

A lot on tap at Boston LRG meet

Future of group will be mapped; key players in GIST fight to be honored

Details have been finalized for the largest gathering of GIST (gastrointestinal stromal tumor) patients in history, May 3-4 in Boston, Massachusetts, U.S.A.

The Life Raft Group — which grew out of a meeting July 13, 2000, by just five patients and caregivers at Dana-Farber Cancer Institute — plans to honor four people key to the survival of Gleevec patients, and the formation of the Life Raft Group. Dr. Daniel Vasella, the chief executive officer of Novartis who pushed for the development of Gleevec, and Dr. George Demetri, one of the foremost sarcoma specialists in the United States, will be presented humanitarian awards.

Special tribute awards will be given to Gilles Frydman, founder of the Association of Cancer Online Resources that today links thousands of cancer patients worldwide, and to Dana-Farber Cancer Institute, represented by Dr. Edward Benz, president of the cancer center.

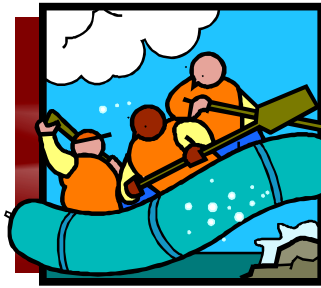
“Unprecedented are the interactions between Dana-Farber and Novartis with the Life Raft Group,” notes Norman Scherzer, coordinator of the Life Raft Group.

In a category all its own, Scherzer said, will be the candle-lighting ceremony at sundown on the banks of the Charles River (weather permitting) in memory of Life Raft members who died.

The future of the Life Raft Group

See Meeting, Page 5

Battling GIST with Gleevec (STI571)



LIFE RAFT GROUP

March 2002

Volume 3, No. 3

Medicare coverage of Gleevec sought

Campaign aims to have all oral anti-cancer drugs covered by program

WASHINGTON — Nearly 90 percent of the American people support Medicare coverage of oral anti-cancer treatments, according to a new survey conducted for the National Coalition of Cancer Survivorship.

That new polling information was released March 14 just before a U.S. Senate Health Care Subcommittee hearing on the “Access to Cancer Therapies Act,” where key members of the Senate called for its passage.

Sen. Olympia Snowe (R-Maine), ranking member of the Senate Finance



Sen. Jay Rockefeller



Sen. Olympia Snowe

Committee, and Sen. Jay Rockefeller (D-W.V.), chairman of the Senate Finance Committee, announced the launch of the national campaign for the act. Several cancer patients spoke at the press conference, joined by representatives from a host of cancer organizations.

See Campaign, Page 2

America responds to Harris poll

Harris Interactive, the New York City based marketing firm known for The Harris Poll, did a telephone survey of 1,007 adult Americans March 7-10 to determine support for expanding Medicare to cover oral anti-cancer medications.

Key findings were:

▶ Americans believe that Medicare

should pay for all medically approved cancer therapies. Nine in 10 (88 percent) Americans feel that Medicare should pay for all medically approved cancer therapies for patients on Medicare. Just 5 percent of Americans do not believe Medicare should cover all medically approved cancer therapies, and 7 percent are not sure.

See Poll, Page 4

Campaign

From Page 1

One of those was Ellen Stovall, president of the National Coalition of Cancer Survivorship, at the Capitol Hill news conference. Stovall unveiled the results of a survey by Harris Interactive, known for The Harris Poll.

The NCCS-commissioned poll surveyed 1,007 adult Americans between March 7 and 10, and found that the vast majority of Americans (88 percent) say that Medicare should pay for all medically approved cancer therapies.

More significantly, when informed that Medicare doesn't cover those cancer drugs that are only in pill form, the poll found that nine in 10 Americans (89 percent) want this policy changed.

Specifically, nine in 10 Americans (89 percent) say that the distinction between oral and intravenous applications should be abolished so that Medicare beneficiaries can have access to the best drugs to treat their form of cancer.

"At this time of unprecedented scientific breakthroughs in the treatment of cancer, we can't stay on the sidelines as Medicare patients are denied access to life-extending drugs simply because of a loophole in Medicare policy," said Stovall

Added Snowe: "This new poll documents that nine out of ten Americans agree it's time to modernize Medicare coverage of cancer drugs to include all medically-approved cancer remedies."

Medicare now covers most cancer chemotherapy drugs — but increasingly does not cover the newest, most effective treatments.

"Scientists are making new, less toxic, more targeted, and more effective therapies available on what seems like a daily basis," said Snowe.

"Sadly, Medicare today will cover only cancer drugs administered by injection, or an oral version if it is identical to an injectable version.

Already, of 40 oral anti-cancer drugs

Life Rafters meet in Toronto



Elsie Hernandez and Michael Josephy and their son, Daniel (that's them on the left) visited with fellow Life Rafters Janice Cheung, Linda Hampson and Michael's brother, David Josephy, while in Toronto, Canada, Jan. 3. The group had lunch at JJ Muggs near the downtown Eaton Centre and chatted about their respective situations.

on the market today, fewer than 10 are reimbursed by Medicare, said Snowe. Even Tamoxifen — one of the most common breast cancer treatments — does not currently qualify for Medicare treatment.

Unless Medicare modernizes, the situation will only grow worse. Rep. Deborah Pryce (R-Ohio), lead sponsor of the legislation in the House (H.R. 1624), has said that while oral drugs make up only 5 percent of the oncology market today, this will increase to an estimated 25 percent or more in the next decade.

"I urge our elected officials to pay attention to the opinions expressed in this poll and take immediate action to pass this legislation into law," said Dwayne Howell, president and CEO

of The Leukemia & Lymphoma Society.

"It is imperative that Medicare's policy be updated to accommodate new, cutting-edge cancer drugs. Medicare must keep pace with pharmaceutical research and development that include new oral anti-cancer drugs as an indispensable feature of quality cancer care."

Added Snowe: "In the battle against cancer, access to cutting-edge therapy can mean the difference between life and death, between surviving to watch a grandchild take his or her first steps, or leaving a family behind with only memories."

Joining in the call for expanding Medicare was Lovell A. Jones, Ph.D., co-founder of the Intercultural Cancer Council.

"As cancer therapy moves toward more use of oral drugs, Medicare policy must be updated to cover these therapies or the most vulnerable



Ellen Stovall

Meet Dave Blender, 'the bread man'

By Dennis Blender

For nearly 40 years, Dave Blender of Monroe Township, New Jersey, was “the bread man,” delivering bread and rolls to schools, hospitals, factory cafeterias and restaurants. Thousands counted on Dave’s nightly visit, and he always delivered. He had a smile on his face and bread in the boxes. And while his work schedule was from 11 at night until noon the next day, Dave always found time to be a devoted husband, father and grandfather.

It was no surprise to his family that he re-channeled his energy upon retirement. He became totally committed to physical fitness. Running, walking, and golf became outlets for his boundless energy — even winning several awards in his age category. Most importantly, his true love is family, and he was able to spend even more time soaking in those pleasures.

In April 1999, Dave started to feel occasional pain in his left shoulder and back. After numerous tests, he was diagnosed as having a tumor attached to his pancreas and stomach. In June 1999, Dr. John Chabot of Columbia-Presbyterian Medical Center in New York City, removed a large tumor. (Ironically, Chabot indicated the tumor was the size of a milk bottle — before he was “the bread man,” Dave grew up on a farm and spent a good deal of his youth as a dairy farmer.)

The tests at that time reported that the tumor was benign. Due to his excellent physical condition, Dave recovered remarkably well. He was up and out of bed the day of surgery, walking around the next day as if nothing had happened.

CT scans in December, 1999, and June, 2000, were clear. In December 2000, a CT scan showed the return of the tumor, 7cm, between the pancreas and liver. The diagnosis was that the



Dave Blender of Monroe Township, New Jersey, pictured with his great-grandson, Aaron. The happy pair wouldn't have gotten to meet but for Gleevec. Dave was diagnosed in April, 1999, and surgery in June, and recurred in December, 2000. He started the clinical trial that month at Columbia-Presbyterian Hospital in New York City.

Photo by Ryan Warsaw

tumor was GIST, and was deemed inoperable. This was actually the first time that Dave or his family learned that the original tumor was cancer.

Chabot referred Dave to his colleague, oncologist Dr. Robert Taub at Columbia-Presbyterian. The hospital was just joined the clinical trial of STI-571 (Gleevec's original name) and Dave was their first patient. With no other options, Dave agreed to join the experimental program.

Dave started on Gleevec in December 2000. He was placed on 800 mg per day, with weekly follow-up visits. Eight weeks after starting the medication, Dave had a CT scan. The results indicated a miraculous shrinkage of the tumor by one-third. In April, a second CT scan determined the tumor to be “dead.” At that time, the dosage was reduced to 600 mg because Dave was experiencing slight blurriness of vision — which was interfering with his golf game.

When Dave got his pills for the first time, he was given detailed instructions on use. One specific direction was to take the pills on a full stomach.

Several family members met Dave at a restaurant that day for lunch. After eating, all eyes were on Dave as he took out the pills, and began to open the bottle. It must have been nervousness, because Dave dropped one of the pills. Well, four people dove under the table in search of the “magic pill.” The restaurant was dark, which only added to the drama. As a waitress started to walk towards the table and ask if she could help, a chorus yelled back, “NO! Don't come any closer!” for fear of her stepping on the pill. After finally locating the lost pill, Dave began the journey of recovery.

Follow-up CT scans in August and November indicated no change — the tumor remained dead. Additional CT scans are scheduled throughout 2002.

Today, Dave is back to his exercise, only slightly reduced. He walks instead of runs and plays only a few rounds of golf per week. His extra time is spent with his wife, Eleanor, children, grandchildren, and first great-grandchild. Dave continues to deliver — only now it's kisses, hugs, and love.

Poll

From Page 1

► Americans feel that Medicare should cover cancer drugs for patients — regardless of whether it is available as an injection or pill. Given that Medicare currently only pays for cancer drugs taken as pills if the drug is also available as an injection or infusion, nine in 10 (89 percent) Americans believe the distinction should be abolished and Medicare should also pay for drugs available only in pill form. Four percent do not think Medicare should also pay for cancer drugs only available in pill form, and 7 percent do not know.

► Americans have favorable opinions about pending Medicare legislation. Four of five (83 percent) Americans believe that new legislation that would have Medicare pay for all oral anticancer drugs should be passed in this session of Congress. One in 10 (9 percent) does not feel that such legislation should pass this term, and nearly one in 10 (8 percent) are not sure.

► The prospect of increased Medicare costs does not dissuade Americans from seeking easier access to cancer drugs for Medicare patients. If adding 1 percent to the cost of cancer care paid by Medicare meant that Medicare patients could have better

access to cancer drugs, four out of five (83 percent) Americans would support adding to the Medicare budget. Just 5 percent oppose adding to the Medicare budget to allow easier access to cancer drugs for Medicare patients, and nearly one in 10 (8 percent) are indifferent. Four percent are not sure.

Here are the specific questions asked in the poll, and the response:

As you may know, Medicare is the government's health insurance program for people 65 years of age and older, and for certain younger people with disabilities. In general, do you think Medicare should or should not pay all medically approved cancer therapies for patients on Medicare?

Should — 88 percent
Should not — 5 percent
Refused/Don't know — 7 percent

Currently, Medicare pays for cancer drugs that can be taken as a pill only if the drug is also available in a form that can be injected or infused into patients. However, some cancer drugs only come in pill form. Many of these cancer pills target specific cancer cells and represent the very latest generation of cancer therapies. Do you

think that Medicare should or should not also pay for these cancer drugs?

Should — 89 percent
Should not — 4 percent
Refused/Don't know — 7 percent

New legislation is under consideration in Congress to have Medicare pay for all oral anticancer drugs for Medicare patients. In your opinion, should this legislation be passed in this session of Congress, or don't you feel that way?

Yes, should be passed — 83 percent
No, don't feel that way — 9 percent
Don't know/Not sure — 8 percent

Currently, Medicare pays more than \$78 billion a year for cancer treatments for Medicare patients. If adding 1 percent to the cost of cancer care paid by Medicare meant that people 65 years of age or older could have easier access to these new cancer drugs, would you:

Support adding to the Medicare budget — 83 percent
Neither support nor oppose adding to the Medicare budget — 8 percent
Not support adding to the Medicare budget — 5 percent
Don't know/not sure — 4 percent

Campaign

From Page 2

among us — seniors and the disabled — will be forced to accept more painful and more toxic treatments,” said Jones. “Up until now, the unequal burden of cancer has been largely a problem affecting the nation’s minorities and underserved. It would be disheartening if an outdated Medicare policy adds seniors to these ranks.”

Added Snowe: “It’s clearly time for Medicare to catch up — or we risk condoning a de facto, two-tier system of health care delivery for cancer pa-

tients: one for those with the money to pay for superior treatment, the other for the rest of America. We believe lesser means should not mean lesser care.”

Speaking in support of the Access for Cancer Therapies Act were Dr. Larry Norton, president of the American Society of Clinical Oncology; Howard Bedlin from the National Council on Aging, and Ora Gelberg from New York City, who’s husband is a GIST patient doing well on Gleevec which

they pay for out-of-pocket.

Other speakers included Ken Regan of Belmont, Michigan, an 8-year survivor of multiple myeloma who's paying out-of-pocket for Thalidomide. Anita Johnson from Long Island, New York, told of being an 11-year survivor of non-small cell lung cancer taking the drug Iressa.

Also speaking were two CML patients on Gleevec, Paige Brown of Nashville, Tenn., and John Rowe, who works for Congressman Dan Burton.

Meeting

From Page 1

will be discussed. Said Gary Golnik, meeting coordinator and group Web-master: "I would ask all of you (those coming and those who are not) to think about what the future may hold for the Life Raft Group. Our collective wisdom is needed to guide us in helping all those with this dread disease."

Golnik suggests those unable to attend contact someone who is coming, so all views can be represented. "In addition to all else, the meeting will be the start of a sort of 'Constitutional Convention' process that will decide how we go forward from this point.

"For all our growth," he added, "the vast majority of GIST patients are not yet in the group. My personal hope is that we can someday be of service to them all, in one way or another."

Here is the agenda for the Life Raft Group meeting:

Friday, May 3rd

**Radisson Cambridge Hotel
777 Memorial Drive**

6-7:30 p.m. Registration

7:30-9 p.m. Dinner/reception

Welcome: Norman Scherzer, Life Raft Group coordinator

Humanitarian Award to Dr. Daniel Vasella, CEO, Novartis

Saturday, May 4th

Radisson Cambridge Hotel

8-9 a.m. Registration

9 a.m. Life Raft Group business meeting (members only), including coordinator's report, treasurer's report, discussion of the Life Raft Group's mission, objectives and structure, and presentation of Special Recognition Awards

10:45 a.m. Break

11 a.m. "GIST-Gleevec 101" — Presentation by the Life Raft Group Science Team

Noon: Lunch

Presentation of Humanitarian Award to Dr. George Demetri, director, Cen-

ter for Sarcoma and Bone Oncology, Dana-Farber Cancer Institute

Special Tribute Award to Dana-Farber Cancer Institute; acceptance by Dr. Edward Benz, president, Dana-Farber

1:30 p.m. Interactive Panel: Novartis and Dana-Farber oncology team

Special Tribute Award To Gilles Frydman, Association of Online Cancer Resources (ACOR)

2:45 p.m. Break

3 p.m. Management Of Side Effects: Joan Canniff, Dana-Farber

Co-Session: Life Raft Group Science Team with Novartis and Dana-Farber Oncology Team

5 p.m. Adjourn

Where it all began

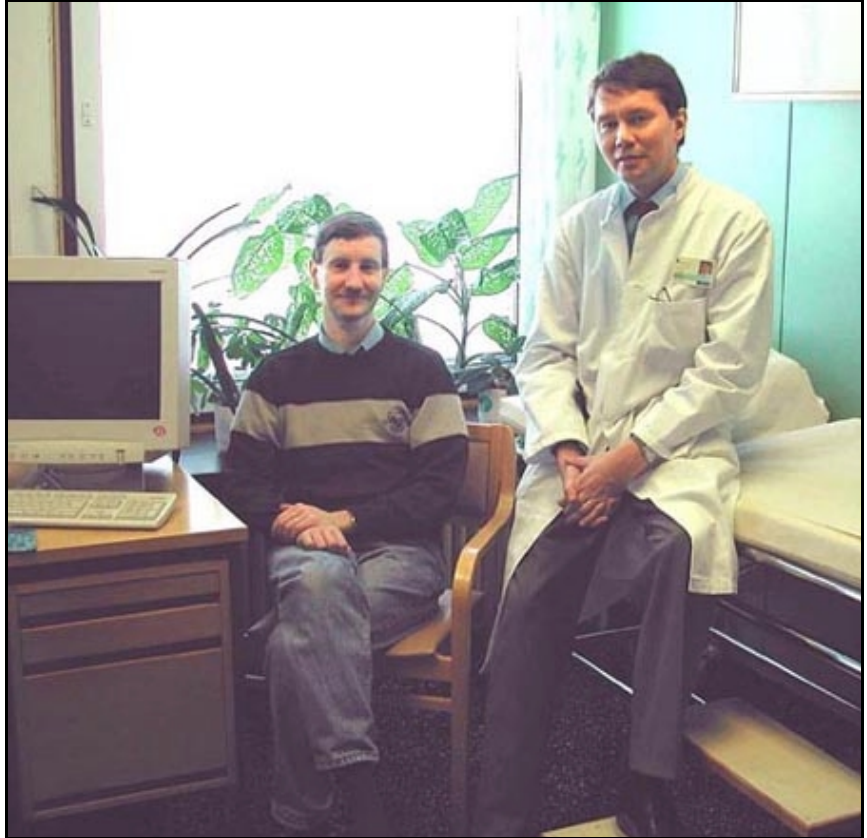


Photo by trial nurse Tuula Kainila-Moilanen

The Life Raft member Tuomas Hemminki, left, shown is celebrating his 1-year anniversary on Glivec (only the U.S. calls it Gleevec) this month with Dr. Heikki Joensuu at Helsinki University Hospital, Finland. Tuomas is sitting in the same chair on which the first GIST patient ever treated with Glivec was sitting in March 2000, when the decision to start Glivec for GIST was made for the first time. "The drug is functioning well," said Dr. Joensuu, "and so is the chair."

6:51 p.m. Candle Ceremony to honor Life Raft Group Members who lost their battle but contributed to GIST research.

Editor's note: There was discussion among Life Raft Group members regarding appropriate dress for the meeting. "Business casual" was deemed most suitable. After further discussion and sober deliberation, it was decided that "business casual" would include tasteful Hawaiian shirts of subtle print and hue, sandals (so long as they're not ratty), expando-waist pants to accommodate Gleevec bellies, hats for chemo hair, and whatever undergirdings members deem physically and emotionally necessary.

THE LIFE RAFT GROUP

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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 listserve 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.

Who's new in the Life Raft

Robert Donohoe of Los Alamos, New Mexico, U.S.A., by prescription.

Kathleen Colwell of Olathe, Kansas, U.S.A., by prescription.

Ulrich and Helga Schnorf of Zug, Switzerland; Ulrich on the trial at the Centre Hospitalier Universitaire Vaudois in Lausanne, Switzerland.

Patricia Ford, at the University of Wisconsin Cancer Research Center Madison, Wisconsin, U.S.A.

Ellen Rosenthal of Royal Oak, Michigan, U.S.A., by prescription from doctors at University of Michigan Cancer Center.

Maggy and George Wolf of New Orleans, Louisiana, U.S.A., George by prescription as of March 2002.

Judie, daughter of **Karin O'Neill**, Karin by prescription, Moffett Cancer Center.



Life Rafter's meet at Dana-Farber

Here are Life Raft members Cynthia Whitson, left, and Maryann Klein. They and their husbands got together Feb. 20 at Dana-Farber Cancer Institute in Boston when both were there for their 16-month checkups.



Here are the caregivers, Gary Klein, left, and Jerry Whitson. "We're not hung up on whether the husbands get in the newsletter," wrote Cynthia, "even though they do suffer a lot more than we do."