

Windy city to host Life Fest 2008

By Norman Scherzer
LRG Executive Director

As many of our readers know, we hold an international GIST patient/caregiver meeting every other year, called Life Fest. This year's meeting is taking place in Chicago, Ill. The meeting is in its final planning phase and more details will be coming to light as we confirm our expanding group of expert guest speakers.

This tradition of bringing patients and caregivers together in person stemmed from a core need to connect with others battling the same rare cancer. In addition to this critical networking, patients and caregivers can hear about new advances in GIST treatment and research from the experts, discuss survival strategies and understand how to navigate the latest clinical trials. It's not often that such a wealth of knowledge about GIST exists in one meeting. It's a golden opportunity to learn about GIST and how to manage it.

The first Life Fest took place in Cambridge, Mass. in 2002. The second meeting in Orlando, Fla., brought together more than 100 patients and caregivers. And the third, in Dallas, Texas, brought together over 150 attendees.

We expect that this year's location and line-up will bring even more people together. All GIST patients and caregivers are welcome and will be made welcome as the GIST community, young and old,

comes together in this heartland of the United States to share their hopes and fears and to unite in the strug-



The Hyatt Regency O'Hare in Chicago

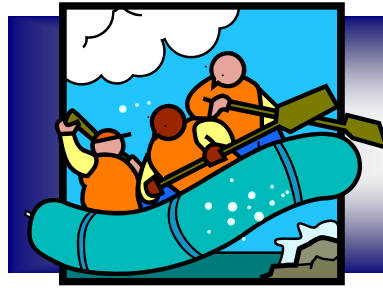
NEWS

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Check out Life Fest 2008 registration details on page 9!

Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

June 2008

In memory of Tony Paonessa, Ronna Lindeken, Jim Barth, Nancy Romero, Brian Denkers, Alice Greenwood & Tony Petruzzello

Vol. 9, No. 6

New target found for wild-type and pediatric GIST

By Jerry Call
LRG Science Coordinator

GISTs without mutations in either of the two genes commonly mutated in GIST typically respond poorly to Gleevec. Andrew Godwin, Ph.D. of Fox Chase Cancer Center and other researchers appear to have found a major driving force in these tumors. Dr. Godwin presented his findings at the 2008 American Society of Clinical Oncology (ASCO) meeting in Chicago on Saturday, May 31. In addition, Dr. Godwin's work is scheduled to be published in the Proceedings of the National Academy of Sciences (PNAS) on June 1, 2008.

Effective targeted therapies such as Gleevec rely on blocking pathways that are critical to a specific cancer. Gleevec inhibits the aberrant signaling caused by KIT and PDGFRA gene mutations (although some mutations are resistant to Gleevec). KIT mutations are involved in about 80 percent of GISTs and PDGFRA mutations are the driving force in another five to eight percent of GISTs. The other ten to 15 percent of GISTs without KIT or PDGFRA mutations are called "wild-type GISTs".

Mutations that alter a proteins shape and function are one cause of abnormal signaling in cancer cells, but they are not the only cause. Sometimes cancer cells

have too much (or too little) of a protein (over expression). Godwin and his colleagues at Fox Chase have found that wild-type GISTs have extra copies of the insulin-like growth factor 1 receptor (IGF1R) gene and they make way too much of the IGF1R protein.

Two groups; Cristina Antonescu, M.D., and colleagues of Memorial Sloan-Kettering Cancer Center and Godwin and colleagues have both shown that IGF1R is also over expressed in pediatric GIST (another type of "wild-type GIST").

In an interview with Michael Smith of Medpage Today, Dr. Godwin said, "Our real excitement is that we think this might be the oncogenic driving force" behind wild-type GIST. "We're talking to companies right now about possible clinical trials," Dr. Godwin told Medpage today.

Godwin's team tested an IGF1R inhibitor, NVP-AEW541 (Novartis) against Gleevec-sensitive and Gleevec-resistant GIST tumor cells and found that it induced a cytotoxic response as a single agent and a strong cytotoxic response in combination with Gleevec.

In an audio interview on the Medpage Today website, Godwin said that Fox Chase currently tests for KIT and PDGFRA mutations and is setting up assays to be used in the clinic to measure

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Canadian GIST patients may soon benefit from Josephy's experience

By Erin Kristoff
LRG Newsletter Editor

In November 2000, just after her 16th wedding anniversary with husband, Michael, Elsie Hernandez's CT scan showed a mass that appeared to be pancreatic cancer; immediate surgery was needed. Elsie, a mathematician, told her students at the Technological Institute in Costa Rica that she had to leave, accepted her colleagues' well-wishes and scheduled her tumor removal. A week later she had a diagnosis: GIST.

It is at this point that David, Michael's brother and research biochemist at the University of Guelph in Ontario, stepped in to contribute whatever help he could.

The journey of Elsie, Michael and David from this point on is somewhat incredible in the telling; a story of luck and perseverance that paved the way for David to take on the struggles of Canadian GIST patients.

"The first serious phone call I made after I found out about the diagnosis was to an oncologist friend in Canada. He told me to find out if it was c-KIT positive because he had just found out about this new drug called STI-571," said David.

"It felt like it was out of a novel, but the initial announcement of Gleevec for GIST was such a breaking news story that most doctors took notice of it." Elsie was indeed c-KIT positive, so David and Michael began researching through the

internet, operating under the assumption that most doctors did not know about this new treatment for GIST. Michael eventually found the Life Raft Group where Executive Director, Norman Scherzer suggested they see Dr. Mary Louise Keohan, who luckily had a few slots open in the trial at Columbia Presbyterian Hospital in New York City.

Elsie got on a plane to New York. Within days of landing, Elsie was randomized into the trial and began taking 800 mg of Gleevec. "It was just incredible, it was all so fast." Just like out a novel, Elsie was diagnosed and receiving treatment within a few

months.

Elsie receives twice yearly scans and has been stable for over seven years.

But the story does not end here for David.

"It was the beginning of something big with the Life Raft Group," he says.

One of the first people David met with GIST was Sheila Murphy. "I realized there are other people out there with this disease."

David donated his time on many science-related materials for the LRG and also began holding meetings for GISTers in Canada. Along with Sheila, and new friends, Lee Cousins and Linda Hampson, the group met occasionally for two years, offering support and advice. They dreamed of doing more with the group, an organization of their own to tackle issues affecting Canadians.

In June of 2006, Sheila lost her battle with GIST. Six months later, in Decem-



HERNANDEZ



DAVID JOSEPHY

The Life Raft Group

Who are we, what do we do?

The Life Raft Group is an international, Internet-based, non-profit organization offering 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 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:
The Life Raft Group
40 Galesi Dr., Suite 19
Wayne, NJ 07470

Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor. As for the newsletter, every effort to achieve accuracy is made but we are human and errors occur. Please advise the newsletter editor of any errors.



MICHAEL JOSEPHY

June 2008 US clinical trials update

By Jim Hughes

LRG Science Team member

AMN107 Phase III: This trial has met accrual goals and enrollment is now closed.

Sunitinib or Imatinib: Five new sites have been added in the United States. Four new international sites have also been added:

1. Lai Chi Kok, Kowloon, Hong Kong
2. Tuen Mun, New Territories, Hong Kong
3. Milano, Italy, 20133,
4. Seoul, Republic of Korea, 135-710

Imatinib + Pegylated Interferon-a 2B:

This trial now has an NCT number and the contact information has changed. Contact Jessica Moehle, 801-587-4438 at the Huntsman Cancer Institute.

Sorafenib Phase II: Contact information has been updated.

Perifosine + Sunitinib: Trial is ongoing but not recruiting.

Imatinib or Sunitinib

Safety and effectiveness of daily dosing with sunitinib or imatinib in patients with GIST

Phase: III
 Conditions: GIST
 Strategy: Inhibit KIT and/or impede tumor vascularization
 NCT#: NCT00372567
 Contact: Pfizer
 pfizercancertrials@emergingmed.com
 Telephone: 1-877-369-9753
 Sites: **Dana-Farber Cancer Institute (DFCI)**, Boston, Mass.
 Melissa Hohos, RN
 617-632-2201
 Creve Coeur, Mo.
 St. Louis, Mo.
 St. Peters, Mo.
 New York, N.Y.

BIIB021 (CNF2024)

Open-Label, 18FDG-PET pharmacodynamic assessment of effect of drug in GIST patients

Phase: II
 Conditions: GIST
 Strategy: Destroy KIT (HSP90)
 NCT#: NCT00618319
 Contact: **Biogen-Idec**
 oncologyclinicaltrials@biogenidec.com
 Sites: Contact Biogen-Idec

Imatinib + Pegylated Interferon-a 2B

Phase II study combines targeted therapy with immunotherapy, Imatinib + Pegylated Interferon-a 2B in imatinib-naïve GIST patients

Phase: II
 Conditions: GIST
 Strategy: Kill GIST cells
 NCT#: NCT00585221
 Contact: **Huntsman Cancer Institute**
 University of Utah, Salt Lake City, Utah
 Jessica Moehle
 Telephone: 801-587-4438

Perifosine + Imatinib

Phase II study of Perifosine + Gleevec in GIST patients

Phase: II
 Conditions: GIST
 Strategy: Multiple Targets
 NCT#: NCT00455559
 Contact: **Online Collaborative Onc. Group**
 ocogtrials@ocog.net
 Telephone: 415-946-2410
 Sites: Los Angeles, Calif.
 Sant Chawla, Md.
 Coeur D'Alene, Idaho
 Park Ridge, Ill.
Oncology Specialists
 Kathy Tolzein, RN
 847-268-8200
 Grand Rapids, Mich.
 Sayre, Penn.
 Houston, Texas
MD Anderson Cancer Center
 800-392-1611

Sorafenib (Nexavar)

Sorafenib in treating patients with malignant GIST that progressed during or after previous treatment with imatinib and sunitinib.

Phase: II
 Conditions: GIST
 Strategy: Multiple Targets
 NCT#: NCT00265798
 Contact: **Univ. Of Chicago Cancer Res. Center**, Chicago, Ill.
 Ravi Salgia, MD
 rsalgia@medicine.bsd.uchicago.edu
 Blase Polite, MD
 bpolite@medicine.bsd.uchicago.edu
 Telephone: 773-834-7424
 Sites: **City of Hope**, Duarte, Calif.
 Warren Chow, MD, 626-256-4673
USC-Norris Cancer Center, Los Angeles, Calif.
 Hein-Josef Lenz, MD,
 323-865-3955
UC-Davis, Sacramento, Calif.
 David Gandara, MD,
 916-734-3771
Decatur Memorial Hospital, Decatur, Ill.
 James Wade, MD, 217-876-6617
Oncology/Hematology Assoc., Peoria, Ill.
 John Kugler, MD, 309-671-5180
 James Knost, MD,
 jknost@ohaci.com
Central Illinois Hem/Onc, Springfield, Ill.
 Edem Agamah, MD, 217-525-2500
Univ. of Michigan, Ann Arbor, Mich.
 Scott Schuetz, MD, 734-647-8925
Memorial Sloan-Kettering CC (MSKCC), New York, N.Y.
 David D'Adamo, MD, 212-639-5720
Medical College of Wisconsin
 Milwaukee, Wis.
 Stuart Wong, MD, 414-805-4603

GIST 101

What exactly is a sarcoma?

Sarcoma are *cancers that arise from cells of connective tissues* (blood vessels, cartilage, bone, etc.)

These are much less common than carcinomas, which arise in epithelial ("lining") tissues (e.g. skin, lung, bladder, colon, and breast).



Because GISTs are a type of sarcoma, hospitals with sarcoma centers often have the most experience with GIST.

XL820

Phase 2 study of XL820 in advanced GIST resistant to imatinib and/or sunitinib

Phase: II
 Conditions: GIST
 Strategy: Multiple Targets
 NCT#: NCT00570635
 Contact: Christiaan McEwen
 Telephone: 415-337-1754
 Sites: **Oncology Specialists**, Park Ridge, Ill.
 Kathy Tolzein, RN
 847-268-8200
DFCI, Boston, Mass.
 Melissa Hohos, RN
 617-632-2201

Cancer in the news: can exercise combat fatigue and Medicare costs swell higher

Exercise combats cancer-related fatigue

NEW YORK (Reuters Health)— Exercise appears to be beneficial for patients suffering from cancer-related fatigue, both during and after treatment, a review of published studies indicates.

Nearly all cancer patients experience fatigue, Dr. Fiona Cramp and colleagues note in the latest issue of *The Cochrane Library*, a publication of The Cochrane Collaboration, an international organization that evaluates medical research.

According to guidelines from the National Comprehensive Cancer Network, treatable factors that may be related to cancer-related fatigue, such as pain, emotional distress, sleep disturbance, anemia, nutrition, activity level, and comorbid illnesses, should be identified and treated.

However, there is no consensus regarding the effect of exercise on cancer-related fatigue once treatable causes have been addressed.

Cramp, of the University of the West of England in Bristol, UK, and colleagues searched the medical literature for controlled trials that evaluated the effect of exercise on cancer-related fatigue. They identified 28 studies involving 2,083 participants. More than half of the studies involved women with breast cancer.

“Statistically significant improvements in fatigue were identified following an exercise programme carried out either during cancer therapy or following cancer therapy,” the researchers report. Most programmes involved moderate-intensity exercise performed two or three times per week.

Cramp’s team recommends that exercise be considered as one of several components of the management strategy for cancer-related fatigue, which may also include other nonpharmacologic interventions, including psychological

and social therapies, stress management, nutrition therapy and sleep therapy.

“Exercise shouldn’t be used in isolation but should definitely be included as one of the components in the package of interventions used during and after treatment,” Cramp said in a written statement.



ance program for people 65 and older. The researchers based their estimates on 1999-2003 data from more than 700,000 cancer patients covered by Medicare and more than 1.6 million people covered by Medicare who did not have cancer.

These per-patient costs were applied to a five-year survival model and extrapolated to the U.S. Medicare population diagnosed with cancer in 2004.

Among the 18 cancer types studied, brain and nervous system cancers were by far the costliest for men in each phase of treatment over five years. In women, these cancers were the most expensive in the first year of diagnosis and the last year of life, but ovarian cancer was the most costly overall.

Cancers with the highest costs overall across women in the Medicare population were lung (\$2 billion), colorectal (\$1.6 billion) and breast (\$1.4 billion). Among men they were prostate (\$2.3 billion), lung (\$2.2 billion) and colorectal (\$1.5 billion).

The estimates reflect Medicare discounts and are reported in 2004 dollars.

“Few of these individual findings are startling; yet, taken together they provide the scientifically strongest picture yet of the incidence costs of cancer in aggregate and by tumor type for the elderly in the United States,” Lipscomb wrote in a commentary.

The researchers did not include the cost of treating younger cancer patients, as they tend to receive more costly and aggressive therapies. As newer, more expensive treatments become more widely adopted, however, the cancer estimates for treating Medicare beneficiaries are likely to rise, they said.

There were about 10 million Americans living with cancer in 2003. The National Cancer Institute has estimated that, overall, the United States spent \$72.1 billion in 2004 in direct costs for cancer care.

Medicare 5-year cancer bill tops \$21.2 billion

CHICAGO (Reuters)— Five years of cancer care for America’s elderly cost Medicare \$21.1 billion, a figure that will swell as the baby boomer generation ages, U.S. government researchers said on Tuesday.

Researchers at the National Cancer Institute said the cost of cancer care over five years varies widely by tumor type - from less than \$20,000 for an elderly patient with breast cancer or melanoma to more than \$40,000 for a patient with lymphoma, brain or other nervous system cancers.

The figures, based on people diagnosed with cancer in 2004, suggest the highest costs occur within the first 12 months of care, when people are undergoing costly treatments, and in the last 12 months of life, when in-hospital costs spike.

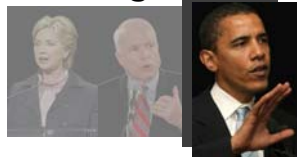
The research by Robin Yabroff of the National Cancer Institute in Bethesda, Maryland, and colleagues, which appears in the *Journal of the National Cancer Institute*, is intended to offer policymakers a tool to prepare as the U.S. population expands and ages.

Joseph Lipscomb, a health policy researcher at Emory University in Atlanta, said the study is the first to combine cost estimates and survival data to arrive at long-term national estimates for 18 of the most common types of cancers in the elderly.

Medicare is the federal health insur-

Campaign 2008

Candidate's histories concerning healthcare



This month, we will finish looking at the healthcare histories and plans of each candidate (in alphabetical order). This month is Senator Barack Obama. **As a reminder, the Life Raft Group does not endorse or promote any candidate.**

Senator Obama's healthcare plan differs from Senator Clinton's and indeed McCain's because it does not follow the traditional guidelines of a "universal" healthcare plan. Obama's core belief is that people desperately want coverage, "The problem is not that folks are trying to avoid getting health care; the problem is they can't afford it."

Obama's plan does not have a mandate for both children and adults, instead it "emphasizes lowering costs, not only setting up a government plan so that people who don't have health insurance can buy into it and will get subsidized." Children will be mandated under Obama's plan and can be covered until age 25.

He also believes that changes can't be made until changes are made in Washington. "The reason we can't negotiate prescription drugs under the Medicare prescription drug plan is because the drug companies specifically sought and obtained a provision in the Bill that prevented us from doing it."

Obama claims that his health care reform plan will save the typical family up to \$2,500 every year.

Much more information on Senator Obama's healthcare plan online at sites such as ontheissues.org and www.thehealthcareblog.com.

[View our new Advocacy page at www.liferaftgroup.org/advocacy.html](http://www.liferaftgroup.org/advocacy.html)

TRIALS

From Page 3

Doxorubicin + Flavopiridol

Doxorubicin and Flavopiridol in treating patients with metastatic or recurrent unresectable sarcomas

Phase: I
 Conditions: GIST/Sarcoma
 Strategy: Inhibits production of KIT
 NCT#: NCT 00098579
 Contact: David D'Adamo, MD
 Telephone: 212-639-7573
 Sites: **MSKCC**, NY, N.Y.

Imatinib + Sunitinib

Imatinib & sunitinib in treating GIST patients

Phase: I
 Conditions: GIST
 Strategy: Multiple targets
 NCT#: NCT00573404
 Contact: Clinical Trials Office
 Telephone: 800-811-8480
 Sites: **Vanderbilt-Ingram CC**, Nashville, TN
 Jordan Berlin, MD

Perifosine + Sunitinib

Perifosine + sunitinib malate for patients with advanced cancers

Phase: I
 Conditions: GIST/Renal cancer
 Strategy: Multiple Targets
 NCT#: NCT00399152
 Contact: **Online Collaborative Onc. Group**
 Telephone: 415-946-2410
 Sites: This trial is ongoing but not recruiting

BEZ235

A Phase I/II multi-center, open-label study, administered orally on a continuous daily dosing schedule in adult patients with advanced solid malignancies including patients with advanced breast cancer

Phase: I/II
 Conditions: Adv. Solid Malignancies/ Adv. Breast Cancer
 Strategy: Target KIT downstream signal (PI3K)
 NCT#: NCT00620594
 Contact: Novartis
 Telephone: 862-778-8300
 Sites: **Nevada Cancer Institute**, Las Vegas, Nev.
 Montessa Linsangan, 702-822-5282
Sarah Cannon Res. Institute, Nashville, Tenn.
 Howard Burris, MD, 615-329-7274

AUY922

Phase I-II study to determine the MTD of AUY922 in advanced solid malignancies and efficacy in HER2+ or ER+ locally advanced or metastatic breast cancer.

Phase: I
 Conditions: Breast Cancer/Solid Malignancies
 Strategy: Destroy KIT (HSP-90)
 NCT#: NCT00526045
 Contact: **Novartis**
 Telephone: 800-340-6843
 Sites: **UCLA**, Los Angeles, Calif.
 Carolyn Britten, MD
 310-825-5268
 cbritten@mednet.ucla.edu
DFCI, Boston, Mass.
 Melissa Hohos, RN
 617-632-2201
Washington University, St. Louis, Mo.
 Paela Fracasso, MD
 314-362-5654
Nevada Cancer Institute, Las Vegas, Nev.
 Sunil Sharma, MD
 702-822-5360

BIIB021 (CNF2024)

Once or twice daily administration of BIIB021 to solid tumor subjects

Phase: I
 Conditions: Advanced Solid Tumors
 Strategy: Destroy KIT (HSP-90)
 NCT#: NCT00618735
 Contact: **Biogen-Idec**
 oncologyclinicaltrials@biogenidec.com
 Sites: **Premiere Oncology**, Santa Monica, Calif.
 Lee Rosen, MD, 310-633-8400

BGT226

A phase I/II study of BGT226 in patients with advanced solid malignancies including those with advanced breast cancer

Phase: I
 Conditions: Solid Tumors, Breast Cancer, Cowden Syndrome
 Strategy: Target KIT downstream signal (PI3K)
 NCT#: NCT00600275
 Contact: Novartis
 Telephone: 800-340-6843
 Sites: **Nevada Cancer Institute**, Las Vegas, Nev.
 Sunil Sharma, MD

The role of CT and PET scans in the evaluation of GIST

By Elizabeth Braun

LRG Research Projects Coordinator

This is a follow-up to an article published in the May 2008 newsletter highlighting the benefits and risks involved in MRIs, PET and CT scans.

In the offices of the Life Raft Group, we receive reports of many CT scans findings that are inconclusive. On a regular basis, scans results are misinterpreted as resistance leading to the premature cessation of imatinib therapy which has the potential to reduce long-term survival. This is of greater concern when the radiologist reading the scans has little experience with GIST or when a patient is not consulting with a GIST specialist. Traditional criteria for the evaluation of tumor resistance are likely to over-diagnose the occurrence of progression. Proper use and interpretation of CT scans is vital for effective GIST treatment. Some experts in GIST imaging are now advocating the routine use of both CT and PET scans for GIST. At the present time however, CT (or MRI) is the recommended imaging method according to the NCCN sarcoma practice guidelines (v.1.2008). The guidelines also state to “Consider PET” and that “PET is not a substitute for a CT.”

Initial Response to Therapy

Frequently, the initial responses of GIST to imatinib therapy do not meet Response Evaluation Criteria in Solid Tumor (RECIST) guidelines for treatment response. GIST tumors may decrease in size slowly or only show a cessation of growth while responding well to treatment. In some cases, tumor size may increase due to hemorrhaging within the tumor, necrosis (tumor cell death) or tumor degeneration. How, then, can treatment success be evaluated?

PET Scans: When available, positron

emission tomography (PET), using fluorine-18-fluorodeoxyglucose (¹⁸FDG) is an excellent tool for evaluating response. Unfortunately due to cost and machine availability PET scans are not available to all patients. Alternatives for PET scans will be discussed later in this article.

If a doctor considers using PET to monitor therapy with Gleevec, Sutent or another tyrosine kinase inhibitor, a baseline PET scan should be obtained before the start of treatment. This provides a tool for comparison of future scans, allowing for evaluation of response.

Using PET scans, it is possible to observe responses to imatinib therapy in as

RECIST criteria- uses tumor size to quantitatively define shrinkage or growth of a tumor. These are used in clinical trials to define complete response, partial response, stable disease, and progression of disease.

little as 24 hours after initiation of treatment. Significant decreases in activity on PET scans can be seen within a month of starting imatinib therapy in patients that are responding to treatment. However, it may take appreciably longer for tumor shrinkage to appear on CT scans even when there is a strong benefit from treatment.

Those patients with primary resistance to imatinib therapy may also be identified using PET scans. These patients may show little to no decrease in activity on a PET scan. At this point it may be advantageous to consider alternatives to imatinib.

CT Scans: Although significant changes in tumor size may not be seen using computed tomography (CT), other changes in tumor characteristics make CT scans valuable in the evaluation of initial response. Tumor density changes may be visible in a single month following the initiation of imatinib therapy in responding tumors. Changes in density have been seen in as little as a single week. In addition to a decrease in tumor density, a decrease in vascularization may be seen. These changes have been

shown to strongly correlate to activity reduction on PET scans. In contrast, using size alone may not show positive tumor response. In patients with primary resistance to imatinib therapy, changes in tumor density and vascularization may not appear indicating a need to explore alternative therapies.

GIST liver metastases that are responding to treatment may become more cystic during imatinib treatment and therefore more visible on a CT scan.

Some lesions may not be visible on a CT scan prior to initiation of imatinib therapy and appear as they respond to treatment. Care must be taken not to misinterpret these findings as progression and prematurely cease imatinib therapy.

Long-term surveillance of tumor response

Both CT scans and PET scans have roles to play in the long-term surveillance of GIST response to imatinib. Traditional RECIST criteria diagnose recurrence or progression based on an increase in tumor size or the identification of new lesions, either at the same site as the primary (a local recurrence) or at distant sites (metastases). Although an increase in tumor size is still important for identifying progression in GIST, the appearance of the tumor needs to be evaluated as well.

CT scans: As mentioned earlier, it is important to evaluate the density and vascularization of a GIST tumor when evaluating progression. Changes in size without changes in these other tumor characteristics may not indicate progression. In addition, it is possible for a GIST tumor to develop intratumoral (within the tumor) nodules when secondary resistance first begins developing.



CANADA

From Page 2

ber, Lee passed. David began to question the feasibility of their aspirations with the loss of his friends. However, knowing that this group would help more GIST patients down the road, he forged on.

“GIST Sarcoma Life Raft Group Canada” (as it is to be called) has since applied to be incorporated in order to receive tax-deductible status and David has formed a Board of Directors and by-laws. Non-profit status can take up to a year to be granted, but David has not been deterred and is concentrating on the

future.

“For at least the first year we will be focused only on Canada-specific problems facing patients.”

His experiences with GIST have taught him one thing that he can share with others. “Make contacts and find out as much as you can. Many doctors know more now so there is little incentive for patients to go out and find out more information. Educate yourself, it’s still really important and by no means routine. If you are not paying attention, you’re not going to know.”

TARGETS

From Page 1

the level of IGF1R in GIST.

Although Godwin found that IGF1R was highly over expressed in wild-type GIST versus GISTs with mutations in KIT or PDGFRA, he did note in his ASCO presentation that IGF1R was, in general, activated in GISTs. C. Braconi and colleagues have shown that the IGF1 receptor (IGF1R) and two IGF growth factors (ligands), IGF1 and IGF2 can be over expressed in some GISTs and that higher levels of IGF1 and IGF2 correlated with shorter times to recurrence after resection of primary tumors. This raises the question of whether or not anti-IGF1R therapy might be useful in GISTs with KIT or PDGFRA mutations as well.

In a paper published in Clinical Cancer Research on May 15, 2008, Dr. Cristina Antonescu reaffirmed her earlier finding that IGF1R was over expressed in pediatric GIST providing additional support for anti-IGF1R therapy for wild-type and pediatric GIST.

In addition, Dr. Antonescu tested several of the most popular KIT inhibitors against cells that were engineered to be dependent on wild-type KIT. In this screen of the five more popular KIT inhibitors, Gleevec was found to be the

IC50 for wild-type KIT	
Nilotinib	35 nmol/L
Sunitinib	245 nmol/L
Dasatinib	316 nmol/L
Sorafenib	910 nmol/L
Imatinib	3,132 nmol/L

least effective at inhibiting wild-type KIT (see Table). Although the KIT gene is not mutated in wild-type GIST, the KIT protein is known to be strongly activated and to date has still been the primary target in wild-

type GIST, including pediatric GIST. It remains to be seen whether therapy that targets both KIT and IGF1R will be needed to control wild-type GISTs.

The new findings and the possibility of new clinical trials provide new hope for both children and adults with wild-type GIST.

A normal gene without a mutation is called a “wild-type” gene. If a GIST tumor has a normal KIT gene (no mutation), it is said to have “wild-type KIT.” If a GIST tumor has a normal PDGFRA gene, it is said to have “wild-type PDGFRA”.

Thus a tumor could be classified in four different ways with respect to KIT/PDGFRA mutations:

1. KIT mutation (wild-type PDGFRA)
2. PDGFRA mutation (wild-type KIT)
3. KIT mutation with PDGFRA mutation (very rare, only 1 or 2 cases found to date)
4. Wild-type KIT; wild-type PDGFRA, usually called “wild-type GIST”

TRIALS

From Page 5

CNF2024

Oral CNF2024 in advanced solid tumors

Phase: I
 Conditions: Tumors/Lymphoma
 Strategy: Destroy KIT (HSP-90)
 NCT#: NCT00345189
 Contact: **Biogen Idec**
 oncologyclinicaltrials@biogenidec.com
 Sites: Scottsdale, Ariz.
 New Haven, Conn.
 San Antonio, Texas
Cancer Therapy & Res. Center,
 San Antonio, Texas
 Pat O'Rourke, RN
 210-616-5976

GDC-0941

An open-label phase I, dose-escalation study in patients with locally advanced or metastatic solid tumors for which standard therapy is ineffective, intolerable or does not exist

Phase: I
 Conditions: Solid Tumors
 Strategy: Target KIT downstream signal (PI3K)
 Sites: **DFCI**, Boston, Mass.
 Melissa Hohos, RN,
 617-632-2201

LBH589

Phase IA, two-arm, multi-center, dose-escalation study, by IV on two dose schedules in adult patients with advanced solid tumors and non-Hodgkins lymphoma

Phase: I
 Conditions: Adv. Solid Tumors/Lymphoma
 Strategy: Destroy KIT, Inhibit Cell Cycle, Apoptosis
Nevada Cancer Institute, Las Vegas, Nev.
 Contact: Donna Adkins, RN, 702-822-5176

MP470

MP470 in treating patients with unresectable or metastatic solid tumor or lymphoma

Phase: I
 Conditions: Solid Tumors/Lymphoma
 Strategy: Multiple Targets
 NCT#: NCT00504205
 Sites: **Virginia Piper Cancer Center**,
 Scottsdale, Ariz.
 Raoul Tibes, MD, 480-323-1350
South Texas Accelerated Research Therapeutics (START),
 San Antonio, TX
 Anthony Tolcher, MD
 210-593-5255

See TRIALS, Page 10

15 steps you can take to reduce your risk of a hospital infection

Reprinted from Committee to reduce infection death's (RID) website:
www.hospitalinfection.org

Most of us will have to go into the hospital some day. Here are specific steps you can follow to protect yourself from deadly hospital infections:

- 1. Ask that hospital staff to clean their hands before treating you, and ask visitors to clean their hands too.** This is the single most important way to protect yourself in the hospital. If you're worried about being too aggressive, just remember your life could be at stake. All caregivers should clean their hands before treating you. Alcohol-based hand cleaners are more effective at removing most bacteria than soap and water. Do not hesitate to say: "Excuse me, but there's an alcohol dispenser right there. Would you mind using that before you touch me, so I can see it?" Don't be falsely assured by gloves. If caregivers have pulled on gloves without cleaning their hands first, the gloves are already contaminated before they touch you.
- 2. Before your doctor uses a stethoscope, ask that the diaphragm (the flat surface) be wiped with alcohol.** Stethoscopes are often contaminated with *Staphylococcus aureus* and other dangerous bacteria, because caregivers seldom take the time to clean them in between patient use.
- 3. If you need a "central line" catheter, ask your doctor about the benefits of one that is antibiotic-impregnated or silver-chlorhexidine coated to reduce infections.**
- 4. If you need surgery, choose a surgeon with a low infection rate.** Surgeons know their rate of infection for
- various procedures. Don't be afraid to ask for it.
- 5. Beginning three to five days before surgery, shower or bathe daily with chlorhexidine soap.** Various brands can be bought without a prescription. It will help remove any dangerous bacteria you may be carrying on your own skin.
- 6. Ask your surgeon to have you tested for methicillin-resistant *Staphylococcus aureus* (MRSA) at least one week before you come into the hospital.** The test is simple, usually just a nasal swab. If you have it, extra precautions can be taken to protect you from infection.
- 7. Stop smoking well in advance of your surgery.** Patients who smoke are three times as likely to develop a surgical site infection as nonsmokers, and have significantly slower recoveries and longer hospital stays.
- 8. On the day of your operation, remind your doctor that you may need an antibiotic one hour before the first incision.** For many types of surgery, a pre-surgical antibiotic is the standard of care, but it is often overlooked by busy hospital staff.
- 9. Ask your doctor about keeping you warm during surgery.** Operating rooms are often kept cold, but for many types of surgery, patients who are kept warm resist infection better. This can be done with special blankets, hats and booties, and warmed IV liquids.
- 10. Do not shave the surgical site.** Razors can create small nicks in the skin, through which bacteria can enter. If hair must be removed before surgery, ask that clippers be used instead of a razor.
- 11. Avoid touching your hands to your mouth, and do not set food or utensils on furniture or bed sheets.** Germs such as "C. Diff" can live for many days on surfaces and can cause infections if they get into your mouth.
- 12. Ask your doctor about monitoring your glucose (sugar) levels continuously during and after surgery, especially if you are having cardiac surgery.** The stress of surgery often makes glucose levels spike erratically. When blood glucose levels are tightly controlled, heart patients resist infection better. Continue monitoring even when you are discharged from the hospital, because you are not fully healed yet.
- 13. Avoid a urinary tract catheter if possible.** It is a common cause of infection. The tube allows urine to flow from your bladder out of your body. Sometimes catheters are used when busy hospital staff don't have time to walk patients to the bathroom. If you have a catheter, ask your caregiver to remove it as soon as possible.
- 14. If you must have an IV, make sure that it's inserted and removed under clean conditions and changed every 3 to 4 days.** Your skin should be cleaned at the site of insertion, and the person treating you should be wearing clean gloves. Alert hospital staff immediately if any redness appears.
- 15. If you are planning to have your baby by Cesarean section, follow the steps listed above as if you were having any other type of surgery.**



mouth, and do not set food or utensils on furniture or bed sheets. Germs such as "C. Diff" can live for many days on surfaces and can cause infections if they get into your mouth.

The stress of surgery often makes glucose levels spike erratically. When blood glucose levels are tightly controlled, heart patients resist infection better. Continue monitoring even when you are discharged from the hospital, because you are not fully healed yet.

It is a common cause of infection. The tube allows urine to flow from your bladder out of your body. Sometimes catheters are used when busy hospital staff don't have time to walk patients to the bathroom. If you have a catheter, ask your caregiver to remove it as soon as possible.

Your skin should be cleaned at the site of insertion, and the person treating you should be wearing clean gloves. Alert hospital staff immediately if any redness appears.

follow the steps listed above as if you were having any other type of surgery.

Visit www.hospitalinfection.org for more in-depth information on this topic.

LIFE FEST

From Page 1



Bob and Jeannie Book enjoy dinner at Life Fest '04 in Florida.

gle to find a cure for this cancer.

Two short years ago in Dallas, Texas a nine-year old GIST patient, Josalin Dunn, walked up to the stage of our banquet hall and, standing on a milk crate hidden behind the speaker's podium,



Dr. Jonathan Trent gives a presentation at Life Fest '06.

Josalin's new best friend), then went on to deliver the key note speech of the meeting and presented the Life Raft Group's Scientist of the Year Award to Dr. Jonathan Fletcher. That began a unique series of defining moments that melded hearts and minds and finally tears as a large group gathered in an aptly

named Survivor's Park to light a candle in celebration of those that were no longer with us. For those that held hands in that circle of life it was clear that we were embarked on a unique journey with many challenges to be overcome but that we were not alone.

This light now passes to Chicago. In the windy city we come together again and once more, we are not alone.

If you would like to participate in selecting some meeting topics, you still have a little while to do so by going to www.liferaftgroup.org/members_lifest.html and taking the workshops survey to let us know what works for you.



Richard Palmer accepts "Volunteer of the Year" at Life Fest '06.



Alice Sulkowski and Dick Kinzig led workshops at Life Fest '06.

LIFE FEST REGISTRATION

Check out the LRG website in the next month to register online for Life Fest 2008.

If you want to make hotel reservations, please call the Hyatt Regency O'Hare at (847) 696-1234

Hyatt Regency O'Hare
9300 Bryn Mawr Ave.
Rosemont, IL 60018

(Website: www.ohare.hyatt.com)

Indicate that you are with the Life Raft Group.

The LRG rate is \$109 (+tax) per night for single and double occupancy rooms.



The GIST community takes a moment of silence for those no longer with us.



Michigan Life Rafter's meet

The Michigan local LRG met on Saturday, May 3 at Gilda's Club in Royal Oak, Michigan. In attendance were Nancy and Ted Wahl; Nancy's mother who is 90 years young; Diane and Dean Schmitz; Jim Mills; Tom Overley; Abbas Patni and Ellen Rosenthal. Topics discussed were the LRG's dosage study, scan frequency, and what's going on in each of our lives. All the patients who were present are doing well.

TRIALS

From Page 7

OSI-930

Dose escalation study of daily oral OSI-930 in patients with advanced solid tumors

Phase: I
 Conditions: Solid Tumors/Sarcoma
 Strategy: Multiple Targets
 NCT#: NCT00513851
 Contact: **OSIP Medical Information**
 Medical-information@osip.com
 Telephone: 800-572-1932 xt 7821
 Sites: **Univ. of Colorado**, Aurora, Colo.
 Mary Kay Schultz, 303-266-1740
DFCI, Boston, Mass.
 Melissa Hohos, RN,
 617-632-2201

SNX5422

Safety and pharmacology of SNX-5422 in patients with refractory solid tumor malignancies

Phase: I
 Conditions: Solid Tumor Malignancy
 Strategy: Destroy KIT (HSP-90)
 NCT#: NCT00506805
 Contact: Catherine A. Ross
 Telephone: 919-376-1330
 Sites: **TGen Clinical Res. Services**
 Scottsdale, Ariz.
 Joyce Ingold, RN, 480-323-1339
Sarah Cannon Res. Institute
 Nashville, Tenn.

SF1126

Phase I open label, safety, pharmacokinetic & pharmacodynamic dose escalation study of SF1126 given twice weekly by IV to patients with advanced or metastatic tumors

Phase: I
 Conditions: Solid Tumors
 Strategy: Target KIT downstream signal (PI3K)
Semaphore Pharmaceuticals
 Contact: Ulrich Schwertschlag
 Telephone: 978-257-1926
 Sites: **Arizona Cancer Center**,
 Tucson, Ariz.
 Daruka Mahadevan, MD
 530-626-0191
Indiana University, Indianapolis, Ind.
 Elena Chiorean, MD
 317-278-6942

STA-9090

Phase I clinical trial of STA-9090

Phase: I
 Conditions: Solid Tumors
 Strategy: Destroy KIT (HSP-90)
 Sites: **DFCI**, Boston, Mass.
 Melissa Hohos, RN,
 617-632-2201
 Geoffrey Shapiro, MD,
 617-632-4942
Premiere Oncology,
 Santa Monica, Calif.
 Lee Rosen, MD, 310-633-8400

XL147

Study of safety and pharmacokinetics of XL147 in adults with solid tumors

Phase: I
 Conditions: Cancer
 Strategy: Target KIT downstream signaling (PI3-K)
 NCT#: NCT00486135
 Sites: **DFCI**, Boston, Mass.
 Pilar del la Rocha Mur
 617-632-5841
 Geoffrey Shapiro, MD
Mary Crowley Med. Res. Ctr.,
 Dallas, Texas
 J. R. Dolan
 214-658-1943

XL765

Study of safety and pharmacokinetics of XL765 in adults with solid tumors

Phase: I
 Conditions: Cancer
 Strategy: Target KIT downstream signaling (PI3-K)
 NCT#: NCT00485719
 Sites: **Karmanos Cancer Institute**,
 Detroit, Mich.
 Theresa Laeder, 313-576-9386
 Pat LoRusso, DO
South Texas Accelerated Research Therapeutics (START)
 San Antonio, Texas
 Gina Mangold, 210-413-3594
 Kyriakos Papadopoulos, MD

XL820

XL820 given orally to solid tumor patients

Phase: I
 Conditions: Cancer/Solid Tumors
 Strategy: Multiple Targets
 NCT#: NCT00350831
 Sites: **The Cancer Institute of New Jersey**, New Brunswick, N.J.
 Pamela Scott, 732-235-7459
 Mark Stein, MD
Cancer Therapy and Research Center, San Antonio, Texas
 Pat O'Rourke, 210-616-5976
 Alain C. Mita, MD

Chicago area GIST patients meet!



Chicago area GIST patients met Sunday, May 7 at the Wellness Place in Palatine, Ill. Guests included Pamela Kaiser, MD and Kathy Tolzein, RN both from Oncology Specialists in Park Ridge, IL. Dr. Kaiser is a clinical investigator in two clinical trials accepting GIST patients (Perifosine + Imatinib Phase II, and XL820 Phase II). She explained the overall trial process and provided background on the trials. Co-group leader, Dick Kinzig led planning for ASCO and Life Fest 2008 and approximately 20 patients and guests shared updates and support.

Can't find a trial here?
 Have you found a trial that should be listed here?
 Write to Jim at:
tjhughes43@comcast.net

SCANS

From Page 6

An intratumoral nodule will appear as change in density and structure.

PET scans: PET scans are very useful for identifying the onset of secondary resistance. When the results of a CT scan are inconclusive or inconsistent with clinical observations, a PET scan may help clarify the situation. When secondary resistance develops, an increase in activity is seen on a PET scan. The use of PET scans may help with early identification of progression as well as prevent misdiagnoses of progression.

Both PET and CT scans are valuable tools in the evaluation and surveillance of GIST. Traditional RECIST criteria may over-diagnose primary resistance and progression. When available, PET scans are an excellent tool for clarifying questionable scans. However, when PET scans are not feasible, evaluation of additional tumor characteristics such as density may help reduce the misdiagnosis of resistance.

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Van den Abbeele, Annick D.
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Journal of the National Comprehensive Cancer Network, Volume 5, Supplement 2

Lindeken: dear friend and Life Rafter

Ronna Lynn Lindeken, 53, of Bellvue, went home on May 15, 2008, surrounded by those who love her.

Ronna was born in Wellsville, N.Y., to Richard and Patricia Weiler on Nov. 27, 1954, three minutes after her twin, Roger Weiler, was born. Ronna attended Bolivar Elementary School in Bolivar, N.Y. In 1969, the family moved and located to Mesa, Ariz. Ronna attended West Wood Jr. High in Mesa and graduated from Moon Valley High School in Phoenix, Ariz., in 1972.

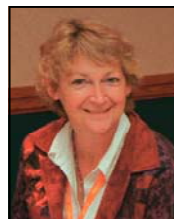
In July 1973, the family, Richard, Patricia, Ronna and Ronald, moved to Colorado. Ronna began dating Chuck Lindeken and soon began working at Teledyne Water Pik in 1973 as a water analysis technician in the water engineering department. Ronna and Chuck were married in June 1974. In 1976, they moved to Bellvue and bought a home in the mountains on 18 acres abundant with wildlife. Ronna never left this home, which is now known as "Ronna's Ranch."

Ronna also worked for Poudre Valley Health System at the main lab as a lab support processor and at the Breast Diagnostic Center from 1999-2004. She retired from Poudre Valley Health System in 2004 to enjoy life, travel and to wage her war on cancer.

Ronna loved nature, animals, and her family and friends. Ronna was a loyal and independent soul who cared for all, big or small. Her adventurous spirit and her tenacious fight against cancer inspired all who knew and love her.

Surviving Ronna are her two daughters, Kimberly Lindeken of Colorado Springs, and Katherine Venzor and son-in-law Mario Venzor of Fort Collins; her parents, Richard and Patricia Weiler of Fort Collins; her boyfriend, Matthew Johnson of Bellvue; her older brother, Ric Weiler of Fort Collins; her twin brother, Roger Weiler and sister-in-law Kimberly Weiler of Phoenix, Ariz.; younger brother, Ronald "Reggie"

Weiler of Masonville; nephew Rob Weiler of Phoenix, Ariz., and ex-husband, Charles Lindeken of Loveland. Preceding her in death are her maternal and paternal grandparents, and a nephew, Richard "Ric" Weiler III.



LINDEKEN

LRG Executive Director, Norman Scherzer posted the following to the LRG email community on May 16, after hearing of Ronna's passing.

Ronna lived in the foothills of Colorado with horses, dogs, cats and chickens. She was one of the original members of the Life Raft Group and first tried Gleevec in 2001. She began Sutent in 2007 and more recently was exploring other treatment options. In March 2008 she composed her last message to the Life Raft Group but was unable to mail it. Her daughter found it in her outbox and posted it in April reporting to us that she was at home with her two daughters and that they were arranging for hospice. She traditionally signed off on her listserv posts: "Ronna in Colorado, there's no place like home."

She is no longer in pain and leaves us with warm memories of a self described cowgirl in Colorado trudging through the snow on her mountain land.

Mark your calendars!

- Ohio GIST patients are meeting on Saturday, **June 14** at 1:00 pm, please contact Kaye Thompson at tnt.1@sbcglobal.net for details.
- Don't forget! The NIH Pediatric GIST clinic will be held on **June 19**. Visit www.liferaftgroup.org/pediatric_gist/gist_pediatric_nihclinic.html for more information
- Pennsylvania-area GIST patients will be meeting on Saturday, **July 12** at 11:30am at the Three Loaves Café in Elizabethtown. Contact Kimberly Trout at musik-withkim@yahoo.com for more details.



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