

Placebo raises stress level of GIST patients

Slow expansion of trial for SU11248 leaves no alternatives for some

By **Norman J. Scherzer**
Life Raft Executive Director

This phase III trial for SU11248 for Gleevec-resistant GIST has gotten off the ground in a number of locations, starting at Dana-Farber Cancer Institute in Boston. More than two dozen Life Raft Group members are already participating in the trial and beginning to share their experiences in a new chat group. We will be monitoring the reports of this growing number of Life Rafterers and collecting data on drug effectiveness, side effects and placebo-related complications that we will report in our newsletter.

One of the first experiences reported was that of a patient who was transferred from placebo to treatment group. This was handled quite expeditiously, given the trial protocol.

Many patients have shared their anxiety over whether they may be in the placebo group. If they are feeling rather well, they agonize over whether they might be on a placebo. If they are not feeling well, they wonder if it is due to the drug side effects or to their

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Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

March 2004

In memory of Dean Gordanier, Jerry Sidfrid,

Vol. 5, No. 3

Leonore Mendelsberg, Gust Vasiliades and Carolyn Lee Lenkszus

Final plans under way for Florida 'Life Fest'

It's the second general gathering since the Life Raft Group was formed

Scores of GIST patients and caregivers will gather April 30 through May 2 in Orlando, Florida, U.S.A. for a weekend of support and information.

Dubbed "Life Fest 2004," it will be the second general gathering of Life Raft Group members since the group's formation in the summer of 2000. The name, submitted by Rachel Tate, was chosen by a vote of members from many names submitted.

Online friends who've never met before will hear GIST researchers share cutting-edge medical and scientific information. There will be small-group meetings on a range to topics, from GIST basics to management of treatment side effects, with a session

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Embassy Suites, Lake Buena Vista, Florida, U.S.

Another resource for Chicago area patients

Multidisciplinary team approach taken at Lurie

After an initial visit and interview by Dick Kinzig, Jim Hughes and Howard Reich of the Chicago chapter of the Life Raft Group, another

"center of excellence" for gastrointestinal stromal tumor (GIST) patients has been found at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University.

Under the leadership and vision of director Dr. Steven T. Rosen, more than 250 world-class scientists and cli-

nicians at the center are dedicated to fostering scientific discovery, advancing medical knowledge, providing compassionate, state-of-the-art cancer care and training the next generation of clinicians and scientists. The Lurie center is affiliated with Northwestern's

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Meeting March 16 at Memorial Sloan-Kettering, from left, were pediatric GIST parents Brian and Dorothy McBride, Dr. Michael LaQuaglia, chief of pediatric surgery; Drs. Pamela Merola and Leonard Wexler, pediatric oncologists; Dr. Christina Antonescu, pathologist, Carol Rossetto, nursing assistant to LaQuaglia; and pediatric GIST parents Patricia and Chris Kastner.

Pediatric GIST collaboration advances

Life Raft, Sloan-Kettering representatives discuss steps that are needed

Creating a center of excellence for pediatric GIST at Memorial Sloan-Kettering advanced when members of the Life Raft Group met with Sloan-Kettering representatives March 16.

The Life Raft Group now includes 10 pediatric GIST patients. For some time the LRG has been putting together a database on this group to see how these patients are doing. Although the LRG database is small, Dr. Leonard Wexler, Sloan-Kettering pediatric oncologist, noted it is nonetheless the largest pediatric GIST database in the world at this time.

From talking to pediatric GIST families and several GIST specialists, it's clear there is no place which has acquired the experience and expertise for taking care of such young GIST patients. As a result, pediatric GIST patients have become a very rare subset of a very rare cancer and have fallen

off the radar screens of both clinical practitioners and researchers

There is one ongoing phase II study of Gleevec in pediatric patients with relapsed or refractory solid tumors which includes GIST along with other cancers. It is noteworthy that this study has opened at nearly 200 sites, just to recruit 100 patients.

This is particularly important because these young patients demonstrate a different form of GIST. Most, if not all, demonstrate a wild-type mutation. That means that most, but not all, do not seem to respond well to Gleevec. On a positive note, however, GIST tumors seem to progress much more slowly in pediatric patients.

The LRG database is made up entirely of girls — something consistent with the experience of Sloan-Kettering pathologist Dr. Christina Antonescu. The youngest LRG patient was 8 at the time of diagnosis. Most have had surgery and most are on Gleevec, taking 200 mg. to 600 mg. per day. It is clear from this diversity that no one has determined the optimal dosage of Gleevec in young GIST patients.

The focus of the March 16 meeting was twofold. The first was to strengthen the current management of pediatric GIST patients so that physicians and families make better day-to-day decisions. The second was research, with priority to identifying downstream targets and drugs that work against those targets.

Attending from the Life Raft Group were pediatric GIST family members Dorothy and Brian McBryde, and Patricia and Chris Kastner, LRG member Dan Cunningham, Administrative Assistant Tricia McAleer and Executive Director Norman Scherzer.

Memorial Sloan-Kettering's Department of Pediatrics was represented by Wexler, Antonescu, and pediatric oncologist Dr. Pamela Merola; Dr. Michael LaQuaglia, chief of pediatric surgery, Carol Rossetto, nursing assistant to LaQuaglia and Susanne Hershowitz, administrative manager.

Several projects were discussed:

1. Creation of an international registry. An example presented by Sloan-Kettering was the pleuropulmonary

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There's a smile of the face of Michael Byrne as he rounds one of the final turns of the Mizuno Martian Marathon in Northville, Michigan. Running with him for the final stretch is his son, 8-year-old Matthew.

The GIST survivor and Life Raft Group member has made it through five surgeries and several rounds of chemotherapy during his decade-long fight with cancer.

Photos courtesy Mia Byrne



Don't beat cancer — outrun it

After a 10½-year battle with GIST, there is little Michael Byrne can't do

After more than 10 years of fighting GIST, several round of ineffective chemo and five surgeries, most folks would say Michael Byrne could use a rest.

Michael isn't most folks.

The Plymouth, Michigan, man ran in his first-ever marathon Saturday, March 27. At the finish line he was greeted by his wife, Mia, son Matthew, and a cousin who presented him with a Guinness Stout. But Michael only took a few swigs ("Probably the first time he couldn't finish one," says Mia) before limping toward his car, opening a medicine bottle and gulping down four Gleevec pills.

Michael started running competitively a few years ago. In 2002 he did three triathlons, and liked it so much he did five in 2003, including one international distance event where he swam 1.5 kilometers, bicycled 40 km., and ran 10 km.

But Sunday was his first crack at a full marathon — 26.2 miles.

Michael ran in the fourth annual Mizuno Martian Marathon in Northville, Mich. Nearly 200 runners did the full



Michael Byrne finishes his first-ever marathon as his family, filled with pride and excitement, look on. Just right of Michael is his son, Matthew, in the blue top. Wife Mia can be seen in the background, in a neon green jacket and holding a camera.

marathon, while several hundred more did a half marathon or ran part of the course as training, as the event is certified to qualify for the Boston Marathon. Many of the runners collected donations to fight cancer, with race proceeds benefiting the Leukemia and Lymphoma Society.

The 40-year-old Michael finished in a very respectable 4 hours, 14 minutes, maintaining a 9:43-mile pace.

He is now considering signing up for the ING New York City Marathon in November. He'd be joining his sister's friend with the goal of raising money for the Life Raft Group.

Chicago chapter holds its sixth meeting

The Chicago chapter of the Life Raft Group held its sixth get-together March 21 at the Wellness Place in Inverness, IL. Two dozen people, including 12 GIST survivors, heard guest speaker Dr. Hedy Kindler, director of GI oncology and head of GIST research at the University of Chicago. Kindler spoke about the new drugs on the horizon and answered questions.

Kindler talked about early results of the Sugen trial, where 50 to 60 percent of patients are seeing tumor stability or shrinkage. She also spoke about some of the new drugs coming down the pike, though it is too early to know if they will be effective on GIST.

Kindler has been a supporter of the

Life Raft Group, passing out the LRG pamphlet to many of her 25+ patients at the university. She has brought several new members into our group as well.

Four new members were at the meeting and were able to obtain useful information from the other members and from Kindler's answers.

The Chicago chapter first met in September of 2002, six GIST survivors and 11 people total attending. The number of GIST'ers has grown to 30 from a three-state area: Illinois, Indiana, and Wisconsin.

The chapter has been searching out "centers of excellence" (see article on page 1) for GIST treatment in the Chicago area, and as a result contacted Dr.

Kindler, Dr. Margo Shoup from Loyola Medical Center, and Dr. Bruce Brockstein of Evanston Northwestern Health Care. All three have been guest speakers at Chicago chapter meetings.

Life Raft Group chapter members have all benefited from their participation, and those who may not have been entirely satisfied with their present physician have hopefully found alternatives for treatment when in need.

The social that followed the formal meeting included fine homemade pastries and snacks provided by Darlene Rigg, and wine provided by Paula and Phil Vettel.

The next meeting is scheduled for July 11, a Sunday, at the Wellness Place.

In Memoriam

There have been 38 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, 2002, 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.

Michael Cornwell, April 19, 2002, husband to Cathy.

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.

The Rev. Philip R. Johnson, 64, June 17, 2002, husband to Grace, father to Peter, brother to Robin Jaruszewski.

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

Chet Duszak, 79, Oct. 5, 2002, husband to Kay, father to Lori.

Nora Shaulis, 42, Nov. 4, 2002, wife to David, mother to Griffin.

Howard Delapenha, 41, Dec. 14, 2002, husband to Sandra, father to Joshua and Hannah.

Kathy Colwell, 45, Jan. 5, 2003, wife to Tom, mother of Katherine, Mary and Tom.

Cynthia G. Whitson, 64, Jan. 19, 2003, wife to Jerry, mother to Steve, Jill, Randy and Donna.

Abdul Hai, 76, Feb. 26, 2003.

William Lawson, 56, July 3, 2003, husband to Gwen, father of Cory, Jennifer and Rhonda.

Laura Blanchette, 47, Aug. 4, 2003; wife of Mitch, mother of Sarah and Curtis.

Maryann Klein, 56, Sept. 4, 2003; wife of Gary, mother of Michelle, grandmother to Brandon.

Pat Ford, 48, Sept. 6, 2003; wife to Brad, mother to David and Laura.

Frank Weigand, 66, Oct. 24, 2003; husband to Ruth, father to Susan and Drew.

Ray Copple, 52, Dec. 16, 2003; husband to Kathy, father to Jon and Matt.

Tuomas Hemminki, 41, Jan. 2, 2004; husband to Leena, father to Heidi and Ilkka.

Donald Kew, 43, Jan. 31, 2004; husband to Jocelyn, father to Erin and Christine.

Jerry Sidfrid, 44, Feb. 8, 2004; husband to Jessica, father to Sara and Maci.

Gust Vasiliades, 38, Feb. 21, 2004; boyfriend to Marion, brother to John and Jim.

Dean C. Gordanier Jr., 55, Feb. 25, 2004; husband to Rachael, father to Amy, Mary and Thomas.

Leonore Mendelsberg, 77, March 10, 2004; five children, 21 grandchildren, 1 great-grandchild.

Carolyn Lee Lenkszus, 65, March 23, 2004; wife to Frank, mother to Rick, Kristine and Dominic.

Dean Gordanier's talents knew no borders

Dean C. Gordanier Jr. was an attorney who heard the music in the minutiae of the tax code.

"He found a rhythm, reason and logic in the tax laws; when he ran into things that were not logical, it was like hitting a wrong chord, it made him sit up and listen and wonder," said William B. Asher, a managing partner of the Boston law firm of Testa, Hurwitz & Thibault.

Gordanier, 55, died Feb. 25 of GIST at Brigham and Women's Hospital.

As a partner in Testa, Gordanier did innovative work on tax legislation, particularly as it pertained to private equity and venture capital. He was the author of "Structuring Securities Partnerships for Foreign and Tax-Exempt Partners" published in the *Journal of Partnership Taxation* in 1990, and an article on the adequate protection of secured creditors under the bankruptcy code published by the *American Bankruptcy Law Journal* in 1980.

He was also "a recovering hippie," said firm partner Mary Kuusisto.

Gordanier helped the Life Raft Group with its Web site and helped the clinical trials advisory committee, said Norman Scherzer, executive director of the Life Raft Group.

At one of their first meetings, "Dean took me for a ride in his yellow Boxer, which he called his chemo car, and drove at breathtaking speeds, top down, through the back roads of Cambridge," said Scherzer.

Last November, Gordanier was at a meeting of LRG directors. He spoke passionately about the ethical need to oppose the placebo in the Pfizer's clinical trial of SU11248.

Gordanier, added Scherzer, "was a corporate lawyer who looked like a hippie, drove like a maniac and walked the earth with the grace of goodness and caring. He reached out to countless GIST patients with wisdom and support. I and everyone else whom he



Dean Gordanier, above and at the November Life Raft Group board meeting, in back, second from right.



came into contact with shall miss him dearly."

Gordanier was born in Seattle and grew up in Portland, Ore. He graduated from Reed College in Portland, where he majored in drama.

"He had a flair for the dramatic, whether he was making a presentation, engaged in a negotiation, or just teaching people," said Asher. "He graduated in the '60s, and he combined a '60s sensibility with tax law."

After graduation, Gordanier spent time in San Francisco, where he was a carpenter and sold office supplies.

"He was inspired by the Watergate hearings to go into law," his wife, Rachael M. Dorr. "He was transfixed. He was looking at the government as inherently corrupt and evil and realized there was a legal system and it worked."

After graduating from Boston University Law School, Gordanier joined Testa in 1984.

His wide desk accommodated two computers, one a PC and the other a Macintosh on which he made his spreadsheets and crunched numbers. It also contained nooks and crannies to hold the various electronic gadgets he collected over the years.

He was the first in his office to purchase a Palm Pilot and "had a CD burner before there were CDs," said

another attorney at the firm, Arnold May.

Mr. Gordanier did not just buy the electronic gear. "He learned how it worked," said Kuusisto. "He read a book a day on a wide range of topics, anything that interested him."

Mr. Gordanier was known to offer a quick hug or a pat on the back to his colleagues. They called it the "Dean hug."

Each year Mr. Gordanier and his family attended the Burning Man Festival, a weeklong celebration of the visual and performing arts that draws tens of thousands of campers to the Black Rock Desert in Nevada. The festival was founded by one of this childhood friends.

A singer, Mr. Gordanier would "break into song at the drop of any phrase that suggested one," said his wife. He also whistled fiddle tunes.

"He was a tax attorney," said Asher, "but his talents knew no borders."

In addition to his wife, Mr. Gordanier leaves three children, Amy, Mary and Thomas, all of Cambridge; his mother, Jacqueline of Oceanside, Ore.; and six siblings: Douglas, Mary, Shirley, Kathleen, Scott, and Rebecca, all of the Pacific Northwest.

A memorial service was held at First Church Congregational in Cambridge, Mass.

Gust Vasiliades, 38, loved art, music and life

Art educator, music lover, good neighbor and life adventurer Gust Vasiliades died Feb. 21, 2004, in his beloved Manhattan.

Gust was born April 10, 1965 in Canton, Ohio. After he graduated from high school, he bought his older brother, John, out of the motorcycle they shared, drove to New York City and never looked back.

He loved art. Gust made his way into the New York art scene in the 1980s, founding the software services company POSTDATA serving such clients as the Pat Hearn Gallery and Leo Castelli Gallery. In 1989 he opened the Gust Vasiliades Gallery in Soho, showing several artists who later became big names and some who already were. He also worked as a museum educator at the Guggenheim Museum in the new education department, and at the New School University in 1996.

Gust spent several years organizing art shows and expanded into photography. He recently worked on photos that explored the emotional cues and facial expressions of pets and our projection of human emotion onto our pets. His photos appeared in *New Observations*, *ArtNet* and various trade magazines.

He was an excellent cook and, according to his girlfriend, Marion Fasel, made the best cappuccino. “No one makes coffee as good as you,” she once told him. He paused for a second and then replied, “Gust-bucks!”

His sense of humor, sharp mind and clever wit could find laughter in any situation, even cancer. When the doctor told him in June of 2002 he had what was called a GIST tumor. He said, “No, it’s Gust.”

He was a great dog-father to his chihuahua, Marcel, and knew the name of every dog in his neighborhood,



Gust Vasiliades was a museum educator at New York’s Guggenheim Museum, and was a great “dog-father” to his chihuahua, Marcel, seen at right flanked by the Statue of Liberty. His recent interests included photography and capturing the emotional cues and facial expressions of pets.



from Marcel’s best friend, Dreyfus, to his mortal enemy, Buick.

Marion says Gust was passionate about music, particularly the Beatles. “Among his vast collection of vinyl there must have been at least seven copies of ‘Sgt. Pepper’s’ alone,” she said. “We even went to Liverpool and took the Magical Mystery Tour.”

He lived in the same building in the Nolita neighborhood of Manhattan for nearly 20 years. He cared for his neighbors like family, campaigned to re-route the commercial trucks that disrupted the neighborhood calm, and when someone cut down the tree in front of the building to steal a bike, he made it his mission to get the tree replaced. And he did.

Gust, says Marion, liked all forms of transportation. He always had a car, was passionate about sailing and

had even logged a couple hours flying. He had a motorcycle and liked vintage bicycles and electric bikes.

“It was not unusual to see him cruising up Broadway — yes, against traffic — standing on top of the motorized vintage scooter with perfect posture,” recalls Marion.

Gust’s last evening out before his hospitalization was a book-signing at Robert Rauschenberg’s studio to benefit Change Inc., a non-profit, tax-exempt foundation established in 1970 to assist professional artists of all disciplines in need of emergency aid.

Contributions in memory of Gust Vasiliades can be made to Change Inc., P.O. Box 54, Captiva, FL 33924; Attention: Ms. Bradley Jeffries.

Gust is survived by his girlfriend of seven years, Marion, and brothers John and Jim Vasiliades of Ohio.

Carolyn Lenkszus battled GIST 11 years

Carolyn Lee Lenkszus died Tuesday, March 23, 2004 at her home in Channahon, Ill., with her family by her side after an 11-year battle with cancer. She was 65.

Carolyn was born and raised in Joliet, Ill., and was a graduate of St. Francis Academy. Carolyn was a remarkable woman who enjoyed cooking, gardening and traveling. She is survived by her husband, Frank R. Lenkszus; children, Rick (Marsha) DeSalvo, Kristine (Tim)



LENKSZUS

Lupton and Dominic DeSalvo; her stepdaughters, Jennifer Lenkszus and Jessica (Chris) Ignasak; eight grandchildren, Mallory, Max and Mitchell DeSalvo; Nicole and Ashleigh Lupton; Daniella, Hannah and Jacob DeSalvo; two sisters, Peggy (John) Hadala and Tasia Dawn

(late Ken) O'Dell; two brothers, Alex (Janet) Bonds and George (Joan Lamb) Bonds. Numerous nieces and nephews also survive.

She was preceded in death by her mother, Jeanette Bonds; father-in-law, Frank Lenkszus Sr.; grandparents, Mary and Zane Santorines.

Services were held March 27 at All Saints Greek Orthodox Church followed by interment at Woodlawn Memorial Park. Memorials in her memory may be made to the American Cancer Society.

LIFE FEST

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just for caregivers. How to avoid relapse on Gleevec will be covered when results of a Life Raft Group survey of members is presented.

The group will also honor two researchers and a key pharmaceutical industry executive for their work advancing GIST treatment.

The meeting will begin Friday at 5:30 p.m. with a reception at the meeting location, The Embassy Suites in Lake Buena Vista, Florida, near Orlando, followed by dinner. Saturday's activities begin at 9 a.m. with the general meeting followed by breakout sessions until a 5 p.m. cocktail hour. Sunday's events begin with breakfast and will conclude no later than 1 p.m.

Speakers (as of deadline) included Dr. Margaret von Mehren of Fox Chase Cancer Center in Philadelphia, Dr. Bob Benjamin of M.D. Anderson Cancer Center in Houston, and Dr. Allan Van Oosterom of the Katholieke Universiteit Leuven, Belgium. Appearing by audio-visual conference will be Dr. George Demetri of Dana-Farber Cancer Institute and Dr. Larry Baker of the University of Michigan.

Topics for the general sessions will include a report by Life Raft Executive



WATSON

Director Norman Scherzer; updates from Das Lebnshaus (The House of Life) from Markus Wartenberg and from Switzerland coordinator Ulrich Schnorf; the latest in clinical tri-

als, and Life Raft Group service and friendship awards

Breakout sessions will include: "GIST 101" led by Prof. David Josephy, Ph.D., professor of chemistry and biochemistry at the University of Guelph, Ontario, Canada; "Management of Side Effects," a session for SU11248 clinical trial patients; an advanced discussion on GIST led by Life Raft Science Coordinator Jerry Call; "Common Medical Procedures Explained," and a session for input on Life Raft Group operations.

The Life Raft Group will honor three people with its Humanitarian Award: Barbara Kennedy, executive director of Oncology Scientific Operations for Novartis Pharmaceuticals; Dr. Brian Druker of Oregon Health & Sciences

Wife, two daughters survive Jerry Sidfrid

Jerry Sidfrid died Feb. 8, 2004 at his home in Katy, Texas. He was 44. Born Jan. 12, 1966, he enjoyed computers, motorcycles and gardening.

He is survived by his wife, Jessica; daughters Sara and Maci, his parents, Jackie and L. C.; brothers Jeff Sidfrid, Larry Stacy and Chris Sidfrid; sisters Deidre Parton, Danya Taylor and Amber Stacy.

University in Portland, key developer of Gleevec, and Dr. James D. Watson, Nobel laureate and chancellor of Cold Spring Harbor Laboratory, New York. Druker and Watson will accept via taped interview.

A conference fee of \$90 includes Friday's cocktail reception, hors d'oeuvres and dinner; Saturday's breakfast, lunch and beverage breaks plus cocktails from 5:30 to 7:30 p.m., and breakfast Sunday with beverage breaks.

For details, contact the Life Raft Group office at (973) 837-9092.

SUGEN

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cancer. If they believe that their disease is progressing (some patients can feel a tumor growing) they pray that they are on the placebo.

All in all, it is hard to convey the additional stress that this placebo is placing on Gleevec-resistant patients who have just gone through the terror of seeing their cancer begin to take over their lives again and now facing the possibility they are on a sugar pill.

If the placebo was not causing enough anxiety, many GIST patients living outside of the United States and Canada have to wait until a trial site opens near their homes. If they cannot wait — possibly because they cannot live long enough to wait — they then have to navigate incredible logistic and financial obstacles.

The following letter reflects the re-

cent experience of a patient in Japan trying to get into a clinical trial in the United States:

*“Dear _____
“We received your email expressing your desire to receive treatment here. At this time I would strongly suggest you consider treatment on the SU11248 Phase III in Australia. To receive treatment here would not only be costly, but you would most likely have to live here for at least the first 3-4 months of treatment and travel here frequently after that.*

*“I also checked with our financial office and found out that standard policy for international patients is **up-front payment before treatment begins for the entire estimated cost of full treatment on this trial. In this case the bare minimum would be \$100,000 and that does not include any travel or living expenses. It would most likely be more.***

“I don’t want to discourage you from

seeking treatment at your place of choice, but the stress of traveling here would be considerable and it would be in your best interest to seek a less tiring route for optimal success of the trial.

“If, however, you can pay the full cost up-front and are still interested in coming here for treatment, please just let us know and we can start facilitating this. ... At this time, I would recommend you contact the sites closer to Japan.” (excerpted, emphasis added)

Many hospitals have similar, if not even more draconian, policies. The point is that access to potentially life-saving drugs in clinical trials carries many burdens — placebos, logistics and finances. Imagine traveling to the United States, spending more than \$100,000, only to discover that you are on a sugar pill.

Does this make patients cynical and angry? Of course. Is there a better way to run a clinical trial? You bet there is.

PEDIATRIC

From Page 2

blastoma registry. Sloan-Kettering volunteered to submit a grant proposal for National Institutes of Health funding to support this project.

2. Creation of a pediatric tumor bank.
3. An annual meeting bringing together experts in the field to discuss progress in pediatric GIST management and research and to plan future efforts. The LRG will seek funding.

4. The referral of patients and case histories to Sloan-Kettering so that a critical body of experience and expertise can be quickly achieved.

5. An outreach program to pediatric oncologists informing them of these projects. Both Sloan-Kettering and the Life Raft will link their Web sites and explore outreach opportunities.

To quote one of the family members

present: “We wanted to let you and the other parents know that this meeting brought us a sense of relief that there will be a forum for us to reference in our battle with pediatric gist. ... this is the first time in the three years since our daughter ... was diagnosed that we have some positive feelings that there is something out there that we can access for information, guidance and help.”

A phase I clinical trial of Gleevec plus PKC412 has started at Charite Campus Buch in Berlin. The January newsletter incorrectly reported that it was a phase II trial, and that Oregon Health & Sciences University in Portland also was starting this trial, when in fact it is a phase I trial.

Adds Life Raft Science Coordinator Jerry Call: “Apparently, the phase I

Setting the record straight

trial in Berlin is demonstrating a significant interaction between PKC412 and Gleevec. Our understanding is that PKC412 is causing the Gleevec to leave the body too quickly. This will require a higher than anticipated dose of Gleevec to achieve normal levels of Gleevec in the body.

“The Gleevec plus PKC412, and

Gleevec plus RAD001 (RAD) phase I trials emphasize the importance of phase I trials for drug combinations. Both trials are demonstrating significant drug interactions. In the Gleevec+RAD trial, the Gleevec is causing an *increase* in the amount of RAD in the body, while in the Gleevec+PKC412 trial, the PKC412 is causing a *decrease* in the amount of Gleevec in the body.”

LURIE

From Page 1

teaching hospitals.

Originally established in 1974, the Robert H. Lurie Comprehensive Cancer Center of Northwestern University is the only cancer center in Illinois and one of only about 40 in the nation to hold the “comprehensive” designation by the National Cancer Institute (NCI). This designation reflects the center’s commitment to the highest standards of research, patient care, prevention, education and community outreach. In addition, the center is a founding member of the National Comprehensive Cancer Network, an alliance of 19 of the world’s leading cancer centers.

The overall goal of the sarcoma department at Lurie and the Feinberg School of Medicine at Northwestern University is to improve the survival and quality of life for patients with bone and soft tissue sarcoma. This goal is met through the multidisciplinary team care of pathology, surgical oncology, radiation oncology and medical oncology.

There are five medical oncology physicians at the Lurie center with significant experience in the treatment of gastrointestinal stromal tumor (GIST), in particular with Gleevec therapy. These physicians include Dr. Andrew Evens, DO, director of the medical oncology sarcoma program; Dr. Al Benson, director of clinical research; Dr. Mary Mulcahy, clinical investigator in gastrointestinal malignancies; Dr. James Brandman, director of the hematology/oncology outpatient clinic, and Dr. Bruce Brockstein, director of sarcoma care. Other sarcoma experts at the center include two sarcoma-specific oncologic surgeons, Dr. Jeffrey Wayne and Dr. Robert Satcher;



EVENS

a sarcoma radiation oncologist, Dr. Krystyna Kiel, and a sarcoma pathologist, Dr. William Laskin. This sarcoma team meets monthly as a group to discuss every sarcoma patient diagnosed or treated at the center. This multidisciplinary care of patients is critical to improving outcome of patients with GIST and other soft-tissue and bone sarcomas.

Prior to the early 1990s, GIST was not diagnosed or treated differently from other types of sarcomas (such as leiomyosarcoma). This is important since GIST is typically not responsive to conventional chemotherapy (adriamycin, ifosfamide, etc).

Oncology researchers discovered that GIST tumors express a marker known as c-kit. C-kit is a proto-oncogene (gene that causes cancer) that is seen in the vast majority of GIST patients, and causes the uncontrolled growth of the tumor cells. This is important because Gleevec is able to reverse/correct this abnormality. Today, Gleevec is the standard of care for patients with metastatic and inoperable GIST.

However, several questions still remain. Should patients receive Gleevec following surgical resection of GIST? Should patients receive Gleevec before surgical resection? This is important because Gleevec has side effects and patients should not be exposed to Gleevec if it will not be beneficial. Furthermore, there are many biologic and genetic questions regarding GIST that need to be studied.

Critical factors that determine the aggressiveness of GIST include patient age, the mitotic index and size of the tumor (less than 5 centimeters vs. 5 centimeters or more). Other biologic questions pertain to the different genetic mutations of c-kit and how other important genes involved with GIST affect the clinical course of GIST patients, in particular, the response to

Gleevec therapy. Also, the appropriate way to incorporate sophisticated imaging tests such as PET scans into patient care needs to be evaluated further.

An avenue to answer these questions and to identify other active therapeutic agents is through clinical research.

Two clinical trials are now open at the center for patients with GIST: A phase III randomized double-blind study of adjuvant STI571 (Gleevec) versus placebo in patients following the resection of primary GIST (ACOSOG Z9001) and a phase II trial of neoadjuvant/adjuvant STI-571 (Gleevec NSC 716051) for primary and recurrent operable malignant GIST expressing the KIT receptor tyrosine kinase, CD117 (RTOG S-0132). The latter trial has incorporated scheduled PET scans as well as detailed genetic analysis of the GIST tumors. Of note, the center participated in two other GIST clinical trials that are currently filled: a phase III trial assessing the clinical activity of STI-571 at two dose levels in patients with unresectable or metastatic GIST (a study through Eastern Cooperative Oncology Group) and a phase II study of adjuvant Gleevec in patients following completely resected high-risk primary GIST (ACOSOG Z9000).

The Lurie center has enrolled 15 GIST patients onto these studies over the last few years. In addition, the center is in discussions to obtain other novel agents for treating GIST.

The center’s sarcoma program also has an active tumor bank to store sarcoma tissue for current and future analysis of these tumors (for study of protein, RNA/DNA and other important genetic markers). This will aid in the identification of prognostic genetic events and development of future gene-targeted drug therapy. Clinical trial research will be an important way to study these novel agents. This is currently being developed through not only drug company-sponsored trials, but also NCI-sponsored, ECOG-sponsored and investigator-initiated analysis of novel drug therapy.

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.

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Disclaimer

We are patients and caregivers, not

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