

Doctors hear of Life Raft experience at London meet

More than 400 physicians attend symposium on Glivec therapy for GIST

The Life Raft Group's profile in Europe skyrocketed this month when Executive Director Norman Scherzer spoke to more than 400 physicians from 32 countries at a three-day symposium, "Glivec: First Successful Systemic Treatment for GIST."

The event was held Sept. 18-20 at the Hotel Intercontinental in London to further the understanding of changes in the management of patients with GIST in the era of Glivec.

Scherzer was the wrap-up speaker at the symposium's first day with a presentation titled "Medicine on the Internet: Impact on Physician-Patient Relationships, the Experience of the Life Raft Group."

Here are excerpts from Scherzer's report which he filed Sept. 22. He cautions: "This is written to the

See LONDON, Page 4

Life Raft charts new waters in U.S., U.K.

The Life Raft Group has made progress in its efforts to reach more GIST patients by adding two regional chapters in the United States and recruiting its first country coordinator.

David Cook of Sheffield, United Kingdom, has agreed to be his

country's coordinator for the Life Raft Group. Cook, who was profiled in June's Life Raft Group newsletter, is director of studies for the University of Sheffield's chemistry department. He just happens to have a next-door neighbor who takes Glivec (as Gleevec is known outside the U.S.A.) for chronic

myeloid leukemia. Cook can be reached at D.Cook@sheffield.ac.uk

In the United States, Life Raft Group chapters have formed in the Illinois and in Southern California. Dick Kinzig of Palatine, Illinois (e-mail RJKinzig@aol.com) is coordinator of the Illinois group, and

See Outreach, Page 7

Battling GIST with Gleevec (STI571)



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Kids walk for a cure



At the Sept. 21 GIST Walk for a Cure held in New Jersey, U.S.A., the five grandchildren of organizers Tania and Robert Stutman donned their walk T-shirts (which will probably fit for the GIST Walk in 2012). They are, from left, Jamie Velardi, Chase Campanella, Ashley Velardi, Tyler Campanella, and Olivia Campanella. Hopefully, they will only know GIST as a curable inconvenience. See story/Page 2



Scores of walkers showed up Sept. 22 for the second annual GIST Walk for a Cure held at Rockland Lake State Park in Congers, New Jersey. The walk was the second organized by Tania and Robert Stutman for the GIST Cancer Research Fund they established, which this year gave three grants totaling \$35,000 for GIST research.

Second time around just as successful

GIST Walk for a Cure raises research money, awareness of disease

Tania Stutman is a full-time health professional, a wife, a mother, grandmother of five and, for the past four years, a GIST patient.

That's a lot to handle by most any standard. But not quite enough for Tania.

On Sunday, Sept. 22, Tania and her husband, Robert, staged the second annual GIST Walk for a Cure at Rockland Lake State Park in Congers, New York state, U.S.A. More than 150 walkers showed up and raised \$23,000 for the GIST Cancer Research Fund which the Stutmans established with help from Dr. Ephraim Casper, chief of medical oncology at Memorial Sloan-Kettering at Saint Clare's in northern New Jersey.

This year the Walk for a Cure got

a big boost from a company already familiar to GIST patients: Novartis. This summer, Tania and Robert got a call from the Novartis offices in East Hanover, New Jersey, inviting them to lunch Aug. 23. There, Carl Kuebler, Gleevec product director, said Novartis was impressed with what the Stutmans had done, and wanted to sponsor this year's GIST Walk for a Cure.

The international pharmaceutical company gave a \$5,000 grant to the effort, and Kuebler showed up Sept. 21 to make a personal contribution and to join in the three-mile walk around Rockland Lake with his two young children. Also joining in the walk was Life Raft member Dr. Barry Jordan.

Two local newspapers were there to record the fund-raiser; the coverage is expected to further spread the word about this rare sarcoma.

This year, the GIST Cancer Research Fund has given \$35,000 to

three cancer research facilities.

The first grant, \$15,000, went to Dr. Robert Maki of Memorial Sloan-Kettering Cancer Center in New York city. The second gift was made May 4 at the Life Raft Group's first gathering in Boston, Massachusetts, U.S.A. Tania presented \$10,000 to Dr. George Demetri, director of the Center for Sarcoma and Bone Oncology, Dana-Farber Cancer Institute.

More recently, the Stutmans gave \$10,000 to Fox Chase Cancer Center in Philadelphia, Pennsylvania, U.S.A., designated for GIST research under the direction of Dr. Margaret von Mehren.

"I greatly admire your determination and drive to accelerate the pace and intensity of GIST research," said an Aug. 14 letter to the Stutmans from Ariel D. Bateman, director of special gifts at Fox Chase. "Your gift will quickly set the wheels in motion."

The world's healthiest GIST patient

Michael Byrne wears race number 571 into three summer triathlons

Michael Byrne may be the healthiest GIST patient on the planet. If the Life Raft ever had a candidate for a "tough man" competition, he'd be it.

Consider: Cancer surgery in 1993, 1997 (deemed "hopeless"), 1998 (football-sized tumor) and 2000; chemotherapy in 1997, 1998 and 2000. And cryosurgery in 1998 before starting Gleevec in October 2000.

This year: Michael enters a triathlon — one of those endurance races that begins with a swim, ends with a run, and has way too much bicycle riding in between. He finishes. And enters another. And another, this time with his wife Mia.

Last month, Mia posted the following to the Life Raft listserve. It chronicles the nine-year odyssey of the Byrne family, and is reprinted with permission.

By Mia Byrne

Tomorrow, Aug. 17, 2002, marks the ninth anniversary of Michael's initial GIST surgery in 1993. He was only 30 years old. He was healthy one day and woke up at 3 a.m. the next in pain. Can cancer really happen overnight?

I can remember every medical moment of the past nine years as if they happened this morning. Back in '93, his tumor was misdiagnosed and we were told that it was not cancer so we remained in blissful



The Byrne family, above, rests after finishing the Windsor (Ontario, Canada) Triathlon held Aug. 11. Son Matthew is at left with mom Mia and dad Michael (who somehow looks the most rested despite cancer). At left, Michael competes in his first triathlon held in June near their home west of Detroit, Michigan, U.S.A. He's wearing number 571, for STI571, Gleevec's clinical trial name.

ignorance for three more years. I used to have so much anger about the mishaps of that first surgery, but if we had been told he had cancer then, would he still be here today? Would we have our beautiful 6-year-old son, Matthew? Probably not.

His disease had a name when it

returned in late 1996, but the name was leiomyosarcoma. In early 1997 a surgeon opened him up and looked at his large tumor and decided that there was no hope. I remember distinctly the suffocating feeling when the surgeon told me that Michael would die.

What would happen to our son, then only 2? What would I do? This could not be.

Fortunately, the surgeon never shared his opinion with Michael, nor did I. Fortunately, we continued searching for doctors that could help him.

See Byrne, Page 4

London: Life Raft Group gets overwhelming response

From Page 1

best of my ability from my notes, and my recollections, while flying back from London. It is always possible that human error may be present, and I would ask you to treat my comments accordingly.”

“I was overwhelmed by the response to my presentation at the London GIST conference and by the acceptance both of my remarks and of the Life Raft Group,” Scherzer said. “Imagine my surprise when the opening and keynote

speaker, Dr. Gordon McVie of the United Kingdom — whom I had never met before — remarked how delighted he was to have the Life Raft Group represented and how important he felt that we were to the proceedings.”

Given to all attendees was an abstract of his remarks and a paper, “Introducing the Life Raft Group,” which read:

“The Life Raft Group is an international, Internet-based, nonprofit

organization providing support to patients with GIST through education and innovative research.

“The paradigm for doctor-patient relationships is changing, and the challenge is how to shape these changes to benefit both doctors and patients. These relationships have been affected recently by managed care and by patient access to data on the Internet. This presentation reports on the evolution of a move-

See London II, Page 5

Byrne

From Page 3

We spent that whole year in limbo, looking for treatment yet enjoying the fact that Michael was asymptomatic despite the tumors growing in his abdomen.

Chemo began in late 1997. Believe it or not, it actually worked a little bit, and a new, more skilled surgeon took a shot in early 1998.

What an unbelievable feeling to hear the surgeon tell us that all tumors had been removed; the largest “inoperable” one being the size of a football. How can this be? Can I let out my breath yet? I had spent a year waiting for him to die from his “inoperable” tumors.

More chemo for the liver mets, but that didn’t work, so back on the table in the fall for liver cryosurgery.

This time he made it 15 months before recurrence. A whole year of no surgery and no chemo. We were starting to think this nightmare might end some day — but not yet. Surgery again in early 2000. Devastation when the first scan post



Finished with the swim and bicycle portions of his first triathlon held last June, Life Rafter Michael Byrne looks strong heading toward the finish line.

surgery showed disease. More ineffective chemo made for a summer of feeling lousy.

Then we started getting e-mails from our friends from the LMS list. Gary and Jerry telling me about a new drug called STI-571. We

called the trial centers, desperate to get in and feeling guilty that we might get in and someone else might not. The only spot available is was Portland, Oregon — a long way from Michigan, but who cares. Michael started STI571 in Portland in October 2000. It was the first time we felt this hopeful, based on the positive results we heard Norman shouting from the mountain tops about Anita.

Michael’s results have been great. He has had over 50 percent shrinkage and now approaches the two-year mark on Gleevec. This summer he celebrated life by entering a triathlon and wearing number 571 to say thanks for the drug and all the doctors who have helped him make it nine years with a disease that he should not have survived. He has run two more races since that first one in June. Matthew and I joined him in the last race last weekend. Boy, was it hard.

Can nine years have really gone by that quickly?

Southern California Life Rafterers hold their first gathering



The first gathering of Southern California Life Raft members took place Saturday, Sept. 7 at the home of Floyd* and Joyce Pothoven, pictured at far left. With them are, from left, Art Olson, Pam Creviston, Bill Crabtree*, Patsy Miller*, Marty Miller, Henrietta Olson*, Cindy Dunigan*, Cecilia and Richard Stevenson*. (All look so healthy you'd never know the ones* with GIST). "We had a wonderful meeting with all of us describing how we discovered we had the disease and the experiences we had gone through up to now," reports Floyd. Much time was spent talking about insurance and how to deal with the massive cost of Gleevec. "One thing becomes very clear after a get-together like this," Floyd added: "No matter how bad your own experience is, there is always someone in the group that has gone through an even greater ordeal."

London II: GIST is more common than once thought

From Page 4

ment from patients accessing data on the Internet to patients creating data and then sharing it with others via the Internet.

"Within six months of the beginning of the Glivic (STI571) clinical trials in GIST, the headline, 'Initial Survey Shows High Response Rate' — appearing in the Life Raft Group's monthly newsletter — introduced the first Internet-based report of drug response. Subsequent newsletters reported on the role of gender in side effects, continued to track rates of response to Glivec, and provided a comprehensive survey of side effects from the patient's perspective. The result has been to turn the flow of clinical

data upside down, with the patient now receiving information first.

"Patient perspective data have introduced a complementary way of looking at side effects, based on a unique measurement scale developed for patients, as opposed to the more traditional toxicity scales of the U.S. National Cancer Institute and cancer agencies in other countries. Data on the quality of medical care and the accuracy of patient reporting in clinical trials are also presented, with a clear correlation demonstrated between them."

Tidbits Scherzer gleaned at the conference:

- Although gastrointestinal stromal tumor is a rare disease, and al-

though no one actually knows how prevalent it is, the growing consensus is that it is more common than originally thought. Medical professionals guesstimate the annual incidence rate at 20 per million people, with an almost equal distribution of men and women, and with a median age in the 60s.

- Primary tumors are most likely to occur in the stomach (50+ percent), followed by the small intestine (30+ percent), followed by the colon/rectum (less than 10 percent).

- The history of the diagnosis of GIST is very recent, with the Japanese credited with finding c-kit in

See London III, Page 7

Illinois chapter of Life Raft has first meeting

Illinois chapter of the Life Raft Group got together for the first time Tuesday morning, Sept. 17, in Inverness, Illinois, a suburb of Chicago. The meeting at the Wellness Place, a cancer support facility affiliated with the Northwest Community Hospital in Arlington Heights, Illinois.

Six Life Rafter, two spouses and a daughter were able to make the meeting, reports chapter coordinator Dick Kinzig.

“There were only nine total Life Raft Group people in the area that I could locate, and two were out of state,” he said. “Two were not able to attend because they work during the day we met and one called in sick the night before but she provided us with her story which I then read too the group as if she were there.”

All agreed that the Wellness Place was an ideal location to meet. “We were well received by the staff there and quite impressed with the luncheon that Linda Murphy provided for us,” said Kinzig. “Linda was one of the founders of Wellness Place.”

A great addition to the meeting was Dr. Margo Shoup, assistant professor of surgery at Loyola University Medical Center, and chief of gastrointestinal surgical oncology at Cardinal Bernadin Cancer Center in Maywood, Illinois.

“Dr. Shoup was able to answer technical questions as well as cover the latest developments in GIST



AT LEFT: The first meeting of the Illinois chapter of the Life Raft brought together, from left first row, Phil and Paula Vettel, Nancy Welsh, Jeannie Book; in back, Tricia Brasen with her mother, Pat, Dick Kinzig, Carol Berres, and Bob Book.
BELOW: Illinois chapter coordinator Dick Kinzig with Dr. Margo Shoup, assistant professor of surgery at Loyola University Medical Center, and chief of gastrointestinal surgical oncology at Cardinal Bernadin Cancer Center in Maywood, Illinois.

surgery and oncology,” said Kinzig. “It is hoped that Life Raft Group can continue our relationship with Dr. Shoup for issues in the future.”

Shoup told the group that Loyola Medical Center has the only team approach to gastrointestinal surgery and oncology in the Chicago area — “something we might want to look into further,” Kinzig added.

“I guess it is safe to say that we were more than satisfied with the meeting, happy to have met face-to-face and were taking home a renewed interest in finding new members and promoting the goals of Life Raft Group and our own survivorship.”

The group is planning its next meeting Saturday, Jan. 11, 2003, to accommodate those who work and



unable to attend a weekday meeting. “So — those of you who were unable to attend, look to January for our next meeting,” said Kinzig. The meeting will be at the Wellness Place.

Outreach: Salas, Schnorf join board of directors

From Page 1

Floyd Pothoven of Lakewood, California (e-mail floyd@lasersealer.com) is coordinator of the Southern California chapter. Both of the chapters met for the first time in September. See photos, stories on Pages 5 and 6.

In addition, the Life Raft Board of Directors has expanded to better represent the international makeup of the group. New directors are Rodrigo Salas of Monterrey, Mexico, and Ulrich Schnorf of Zug, Switzerland. They join board Presi-

dent Stan Bunn of Tampa, Florida; Secretary-Treasurer Bernie Kaplan of New York; director Gary Golnik of Cambridge, Mass., and Canadian directors Mike Matthews of Halifax, Nova Scotia, and Sylvia Williams of Winnipeg, Manitoba.

London III: C-kit test antibodies vary in accuracy

From Page 5

GIST in 1998 — the forerunner of c-kit testing which got underway, on a small scale, in clinical practice in early 2000. Prior to c-kit testing, the most common misdiagnosis of GIST was leiomyosarcoma, followed by leiomyoblastoma.

- Prognosis for recurrence: There was a consensus that the best predictors for the recurrence of GIST, following initial surgery, are tumor size and mitotic rate, although it was noted that GIST has a lower mitotic rate than other soft tissue sarcomas. About 70 percent of GIST displays spindle cells.

- About 95 percent or more are CD117 (c-kit) positive. That means that some GIST tumors are c-kit negative, although the diagnosis for GIST will continue to depend upon a positive c-kit test as the gold standard.

- Testing for c-kit is based upon using commercially available antibodies. There has been no systematic evaluation of the quality of these antibodies. A paper was presented comparing the reliability of several of the most common. DAKO was considered the best, followed closely by Novocastra. Santa Cruz and Neomarkers were considered much less reliable, pro-

Quote:

“There were no clear answers about the value of Glivec pre- and post-surgery, nor about the optimal dose, nor how long patients should remain on the drug.”

— Norman Scherzer,
LRG executive director, on
information gleaned from the
London symposium on Glivec

ducing an unacceptable number of false positives. What this all means is that accurate c-kit testing depends upon experienced pathologists using a reliable commercial antigen.

- Dr. Stephan Dirnhoffer of the University of Basel, Switzerland, in collaboration with Dr. Chris Corless of Oregon Health Sciences University, has produced the first GIST micro array (think of about 1,000 tissue samples on a single

slide).

- Treatment response and genetic mutation: As reported at the May conference of the American Society of Clinical Oncology, there is a clear correlation between genetic mutation and response to Glivec, with mutation in exon 11, having the best response. “What I learned for the first time was that exon 9 — which has a poorer response to Glivec — has been found only in patients with a primary tumor in the small bowel or colon; and that exon 9 has not been found in any patients with a primary tumor in the stomach,” said Scherzer.

- There were no clear answers about the value of Glivec pre- and post-surgery, nor about the optimal dose, nor how long patients should remain on the drug. Of importance to many was the current treatment protocol being used at Dana-Farber Cancer Institute in Boston: Start patients at 400 mg per day, increasing to 600 mg per day as indicated.

There are a number of new trials for GIST patients using Glivec, with some at the meeting expressing concern that there may be too many for a relatively small number of patients. These trials include the

London IV, Page 8

Christian Life Raft members begin sharing

A sublist of the Life Raft Group has been started by Cynthia Whitson.

“We’re an informal group sharing prayers, hopes, fears, and Christian experiences during this difficult time in our lives,” says Whitson. “The group is open to anyone — those with GIST and caregivers.

“We encourage everyone to continue their contact with the main Life Raft Group,” she adds. “Anyone who is interested in joining us can e-mail me at seawhitson@mindspring.com.

In Memoriam

There have been 18 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.

Jerry Pat Rylant, 61, May 5, 2002, husband to Pamela, father of four, grandfather to 10.

Jill B. Meyer, 53, June 9, 2002, mother of Aliza.

Todd Hendrickson, 44, June 29, 2002, husband to Janet, father to Max, Tyler and T.J.

London IV: Doctors speculate Glivec resistance grows

From Page 7

neoadjuvant (before surgery) and adjuvant trials that Life Raft Group members have reported on, plus a new French trial run by the French sarcoma group.

Although the treatment with Glivec seems to be lasting for most, there is concern that remaining dormant cancer cells can produce recurrence with the cessation of treatment, and sometimes in the presence of treatment. The speculation is that this resistance to Glivec will grow over time.

The objective is to find ways to manage GIST in the interim and to find new treatments. There was a great deal of discussion, both in the formal sessions and in the many informal ones that followed, about the need for international collaboration to evaluate strategies for over-

coming resistance, including working with the Life Raft Group whose daily discussions provide a sentinel system for reporting the incidence of resistance and any success in overcoming this.

There was also an emphasis on the need to obtain fresh tissue in such situations, particularly pre- and post-surgery. Once again the collaboration of the Life Raft Group, including the goal of creating a patient-driven tumor bank, was discussed.

“A developing consensus I walked away with was that patients who stop responding to Glivec should not be taken off the drug,” said Scherzer.

The consensus on how to take Glivec remains: Take Glivec with food, not because it is relevant to

drug absorption, but because it may be helpful in avoiding certain gastric related side effects. Also, do not to take Glivec with grapefruit juice, because it may interfere with drug absorption.

Scherzer also met with about a dozen key clinicians and researchers outside the formal meeting to discuss collaborative efforts.

Also, Scherzer met with David Cook, United Kingdom Life Rafter, “who was kind enough to come down to London from Sheffield, England, to meet with me.”

Those with Microsoft Power Point software can get a copy of the slides Norman presented, and the Microsoft Word document, “Introducing the Life Raft Group,” by contacting him via e-mail at normanis@bellatlantic.net.

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Who are we and what do we do?

The Life Raft Group is an international, Internet-based, non-profit organization providing support through education and research to patients with a rare cancer called GIST (gastrointestinal stromal tumor), most of whom are being successfully treated with an oral cancer drug Gleevec (Glivec outside the U.S.A.) This molecularly targeted therapy inhibits the growth of cancer cells in a majority of patients. It represents a new category of drugs known as signal transduction inhibitors and has been described by the scientific community as the medical model for the treatment of cancer.

GIST is a rare soft tissue cancer, notoriously resistant to traditional chemotherapy and radiation. Before Gleevec, the only treatment for slowing this cancer was surgery.

The Life Raft Group started in July 2000 as GIST patients and caregivers in the Gleevec (STI571) clinical trials, and later extended membership to all GIST patients. We became a nonprofit group (501-c-3) in the U.S.A. as of June 10, 2002.

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, including medical professionals. However, this newsletter serves as an outreach and is widely distributed. Hence, all newsletter items are edited to maintain the anonymity of members unless they 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 should be used with caution, and is not a substitute for careful discussion with your doctor.

As for this newsletter: 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.