

Running for the Life Raft

GIST survivor, friend to join New York marathon and help battle cancer

By Mia Byrne

Michael Byrne, the Life Raft Group's answer to Lance Armstrong, and family friend Jennifer Hartzler Corrao will be running the ING New York City Marathon on Nov. 7 to help raise money for the Life Raft Group.

Michael has been fighting GIST (gastrointestinal stromal tumor) for more than 11 years. Prior to 2001, surgery was the only effective treatment option for GIST; however, even



BYRNE

when the cancer was completely removed, it often returned and spread. Michael had five abdominal surgeries between 1993 and 2000. In each case, the cancer returned.

Michael underwent ineffective chemotherapy treatments in 1997, 1998 and 2000, and liver cryosurgery in 1998. Michael is extremely lucky. Though his conventional cancer treatments did not stop his cancer, they did keep him alive until the arrival of an experimental oral cancer drug. Now

See **MARATHON**, Page 4

Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

September 2004

In memory of Nelly Beel, Pamela Bowden, Tom Cooper, Bernie Kaplan and Stan Natanson

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Glivec at higher doses combats progression

Largest study of GIST finds 800 mg. keeps cancer at bay longer

BASEL, Switzerland – Clinical trial patients taking an 800 mg. daily dose of Glivec for treatment of gastrointestinal stromal tumor (GIST) had significantly longer progression-free survival compared to the patients taking the standard 400 mg. daily dose, according to results published Sept. 24 in *The Lancet*.

The results showed that doubling the daily dose of Glivec (imatinib, or Gleevec in the U.S) may improve progression-free survival of patients with KIT (CD117)-positive GIST that is inoperable and/or has spread.



Novartis AG

A technician fills capsules at Novartis.

See **DOSAGE**, Page 2

Fourth 'Walk for a Cure' happens Sunday in New York

Former New York Knicks basketball great Walt "Clyde" Frazier will appear at the fourth annual "Walk for a Cure" happening Sunday morning, Oct. 10, at Rockland Lake State Park in Congers, New York.

The walk is the cornerstone fundraiser for the GIST Cancer Research Fund, started by Robert and Tania Stutman, members of the Life Raft Group and GIST Support International. This year more than 400 people are expected, not only from nearby

New York City and vicinity, but also from California, Florida, Massachusetts, Ohio, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia.

Frazier was voted one of the 50

See **WALK**, Page 5

DOSAGE

From Page 1

At a median follow-up of 760 days, patients receiving 800 mg. per day experienced five months longer progression-free survival compared to patients on 400 mg. a day.

“The introduction of Glivec has dramatically improved the prognosis of patients diagnosed with advanced KIT-positive GIST,” said Jaap Verweij, head of the Division of Experimental Chemotherapy, Department of Medical Oncology, Erasmus University Medical Center, Rotterdam, The Netherlands, the principal investigator and lead author of this publication.

“While further research is needed to establish the impact of a higher starting dose on patients’ survival, the prolonged progression-free survival seen in this study represents benefit to patients.”

The international, randomized, phase III study was conducted by the EORTC



VERWEIJ

(European Organization for Research and Treatment of Cancer), ISG (Italian Sarcoma Group) and the AGITG (Australasian Gastrointestinal Trials Group). A total of 946 patients with advanced and/or metastatic KIT-positive GIST received either 400 or 800 mg. of Glivec per day. Patients who experienced any disease progression on 400 mg. were allowed to increase to 800 mg. to regain control of the disease. At the time of the analysis (May 2004), a total of 412 patients had completed treatment in the trial, which had progression-free survival as the primary endpoint.

Patient treatment with 800 mg. of Glivec per day significantly increased progression-free survival compared to treatment with 400 mg. per day. Although side effects were more common and more severe with the higher

European study confirms LRG findings on relapse

By Norman J. Scherzer
Executive director, Life Raft

As noted on the front page, the European Organization for Research and Treatment of Cancer, the Italian Sarcoma Group and the Australasian Gastrointestinal Trials Group have formally reported that higher doses of Glivec significantly improves progression-free survival in GIST patients. This is consistent with the data being reported by the Life Raft Group that development of resistance to Glivec is significantly reduced by higher doses.

Interestingly, the companion study in the United States has not shown a significant difference in progression free survival. How can that be?

Both the European and U.S. studies use a method of data collection that focuses exclusively upon the patient’s starting dosage. Called “intent to treat,” this

methodology ignores any subsequent change in dosage brought about either by the physician changing the dosage or by the patient changing the dosage themselves.

The Life Raft Group has looked at the actual dosage taken by the patient in addition to the starting dosage. The results of this Life Raft Group study will be formally presented at the November meeting of the Connective Tissue Oncology Society in Montreal.

At the June meeting of the American Society of Clinical Oncology, one speaker speculated that the difference between the European and American study was the higher number of patients in the European study. We offer another speculation: that more American patients had dosage reductions than their European counterparts.

As we go to press we have learned that the Europeans have begun to look at the issue of actual dosage.

dose, the majority of patients did not require a dose reduction. Treatment in both groups was fairly well-tolerated.

The most common undesirable side effects of Glivec treatment are: headache, nausea, vomiting, diarrhea, dyspepsia, myalgia, muscle spasm and cramps, joint swelling, dermatitis, eczema, rash, edema, fluid retention, neutropenia, thrombocytopenia or anemia.

GIST is the most frequent form of gastrointestinal cancer, a life-threatening disease highly resistant to

traditional chemotherapy and radiation. Surgery is considered the best way to initially treat GIST. However, many GISTs cannot be surgically removed because they are too large or have already spread to other parts of the body before diagnosis.

When surgery is performed, cells from the original GIST may remain behind or the cancer may return in another site. Experts believe that GIST may be more prevalent than previously believed, affecting approximately 15 people per 1 million per year.

192-mile bike ride = 1 luminometer

Caregiver overcomes helplessness, rides to speed GIST research

By Maura Cesarini

When I was diagnosed with GIST two years ago, one week after having my second child, life as I had known it stopped. I was 33 years old, I had a newborn, an 18-month-old, and malignant cancer. I felt overwhelmingly helpless.

But as hard as it was for me, I think it was even harder for my husband.

I watched Michael and sensed the helplessness he felt. He was beside me for two surgeries, and he remains beside me for my frequent trips to Dana-Farber Cancer Institute in Boston for blood tests, MRI's and CT scans. Feeling powerless against GIST, Michael has been seeking a way to help me battle cancer. This summer, Michael found a way to regain some power.

Aug. 7 and 8, Michael participated in the Pan Mass Challenge. This is a 192-mile bike ride across Massachusetts to raise money for life-saving cancer research at Dana-Farber. More than 4,000 riders participated with this year's goal of raising \$17 million dollars.

The evening before the start of the ride, my daughters and I drove Michael and his bike to the other side of the state to a town called Sturbridge. It took us three hours to drive there and he was going to ride his bike all the way back and beyond. We kissed him goodbye, and I felt both nervous and excited that he was doing this for me.

Saturday morning he called to say he had already ridden 80 miles. Eighty miles!!! I felt so much love for him, through that telephone, I couldn't contain myself. I wanted to be with him to tell him how much it meant to me that



Dr. Jonathan Fletcher showed Mike and Maura Cesarini around his research lab at Dana-Farber Cancer Institute. Mike's participation in the Pan Mass Challenge bicycle ride a few weeks later raised the \$10,000 needed to equip the facility with a luminometer, an instrument that will allow researchers to screen new drugs for GIST potential in weeks rather than months.

he was doing this, but when I said it through the telephone the words just sounded flat.

Saturday night he called to say he finished riding for the day — 111 miles. I am so thankful he is OK. He is tired but confident that tomorrow he will finish fine. My little girls are having a "sleepover" at my sister's and my house is incredible lonely without them and Michael.

I look through old photos of when we met at the police academy, our dog as a puppy who was really our first baby, our wedding, our little girls. I am crying and can't determine whether I am crying because I have cancer and all of this could be so easily taken away from me, or if I am crying because I am so thankful to have all this — a husband I love completely, two beautiful healthy little girls, even my old black lab who is

keeping me company.

The alarm clock wakes me a 6 a.m. Sunday. It is still dark. Is Michael already on the bike? I quickly get dressed and head for Provincetown - the very tip of Cape Cod where the Pan Mass Challenge finishes. I pass lots of riders on the road. I am afraid if I keep trying to figure out if one of them is Michael (they all seem to look alike with helmets, sunglasses and PMC bike shirts), I will accidentally run someone over.

Hours later, I arrive in Provincetown and am relieved that no one has crossed the finish line yet. Slowly, the riders start to arrive, and the bystanders go crazy cheering and clapping and looking for their loved one. I finally see Michael — I spot him because his helmet has the colors of the

MARATHON

From Page 1

called Gleevec, this molecularly targeted therapy is one of the most remarkable cancer treatments in decades. Michael has been taking Gleevec daily since the fall of 2000.

Jennifer is a friend of Michael's sister, Katie Byrne. For many years, Jennifer entertained the idea of running a marathon but couldn't find a good reason to run 26.2 miles.



CORRAO

One day last fall she mentioned this to Katie, who responded: "Why don't you run and raise money for my brother, Michael?"

At that moment, Jennifer knew she found the reason to run her first marathon, to raise money for the Life Raft Group, which has provided invaluable support for the Byrne family during Michael's battle with GIST.

Although many patients with GIST are being successfully treated with Gleevec, GIST patients continue to die due to delays in diagnosis, obstacles to getting treatment, or because their cancer develops resistance to Gleevec.

However, new molecular breakthroughs have identified this rare cancer as having a comparatively simple genetic mechanism. This has transformed GIST from an isolated rare disease into a model for beginning to understand how to treat many other cancers.

All of the money Michael and Jenni-



Michael Byrne, with his son, Matthew, and wife, Mia, will be running Nov. 7 in the ING New York City Marathon to raise money for the Life Raft Group. A GIST patient for more than 11 years, Michael had five abdominal surgeries, one cryosurgery and chemotherapy three times before starting Gleevec in 2001.

fer raise will help further the efforts of the Life Raft Group in its mission to support and preserve the lives of patients with GIST around the world. The Life Raft Group is a 501(c)(3) nonprofit organization and all donations are tax deductible in the United

States. Please make checks payable to "Life Raft Marathon Fundraiser," and mail them to Life Raft Marathon Fundraiser, The Life Raft Group, Inc., 40 Galesi Drive, Wayne NJ 07470.

For more information, please visit www.liferaftgroup.org.

Life Raft Group Board of Directors will add five members come January

To keep pace with the increasing size and complexity of the Life Raft Group, the board of directors has been expanded from seven to 11 members. The change was approved at the board meeting held April 30 during the LRG gathering in Orlando, Fla.

Coming on board next January are:

- Jerry Cudzil, New York, N.Y. Jerry joined the Life Raft Group because his father-in-law has GIST.
- Dr. Arnold Kwart, Chevy Chase, Md. A surgeon, Arnold joined the Life Raft after he was diagnosed with GIST.
- Jerry Knapp, Carmichael, Calif.

Jerry joined the Life Raft after his GIST diagnosis.

Jim Hughes, Evanston, Ill. Jim joined the Life Raft because his daughter, Nancy, has GIST.

Allan Tobes, West Bloomfield, Mich. Allan joined the Life Raft after he was diagnosed with GIST.

Bernie Kaplan survived by wife, 2 sons, 2 daughters

By Trish McAleer

It was a shock to learn that Bernie Kaplan, the “On Again, Off Again” man, lost his fight against GIST.

There had been so many scares but each one had been followed by a sigh of relief from his family and friends. But not this time.

In the custom of Orthodox Judaism, the funeral service was held within 24 hours after Bernie died early the morning of Sept. 7, 2004. Even though there was little notice, the synagogue on Staten Island, New York, was full of those who loved and respected Bernie. The crowd was a testament to Bernie’s philanthropic endeavors and active role in his community.

Bernie is survived by his wife,



Bernie and Bracha Kaplan, at the first Life Raft Group gathering in Boston, Mass., May, 2002

Bracha, two sons, Noam and Yaron, and two daughters, Talia and Shira Kaplan-Walker.

All four of Bernie’s children took the podium. While crying for their Abba (father), they all expressed their

love and gratitude. It was obvious that Bernie had set a high standard in his life.

Bracha cried out with each hug of condolence. She had seen Bernie through this battle and was utterly shattered by its end.

All those who spoke that day paid tribute to Bernie’s activism, his love, his faith and most importantly, his bravery.

Bernie held the Life Raft Group close to his heart. He was always ready to help in any way possible. As well as being a

board member, Bernie was very active in many other endeavors. He even founded a cancer support group in his home town. He was willing to help anyone who needed him.

He will be truly missed.

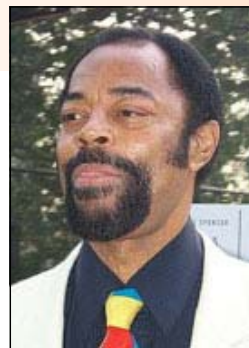
WALK

From Page 1

greatest players in the history of the National Basketball Association. He was named to several NBA all-star teams, the NBA’s 50th Anniversary All-Time Team and the Basketball Hall of Fame. His ball-stealing ability won him the nickname “Clyde,” as is Bonnie and Clyde. When he left the game, the Knicks retired his No. 10 jersey.

Frazier is currently an announcer and analyst on Knicks broadcasts. He delights and confounds New York fans with a constant barrage of rhyming phrases and creative word usage — “Clyde-isms,” as they have become known. “Mr. New York” will sign autographs and pose for pictures with walk participants.

Walkers will gather Saturday at parking lot no. 1 on the north side of Rockland Lake State Park between



FRAZIER

there are benches along the way to sit and rest.

Registration forms can be downloaded and printed from Tania Stutman’s Web site for the GIST Cancer Research Fund (GCRF), <http://www.gistinfo.org/walk.html>

Anyone who can not make it to the walk can still support this fundraising effort as a “virtual walker” by downloading a registration form, soliciting donations and mailing them

9:30 and 10:15 a.m., rain or shine. The three-mile walk around the picturesque lake will start at 10:30 a.m. Should anyone care to,

in. Donations can also be made online, by anyone around the world, by using the “donate” link that’s on the Web Site <http://www.gistinfo.org>.

Lunch will be served in the park directly after the walk, so that those that want to will have the opportunity to spend some time getting acquainted, socializing, networking, comparing experiences with the many other GIST patients, their families, caregivers and friends who will be there.

GIST doctors and researchers from both Memorial Sloan-Kettering Cancer Center in New York and Fox Chase Cancer Center in Philadelphia, plus representatives from Novartis and Pfizer pharmaceutical companies have indicated that they will be at the walk.

See **MORE WALK**, Page 6

MORE WALK

From Page 5

This year's walk will be held in memory of Dean Gordanier, a tax attorney and valiant GIST warrior who took part in the clinical trials of both Gleevec and SU11248. Gordanier gained the admiration and respect of fellow patients as he gave generously of his time and shared his experience, knowledge, wit and wisdom with GIST patients worldwide as he participated in GIST cancer support groups. His outlook was always positive and uplifting.

For example, last year Gordanier went to extraordinary lengths to make sure a fellow GIST patient could participate in the walk. He flew from his home in Massachusetts to Chesapeake Bay in Maryland where he met Dr. Mel Heller, then 81, whom he'd gotten to know via online support groups. Gordanier then drove Heller to the walk in New Jersey. Afterwards, they joined in a gathering at the Stutmans' home before Gordanier drove his new friend back to Maryland and boarded a plane to his home in Massachusetts. Dean Gordanier lost his battle with GIST in February.

The GIST Cancer Research Fund

has raised more than \$130,000 (U.S.) to date and provided research grants to Fox Chase, Memorial Sloan-Kettering, Dana-Farber Cancer Institute in Boston, and Oregon Health & Sciences University in Portland, Ore. Ninety-seven percent of all the funds raised go directly to GIST research. The fund is under the advisement of Dr. Ephraim Casper of the Memorial Sloan-Kettering.

For more information, contact Tania or Robert Stutman at :GIST Cancer Research Fund, 55 Saw Mill Road, New City, NY 10956; phone 1-845-634-6060 or 1-845-634-1174; e-mail Tania5kids@aol.com.

CYCLIST

From Page 3

Italian flag on it.

When I hug him, he's drenched with sweat. I don't mind. I am so proud that he did this but those words just don't seem strong enough to convey my feelings. It was just so sweet. It is an unbelievable feeling to witness thousands of people crossing the finish line. We drive back home and Michael takes a much-deserved nap.

A few weeks earlier, Michael and I were fortunate enough to meet Dr. Jonathan Fletcher and some of his researchers at Dana-Farber. Dr. Fletcher gave us a tour of his lab and talked with us about current GIST research. He also mentioned the need for a luminometer, a \$10,000 instrument that would allow his staff to screen new drugs for GIST in weeks rather than months.

That gave Michael a goal. And Michael raised the \$10,000. Through the generous support of so many in the GIST community, especially Gist Support International, which embraced and encouraged our efforts.

Also riding the Pan Mass Challenge were several other police officers, including my boss, Chief Paul Frazier. The Massachusetts Chiefs of Police



Team Cesarini: Mike, his bike, and Maura. Putting his mettle to the pedal.

Team, of which Michael was a member, collectively raised more than \$60,000. When they learn of our efforts to raise money for GIST research, they request that the team total also be earmarked specifically for GIST research.

Michael quickly recovered from the

ride. He is already talking about doing it again next year.

Donations can still be made by sending a check payable to the Pan Mass Challenge to M. Cesarini, 2 Settlers Path, Duxbury, MA 02332 or at www.pmc.org, e-gift ID No. MC0220.

THE LIFE RAFT GROUP

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Who are we, 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). The Association of Cancer Online Resources provides the group with several listservs that permit members to communicate via secure e-mail. Many members 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. Several new drugs are now in clinical trials.

How to join

GIST patients and their caregivers may apply for membership free of charge at the Life Raft Group's Web site, www.liferaftgroup.org or by contacting our office directly.

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 articles are edited to maintain the anonymity of members unless they have granted publication of more information.

How to help

Donations to The Life Raft Group, incorporated in New Jersey, U.S.A., as a 501(c)(3) nonprofit organization, are tax deductible in the United States.

Donations, payable to The Life Raft Group, should be mailed to:

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