Battling gastrointestinal stromal tumor

LIFE RAFT GROUP

April 2008 | In memory of Jaime Peralta, Doris Talley, Harold Greene, Xiangjie Mu & Shaoqiu Hu Cheng | Vol. 9, No. 4

French "Rebirth" program breathes new life in women

By Erin Kristoff
LRG Newsletter Editor

A French program has just been implemented that is targeting the psychological impact cancer treatment has on women who are often suffering from physical changes and who often think they've lost their femininity.

Drs. Pierre Secnazi, aesthetic doctor and Mark Runge, plastic surgeon, under the control of Dr. Axel Le Cesne, oncologist at the Gustave Roussy Institute in Villejuif, will provide two free years of "aesthetic" treatments. These will range from botox and hyaluronic acid injections to laser peels.

Originally nameless, it was Estelle Lecointe (GIST patient, LRG member and Director of Ensemble Contre le GIST) who insisted a focused program such as this was in need of a name to set it apart. She immediately came up with the title, "Renaissance" (Rebirth in English). Says Secnazi, "She thought that asking for aesthetic cares during the disease is the obvious sign of a positive psychological evolution of the patient. By expressing the need to take care of [his/her] own body despite the disease and [his/her] treatments, the patient signifies its wish to end with a psychological withdrawal in order to live in 'harmony' with the disease. Taking care of its own self during the disease is clearly a way to express a fighting spirit and let the people know that above all, patients want to remain men and women and be considered as such on a social level."

With this "Rebirth" in place, the doctors set out to help their first patient, Estelle. "The effect is very surprising. No more wrinkles on my face. It looks like I've never been treated before."

Secnazi feels that this should be a vitally important step in a cancer patient's journey, "I personally think that these women might need a little help to feel like women again. Some oncologists may find this type of cares anecdotal, pointless or even not desirable but Estelle's account… clearly shows that it is a real craving, a real need."

And for those who disagree with this type of service? "I wish they will never be touched by this disease to realize they're wrong," says Secnazi.

The program is also designed for those people who cannot afford these luxuries. In order to offer this service

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Call dissects 2007 LRG study

By Jerry Call
LRG Science Coordinator

CALL

In last month's newsletter, the Life Raft Group published its study on the effects of imatinib dose upon the survival of metastatic GIST patients. On February 4, we also held a webcast, "The link Between Dosage and Survival". Since then we have had a number of questions about the study.

Some of the questions had to do with the design of the study. To answer these questions, it helps to remember that the original study was prepared in 2004 and at that time only looked at progression.

One key question asked was, " How accurately can patients report progression?"

To put this in perspective, and to understand the basis for our patient selection criteria, it might be helpful to review how this is done in clinical trials as well as with patient-reported data.

In clinical trials a number of "target" and "non-target" lesions (tumors) are identified at the start of treatment and form a "baseline". Target lesions are measured and if they increase by a specified amount, or if new tumors appear, the patient is deemed to have progressed. This typically results in the patient being removed from the study, or crossing-over to another treatment (such as a higher dose of Gleevec). One of the most popular methods to measure progression and response is the RECIST method. Using the RECIST method, the response of target lesions and non-target

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NEWS

Life Fest 2008 is set for September 12th-14 in Chicago!

More than a survivor

By Rob Anthes
Lawrence Gazette Staff Writer

This article was originally printed in March 2008 edition of Lawrence Gazette. It is reprinted here with permission.

February 29, 2008— Lawrence High School senior Chandell Fuqua widened his brown eyes and inhaled a deep, calming breath.

Propped against a locker while resting after drills with the Cardinal track team, Fuqua stopped to think about what he's accomplished this winter. He took his forearm to wipe the sweat rolling down his brow and shrugged.

He offered a demure explanation of how he wasn't surprised he set a Lawrence High record in the 55-meter hurdles and qualified for three events in the 2008 New Jersey state indoor track championships this February, but he appreciated the accomplishments just the same.

Forgive Fuqua when he downplays himself. It's a defense mechanism.

Fuqua's record-setting performance came just nine weeks after undergoing surgery to remove cancerous tumors from his abdomen. The procedure kept him in a hospital for five days and out of school for three weeks. It rendered him unable to participate in any physical activity for six weeks.

It was the third time in the 18-year-old's life he needed this kind of surgery.

Fuqua doesn't talk about it often. He doesn't bring it up unless asked, and even then he offers only a brief explanation. He fears he'll be known more for his illness than his accomplishments, even when his achievements place him among the top track athletes in the state and in the Lawrence High record book.

After just 10 days of training, Fuqua ran the 55-meter hurdles in a school-record 8.1 seconds and placed fourth at the Mercer County Winter Track Championship on Feb. 3. He finished fourth in the 55-meter hurdles and sixth in the 400-meter dash the next week at the Central New Jersey Group III Sectional Championships. The 400-meter relay team he belongs to ran the second-fastest time in school history and finished fourth at the Feb. 17 Group III State Championships.

The champ in action.

"If you didn't see the medical report, you would never know," Lawrence High track coach Dave O'Neal said. "He would never let on or indicate or make mention of it. He doesn't want that to identify him. He doesn't want to be the great athlete who has cancer. He just wants to be a great athlete."

O'Neal didn't know Fuqua suffered from a rare cancer called gastrointestinal stromal tumors, or GIST, until he happened to glance at the athlete's physical form one day in Fuqua's freshman year.

About 20 percent of GIST occurrences are cancerous, and GIST encompasses less than one percent of all cancer cases, said Dr. David August, director of the Cancer Institute of New Jersey's gastrointestinal and hepatobiliary oncology program and chief of the institute's division of surgical oncology.

After suffering from the cancerous form of GIST at ages 12 and 14, Fuqua went through his first three years of high school healthy.

A team of doctors based at New Brunswick's Cancer Institute of New Jersey and New York's Memorial Sloan-Kettering Cancer Center constantly review his health. Fuqua visits the Cancer Institute of New Jersey every three months, where he gives blood and undergoes PET scans.

See FUQUA, Page 13

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.

April 2008 US clinical trial update

By Jim Hughes
LRG Science Team Member

Clinical trial contact information for Dana Farber Cancer Institute (DFCI) in Boston has changed. Michael (Travis) Quigley, RN has been replaced by Melissa Hohos, RN. Melissa can be reached at 617-632-2201 or mhohos@partners.org. Melissa is the main contact for all GIST related trials at DFCI.

AMN107 Phase III: The St. Vincent's site in New York, N.Y., is now open. We have heard unofficially that U.S. accrual for this trial is nearly complete and is expected to end March 31, 2008.

Sunitinib or Imatinib Phase III: The Fox Chase Cancer Center (FCCC) site in Philadelphia, Penn. is pending and expected to open shortly. Check with Monica Davey, RN, 215-728-5534.

BIIB021 Phase I & II: *New trials.* Phase I- This drug from Biogen Idec is a HSP90 inhibitor (Was called CNF2024 in Phase I and administered twice weekly) and will be administered once or twice daily. Phase II- New York site is open. The Mayo Clinic site in Rochester, Minn. is pending.

Sorafenib Phase II: Sites have been updated. Ohio State University and DFCI have been removed. Added sites can be found in the table on page 8.

XL820 Phase II: A DFCI site has been added. Unofficially, we have been told that eight more sites are pending. Christiaan McEwen at Quintiles is the project manager 415-337-1754, christiaan.mcewen@quintiles.com.

Imatinib & Sunitinib Phase I: This new trial, sponsored by Vanderbilt and the National Cancer Institute. Both are approved GIST treatment, but toxicity and dose optimization studies must be conducted.

IPI-504 Phase I: Trial has met accrual and is no longer accepting patients. Maximum Tolerable Dose (MTD) was also reached. A Phase II trial is planned.

BGT226 Phase I: This new drug from Novartis is a PI3K inhibitor. It acts by inhibiting KIT downstream signaling. PI3K is a key protein in multiple cell functions and in cancer cell signaling including GIST signaling. Researchers hope to inhibit growth and stimulate cell death by inhibiting PI3K.

GDC-0941 Phase I: This new drug from Genentech is a PI3K inhibitor.

KOS1022 Phase I: According to Kosan's (the manufacturer) press release, drug development will stop with focus shifting to another HSP90 inhibitor.

Perifosine & Sorafenib Phase I: This trial is in the second of a two part Phase I and no longer accrues GIST patients.

SF1126 Phase I: This Phase I trial sponsored by manufacturer, Semafore, tests the safety of SF1126, a pro-drug that produces LY294002 (a pan PI3K inhibitor) in the body. However, Semafore designed SF1126 to concentrate in tumors and thereby avoid toxic side-effects associated with these inhibitors.

STA-9090 Phase I: This is now open at Premiere Oncology in Santa Monica, Calif.

XL147 Phase I: XL147 is a PI3K inhibitor from Exelixis. XL147 targets PI3K primarily and is given orally. XL765, another Exelixis PI3K inhibitor in Phase I (reported in January LRG issue) inhibits both PI3K and mTOR.

AMN107 (nilotinib, Tasigna®)

Efficacy and safety of AMN107 compared to current treatment options in GIST patients who failed imatinib and sunitinib

Phase: III
Conditions: GIST
Strategy: Inhibit KIT
NCT#: NCT00471328
Contact: Novartis # 862-778-8300 refer to trial# CAMN107A2201.
Sites: **UCLA**, Los Angeles, Calif.
Myung Lee, 310-825-4494
Wash.Cancer Inst., Washington, DC
Jake Paterson, 202-877-5371
H.L. Moffitt Cancer Center (CC), Tampa, Fla.
Bonnie Murray, 813-745-3819
Univ. of Chicago, Chicago, Ill.
773-834-7424
DFCI, Boston, Mass.
Melissa Hohos, RN, 617-632-2201
Karmanos Cancer Institute, Detroit, Mich.
Anne Marie Ferris, 313-576-9373
Washington Univ., St. Louis, Mo.
Nick Fisher, 314-354-5102
St. Vincent's Comprehensive CC
New York, NY, Larry Giove, 212-367-1729
Wake Forest, Winston-Salem, N.C.
Scarlet Hutchins, RN, 336-713-6915
FCCC, Philadelphia, PA
1-800-FOX-CHASE
MD Anderson, Houston, TX
Sylvia Abanto, 713-794-1919

Sunitinib (Sutent®) or Imatinib (Glivec®)

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

Phase: III
Conditions: GIST
Strategy: Multiple Targets
NCT#: NCT00372567
Contact: Pfizer– pfizercancertrials@emergingmed.com
Telephone: 877-369-9753
Sites: Contact Pfizer
DFCI, Boston, Mass.
Melissa Hohos, RN, 617-632-2201

Imatinib (Glivec®) + 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#: HCI 22172
Contact: **University of Utah**, Salt Lake City, UT
Huntsman Cancer Institute
Suzanne Dodd, Study Coordinator, 801-581-4477

BIIB021 (also called 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: oncologyclinicaltrials@biogenidec.com
Sites: Contact Biogen-Idec

Perifosine+Imatinib (Glivec®)

Phase II study of Perifosine+Gleevec in GIST patients

Phase: II
Conditions: GIST
Strategy: Multiple Targets
NCT#: NCT00455559
Contact: Online Collaborative Oncology Group
ocogtrials@ocog.net
Telephone: 415-946-2410
Sites: **CC at Century City**, Los Angeles, Calif.
Sant Chawla, MD
Coeur D'Alene, ID
Oncology Specialists, Park Ridge, Ill.
Kathy Tolzein, RN, 847-268-8200
Grand Rapids, MI
Sayre, PA
MD Anderson, Houston, TX
800-392-1611

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WEBSITE OF WORTH

SeventyK.org is a website dedicated to advocating on behalf of the adolescent and young adult ("AYA") cancer community. Roughly 70,000 people aged 15-39 are diagnosed each year with cancer, with little or no improvement in survival for this age group, according to SeventyK.

SeventyK sponsors a bill of rights that it hopes will raise awareness to the lack of rights that this patient demographic has in the medical community, with its ultimate goal being a Patient Bill of Rights in every hospital that reflects the needs of AYA community.

The sponsor of this bill is Dr. Leonard Sender, Medical Director of the Cancer Institute at Children's Hospital of Orange County and Medical Director of Clinical Oncology Services at the UC Irvine Medical Center's Chao Family Comprehensive Cancer Center. "This group of patients [does] not get the type of care that they should get in terms of access to experienced and educated practitioners in the field of adolescent and young adult cancer. They do not get access to clinical trials when there is a paucity of clinical trials available. There are very few biobank opportunities to store material in order for research to be done to try and understand the etiology of their cancer. There is very little work done involving the epidemiology or the study of the cause of their cancer. We also know that we have not paid attention to the fertility issues related to being a young adult cancer patient and survivor," says Sender.

Do you want to support SeventyK.org?

Go to www.seventyk.org and you can:

☑ Read a detailed and comprehensive explanation of the bill
☑ Sign the bill and take a stand
☑ Learn how to spread the word
☑ Read the SeventyK blog

AYA Patient Bill of Rights

We are neither pediatrics nor geriatrics,
we have unique needs- medically, socially, and economically.
However, the rights and dignity of adolescent and young adults are
equal and vital to all individuals.
We deserve to have our beliefs, privacy,
and personal values respected.
Access to care is a right,
not a privilege.

Our rights, as we perceive them to be and intend to preserve them, are:

- The right to be taken seriously when seeking medical attention to avoid late diagnosis or misdiagnosis, and entitlement to separate and confidential discussions regarding our own care.
- The right to affordable health insurance, as well as early detection tests unhindered by insurance or socioeconomic status.
- The right to be offered fertility preservation as well as current information and research regarding ongoing and potentially lifelong effects of cancer treatment that would affect our fertility.
- The right to be informed about available clinical trials and given reasonable access to them.
- The right to untethered access to adolescent and young adult cancer specialists and, when requested, a second opinion regardless of insurance or geographic location.
- The right to access a social worker or caseworker who is well-versed in adolescent and young adult cancer specifics.
- The right to "generationally applicable" psychosocial support.
- The right to have our insurance and position as a student or employee protected by law while dealing with our cancer in order to minimize discrimination.
- The right to clear explanations regarding the long-term side effects of our disease and its treatment, and to be offered all available and applicable physical reconstruction and rehabilitation options.
- The right to have all of our treatment options explained to us in full detail, to have our questions answered, and to receive clarification when requested so that we can be an active part of our own care.

Preserve our potential.

This website has been highlighted as a "Website of Worth" in our newsletter. We will periodically highlight more websites like this in the future. If you have found a particular site helpful or relevant to your struggles as a GIST patient. Please let us know at liferaft@liferaftgroup.org.

Candidate's histories concerning healthcare

This month, we will begin looking at healthcare histories and plans of each candidate (in alphabetical order), beginning with New York Senator Hillary Clinton. **The LRG does not endorse or promote any candidate.**

Senator Clinton has had a long and complex engagement with healthcare issues.

In 1979, as Arkansas governor, Bill Clinton appointed Hillary to head his health care advisory committee to solves the problem of delivering expanded healthcare to the poorest counties in Arkansas, without lowering doctors' fees. Four rural clinics were opened very quickly, construction began on three, and the use of midwives and nurse-practitioners was expanded.

During Bill Clinton's presidency, Hillary worked on an ambitious universal health care plan that did not have as much luck and failed in the Senate.

Now Clinton is using the 90s as a base and a learning tool for another universal health care plan. Important points covered in the Clinton plan include:

• Requiring insurance companies to make no exclusions for preexisting conditions

• Avoiding of "cherry -picking" by insurance companies who pick and choose who gets healthcare

• Managing chronic diseases, using health care tax credits to help make health care affordable.

Much more information regarding Senator Clinton's healthcare plan can be viewed online. Websites of note are:

• **www.ontheissues.org**

• **www.congress.org**

Also, view our new Advocacy page at www.liferaftgroup.org/advocacy.html

Concerns raised, FDA meets on ESAs

By Elizabeth Braun
LRG Research Projects Coordinator

Erythropoetin stimulating agents (ESAs) promote the production of red blood cells by red blood stem cells. They are commonly utilized to reduce the frequency of transfusions in cancer patients. In recent months, significant concerns have been raised about ESAs, questioning whether or not the risks outweigh the benefits. ESAs include drugs such as Procrit/Eprex (epoetin alfa) and Arenesp (darbepoetin alfa). Recently, a Food & Drug Administration (FDA) advisory committee met to discuss these concerns and vote on changes regarding the ESA's.

Concern one: Early studies have shown that ESAs may stimulate specific cancers to grow more quickly or recur more frequently. These studies have included small cell lung cancer, non-small cell lung cancer, breast cancer, head and neck cancer, lymphoid cancers, and cervical cancers. With the exclusion of small cell lung cancer, all of the above listed cancers showed a worsening of disease associated with the use of ESAs. Potential adverse side-effects have not been examined for many other cancers including sarcomas.

Concern two: According to a recent study, ESAs increase the risk of venous thromboembolism (blood clots in the legs or lungs) and mortality[1]. The increased risk of thromboembolism does not completely explain the increased rate of mortality in this study.

Concern three: ESAs are frequently used off-label to improve the quality of life of cancer patients. This includes the use of ESAs to reduce cancer-associated fatigue and to increase levels of hemoglobin to as high as 13 or 14 grams as opposed to 12 grams, the level at which anemia-related symptoms are reduced[2].

The vote by the FDA advisory panel recommended the following:

• Chemotherapy-induced anemia should be an indication for the use of ESAs.

• The use of ESAs should not be limited to those cancers such small cell lung cancer which has been shown to be unaffected by ESAs.

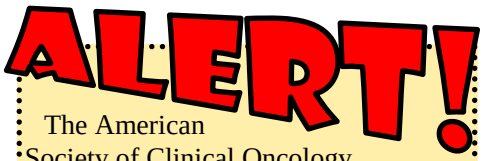
• ESAs should not be used in patients with head and neck cancer or metastatic breast cancer due to the potential increased progression.

• If a patient has a potentially curable cancer, ESAs should not be used.

• A restricted distribution system for ESAs should not be mandated.

• No recommendation was made on the hemoglobin level at which initiation ESA therapy should be considered.

For GIST patients, this means that ESAs are still available for use. Based on these recommendations, coverage of ESAs by Medicare and private insurance companies should not be affected. The effect of ESAs on GIST progression rates has not been studied. Patients and caregivers need to be aware of the potential risks and benefits when deciding whether to initiate ESA therapy.



The American Society of Clinical Oncology (ASCO) is now accepting artwork submissions for their annual "Expressions of Hope" wall calendar. All who are affected by cancer— patients, friends, families, caregivers are invited to share their emotions through art and inspire hope in others.

For list of specifications and an artwork submission form go to www.cancer.net. Click "News and Events" in the left-hand menu and then, "2009 Expressions of Hope Calendar". If you encounter any difficulties, email liferaft@liferaftgroup.org for assistance. All artwork must be submitted by **May 31, 2008**.

1. Barbara LM. Erythropoiesis Stimulating Agents: Benefits/Risks in Supportive Care of Cancer. *Current Oncology; Going Beyond Efficacy*. 2007.
2. Bennett CL, Silver SM, Djulbegovic B et al. Venous Thromboembolism and Mortality Associated With Recombinant Erythropoietin and Darbepoetin Administration for the Treatment of Cancer-Associated Anemia. *JAMA*. 2008;299:914-924.

STUDY

From Page 1

lesions, as well as the appearance of new lesions, are combined into an "overall response".

A "response" to treatment is the flip-side of progression. Instead of tumors growing by a certain amount, it is when tumors shrink by a certain amount. For RECIST criteria, to have a "partial response" the shrinkage must be at least 30 percent in the sum of the longest dimensions of target lesions.

So using a change in size of tumor, response to treatment can be described as:

• Complete response - Tumors shrink until they are no longer visible on CT scans
• Partial response – Shrinkage of more than 30 percent
• Stable disease - Ranges from shrinkage of less than 30 percent to growth of less than 20 percent
• Progression - Greater than 20 percent growth

Response (shrinkage) is often used in early studies as a "screen" to help evaluate whether a new drug or treatment is worth further studies. Response rate can also be used in larger randomized phase III trials, but it is seldom the only measurement criteria (end point). Other endpoints that are better indicators of clinical benefit include survival (the gold standard), progression-free survival (PFS) , and improvement in symptoms and/or quality of life. The most reliable and preferred endpoint is survival.

The two large phase III GIST trials both used RECIST criteria to measure tumor response. However, concerns about the use of RECIST as response criteria for GIST have been raised in the past few years. In particular, clinical benefit for GIST patients taking Gleevec does not appear to be strongly related to tumor shrinkage (response). Patients that only achieve "stable disease" as their best response have overall survival (OS) times that are just as good as those that have significant shrinkage.

One of the problems related to the use of RECIST in GIST is that tumor cell death does not always result in tumor shrinkage. In fact, a dying tumor can sometimes increase in size and this can be misinterpreted as progression. A related problem is that before starting Gleevec, existing tumors sometimes have a very similar appearance and density as surrounding tumors and are not visible (or easily missed) on CT scans. Upon successful Gleevec treatment, these tumors can start dying and become less dense. The less dense tumors now become visible on CT scans and look like new tumors.

So when considering the predictive ability of RECIST, it's method of measuring response does not appear to be very good for GIST. However, with the exception of false progression, RECIST progression criteria do seem to be a pretty good predictor of benefit for GIST patients on Gleevec. The newer "Choi criteria", which also takes tumor density into account, may prove to be a better predictor of benefit than RECIST.

The RECIST method uses (and requires) precise tumor measurements, with progression (tumor growth) being more predictive of benefit than response (tumor shrinkage).

Patient-reported progression/response data is not nearly as precise as that gathered in clinical trials. Patients may say their tumors grew, shrank, did not change in size, or they may say some tumors grew and some shrank or new tumors appeared. In general, they can not say things like, "The sum of my target lesions increased by 20 percent".

So if we look at the limited usefulness of measuring tumor shrinkage using the RECIST criteria, the inability of patients to adequately quantify shrinkage in the LRG study does not seem to be a major concern. More importantly, can they tell you if they progressed? The answer comes from the 2007 update to the LRG study.

In the 2007 update, the LRG looked at the same 169 patients from the original study in 2004. One of the major reasons for not expanding the study to include more patients was so that we could go back and look at the original 169 patients and see what happened to them.

As of December 2007, 81 percent of patients that told us their tumors had progressed by October 2004 died versus 11percent for those that had not progressed by that date. This tells us that patient-reported progression was a very good surrogate for benefit (survival is the gold standard for benefit).

Additional support for the reliability of the patient-reported data can be found by comparing the survival curves of the LRG study and the MetaGIST project. The curves are different for the first year because patients in the LRG study had to have been on Gleevec for one year, but beyond the first year the data (both PFS and OS) is very comparable (see the March 2008 LRG newsletter for details) when starting dose is used for the analysis.

See STUDY, Page 11

Mayer's work on display through April

Ellen Mayer, GIST patient, LRG member and painter has another art show to delight art connoisseurs.

Beginning on March 30, Mayer's gallery show entitled, "Evolution of the Original Eye" will solely feature Mayer's work.

A reception for this "powerful, intense and thought-provoking show" will be held from 3:00 pm to 5:00 pm on March 30 and will include a Silent Art Auction for her painting, "Abril de Santiago". However, selective art showings will run until April 30.

"The WatchTower"

Those interested in attending may go to the Jubilee Multi-Cultural Arts & Dance Center at 87 Ronald Reagan Blvd in Warwick, New York. For more information contact Jubilee Multicultural Arts, Inc. at 845-987-4207 or Judy@jubileepresents.com.

First national A.I.G. meeting held in Milan

On March 1, the first National Associazione Italiana GIST (A.I.G) meeting at the National Institute of Tumors (INT) and organized by A.I.G. founder, Anna Costato, was held in Milan, Italy.

Beginning with a celebratory "Pizza Party" on Friday night to kick off the weekend, over 100 GIST patients and caregivers met to interact and learn from GIST specialists and each other. One LRG member, Gabriella Tedone, remarked, "It was the first meeting and it was almost unbelievable to see how many people came to Milan from all over the Italy, and Italy is big!"

The first session was conducted by Dr. Paolo Casali, of INT, who discussed biological factors that give rise to GIST and its progression, new drugs and clinical trials and side effects of Gleevec and Sutent. A second session was hosted by Dr. Alessandro Gronchi, also of INT, who discussed surgical treatment for GIST.

Additionally, the INT Doctors and A.I.G. committed to working on the Italian Rare Tumor National Network in an effort to help GIST treatment.

Perhaps most importantly, relations between doctors and patients was very good with both parties leaving fulfilled, "People learned that a GIST community exists and is there to share and educate each other. They were so pleased and helped to learn of this big, caring GIST family," said Costato.

"A GIST community exists," proclaims Anna Costato, A.I.G. founder (pictured opposite, center right).

GISTers meet over pizza and discuss treatment issues at first national Italian patient meeting.

The doctor is in: common patient questions answered

By Dr. Jonathan Trent
MD Anderson Cancer Center

This is part two of a two-part series answering commonly asked questions by GIST patients. The first part can be viewed in our February 2008 issue.

A: This means that no *kit* protein was detected on your tumor cells by immunohistochemistry performed by the pathologist. I generally have the *kit* immunohistochemical test repeated and make sure that this tumor is not some other type of sarcoma. Mutation testing for *kit* and *PDGFR-alpha* may be helpful.

A: I usually recommend increasing the amount of fluids one is drinking as the initial step. I've found that drinking more water helps some but drinking sports drinks such as Gatorade or POWERade are particularly helpful. Daily calcium supplements such as calcium carbonate may also help some patients.

TRENT

A: This is currently a hot topic of considerable debate. There are no published prospective studies nor is there Federal Drug Administration (FDA) approval supporting the use of Gleevec after the patient has resection of a primary tumor (this is often called "adjuvant" or "postoperative"). However, patients with primary GIST that are at risk for recurrence should consider taking Gleevec after surgery. This is an individualized decision that takes place between a patient and their physician. When I see a patient after surgical removal of their primary GIST sometimes the patient and I decide on taking Gleevec and sometimes we don't.

TRIALS

From Page 3

Sorafenib (BAY 43-9006, 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: **U. of Chicago Cancer Res. Cent**., Chicago, IL
Telephone: 773-834-7424
Ravii Salgia, MD 773-702-4399
Sites: **City of Hope**, Duarte, Calif.
Warren Chow, MD, 626-256-4673
Norris Comp. CC (USC), Los Angeles, Calif.
Hein-Josef Lenz, MD, 323-865-3955
Univ. of Calif., Davis, Sacramento, Calif.
David Gandara, MD, 916-734-3771
Decatur Memorial Hospital, Decatur, Ill.
James Wade III, MD, 217-876-6617
Oncology/Hematology Assoc., Peoria, Ill.
John Kugler, MD, 309-671-5180
Central Illinois Hem/Onc, Springfield, Ill.
Edem Agamah, MD, 217-525-2500
Univ. of Michigan, Ann Arbor, Mich.
Memorial Sloan-Kettering CC (MSKCC), New York, N.Y.
David D'Adamo, MD, 212-639-5720
Scott Schuetze, MD 734-647-8925
Medical College of Wis., Milwaukee, Wis.
Stuart J. Wong, MD, 414-805-4603

Imatinib (Gleevec®) + Sunitinib (Sutent®)

Imatinib & sunitinib in treating GIST patients

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

Doxorubicin & Flavopiridol

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

Phase: I
Conditions: GIST/Sarcoma
Strategy: Inhibits Production of KIT
NCT#: NCT00098579
Sites: **MSKCC**, New York, N.Y.
David R. D'Adamo, MD, PhD
212-639-7573

IPI504

Safety of IPI-504 for GIST or soft tissue sarcoma

Phase: I
Conditions: GIST or Soft Tissue Sarcoma
Strategy: Destroy KIT, (HSP90)
NCT#: NCT00276302
Sites: **This Phase I trial is now closed. A Phase II trial is pending.**

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, 415-337-1754,
Sites: **Oncology Specialists**, Park Ridge, Ill.
Kathy Tolzein, RN, 847-268-8200
DFCI, Boston, Mass.
Melissa Hohos, RN, 617-632-2201

Perifosine+Sunitinib (Sutent®)

Perifosine + sunitinib for patients with advanced cancers

Phase: I
Conditions: GIST/ Renal Cancer
Strategy: Multiple Targets
NCT#: NCT00399152
Contact: Online Collaborative Oncology Group
ocogtrials@ocog.net
Telephone: Telephone:415-946-2410
Sites: Huntsville, Ala.
Tower Hem./Onc., Beverly Hills, Calif.
Pomona, Calif.
Santa Monica, Calif.
Oncology Specialists, Park Ridge, Ill.
Kathy Tolzien, RN, 847-268-8200
Kalamazoo, Mich.

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, 800-340-6843
Sites: **UCLA**, Los Angeles, Calif.
Carolyn Britten, MD., 310-825-5268
DFCI, Boston, Mass.
Melissa Hohos, RN, 617-632-2201
Stephen Hodi, MD, 617-632-5053.
Wash. University, St. Louis, Mo.
Paula Fracasso, MD, 314-362-5654
Nevada Cancer Institute, Las Vegas, Nev.
Sunil Sharma, MD, 702-822-5360

BEZ235

A Phase I/II, multi-center, open-label study of BEZ235, 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 Signaling (PI3K)
Contact: Novartis, 862-778-8300
Sites: **Nevada Cancer Inst.**, Las Vegas, Nev.
Montessa Linsangan 702-822-5282
Sarah Cannon Res. Inst., Nashville, Tenn.
Howard Burris, MD, 615-329-7274

BIIB021 (also called CNF2024)

Once or twice daily administration of BIIB021 to solid tumor subjects

Phase: I
Conditions: Advanced Solid Tumors
Strategy: Destroy KIT (HSP90)
NCT#: NCT00618735
Contact: Biogen Idec,
oncologyclinicaltrials@biogenidec.com
Sites: **Premiere Onc**., 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 signaling (PI3K)
NCT#: NCT00600275
Contact: Novartis, 800-340-6843
Sites: **Nevada CC**, Las Vegas, Nev.
Sunil Sharma, MD

CNF2024

Oral CNF2024 in advanced solid tumors

Phase: I
Conditions: Tumors/Lymphoma
Strategy: Destroy KIT, (HSP90)
NCT#: NCT00345189
Contact: Biogen Idec
oncologyclinicaltrials@biogenidec.com
Sites: Scottsdale, Ariz.
New Haven, Conn.
Cancer Therapy and Research Center, San Antonio, TX
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 signaling (PI3K)
Sites: **DFCI**, Boston, Mass.
Melissa Hohos, RN, 617 632-2201

LBH589

Phase IA, two-arm, multicenter, dose-escalating study administered by IV on two dose schedules in adult patients with advanced solid tumors and non-Hodgkin's lymphoma

Phase: I
Conditions: Advanced Solid Tumors / Lymphoma
Strategy: Destroy KIT, Inhibit Cell Cycle, Induce Apoptosis
Contact: **Nevada Cancer Institute**, Las Vegas, Nev.
Donna Adkins, RN
Telephone: 702-822-5173

See TRIALS, Page 9

ALICE SULKOWSKI JUST CELEBRATED HER 20TH PET SCAN...

...And she's stable! Sulkowski (center) holds the record for number of PET scans at Mountain States Health Alliance, in Johnson City, Tennessee. Pictured with Alice are Darlene Blackhurst (left) and Diane Cohee (right), her trusted PET scan technologists.

Just passed your own GIST milestone? Email us at liferaft@liferaftgroup.org and you may see *your* name in print.

Editor's Note

While every effort has been made to list trials by phase, strategy and alphabetical order, position changes are unfortunately necessary when editing. We want to remind our readers that no special priority has been given to any clinical trial.

TRIALS

From Page 3

KOS-1022

Oral drug in patients with advanced solid tumors

Phase: I
Conditions: Advanced Solid Tumors
Strategy: Destroy KIT (HSP90)
Study#: COMIRB 05-0627
Contact: ***Drug development stopped (see page 3)**

OSI-930

Phase I dose escalation study of daily oral OSI-930 in patients with advanced solid tumors

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

MP470

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

Phase: I
Conditions: Solid Tumor/Lymphoma
Strategy: Multiple Targets
NCT#: NCT00504205
Sites: **Virginia Piper CC**, Scottsdale, Ariz.
Raoul Tibes, MD, 480-323-1350
S. TX Accelerated Research Therapeutics,
San Antonio, TX
Anthony Tolcher, MD, 210-593-5255

Perifosine+Sorafenib

Phase I study of Perifosine + Sorafenib for patients with advanced cancers

Phase: I
Conditions: Renal Cancer/Tumors
Strategy: KIT downstream targets, Multiple targets
NCT#: NCT00398814
Contact: ***GIST patients are no longer being accrued (See page 3).**

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

SF1126

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

Phase: I
Conditions: Solid Tumors
Strategy: Target KIT downstream signaling (PI3K)
Contact: Semaphore Pharmaceuticals,
Ullrich Schwertschlag, 978-257-1926,
ullrich@semaforepharma.com
Sites: **Arizona CC**, Tucson, Ariz.
Daruka Mahadevan, MD, 520-626-0191
Indiana University CC, Indianappolis, Ind.
Elena Chiorean, MD, 317-278-6942

SNX-5422

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#: NCT 00506805
Contact: Catherine A. Ross, 919-376-1330
Sites: **TGen Clin. Res. Services,** Scottsdale, AZ
Joyce Ingold, RN 480-323-1339
Ramesh Ramanathan, MD
Sarah Cannon Res. Inst., Nashville, Tenn.

XL147

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

Phase: I
Conditions: Cancer
Strategy: Target KIT downstream signaling
NCT#: NCT00486135
Sites: **DFCI**, Boston, Mass.
Pilar de la Rocha Mur, 617-632-5841
Mary Crowley Med. Res. Center, Dallas, TX
J. R. Dolan, 214-658-1943

XL765

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

Phase: I
Conditions: Cancer
Strategy: Target KIT downstream signaling
NCT#: NCT 00485719
Sites: **Karmanos Cancer Institute**,
Detroit, Mich.
Theresa Laeder, 313-576-9386
Pat LoRusso, MD
S. TX Accelerated Research Therapeutics,
San Antonio, TX
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 NJ**, New Brunswick, NJ
Pamela Scott, 732-235-7459
Mark Stein, MD
Cancer Therapy and Res. Center,
San Antonio, TX
Pat O'Rourke, 210-616-5976
Alain C. Mita, MD

REBIRTH

From Page 1

free of charge, Secnazi had to negotiate a deal with Allergan, makers of Botox and Juvederm; they will provide the products for a period of two years, "It was hard and long, but they accepted." Patients will be received by the doctors on the last Saturday of each month, with about 12-15 patients being seen a day.

While the program may seem geared for the ladies, patients of both sexes are welcome. "We know that women show a bigger interest for that particular kind of treatment than men do. Yet, the recruiting of our patients will only be based on social and medical criteria," says Secnazi.

I asked Estelle despite the obvious physical change she has experienced, what emotional and psychological changes has she felt as a participant in the Renaissance program?

"The first thing I can say is that the physical change and the internal feeling are intimately linked.

When you have such a serious disease and you are under treatment, there are so many good reasons why you can doubt yourself as a woman. Your femininity is regularly suffering hardships because of the various treatment side-effects (which don't really make you feel glamorous) and/or the scars you might have from your surgeries. Sometimes, you look at yourself in the mirror and realize that your body looks like a battlefield. In general, women tend not to be plainly satisfied by their physical appearance. This is even more true when this body has been traumatized by the consequences of a disease. This terrible vision of yourself often brings additional psychological suffering. Yet, you have to cope with it!

I think that one of the major fears women have at the very beginning of a disease is one of losing their femininity, which also means the fear of losing their powers of seduction because, as a matter of fact, cancer treatment doesn't make you beautiful! Suddenly, the vision of yourself changes in the eye of others. Some women fear they will not be desired by their husband anymore; young women like me may fear they will not be able to seduce anyone for the rest of their lives. I personally think our powers of seductiveness are definitely a kind of internal strength which can give you the "fighting spirit" because being desired by someone is really a part of what makes you feel alive as a woman.

To me, taking care of myself has always been an important part of my fight against GIST, a way to tell people that I'm not only a patient but a woman first. This is the way I want to be looked at and considered. It's also an indirect way to say that I still believe in the future.

During the French national information campaign I participated in last year, my favorite motto was, "I don't want to be a pajama patient." I sincerely think that if I was to become that kind of person, then this would clearly mean that I would have given up the fight.

Lecointe's first "Rebirth".

Looking like a normal woman, being able to seduce anyone I want, being able to merge into the crowd like any other person without being identified as sick is something really important to me as it allows me to remain socially integrated.

Yet, looking fine and beautiful is not always an easy thing to do even though it's also a matter of social survival. Cancer has made us lose all our marks, our joy, our self-confidence and effortlessness. Looking fine can really require an important effort from a psychological point of view. It's a good thing some people like these two doctors have realized this and wish to help us to regain this self-confidence.

See REBIRTH, Page 14

STUDY

From Page 6

The following are some other common questions regarding the 2007 LRG study:

Question: Why were patients with stable disease excluded from the LRG study?

Answer: Because of the limitations of patient-reported data. At the time of the original study (2003/2004), there was some question in our mind about how well these patients were responding to Gleevec. Were they truly responding, or did they just have slow-growing disease that mimicked a response?

Because of the limitations that patients have in reporting very small changes in tumor size and because at the time of the original study we were only looking at PFS and not OS, we were concerned that we might not be able to adequately distinguish between those responding and those progressing.

In 2008, due to the efforts of the GIST medical community, we know a lot more about stable disease. It would be interesting to expand the LRG dataset and look at more patients including those with stable disease.

Q: Why are the median PFS and median OS times so much longer than seen in the phase III trials?

A: About 15 percent of GIST patients do not respond to Gleevec. These patients will typically have progression fairly early, usually within the first six months or so. This is called "primary resistance". Because our study design required patients to be on Gleevec for at least one year, it eliminated patients with primary resistance. By removing those that never respond to Gleevec, it restricts the study to those most likely to benefit from Gleevec (except for stable patients which are discussed separately). This increases both median PFS and median OS. All of the randomized trials include all patients, including those with primary resistance and stable disease.

Q: Which PFS and OS data is more likely to apply to me; the LRG data or the MetaGIST data?

A: All patients are individuals and will have unique characteristics that help define how well they will respond to therapy. When looking at how well someone is likely to respond, the most important variable is probably mutation type, but there are other factors. In contrast to the MetaGIST data, our data, which is preliminary, suggests dose may be a significant factor as well. The preliminary data presented by Dr. George Demetri at 2008 Gastrointestinal American Society for Clinical Oncologists (ASCO) meeting suggests that Gleevec drug levels may be a significant factor as well. Of course there will be a general relationship between dose and drug concentrations and it remains to be seen which is more important.

I think an important point to consider is that when patients with primary resistance are included in an analysis, it "drags down" the average (or more accurately, the "median"). So when a patient that has been on Gleevec for one year looks at the MetaGIST "median PFS" data, they conclude that they can only expect another seven to 11 months of PFS. However, the benefit that this patient can "expect" is probably higher than this (on average) and probably more closely matches the benefit shown by the LRG data.

To simplify, if a patient meets the criteria of the LRG study; that is, on Gleevec for one year with some initial shrinkage, then the median PFS and OS times shown by the LRG data may be a better predictor than those of the MetaGIST data. For patients just starting Gleevec, the MetaGIST data may more accurately reflect the median PFS and OS times, at least until they get beyond one year on Gleevec.

Even more importantly, we must always remember that each patient is different and statistics apply to groups of patients, not individual patients. Interested readers might want to read an excellent article on applying statistics to their situation. It is called "The Median isn't the Message" and was written by Stephen Jay Gould. Gould was a 20-year survivor of Mesothelioma, a type of cancer with a "median survival" of eight months at the time of Gould's diagnosis.

Q: I am taking 400 mg of Gleevec to prevent a recurrence. Based on the LRG study, should I be taking more?

A: Neither the LRG study or any other study has looked at the question of higher doses for adjuvant (preventative) treatment. So we don't know the answer to that question.

The biggest concern here might be for those with exon 9 mutations. These seem to exhibit a "primary resistance" type of behavior at the standard 400 mg dose. So what happens to these GIST tumor cells if they are exposed to subtherapeutic drug levels for a year? I am concerned that this may be doing more harm than good for exon 9 patients.

Global GIST Network adds new GIST representatives

Global GIST-Network

Colombia
Rafael Vega
ravega63@yahoo.es

Pakistan
Muhammad Shahid Rafique
sr_srs@yahoo.com

Abigail case denied: Court rules against patients' right to choose

By Erin Kristoff
LRG Newsletter Editor

The legal battle that had been waged by the Abigail Alliance since 2003 ended abruptly on January 14 when the Supreme Court refused to hear the appeal by the patient advocates.

Currently, it is illegal for a drug maker to sell unapproved drugs under the Food & Drug Administration's (FDA) policy.

The Alliance argued that terminally ill patients who have run out of options have a constitutional right to try experimental drugs without FDA approval. The plaintiffs cited "due process", saying that it was the patient's right to choose to take medication of unknown benefit or risk that may save their life. According to the appeal, "If a patient has a right to refuse all treatment and die, surely she also had a right to assume some risks in a good faith attempt to save her own life."

Due process- the principle that the government must respect all of a person's legal rights instead of some or most of those legal rights when the government deprives a person of *life,* liberty, or property

The Abigail Alliance was founded by Frank, the father of Abigail Burroughs, who died at the age of 21 waiting and fighting for a cancer drug that had not been approved by the FDA. Three years later, that drug was approved. Her father and friends continue her fight now in her memory.


BURROUGHS

The FDA contended that the suit would have radically altered the process of clinical cancer research. It would have given terminally ill patients practically unregulated legal access to experimental drugs. The FDA argued that these patients, would then have little incentive to enter Phase II and III clinical trials, which are used to determine the side effects and efficacy of new drugs. This could greatly affect all cancer patients.

Originally, a federal district judge dismissed the Alliance's case, but in May 2006, a court of appeals in Washington DC voted two to one in favor of the plaintiffs. The FDA then urged the Court of Appeals rehear the case.

The America Society of Clinical Oncology (ASCO) along with National Coalition for Cancer Survivorship (NCCS) and the Association of American Medical Colleges (AAMC) filed an *amicus* brief supporting the FDA's position. Stating that they were, "deeply disturbed by the panel's decision...because establishment of the individual "right" sought by appellants will not only pose unreasonable risk to individual patients but also threaten the cancer clinical trial system as it currently exists." The parties followed this statement by citing a National Cancer Institute (NCI) *Cancer Trends Progress Report* and asserting, "It is only though clinical trials that we are beginning to see tangible results in progress against cancer." In August 2007, a full appeals court reversed the panel's decision by an eight to two vote.

***Amicus* brief- A document filed in a legal proceeding by an interested party who is not directly part of the case**

This appeal by the Alliance to the Supreme Court was the final step in the case.

For more information, please go to www.abigail-alliance.org.

Did you Know...

...You can subscribe to our YouTube page?

The Life Raft Group uploads various videos to YouTube, such as a speech by Dr. Dan Vasella at the 2006 Life Fest meeting and a discussion of patient registries by Dr. Charles Blanke. By subscribing you can be notified when the LRG adds new videos.
Just click the orange "Subscribe" button either on the main video page or at the Life Raft Group's user page: www.youtube.com/user/LifeRaftGroup.

Did you Hear...

...The "Group Room"?

"The Group Room", which was launched in 1996, is a live, call-in radio talk show, broadcast on Sundays and dedicated to cancer.
Listeners can tune in from 4:00 pm to 6:00 pm ET and 1:00 pm to 3:00 pm PT on select stations across the United States, XM satellite radio, podcast and online at www.vitaloptions.org. Callers can also participate in on-air discussions through the toll-free hotline at 800-477-7666 (foreign access numbers for international listeners are listed on the website), and are invited to e-mail their questions and comments to info@vitaloptions.org. All show and feature interviews are also archived for later listening.

Two hours each week provide people with an opportunity to teach, learn and speak about the cancer experience from the privacy of their own home, automobile or hospital. For more information and to find a radio station near you, visit www.vitaloptions.org.

FUQUA

From Page 2

The radioactive material doctors administer to Fuqua for the PET scan usually makes him woozy for a day or two, but there aren't any ill effects beside a limitation on physical activity for a few days, said Kanya Pannell, Fuqua's mother.

But, in October 2007, the doctors saw something. Cancerous tumors, 23 of them, grew in Fuqua's stomach.

He needed surgery.

Surgery is one of the few options to treat GIST, and it's the only option Fuqua has taken. The tumors resist chemotherapy.

One month after Fuqua found out he had cancer for a third time, he spent five days in a hospital bed recovering from the late November procedure to remove 23 tumors. His doctors considered the recovery exceptionally quick. Normally, it takes more than a week before patients can be released from the hospital after the surgery.

Fuqua continued fighting through his recovery once he went home, wanting to return to the track team sometime during the winter season.

"His drive is amazing," Pannell said. "Despite his illness, he doesn't miss practice. He fights me when I tell him he has to miss an exam or practice. He doesn't want to let his team down."

He sat out six weeks before returning to practice. Fuqua didn't ease in; he went straight for the hurdles despite still feeling sore from the surgery.

He ran the 400-meter dash in 53 seconds in a meet against Hopewell Valley a few days later on Jan. 29. Then on Feb. 3, he set the school record in the 55-meter hurdles at the county championship and won an award for courage.

"You hear about a student that had abdominal surgery to remove 23 tumors, and you can't imagine that being a simple thing," O'Neal said. "But I think a lot of that is just his heart, his determination."

Nothing is really simple in Fuqua's battle with GIST, especially not the disease itself.

Not much is known about GIST except that it defies a lot of conventional thinking about cancer. Most cancers form in the inner lining of organs, called the epithelia. Gastrointestinal stromal tumors, meanwhile, occur in the muscle layer of organs and even appear to be a normal part of the muscle. It's difficult to detect GIST, and it's almost impossible to do so in children, said August, who also is a professor of surgery at Robert Wood Johnson Medical School.

So it's easy to understand Pannell's confusion in 2002 when she noticed the stomach of her 12-year-old son beginning to swell. At first, she passed it off as bloating from indigestion. But when Fuqua's stomach continued to swell gradually during the course of a month, she knew something was not right.

Doctors at the emergency room in Princeton's University Medical Center discovered the swelling was not due to indigestion; there were two tumors on the sixth grader's stomach.

He underwent emergency surgery at Bristol-Myers Squibb Children's Hospital in New Brunswick. There, doctors revealed the tumors were cancerous.

Fuqua still does not know why he developed the tumors initially. The reoccurrences in 2004 and 2007 are most likely because microscopic tumors went undiagnosed and weren't removed during surgery. Microscopic tumors are so minute they are impossible to find, August said.

"There's no known cause of these, and we have no known risk factors," August said. "The way I look at it is, unfortunately, it's bad luck. Some people say you're challenged in this life up to your ability to handle it. From what I know about this young man, I can't express enough my admiration for all the hardship he's gone through and what he's achieved."

Fuqua said he doesn't believe in bad luck, and he certainly won't quit because things haven't always gone his way.

While he's not sure if he'll ever be completely cancer-free, he continues to work toward his goals.

He wants the Lawrence High relay team to qualify for June's national outdoor track championship in Greensboro, N.C. He wants to run in college — he's been in touch with the coaching staff at Manhattan College — and major in engineering.

And more than anything, if he's going to be in the public eye, Fuqua wants to be known for his accomplishments. Cancer will not define him.

Maybe that explains his quicker-than-expected release from the hospital in November or his state meet performance in February. Because even if Fuqua won't acknowledge the trials GIST presented him, a 400-meter race — even with hurdles — doesn't seem quite as challenging after that.

"I'm just extremely hard-working," Fuqua said. "I don't like to give up. I don't like losing at anything, no matter what it is."

If you would like to leave a comment for Chandell visit lawrencespace.com.

Rafters in Ohio meet

On February 16, LRG members from Ohio met at the home of Kaye Thompson to discuss individual problems, upcoming trials and other issues facing GIST patients. "We welcomed a new GISTers to our group, Kathyrn Leach. It is so nice to meet and talk with other GISTers," said Thompson. The next meeting is scheduled for June 14, 2008.

From left to right, seated: Mary Netting, Kaye Thompson, Susan Arnoczky
Standing: Clark Davis, Terry Thompson, Kathyrn Leach.

REBIRTH

From Page 1

"I looked at my face in the mirror and saw that I was beaming"

When you're diagnosed with a life-threatening disease, the only thing that logically suddenly matters is survival. Nevertheless, if you don't try to give your life a chance by taking care of yourself and by trying to live a life as normal as possible, then you will offer to the people around you the limited vision of a sick person. Personally, this would be the worst thing that could happen to me.

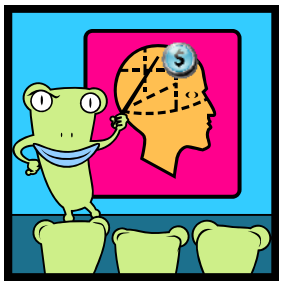
Once I had had my botox injections, I looked at my face in the mirror and saw that I was beaming. Believe me, it's been like a second breath to me. It made me think that okay, I had cancer but I could look fine and beautiful like any other woman around me. Everything seemed possible again. I was not a patient anymore, I was just this woman in the mirror, with a large smile upon her face. I immediately regained self-confidence. This is precisely the reason why I want to support this program. Because if it's been good for me, it's going to be good for other women. The major interest of the "Renaissance" program is that it allows sick women to escape from their patient condition for a moment to simply become women. There is absolutely no reason why beauty should be the privilege of healthy people because for us, beauty is also a matter of social survival. These two doctors perfectly understand this.

According to Dr. Runge, "The aim of the "Renaissance" program is neither to treat cancer nor to cure it. The aim is to help women to reconstruct themselves after difficult moments. Regaining their femininity and self-confidence is definitely the priority."

Placebo effect: can a $2.50 placebo work better than one worth 10¢?

According to a new study done at Duke University, a 10-cent pill doesn't alleviate pain as well as one costing $2.50 pill, even when they are identical placebos.

Sounds a little strange, right?



Researchers at Duke used a standard protocol for administering light electric shock to participants' wrists to measure their subjective rating of pain. These shocks were given before and after the 82 study subjects took the placebo.

Researchers introduced the cost factor by giving half the participants a brochure describing the pill as a newly-approved painkiller which cost $2.50 per dose. The other half received a brochure describing it as marked down to 10 cents.

Eighty-five percent of subjects in the full-price group experienced a reduction in pain after taking the placebo. In the low-price group, 61 percent said the pain was less. This result brings up a host of larger questions, said the researchers in the *Journal of the American Medical Association.*

"Physicians want to think it's the medicine and not their enthusiasm about a particular drug that makes a drug more therapeutically effective, but now we really have to worry about the nuances of interaction between patients and physicians," said Dan Ariely, a behavioral economist at Duke University.

Ariely said the results fit with existing data about how people perceive quality and how they anticipate therapeutic effects. Perhaps more interesting is the combination of the price-sensitive consumer expectation with the well-known placebo effect of being told a pill works. "The placebo effect is one of the most fascinating, least harnessed forces in the universe," he noted. At the very least, doctors should use their enthusiasm for a medication as part of the therapy. "They [doctors] have a huge potential to use these quality cues to be more effective," Ariely said.

Source: Duke University

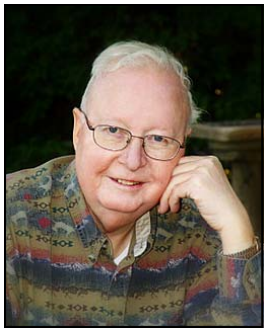
Canada rafters meet!

The Canadian branch of the Life Raft Group held a gathering on Saturday, March 1 at the Four Points Sheraton hotel in London, Ontario. About 30 patients and caregivers attended. David Josephy, the Canada country representative for LRG, provided an update and overview of LRG resources and initiatives. He also gave a brief presentation of the ongoing LRG Gleevec dose study. Dr. Jawaid Younus gave a talk providing a medical introduction to GIST diagnosis and treatment. A particular success of the meeting was that almost all of the attendees were new to the Life Raft Group, so this meeting provides a great opportunity for growth of the Canadian branch.

The group hopes to hold another meeting within the next few months. LRG Canada wants to thank Dr. Younus and our Novartis Canada contacts, Jennifer Burton and Zonia Wasik, for making the meeting a success.

Gerald & Deanne got 45 happy years

Due to random error, Gerald Snodgrass's obituary was not included in the LRG January newsletter. We would like to include it now because it is never too late to remember a dear friend.



SNODGRASS

Gerald Eugene Snodgrass passed away peacefully at his Renton, WA home on Thursday, Nov. 15, 2007 at the age of 70. For over seven years he courageously battled GIST. Born Oct. 5, 1957 to loving and goodly parents, Glenn and Dorothy Snodgrass, he grew up in Yakima, WA. He graduated from the University of Washington in 1962 with a degree in Electrical Engineering and began a 36 year career with The Boeing Co. He was highly respected in his career and worked on many programs ranging from the Minuteman Missile program to the 777 commercial airplane.

On Oct. 20, 1963 he married Deanne Fye and settled down to a happy family life. This year Gerald and Deanne celebrated their 45th wedding anniversary. Together with their two children, Layne Snodgrass (wife Gena) of Kent, WA and Julie Herlin (husband, Bob) of South Jordan, UT, they enjoyed hiking and camping, water activities, and just being together. Gerald was a skilled woodworker and his home is filled with fine furniture he crafted. He could fix anything and everything and always kept the cars running and their home in excellent condition. He was kind, caring, gentle, hard working, and compassionate.

In addition to his wife and children, he is survived by seven grandchildren and one great grandchild and sister Glenda Jensen of Yakima, WA. He loved his Heavenly Father and Jesus Christ and knew that life is eternal and that families can be together forever. A memorial service with a reception following was held at the Church of Jesus Christ of Latter-day Saints on Friday, Nov 23rd. Burial was in Bickleton, WA. Gerald will be missed but not forgotten by all who knew and loved him.

NY/NJ GISTers meet

On February 16, LRG members (and a few staff members) from the New York and New Jersey area met at Gilda's Club in Hackensack, NJ. Organized by LRG NY/NJ local group leader, Anita Getler, the meeting was a tremendous success. "It was great to share stories and learn more about this battle we are all fighting and WILL WIN! It is like having an extended family we can all relate to when we are together....so much support and camaraderie. Gilda's Club was so accommodating and pleased that we used their facility, " said Getler. Another meeting may be as soon as late spring.

Drum roll please...

Arnie Kwart's total amount of dollars raised for the Life Raft Group has finally reached a Grand Total. In the most spectacular fundraising effort in LRG history, Dr. Arnold Kwart, LRG board member and GIST patient raised over **$120,000**! Congratulations and thank you Arnie! Support and generosity such as yours keeps the Life Raft "afloat".

Mark your calendars!

- The Wellness Community and the Lance Armstrong Foundation present, "Live Well! Life Beyond Cancer," at multiple locations throughout **April**. The workshop is focused on helping survivors transition from active treatment to post-treatment care. See www.thewellnesscommunity.org/education/live_well/index.php for more information.
- The National Cancer Institute's Office of Cancer Survivorship will hold a cancer telephone education workshop series, "Living With, Through & Beyond Cancer," on **April 22**, **May 13** and **June 24**. Visit http://dccps.nci.nih.gov/ocs/conf-meetings.html for further information.
- A regional "Midwest" meeting will be held in St. Louis, Mo. on **April 26**. Visit http://gistlouis.blogspot.com for more information.
- The NIH Pediatric GIST clinic is scheduled to begin on **June 19**. Please see February 2008 issue for more details.
- The GIST Cancer Research Fund have begun their check presentations, the next event is **April 2** at Fox Chase Cancer Center in Philadelphia, Penn. Followed by the University Of Pittsburgh Cancer Institute on **April 14**, Dana Farber in Boston on **April 30** and Oregon Health & Science University in Portland, Ore. on **May 14-15**. Visit www.gistinfo.org for more detailed information.

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