetings. I thank you for the tear, and I wish you

well. Thank you so much." The human face representing the pharmaceutical industry had spoken directly to the faces of terminal cancer who filled the room. The "rescuer" had thanked the ones whom he had rescued. And at that moment, I appreciated that underneath the CEO of Novartis, there was a person named Dan.

Later, I turned around to find Dan standing in front of me. He eagerly said, "I want to tell you how profoundly you touched me." Again, I was unable to express my gratitude without crying. So instead, I showed him what I could not verbalize. I brought out a photograph dating from when I was in hospice. The photograph was taken four months before I started Gleevec, at a time when my health was in uncontrolled free fall. The photograph did not fully docu-



Photo by Paul Zalewski, RavenwoodPhoto.com

Dr. Dan Vasella speaks to the Life Raft Group at the May 3 dinner meeting in Boston. Vasella, CEO of Novartis, set aside his prepared comments to speak from the heart to Life Raft members. He talked about the development of Gleevec, and of how meeting Life Raft patients has touched him.

More gathering

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research and my colleagues in development and, above all, Alex Matter, who in his stubbornness did pursue a drug which he did believe in, which was logical, which ‘had’ to work.”

Vasella recalled one instance when a colleague showed him the charts of 37

chronic myeloid leukemia patients who’d been given the compound that was to become Gleevec. “I looked at it and I thought, ‘That’s not possible!’ because *everyone* responded!” But the colleague lamented that the drug couldn’t be developed, because Novar-

tis hadn’t produced a substance that could deliver the compound.

Vasella’s response: “Well, we *will* produce!”

Novartis workers in Ireland worked seven days a week to develop Gleevec, Vasella said, “and nobody complained, and they didn’t because some colleagues from clinical development went and they explained what this was all about.”

Since the first clinical trials, “Gleevec has had a tremendous effect,” Vasella said. “But it’s not a wonder drug. It is a drug which has its limitations. We know Gleevec is not the final answer.”

Vasella challenged portrayals of pharmaceutical companies as being motivated by greed. “For most of us, that’s not what drives us. That’s not what gives us purpose,” he said. “It is what we can do — sometimes, not often, but sometimes — with a drug like Gleevec.”

“I would like to thank every one of you for having been willing to participate in its development,” he said, “and to have had the courage ... to go

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The CEO

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ment my abyss in the days immediately preceding my first dose of Gleevec. However, the photograph told enough.

He studied the photograph and saw an image with advanced cachexia, ashen face, sunken eyes, and a melon-sized mass of tumor protruding from the abdomen. There was a moment of reflection that the image in the photograph could have actually once been the person standing beside him that night.

He called for a colleague to look at the picture. My hospice era photograph gave the CEO of Novartis something that a businessman would like to have. It validated the work of his com-

pany. The photograph also told a compelling human story to the doctor and private person who stood beside me. For a few seconds, Dan had a look of satisfaction on his face.

Then we parted company. He left to run his multi-billion dollar business, and to give press conferences. I went home to run my household, pick up laundry off the floor, and to continue the task of learning how to live with hope again.

At some point during my flight home, I became dissatisfied that I hadn’t quite articulated my feelings on May 3. And so I decided to write a letter, and send it to the Life Raft newsletter. Maybe Dan will find it:

“Dear Dr. Vasella,

“You, too, have touched me very profoundly. I thank you for the past 20 months of life. The time was more than I ever dreamed possible, and yet, 20 months won’t satisfy my yearning for life. I am sometimes afraid that my miracle will end. I have used my second chance at life as an opportunity to cleanse myself from bitterness against cancer. And though we won’t likely cross paths again because we live on different continents and circulate in different crowds, our lives remain intertwined over a small orange pill named Gleevec.

*“Signed, One of Your
GIST Patients”*

Saturday: The Life Raft gets organized

By Richard Palmer

Life Raft Group members rolled up their sleeves and went to work during the second and final day of the Boston gathering, deciding to begin the process of becoming an official non-profit group.

Coordinator Norman Scherzer said the key will be to create a lasting organization that doesn't depend on a handful of people, to "sustain what we're doing, keep it going."

Scherzer admitted he often spends 50 hours a week handling the affairs of the group. "The time this is beginning to take is overwhelming," he said.

Gary Golnik, organizer of the Boston meeting, noted he's the only person maintaining the Life Raft Group Web site, www.liferaftgroup.org. "If I get hit by a truck, God forbid, right now the Web site is dead," he said. "Nobody else knows how to access it."

Similarly, data gathering is done by one person, as is the newsletter. If circumstances change for those individuals, those vital functions could come to a screeching halt.

Gilles Frydman, president of the Association of Cancer Online Resources,



Marina Symcox and Prof. David Josephy tell how GIST works and how Gleevec stops it during "GIST 101," which took place Saturday morning in one of the Cambridge Radisson's restaurants.

Photo by Richard Palmer

noted that the events of Sept. 11 should serve as a "wake-up call."

"I live three blocks from the World Trade Center. The first plane flew over my head," he said. "In an instant I realized that if I'd lived two blocks closer, I would probably not be here today and ACOR would have ceased to exist.

"We need to build up organizations that are sustainable without the people that started them," Frydman said.

Attaining non-profit status would give the group some formal structure and continuity, Scherzer said, and

would eventually allow for the hiring of part-time help.

Following questions and some discussion, Golnik put the question to the group: Should the Life Raft seek non-profit status?

A sea of hands rose in affirmation.

Golnik and Scherzer also spoke of creating a "tumor bank" that could further research of GIST. Such a bank could be set up at a sarcoma center like Dana-Farber's, for use by researchers worldwide.

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Vasella

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through all the uncertainties which are linked to such a decision."

Vasella then shared where his motivation to beat cancer began, and how meeting members of the Life Raft Group renew that motivation.

"I looked at one of you this evening, and I saw the tears in the eyes and it touched me, very profoundly. And I thought back to 1963.

"In 1963, my then-18-year-old sister — I was 10 at the time — she had been sick for three years with Hodgkin's disease, a kind of cancer of the

lymphatic system — and she died at home." There was radiotherapy, he said, but no life-saving chemotherapy.

"I'll never forget her, and how it was to watch my parents mourn, and lose a child," Vasella said.

The same cancer touched his family again. "My sister-in-law, in 1988, got the same disease — and she was cured! She was cured, thanks to chemotherapy."

"I can assure you that our team and our company will remain dedicated to finding new solutions, new ways. We

will lose, sometimes — and sometimes we will win. And it will be a win for all of us — the patients, and the physicians, and the company."

"I thank you for the letters, I thank you for the greetings, I thank you for the tear, and I wish you well. Thank you so much."

Vasella's speech capped an evening of firsts, a series of emotional high points. Even when the program ended, people stayed to talk, take photos, and see all the good friends they'd never met before.

Saturday

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Life Rafter Dr. Barry Jordan, GIST patient and surgeon, said a tumor bank would give researchers the samples they need to figure out why a tumor didn't respond, or why it stopped responding, or why there was a partial response. "There are all sorts of things they can look at, if they have the tissue," he said.

The answers to these questions could point the way to new drugs like Gleevec, only better.

Said Scherzer: "We're not proposing that people who're responding give samples." But, if people have surgery for a tumor that didn't respond, this would be the chance to collect samples for the tumor bank.

Setting up a tumor bank is a way of leveraging a relatively small amount of money, Scherzer said. "Fifty-thousand dollars may get us more results than \$5 million given to a [large] research organization that five years from now is going to develop a new drug."

"I think we ought to put our money and priorities to supporting research that is most likely to have a payoff in the short term in identifying new drugs," said Scherzer.

The Life Raft Group also needs to track new cancer drugs to see if they might work on GIST. Gleevec, Scherzer noted, was originally developed for chronic myeloid leukemia. "We have to monitor the new drugs coming online," he said.

The last topic tackled Saturday morning was "GIST 101," a presentation on how GIST happens and Gleevec works, by Marina Symcox, Ph.D. (biochemistry), part-time GIST patient, full-time wife and mother, and David Josephy, Ph.D., brother-in-law to Life Rafter Elsie Hernandez and professor of biochemistry at the University of Guelph, Ontario, Canada.

Using dozens of slides, the two showed how normal cells grow, how cancer occurs, and how Gleevec shuts



Dr. George Demetri, head of sarcoma oncology at Dana-Farber Cancer Institute, accepts a \$10,000 check from Tania Stutman of the GIST Cancer Research Fund, which she and her husband, Robert, started. Tania staged the first-ever GIST Walk for a Cure last September, raising \$23,000 in one day.

Photo by Richard Palmer

down cancer cells. Even with questions, the presentation came in under the allotted hour, a testimony to the clarity of the presenters and the education of the GIST patients.

In an effort to put every moment to good use, the presentations continued during lunch. Life Rafter Tania Stutman was applauded for putting together the first-ever GIST Walk for a Cure held last September in Congers, New York, which raised \$23,000 for the GIST Cancer Research Fund, established by Tania and her husband, Robert.

Tania took the podium and asked Dr. George Demetri to come forward. As she presented Demetri a check for \$10,000, Dana-Farber's GIST expert was visibly moved.

"It's really an honor to be here," Demetri said. In recognition of the Life Raft "family," Demetri had brought his own family to the luncheon, and introduced them as "the people who really support me and let me do what I do, my wife, Dr. Susan Franco, and my son, Daniel."

"We have this joke in my family," he added. "I come home from work and say goodnight to everybody, they go to sleep and then I live my other life on the Internet, answering questions and

sort of being the Ann Landers of the sarcoma world, trying to do whatever I can to support the doctors and patients and caregivers from around the world through the magic of technology that my friend and colleague, Gilles Frydman, help organize."

"I feel very humble being here," Demetri said, noting that the progress made against GIST is due to the efforts of many people.

"I think my friend and colleague, Dr. Brian Druker of Oregon, used the Isaac Newton quote when he presented to an audience of 25,000 screaming hematologists in 1999 the first CML data, when it was clear that leukemia patients were responding in unprecedented numbers to this drug, when he said, 'If I have seen further than others, it is because I have stood on the shoulders of giants.' I feel the same way."

Scherzer then asked Dr. Edward Benz, president of Dana-Farber, to join he, Demetri and Golnik at the podium.

"We looked over their resumes when we were trying to choreograph this yesterday," said Scherzer. "Both of these guys have very prestigious resumes. But if you looked back into George Demetri's medical history, at

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Q&A with Novartis, Dana-Farber on Saturday afternoon

Doctors from Novartis and Dana-Farber Cancer Institute held a question-and-answer session with the Life Raft Group to lead off Saturday afternoon's agenda.

To allow for a free exchange, Life Raft Coordinator Norman Scherzer asked all to respect the confidentiality

of the discussion. That said, some information of a general or public nature can be reported.

Scherzer shared the most recent data gathered from the Life Raft Group, which indicates the positive response to Gleevec has been durable.

For 118 Life Raft Group members who've been on Gleevec at least three

months, 70 percent have had tumor shrinkage and 17 percent are stable, for a total response rate of 86 percent.

For 61 Life Rafterers on Gleevec at least 12 months, 61 percent have tumor shrinkage, 10 percent are stable, for an overall response rate of 71 percent.

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More Saturday

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the courses he took in medical school, you'd find he flunked the one in medical arrogance. And I suspect Edward Benz failed his as well."

Demetri was then presented with the second-ever Humanitarian Award given by the Life Raft Group, and Benz accepted the first-ever Special Tribute Award, given to Dana-Farber Cancer Institute. Both carried the inscription, "He who saves one life, is as if he has saved an entire world."

Benz, who didn't know he'd be accepting such an award, said the people of Dana-Farber are very honored to be worthy of the work of George Demetri, and the trust of the Life Raft Group.

"You people are what it's all about," Benz said. "Our goal: this year we fill a room with people who might not otherwise be here; next year we want to fill Fenway Park."

Added Demetri: "I don't want any of you to think we're going to rest on our laurels right now. ... There is an incredible amount of energy at Dana-Farber and, frankly, worldwide, to move this field ahead. We've only just started.

"This is something that has been absolutely unprecedented," Demetri said. "This drug [Gleevec] got on the cover of Time magazine; I don't know that penicillin ever got on the cover of Time magazine."

ACOR founder Frydman was then



Photo by Richard Palmer

Gilles Frydman, right, president of the Association of Cancer Online Resources, with his Special Tribute Award, presented by Life Raft Group Coordinator Norman Scherzer.

called forward to receive the second-ever Special Tribute Award.

Scherzer gave an example of the incredible reach of the Internet organization Frydman has put together: Last year, the son-in-law of an Israeli GIST patient was trying to figure out how to get his father-in-law into the Gleevec trial. Through ACOR, he was able to "talk" to the daughter of a Japanese GIST patient who'd just been admitted to the Gleevec trial in Belgium. She was able to connect him to the doctor running the trial, and his father-in-law was accepted. "This discussion was taking place on the [computer] server

in New York City that set up ... by a French Jew who'd found his way through Israel to New York City.

"We could not have made up a more mind-boggling example of the power of the Internet," said Scherzer.

Frydman took the microphone, saying he wasn't good at public speaking, and then immediately gave lie to that statement.

"I left France because I always thought that they wouldn't let me do things that didn't exist," Frydman said. "As a Jew, my entire family, two generations ago, disappeared because of the idea you have to keep people down.

"So I came here, and I had an idea in 1995 that by creating a system that was completely open, and letting the intelligence of the human family gather ... by allowing people to discuss, that cancer patients would get better care. I never thought we would get so incredible a group as you have been."

"Quite a few of you have come here and talked to me, saying thanks to this group, you learned about this drug and the clinical trial."

Visibly moved, Frydman concluded by saying. "You, you've really made my day."

And after Frydman left the podium, many more Life Rafterers would make his day, thanking him for the Internet group that's saving lives.

Letters to the editor

To all,

I would like to thank all those who contributed to making the meeting in Boston a success (sorry for the delay in getting this out, as my life has not yet established any sort of equilibrium). I would like to recognize the following people, at the risk of having my memory fail me and miss someone (if I have, please e-mail me and let me add you to the list).

First, Sheila and Al Murphy for providing our great name badges, with my special thanks and most humble apologies for forgetting who was bringing the badges. Sheila, I am sorry, and I will try never to forget you and Al again!

For those who volunteered/helped in the candle ceremony. Each of these people represented one of our departed: Sheila Murphy, Andrea Fuller, Dan Cunningham, Frank Weigand, Cynthia Whitson, Dan Hoffman, Tania Stutman, Leonie Cousins, Roberta Gibson, Rob Ryninger, Tuomas Hemminki, Linda Martinez, Eleanor Lewis, Henrietta Olsen and Rich Schlott.

For the registration desk crew, who made everything run smoothly while I ran around like the proverbial headless chicken: Frank and Ruth Weigand, Cynthia Whitson, Deb Rinehart and Betty Rosenbluth.

To Cynthia and Jerry Whitson, for the professional Life Raft Group banner that greeted participants and will appear in the countless photos that were taken.

To our leader, Norman Scherzer, for his extraordinary efforts to bring us all together, and provide us the chance to meet Dan Vasella, Edward Benz, George Demetri, and all the other doctors, nurses, and researchers. Also for the legwork in generating all of the plaques and awards.

For Mia Byrne, who pulled together the lovely scrapbook for Norman, with each page representing one of our patients.

To Tania and Robert Stutman, for Norman's plaque as well as for Tania's work in raising money for GIST research.

For the anonymous donors who gave to assist in balancing the books for the

meeting.

To John Poss for his efforts in keeping us on track financially and his concise report which helped keep us on schedule.

For the science team, for the GIST 101 presentation (Marina Symcox, David Josephy, and Jerry Call) as well as the afternoon session (Barry Jordan, Penny Duke, Marina, David, and Jerry).

"Meeting gifts" were provided by Cordelia and Rodrigo de Salas (lovely silver medallions), Eleanor Lewis (flowers), Richard and Linda Palmer (macadamia nuts!), Maryanne Klein (ribbons), and Becky Harper ("Gleevec-eyes" Kleenex).

For Tuomas Hemminki and Richard and Linda Palmer, who traveled the farthest, from Finland and Hawaii to be with us.

And finally, but most of all, to the 39 patients who braved the rigors of travel, the fatigue and pain of the disease, and the stress of meetings to come and inspire us all!

Gary Golnik,
Gathering organizer

Afternoon

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For 23 Life Rafterers on Gleevec at least 16 months, 70 percent still have shrinkage, 4 percent are stable, for an overall positive response of 74 percent.

Dana-Farber's Dr. George Demetri clarified the various clinical trials of Gleevec for GIST.

The first "study" of Gleevec for GIST involved just one patient in Finland, who started Gleevec in March 2000. That study is ongoing (the patient is still taking Gleevec).

The next clinical trial was the "Novartis" study, or the "B2222" group (also known to Life Rafterers as

the phase II clinical trial), done at three U.S. cancer centers: Dana-Farber Cancer Institute in Boston, Mass.; Fox Chase Cancer Center in Philadelphia, Pa., and Oregon Health Sciences University in Portland.

That study enrolled 147 patients, first patient starting Gleevec at Dana-Farber in July 2000.

The third study started in December 2000 at Columbia University (in January 2001 at dozens of other U.S. cancer centers). It's called the NCI (National Cancer Institute) or SWOG (Southwest Oncology Group) study — also known to Life Rafterers as the

phase III trial. This study enrolled 747 patients.

In Europe, Demetri said his colleagues in Belgium had a study similar to the Novartis/phase II study with roughly 100 patients, and they had a study similar to the NCI/SWOG study that stayed open longer, gathering about 900 patients.

Demetri said the pivotal Novartis phase II trial called for people to take the drug for two years. "When we wrote this — remember, GIST was an untreatable disease — and we said we're being overly optimistic," De-

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Candle-lighting tradition ends gathering

The tradition began in July of 2001 with the death of Life Raft member Jeff Prichard. Jeff was one of the first leiomyosarcoma patients to have a more refined diagnosis that deemed his cancer GIST. He was one of the first to write about GIST in a post to ACOR's leiomyosarcoma list. He was the fifth Life Raft Group member to die.

In a July 14, 2001, e-mail, Norman Scherzer exercised his prerogative as coordinator to begin a tradition for the Life Raft Group.

"Tomorrow evening I would ask those of you who are so inclined to light a candle before you go to bed. Say whatever prayer or thought enters your mind. And give someone you care about an extra hug, or if you are alone, give someone a call and tell them that you love them."

And so started the candle-lighting tradition.

In Boston, the first-ever Life Raft Group meeting ended with a candle-lighting ceremony, held near the Charles River in a small park across from the Cambridge Radisson.

Gathering organizer Gary Golnik welcomed the several dozen patients and caregivers.

"We are gathered here to honor our loved ones who have passed from our group to a better place. We will light a single candle for each of the 15 we honor by name. From these 15 candles, we will light the remainder of the candles as a symbol of all others who have passed on due to GIST.

"To begin our ceremony, I offer these words, common to many beliefs, for our loved ones:

"The Lord bless thee and keep thee,
"The Lord make his face shine upon thee, and be gracious unto thee,

"The Lord lift up his countenance upon thee and give thee peace."

As each name was read, a volunteer



Photo by Richard Palmer

Life Raft Group members gather for the candle-lighting ceremony Saturday afternoon, May 4.

There have been 15 deaths in the Life Raft Group to date:

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

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

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

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

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

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

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

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

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

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

Jonathan Montague, 23, Jan. 19, 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.

with a candle came forward. Soon, 15 volunteers stood together, 15 flames flickering in the late afternoon breeze. Then, the 15 turned to the rest of the assembly, and soon dozens of carefully sheltered flames were burning. A moment of silence followed.

"For all our loved ones, I offer these words of parting from an Irish prayer," Gary said. "Somehow the Irish seem to

have a way with words of this sort."

"May the road rise up to meet you,

"May the wind be always at your back,

"May the sun shine upon your face,

"Until we meet again, may God hold you in the hollow of his hand."

As the flames were extinguished, there were few words, but many tearful hugs.

THE LIFE RAFT GROUP

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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.

ASCO

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hren, associate member of the Fox Chase Cancer Center in Philadelphia.

“GISTs are an extremely difficult cancer to treat, so the fact that a convenient, oral, once daily therapy, like Gleevec, can offer this type of response is very welcome news to patients and oncologists.”

In this phase II study, 147 patients received Gleevec, either 400 mg or 600 mg a day. The response rate did not differ substantially between the two dosages.

Only 12 percent of patients saw their disease get worse. Studies are already underway to learn why a tumor that initially responded to Gleevec has become resistant to the drug, said von Mehren.

The drug was generally well tolerated, although some patients experienced side effects that included nausea, diarrhea, muscle cramps, and skin rash. About 23 percent of patients had severe side effects that included low white blood cell counts, tumor hemorrhage, and abdominal pain. The drug

More afternoon

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metri said. “We said we’re never going to have people on the drug for two years. It turned out we were lucky,” Demetri said, a sentiment no doubt echoed by GIST patients.

Demetri noted that when the U.S. Food and Drug Administration approved Gleevec for GIST in February, Novartis was no longer under any obligation to continue providing the drug free to U.S. clinical trial patients. But the maker of Gleevec feels it’s important to follow patients in the Novartis/phase II study, and so the trial was recently revised. Novartis will continue to provide Gleevec to patients, Demetri said, if they continue to be followed at their study center.

“There are rules about giving out trial drugs that are quite strict, and

you have to get it in a certain way,” Demetri said.

As for the NCI/SWOG/Phase III trial, that is not under Novartis’ control. “Decisions are being made to probably segue people to a commercial supply of drugs,” Demetri said, with provisions made so patients’ insurance covers the cost or other provisions are made to ensure that everyone gets the drug.

At mid-afternoon Saturday, the assembled group broke into three different groups. Joan Canniff, nurse practitioner at Dana-Farber, led a discussion on management of side effects. Members of the Life Raft Group’s science team met with doctors from Novartis and Dana-Farber. And Gary Golnik led caregivers in a third group discussion.

was discontinued due to “adverse events” in 13 patients (9 percent). Seven patients (5 percent) had gastrointestinal and/or intratumoral bleeding.

Historically, GISTs have been very difficult to treat due to their high levels of resistance to treatment with traditional chemotherapy and radiation.