Battling gastrointestinal stromal tumor

LIFE RAFT GROUP

March 2009 | In memory of Dan Wiseman, Berthe Gowdy, Dennis Janz, Ellen Heppler & Fatima Ouassini | Vol 10, No. 3

Eleven year-old battles GIST with brave face for six years

By Jodie & Patrick Brennan
LRG member

Brittany is a five and a half year GIST survivor.

At the age of five, Brittany became anemic due to internal bleeding that was caused by an ulcerated tumor in her stomach. She was admitted to The Hospital for Sick Children where she underwent a ten hour surgery to remove the tumors. During this surgery, they removed 75 percent of her stomach and reworked the layout of her gastrointestinal tack.

BRENNAN (age 5)

Over two years later, when Brittany

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Better monitoring for Sutent-related heart problems may be warranted

By Jerry Call
LRG Science Coordinator

Reviews of patients treated at three major cancer centers suggest that Sutent-related heart problems may be more common than initially reported. Reports of heart failure ranged from eight percent in 75 GIST patients treated at Dana Farber Cancer Institute, to 15 percent in 48 patients treated at Stanford University Cancer Center. High blood pressure (hypertension) was cited by each study as a possible contributing factor to heart damage. A ten percent or greater reduction in left ventricular ejection fraction (LVEF) was noted in 28 percent of the Dana-Farber patients. In comparison, the Sutent (sunitinib) prescribing information reports 11 percent of patients had reduced LVEF in the Phase III registration trial. LVEF is one measure of how efficiently the heart is working.

In January 2006, Sutent was approved for renal cell carcinoma and Gleevec (imatinib)-resistant GIST. To date, over 33,000 pa-

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New developments in gene expression profiling

By Matt van de Rijn
LRG Research Team member
Stanford University

There are many types of cancer that can affect humans; they can arise in many different organs and from many different cell types within these organs. GIST is a relatively rare type of malignancy that arises from cells within the muscle wall of the digestive tract. Despite the wide variety of tumor types that exist in human pathology, what they all have in common is that once a tumor has originated somewhere within the body, it can start growing in a destructive manner. A major discriminating feature of malignant cells compared to benign cells is that they can grow in an unrestricted manner and can form metastases throughout the body. One of the ways to study cancer is by looking at the manner in which malignant cells differ from benign cells in the proteins that they express.

VAN DE RIJN

To take a step back, the human body consists of cells where the genetic information resides in the nucleus in the form of DNA. This DNA encodes for about twenty-thousand different genes. Each gene can be "transcribed" into a unique mRNA that in its turn is "translated" into the specific protein for which that gene carries the genetic code. The proteins are the actual building blocks of the cells and determine to a great extent the behavior of the cells, including the malignant behavior seen in cancer cells. Here I would like to describe some of the new technologies that have been developed in the past years that will allow for a much more detailed analysis of the repertoire of proteins that are expressed by GIST cells.

In the past the expression levels of proteins encoded by individual genes had to be examined one gene at a time using laborious techniques. In the April 2007 issue of this newsletter, I described how a new technique (developed in 1995

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Italian GISTers gather en masse for the second time, drug options and adjuvant therapy among key topics

By Gabriella Tedone
Associazione Italiana GIST

On the February 21, the A.I.G. (Associazione Italiana GIST) held its second annual General Meeting at the NCI (Istituto Dei Tumori) in Milan, Italy. The event was fabulous, and we had a great turn out. Patients and caregivers benefited from the information about GIST treatments, medical therapy in advanced disease, side-effects management, drug interactions, role of imaging, stress management of GIST patients and social problems like health insurance, work problems and the cancer patient's legal rights.

Another positive aspect of the event was discovering how well-informed Italian GISTers are about their disease, and Dr. Paolo Casali (Head of the Adult Sarcoma Medical Unit at NCI-Milan) highlighted how the patient community worldwide plays an outstanding role in claiming patient's rights and even in conducting research.

Some of the topics of focus were:

- Drugs for GIST (approved drugs/off label drugs/new trials)
- Gleevec plasma testing
- Gleevec as adjuvant therapy
- Imatinib, Sunitinib, Nilotinib, RAD001, PKT787, Sorafenib, Dasatinib, Perifosine, Masitinib, PKC412, IPI504 (will be activated as a phase III trial in the near future).
- The European Medicines Agency is about to examine Gleevec as adjuvant therapy. According to Dr. Casali, there is currently a European study to establish the time to secondary resistance. In the last decade, GIST has been redefined and in a few months we will have the data of the retrospective study concerning the natural history of this disease, based on the molecular analysis of a thousand patients.

CASALI

It was very pleasant for all of the GISTers to meet each other, who we have known through our forum. We also spent a wonderful evening before the event having a nice pizza party.

The Life Raft Group

Who are we, what do we do?

The Life Raft Group (LRG) directs research to find a cure for a rare cancer and help those affected through support and advocacy until we do. The LRG provides support, information and assistance to patients and families with a rare cancer called Gastrointestinal Stromal Tumor (GIST). The LRG achieves this by providing an online community for patients and caregivers, supporting local in-person meetings, patient education through monthly newsletters and webcasts, one-on-one patient consultations, and most importantly, managing a major research project to find the cure for GIST.

How to help

Donations to The Life Raft Group, a 501(c)(3) nonprofit organization, are tax deductible in the United States.
You can donate by **credit card** at www.liferaftgroup.org/donate.htm or by sending a **check** 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. Please advise Erin Kristoff, the Newsletter Editor, at ekristoff @liferaftgroup.org of any errors.

A few of the Italian GISTer smile for the camera at a pizza party the night before the 2nd annual general meeting in Milan.

March 2009 international clinical trials update

By Jim Hughes
LRG Clinical Trials Coordinator

International

Surgery or Imatinib Phase 2: Two new Phase II trials have opened for GIST at multiple locations in Japan. Both are sponsored by Niigata University Medical and Dental Hospital. There are approximately 30 sites for each trial. So we have only listed contact information for the Principal Investigator in Niigata. Together, the two trials plan to accrue over 80 GIST patients. Patients may have up to three liver metastases that are clinically judged to be surgically resectable without residual macroscopic disease, but patients with recurrence or metastases outside the liver are excluded. The studies will measure recurrence-free survival. The Principal Investigator in Niigata is: Tatsuo Kanda, MD, 81-25-227-2228. Trial titles are: *"Surgery in Treating Patients With Liver Metastasis From a Gastrointestinal Stromal Tumor – Phase 2"* and *"Imatinib Mesylate in Treating Patients With Liver Metastasis From a Gastrointestinal Stromal Tumor – Phase 2"*

Sunitinib Phase IV: A Phase IV trial of Sunitinib, sponsored by manufacturer, Pfizer, for advanced GIST has recently opened in China. Accrual plans call for 60 patients and a primary end point of progression-free survival. Patients must have failed or be intolerant of imatinib. Three sites are recruiting, two in Beijing and one in Nanjing. The trial title is: *"Safety And Efficacy Study Of Sunitinib Malate In Chinese Patients With Imatinib Resistant Or Intolerant Malignant Gastrointestinal Stromal Tumor (GIST) – Phase 4"*

Masitinib Phase III: A phase III trial of Masitinib (AB1010) versus Imatinib in the first line is now recruiting internationally. The trial is sponsored by the manufacturer AB Science. This is a first-line trial for newly diagnosed GIST patients who have not received prior TKI therapy, but may have had adjuvant Imatinib. Patients must be either non-resectable or must have a recurrence after prior surgery. Patients will be randomized to receive either Masitinib 7.5 mg/kg or Imatinib 400 or 600 mg daily. Plans call for accrual of 222 patients and a primary end point of progression free survival. There are 14 sites in France, three in the United States and six in Lebanon currently recruiting. A single contact point is provided: Antoine Adenis, M.D., +33 (0)3 20 29 59 59, a-adenis@o-lambret.fr. The trial title is: *"Efficacy and Safety of Masitinib (AB1010) in Comparison to Imatinib in Patients With Gastro-Intestinal Stromal Tumour"*

United States

IPI-504 Phase III: In the United States a new site has opened for the IPI-504 Phase III trial in GIST. Recruiting has begun at St. Vincent's Comprehensive Cancer Center in New York City. The contact is the Principal Investigator, Gerald Rosen at 212-604-6020. Contact information is also now available for the two sites in Australia. See the listing below.

IPI-504

Study of IPI-504 in GIST patients following failure of at least imatinib or sunitinib

Phase: III
Conditions: GIST
Strategy: Destroy KIT
NCT#: NCT00688766
Contact: GIST Phase 3 Team, 877-504-4634, RINGtrialinfo@infi.com
Sites: **Flinders Medical Center**, Bedford Park, SA, Australia +08 8204 4830
Ashford Cancer Center, Ashford, SA, Australia +08 8351 0211

Masitinib (AB1010)

Efficacy & safety study of masitinib compared to imatinib in GIST patients

Phase: III
Conditions: GIST
Strategy: Block KIT
NCT#: NCT00812240
Contact: Antoine Adenis, MD a-adenis@o-lambret.fr
Telephone: +33 (0)3 20 29 59 59
Sites: See www.liferaftgroup.org/treat_trials.html for site info

Imatinib (Glivec) or Sunitinib (Sutent)

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

Phase: III
Conditions: GIST
Strategy: Block KIT
NCT#: NCT00372567
Contact: Pfizer Oncology Clinical Trial Information Service Pfizercancertrials@emergingmed.com
Telephone: 1-877-369-9753
Sites: See www.liferaftgroup.org/treat_trials.html for site info

AMN107 (Tasigna, Nilotinib)

Treatment of metastatic or unresectable GIST patients in first line

Phase: II
Conditions: GIST
Strategy: Block KIT
NCT#: NCT00756509
Telephone: +41 61 324 111
Sites: Bad Saarow, Germany

Study to the optimal duration of therapy with oral angiogenesis inhibitors

Phase: IV
Conditions: GIST
Strategy: Block tumor blood vessel growth
NCT#: NCT00777504
Contact: C.M.L. van Herpen, MD 31 24 3610353
Sites: **Univ. Medical Center, Njmegen st Raboud,** Njmegen, Gelderland Netherlands

Sunitinib

Safety & efficacy study in imatinib-resistant or intolerant-malignant Chinese patients

Phase: IV
Conditions: GIST
Strategy: Block KIT
NCT#: NCT00793871
Contact: Pfizer Oncology Clinical Trial Information Service Pfizercancertrials@emergingmed.com
Telephone: 1-877-369-9753
Sites: Beijing, Nanjing

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Spanish-speaking GISTers create an online home for themselves

By Vicky Ossio
LRG Latin America Representative

Some of our GIST friends might think it was fortunate that my daughter Carolina was diagnosed with GIST in the United States. The truth is that she, like so many GISTers in America and internationally, was actually misdiagnosed, but it is fortunate that she lives in the United States where she has insurance to help her pay for her treatment.

The true best thing in this terrible and difficult process is as a caregiver I can speak English. Because of this, I found the Life Raft Group and all the information and support we needed to define my daughter's best possible treatment.

This was three years ago. At that time, I could not find any other GIST patient in my country, Bolivia. I found one in Colombia and immediately contacted him. Shortly after, I learned of another one in Uruguay.

Later, I found other patients in other Spanish speaking countries. All of these people had one thing in common: Almost no access to GIST information in Spanish, and therefore, incorrect treatments, avoidable surgeries, and even early death.


OSSIO

As a group of Spanish-speaking people, we understood that the most powerful tool against this disease was information, and decided to create a listserv (email group) in Spanish.

We are very proud to officially announce that our Spanish email community has been running since January 6, 2009. Most Spanish-speaking patients are not used to communicating and being part of support groups, but nevertheless, our listserv is starting to give important information to our members and gradually increase membership and participation. We have already translated some pamphlets and articles, and answered many questions that our Spanish-speaking patients have.

Our goal is to reach patients in all Spanish-speaking countries to create a wide-reaching network of support, and together fight against the disease in every possible way.

To join the Latin American email community, send an email to lrg-en-latinoamerica@googlegroups.com or by going to http://groups.google.com/group/lrg-en-latinoamerica

Cancer terms in Spanish

Our friends at Cancer.net have put together a four-part series which explains frequently used terms throughout all stages of cancer treatment: basic oncology terms (términos oncológicos básicos), newly diagnosed (nuevo diagnóstico),during treatment (durante el tratamiento), and after treatment (después del tratamiento). Go to www.cancer.net and click on "Cancer.net en espanol" and then "Conociendo la Terminología del Cáncer" to view the series.

Colombian GISTers meet in-person for first time in Bogota

By Vicky Ossio, LRG Latin America Representative **& Rafael Becerra** GIST survivor

On February 28 the first meeting of Columbian GIST patients was held in Bogotá at the Hotel Dann Carlton. GISTers came from all over, including Bogotá, Cali, Pereira, Neiva, Barrancabermeja, Girardot, Cúcuta.

Although we completed the planned program, we were short on time since there were many stories to tell and experiences to share. The presentation by Dr. Jesus Insuasty on understanding GIST was magnificent and gave clarity about the disease.

The testimony of Dr. Rafael Vega, who is both a physician and patient, showed us a different view of our disease. It combined the scientific, medical, and theoretical sides of the disease with the real experience of a patient in a way that showed not only what GIST is but what one faces when living with GIST and its treatments.


VEGA

Rafael Becerra's testimony was focused on the GIST patient. He spoke about how to live with the disease and its treatment options, the positive attitude we should take when living with GIST, and giving thanks to our family and friends, who truly share your trials and tribulations in dealing with GIST.

Vicky Ossio of Bolivia and Life Raft Group representative for Latin America made us see the importance of uniting in patient-support groups. She shared her LRG story with the group, discussing how she found the LRG after her daughter's GIST diagnosis and through the LRG, which today has over 1,000 members in the United States, she researched the best treatment option for her daughter. The LRG currently sup-

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The Managing Side-Effects pamphlet has now been translated into Spanish! You can order one by emailing us at liferaft@liferaftgroup.org

LRG holiday campaign update: Raising support and spirits

By Tricia McAleer
Director of Operations

The LRG would like to thank our top three support-raisers! A support-raiser is someone who demonstrates their commitment by volunteering, donating and spreading the word about GIST throughout the year.

We all know it can be a challenge to reach out to family and friends and ask for help. So we would like to recognize these courageous individuals. (Pictured below from left to right) Ellen Rosenthal, Erwin Johnson & Michael Byrne as our top three support-raisers.

The Cure campaign has now raised over $47,000 to date! Thank you everybody, let's keep it going!

What Does a Cure Mean For You?

Hoping for the future; seeing how my son's life turns out.

More Sunny Florida Days with Family & Friends!

My husband can run another race with our son.

Kim Trout talks about recent Pennsylvania Life Rafter meeting

"We had a GREAT meeting on March 21 in Pennsylvania! Mike and Kim Hoffman, Judy and Matthew Galbo and I had lunch, got to know one another and shared our stories. We discussed medical treatments and experiences, coping strategies and even made plans for our next get-together. Look for more information to come on a June gathering to include lunch and a bowling tournament! GIST patients, their children and other family members, caregivers and friends are all invited to participate in this unique and fun event!"

Cancer in the news: CMS broadens PET scan coverage, President Obama calls out cancer

The following article was reprinted from an email alert sent by LegisLink Action Center*, a community education service of US Oncology.*

On September 16, the Centers for Medicare & Medicaid Services (CMS) broadened the scope of its National Coverage Analysis (NCA) on PET coverage after receiving public input indicating that the current coverage framework which requires cancer by cancer consideration of diagnosis, staging, restaging and monitoring response to treatment should be replaced by a more omnibus consideration. CMS requested comment on whether the current coverage framework should be retired and replaced with a general policy that could be developed and applied to oncologic FDG PET imaging. On October 17, in comments submitted to CMS, US Oncology physicians expressed their belief that it is both clinically appropriate and practical for CMS to adopt a comprehensive omnibus cancer coverage framework for PET.

January 2009 Proposed Decision Memorandum

On January 6, 2009, CMS posted a proposed decision memorandum (PDM) for PET that would expand its standard coverage of a number of tumors for certain indications, while maintaining other indications under the Coverage with Evidence Development (CED) category. All patients scanned under the auspices of CED must either be enrolled in the NOPR database (National Oncology PET Registry), as has been the case for the past several years, or be enrolled in another evidence-gathering clinical trial, as outlined in the PDM. CMS would now routinely cover PET or PET/CT imaging for the initial diagnosis or the initial staging of primary brain tumors, ovarian cancer, pancreatic cancer, small-cell lung carcinoma, soft-tissue sarcomas, thyroid cancer, and testicular cancer, as well as all other solid tumors. All subsequent studies (for restaging or therapy monitoring) in these tumors will still be in the CED category. The one exception is that prostate carcinoma, which had been covered under the CED category for diagnosis, staging, restaging and therapy monitoring will no longer be covered (with or without evidence development) for diagnosis and initial staging, but it would still be covered under CED for restaging and therapy monitoring.

An additional modification proposed in the PDM is to condense the four categories of indications (diagnosis, staging, restaging and therapy monitoring) previously utilized for the approved tumors into just two categories: Initial Treatment and Subsequent Treatment. Under the proposed new structure, only one scan would be allowed in the first category for diagnosis and/or initial staging, while all other restaging and treatment monitoring scans would fall into the second category. In effect, this amounts to a significant expansion of coverage for the tumors most commonly imaged with PET (NSCLC, colorectal, lymphoma, melanoma, esophageal, head & neck, cervical, etc.), because it would allow PET imaging to be performed during therapy for therapy monitoring. Previously only breast cancer was covered (without CED) for therapy monitoring.

Today, US Oncology submitted comments to CMS supporting the coverage expansion in the PDM while requesting additional coverage enhancements that reflect the current standard of care for cancer patients. For example, a number of patients get an initial scan for diagnosis and/or initial staging, but then require a second study, with appropriate positioning, for radiation therapy planning. In US Oncology comments, it is suggested that a second, covered scan (typically a "limited" body scan) be added into the "Initial Treatment" category, when needed, for therapy planning.

CMS is expected to issue a Final National Coverage Determination (NCD) in April.

"Our recovery plan... It will launch a new effort to conquer a disease that has touched the life of nearly every American, including me, by seeking a cure for cancer in our time."

President Barack Obama
Address to Congress-February 24, 2009

Did you Know...

Do you need a counselor or psychologist but don't know what to look for or how to find one? Cancer.net offers helpful information about types of counselors, where to look and benefits to counseling. Just go to www.cancer.net and go to Library>Cancer.net Features>Living with Cancer

GENES

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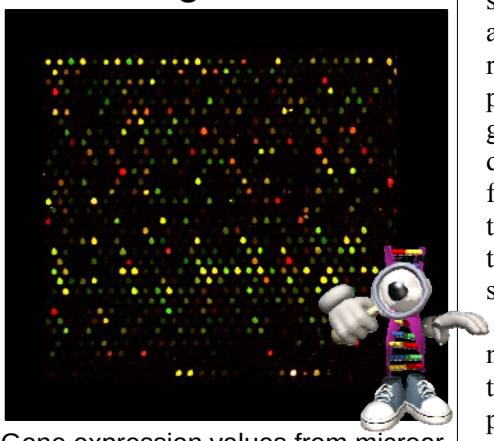
by Pat Brown at Stanford University) allowed us to use high density "microarrays" to examine the differences in mRNA for all human proteins in a single experiment. There is a good (though not absolute) correlation between mRNA levels and protein levels in tissue and studying the mRNA is technically much simpler and quantitative than looking directly at large numbers of proteins. The gene microarray technique was a tremendous advantage over the previous techniques that were available. In a single overnight experiment one could look at the mRNA levels for essentially all human genes. The analysis of these levels is called "gene expression profiling".

Recent developments in gene sequencing techniques now allow for a different approach to the quantification of mRNA for all proteins by microarrays. Rather than relying on the specific hybridization of mRNA sequences (that first have been reverse transcribed into cDNA) to probes on microarrays, scientists can now sequence all cDNAs that are derived from all mRNA species in a cell. In this so-called "Ultra High Throughput Sequencing (UHTS)", a several hundred-fold increase in the number of base pairs that can be sequenced with conventional sequencing techniques is obtained. A base pair consists of two nucleotides on opposite complementary DNA strands that are connected via hydrogen bonds. The approach to determine mRNA levels by cDNA sequencing rather than hybridization is referred to as "RNA-seq". The number of times a certain cDNA (that is unique for a particular protein) is found to be sequenced during this procedure is a direct indication of the number of mRNA molecules for this protein that were present in the sample analyzed.

There are several approaches to UHTS that can be used for RNA-seq and these techniques can be used in a complementary fashion. The sequencing technique by Illumina, Inc (www.solexa.com), can analyze millions of cDNA fragments per run, but generates relatively short fragments of sequence (about 40 base pairs per sequence). Another technique, the 454 system by Roche (www.454.com) yields fewer sequences per experiment but can produce longer sequences of about 400 base pairs. As a comparison, the current most commonly used Sanger method can sequence lengths of DNA up to 800 base pairs long but can perform far fewer runs per experiment. To be more specific, the technique from Illumina can do 100,000 times as many runs in a single experiment. Thus, while the fragments of DNA that can be sequenced in the UHTS approach are shorter, this is overcome many times over by the massive increase in the number of DNA fragments that can be sequenced.

Figure 1



Gene expression values from microarray experiments can be represented as heat maps to visualize the result of data analysis.

An interesting aspect of the Illumina approach is that, unlike the Sanger method, it does not require long stretches of intact mRNA (and the cDNA that we generate from that) as the start material to determine the base pair sequence. This is important because the field of research in GIST (and most other tumors) is still frustrated by a lack of availability of fresh frozen tumor samples, which are needed to generate long stretches of mRNA. While large tumor resections often have a sufficient amount of material to allow freezing this often is not done in routine fashion and small sample needle core biopsies (such as those performed to diagnose a recurrence) are often submitted entirely for paraffin embedding. Essentially all surgery specimens are sent to a pathology department where the tissue is fixed in formalin and embedded in paraffin so that thin tissue sections can be obtained that can be examined under the microscope. Thus we hope to apply the RNA-seq technique not only to newly diagnosed GIST tumors but also to tumors that recur during imatinib or other therapies. In addition we hope to be able to analyze samples for which no frozen tissue is available from rare subsets of GIST tumors such as pediatric GIST, wild-type GIST, etc.

In preliminary experiments to assess the ability of RNA-seq to perform reliably on archival formalin fixed paraffin embedded (FFPE) tissue, we performed RNA-seq on 5 matched fresh frozen and FFPE samples. Additionally, we performed gene expression profiling with microarrays on 3 of the same matched fresh frozen and FFPE samples. We then compared the performance of RNA-seq vs. microarray for reliably quantifying gene expression on archival FFPE tissue using the correlation of the fresh frozen and FFPE tissue measurements as a metric of reliability. There is significantly higher correlation of the gene expression measurements from the matched fresh frozen and FFPE samples using RNA-seq compared with the microarrays. These preliminary data suggest that RNA-seq is a more robust platform for quantifying gene expression from archival FFPE tissue than the gene microarrays.

Please help us in the fight to cure GIST. Email us at liferaft@liferaftgroup.org to learn how to submit a sample to the LRG Tissue Bank.

Such strong correlation is of critical importance because it shows that archival specimens retain the characteristics of the original state even though they have been stored for extended periods of time, up to several years. Moreover, this technique allows us to perform exploratory experiments on archival material which gives us access to many more specimens and a greater variety of specimens than fresh frozen tissue banks.

SUTENT

From Page 1

tients have taken this drug, which has significantly extended the lives of many patients. All drugs have potential benefits and potential risks. In the vast majority of cases, the benefits outweigh the risks when drugs are used for their approved indications.

Some degree of cardiotoxicity has been noted with most of the new tyrosine kinase inhibitors including imatinib, sunitinib, sorafenib, nilotinib and dasatinib. In spite of this, these drugs remain among the most exciting of the new drugs used to treat cancer.

Some of the key aspects of optimizing drug therapy for cancer are understanding the risks, proper monitoring and management of side-effects. This allows cancer patients to stay on their therapy as long as possible and at the optimal dose for the individual.

In spite of the concerns raised by the cardiologists in these reviews, none have suggested that the risks associated with Sutent outweigh the potential benefits. Their concern seemed to be more focused on **early and proper monitoring for hypertension and heart problems and early treatment for those patients needing it.** As Dr. Ming Hui Chen, the author of the study of Dana Farber patients noted in an interview with heart*wire* (from *Web*MD), "Patients should be encouraged that with cardioprotective measures, they can stay on their lifesaving therapy longer. . .the paradigm for cardiologists still remains to treat the cancer while caring for the heart."

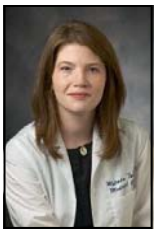
CHEN

The Life Raft Group has talked to Pfizer, manufacturer of Sutent, about the recent reports of heart toxicity. Pfizer has informed us that they are working with many of the investigators that have reported these issues and are performing studies to try to understand the mechanisms of toxicity. They are also gathering data from ongoing trials and encourage physicians to report adverse events. Pfizer and the Life Raft Group discussed the need to work together for more education.

LENIHAN

The studies raising concerns about heart toxicity were:

- A retrospective review of 75 GIST patients enrolled in the Phase I/II trial at Dana-Farber Cancer Center. This study was led by Dr. Chen of Children's Hospital Boston and Harvard Medical School.
- A retrospective review of 48 renal cell carcinoma (RCC) and GIST patients treated at Stanford University Cancer Center. Dr. Melinda Telli and Dr. Ronald Witteles reported preliminary results at 2008 Genitourinary American Society of Clinical Oncology (ASCO) and at 2008 ASCO.



TELLI

- An observational study of 86 patients treated with sunitinib (Sutent) or sorafenib (Nexavar) at the Medical University of Vienna in Austria.

Another study by Dr. Aarif Khakoo, Dr. Daniel Lenihan and colleagues at MD Anderson Cancer Center in Houston, Texas raises concerns about the severity of some of the heart problems. However, the incidence they noted was lower at 2.7 percent (possibly because of different monitoring and/or reporting).

KHAKOO

The factors affecting possible under-reporting of heart concerns are not entirely clear. Inconsistent use of reporting terms might be one issue, but another issue seems to be that in some cases heart failure was diagnosed based on clinical symptoms, resulting in under-reporting. In other cases it is based on specific diagnostic tests such as echocardiograms, biomarkers and MUGA scans.

According to Dr. Ronald Witteles, a cardiologist at Stanford, "Most trials only report symptomatic heart failure. . . sometimes symptoms are attributed to something else, for example edema may be thought to be drug-related . . (instead of heart-related)."

WITTELES

The symptoms caused by cancer treatment, especially many of the new tyrosine kinase inhibitors, are many of the same symptoms caused by heart failure. These include fluid retention (edema), fatigue and shortness of breath.

The similarities among symptoms caused directly by the drugs and those caused by heart failure, result in several problems. First, the incidence of heart problems can be underestimated if reporting is based only on clinical symptoms and not on routine cardiac testing. Second, if a patient does not undergo cardiac testing, symptoms caused by cardiac problems may simply be attributed to the "normal" side-effects of the drug and the cardiac problems may go

Glossary

Left Ventricular Ejection Fraction (LVEF)- LVEF is the fraction of blood pumped out of the left ventricle of the heart with each heart beat. For example, if there is 120 ml of blood in the left ventricle before the heart beats and 70 ml of blood is pumped out when the heart beats, **58%** of the blood (the LVEF) was ejected from the left ventricle (70/120 = 58%). It is a measure of how effectively the heart is working. Healthy individuals typically have an ejection fraction between 50% and 65% (this varies by the method used to test ejection fraction).

Ejection fraction is commonly measured by an echocardiogram (commonly called an echo) but can be measured by other means such as a MUGA scan.

Heart Failure- Heart failure (HF) is a condition in which a problem with the structure or function of the heart impairs its ability to supply sufficient blood flow to meet the body's needs.

Heart failure can cause a large variety of symptoms such as shortness of breath, coughing, ankle swelling and reduced exercise capacity. Heart failure is often undiagnosed due to a lack of a universally agreed upon definition and challenges in definitive diagnosis.

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TRIALS

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Dasatinib (BMS-354825)

Dasatinib as first-line therapy in treating GIST patients

Phase: II
Conditions: GIST
Strategy: Block KIT + Block KIT signal path
NCT#: NCT00568750
Telephone: 41-21-314-0150
Sites: **Centre Hospitalier Universitaire Vaudois,** Lausanne, Switzerland CH-1011
Michael Montemurro, MD

Imatinib (Gleevec)

Imatinib in GIST patients with liver metastasis

Phase: II
Conditions: GIST
Strategy: Block KIT
NCT#: NCT00764595
Contact: Tatsuo Kanda, MD
81-25-227-2228
Niigata University Medical & Dental School, Niigata, Japan

Imatinib + RAD001 (everolimus)

Treatment with everolimus + imatinib in progressive GIST and imatinib-resistance

Phase: II
Conditions: GIST
Strategy: Block KIT+Block KIT signal path
NCT#: NCT00510354
Telephone: Novartis Basel, 41-6-1324-1111
Sites: Use the Novartis number above for specific site information or go to the German Novartis site at www.novartis.de.

AMN107 (Tasigna, Nilotinib)

Efficacy & Safety of AMN107 in GIST patients who have failed imatinib & sunitinib

Phase: II
Conditions: GIST
Strategy: Block KIT
NCT#: NCT00718562
Contact: Novartis Japan, 81 3 3797 8748
Sites: Japan: Hokkaido, Niigata, Chiba, Tokyo, Kyushu, Aichi, Osaka, Shizuoka

AMN107 (Tasigna, Nilotinib)

Phase II study evaluating efficacy & safety of AMN107 in GIST patients

Phase: II
Conditions: GIST
Strategy: Block KIT
NCT#: NCT00633295
Contact: Novartis Basel, 41 61 324 111
Sites: Israel: Tel Aviv, Tel Hashomer

Surgery

Surgery in treating GIST patients with liver metastasis

Phase: II
Conditions: GIST
Strategy: Surgery
NCT#: NCT00769782
Contact: Tatsuo Kanda, MD
81-25-227-2228
Niigata University Medical & Dental School, Niigata, Japan

RAD001(everolimus)

Treatment of patients with RAD001 who have progressive sarcoma

Phase: II
Conditions: Sarcoma
Strategy: Block KIT signal path
NCT#: NCT00767819
Contact: Novartis Basel, +41 61 324 1111
Sites: Germany: Berlin, Munchen, Dusseldorf, Mannheim

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: Solid Tumors
Strategy: Destroy KIT
NCT#: NCT00526045
Contact: **Novartis**
Telephone: 1-800-340-6843
Sites: Bellinzona, Switzerland

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
Strategy: Block KIT signal path
NCT#: NCT00600275
Contact: Novartis, 800-340-6843
Sites: **Hospital Vall d'Hebron**, Barcelona, Spain
Princess Margaret Hospital, Toronto, ON, Canada

Imatinib+ IL2

Gleevec+IL2

Phase: I
Conditions: Solid tumors and GIST
Strategy: Block KIT+Stimulate the immune system
Contact: Dr. Patricia Pautier
Telephone: +33(0)1 42 11 42 11
Sites: **Institute Gustave Roussy,** Villejuif, France

Multi-Bacteria Vaccine

A Phase 1 study of mixed bacteria vaccine in patients with tumors expressing NY-ESO-1 Antigen

Phase: I
Conditions: GIST
Strategy: Stimulate the immune systen
NCT#: NCT00623831
Contact: **Krankenhaus Nordwest**, Frankfurt, Germany, 069 7601 4161
neumann.antje@khnw.de

Radiation Therapy as Palliative Treatment of GIST (GIST RT)

Phase: I
Conditions: GIST
NCT#: NCT00515931
Contact: **Helsinki University Central Hospital**, Helsinki, Finland
Heikki Joensuu, MD
947173208 Ext. 358
heikki.joensuu@hus.fi

XL147

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

Phase: I
Conditions: Solid Tumors
Strategy: Block KIT signal path
NCT#: NCT00486135
Contact: Exelixis, 866-939-4041
Sites: **Hospital Universitario Vall d'Hebron**, Barcelona, Spain
Gemma Sala, +34 93 489 4158
Jose Baselga, MD, PhD

XL765

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

Phase: I
Conditions: Solid Tumors
Strategy: Block related tumor signal paths
NCT#: NCT00485719
Contact: Exelixis, 866-939-4041
Sites: **Hospital Universitario Vall d'Hebron**, Barcelona, Spain
Gemma Sala,+34 93 489 4158

Has your GIST treatment caused you any dry skin or rashes? View an archived presentation by Dr. Mario Lacouture on skin side-effects at www.liferaftgroup.org/library_videos.html

COLUMBIA

From Page 4

ports ten investigators aimed at finding a cure for GIST.

Thanks to Dr. Rafael Vega, what began as a chat and flight of fancy crystallized into a dream come true. Thanks to everyone who helped us hold this first meeting of GIST patients in Colombia, and special thanks to the participants, Vicky, Helen Luz, Consuelo, Maria Helena, Fanny, Maria Consuelo, Socorro, Maria Enit, Vilma, Lilia Simón, Jorge, Luis, Miguel, Rafael, Jesús and especially Johana who, at 22 years old, is the youngest patient in our group. I apologize for any names I may have omitted. Thank you all.

It was the first step and was a success. Now keep going forward, Colombian GISTers!

Meeting attendees pause for a picture at the first gathering of Colombia GISTers.

Colombian GIST survivors and caregivers listen to a doctor's presentation at Hotel Dann Carlton in Bogotá.

BRITTANY

From Page 1

was seven years old, the disease recurred, this time in her liver. The course of action at that time was to use a drug called Gleevec to control or shrink the tumor. Though this drug has been used with success in adult GISTs, it failed to help Brittany.

A few months later Brittany had her second surgery to remove the tumor from her liver and during that surgery they found three more tumors in her stomach. They were successful in removing the four tumors after 12 hours in the operating room, but this left her with two ounces of stomach.

We continued to work with The Hospital for Sick Kids to monitor her for any redevelopment of the disease. We thought the disease had gone away as Brittany looked and acted healthier than we had ever seen her.

Unfortunately, a scan in February 2008 revealed the disease had reoccurred again. There were a total of three tumors, which were removed from her remaining stomach in a six hour surgery on May 23, 2008.

The doctors were concerned that she would lose the remaining portion of her stomach. The good news is that her stomach had stretched enough from the second surgery and they were able to keep one and a half ounces of capacity. So her battle continues to ensure she is eating enough to sustain growth.

The disease is relentless. In August 2008, a follow-up scan discovered the disease had returned once again.

Brittany got in a first stage clinical trial, taking a drug called Sutent. We were optimistic this drug would help.

She has now been switched over to a newer treatment, presently referred to as IGF1R. It is an insulin base growth hormone receptor that might deal with the disease more effectively. Brittany seems to be on the leading edge of new treatments as she is the first and only pediatric GIST Patient on IGF1R.

Our daughter Brittany is an amazing person who has been fighting battle after battle and continues to win. We as parents couldn't be more proud of her bravery and her courage through everything she has faced and continues to face.

SUTENT

From Page 8

untreated.

While there is clearly concern being voiced by the cardiologists in these four studies, the scope of the problems are not well-defined. Because each of these reviews used different monitoring methods/schedules, their results are hard to compare directly and they don't directly compare to previous trial results. In addition, some trials, especially the GIST trials, allowed previous anticancer drugs that have known or suspected cardiotoxicity. In the phase I/II GIST trial, 20 percent of patients had previous anthracycline chemotherapy (typically doxorubicin, a drug with known cardiotoxicity) and 100 percent had previous Gleevec (which has a low reported rate of cardiotoxicity). One theory is that this may have predisposed patients to increased risk of cardiotoxicity with Sutent. However, studies of Sutent in mice showed cardiotoxicity in the absence of previous imatinib.

We would like to point out that Jerry Call's wife, Stephanie, received extensive benefit from Sutent in spite of being a "high-risk" patient with pre-existing heart problems. In addition to GIST, Stephanie has secondary pulmonary hypertension (high blood pressure in the lungs), a condition that puts a lot of strain on the heart. Stephanie was on Sutent for 39 months without detectable heart toxicity.

Sutent is a potent inhibitor of the VEGF receptors. The VEGF pathway is one of the most important pathways affecting new blood vessel growth. Inhibiting the VEGF pathway is a promising anti-cancer therapy, however, a common side effect of drugs that target this pathway, including Sutent, is high blood pressure. Chen et al. commented on the hypertension noted in their study, "The degree and rapid onset of hypertension associated with sunitinib in our study were unexpected, since phase III studies have shown a 15–24 percent rate of hypertension with sunitinib, compared with 47 percent (35 of 75 patients), that we recorded. The low rate of hypertension reported in phase III trials might have arisen because patients with uncontrolled hypertension were excluded at trial entry. Our patient population had their blood pressure monitored every week and, therefore, had an increased number of data points from which to assess the rate of hypertension.

JOENSUU

"In view of our findings in the mouse suggesting that hypertension might play a part in myocardial injury and apoptosis, the contribution of hypertension to sunitinib-associated left ventricular dysfunction needs to be closely examined."

In addition to the rapid onset of hypertension noted in some patients in the study by Chen and colleagues, a rapid onset of heart failure was noted in a small number of patients at M.D. Anderson (Khakoo et al.). In the six patients (out of 224) that developed heart failure in this series, the duration of drug administration before the onset of heart failure was short, 44, 4, 4, 29, 20 and 29 days. The authors commented on these results, "Notably, the short amount of time between onset of heart failure after initiation of sunitinib suggests that this toxicity is mechanistically distinct from anthracycline mediated cardiotoxicity (drugs like doxorubicin), which is dose dependent and typically occurs after prolonged drug exposure."

Dr. Heikki Joensuu (Helsinki University Hospital, Finland) is one of the pioneers in the treatment of GIST with targeted drugs like Gleevec and Sutent. Dr. Joensuu commented on the article by Chen, Chu and colleagues in the journal, *Lancet*, "Chu and colleagues can be congratulated for vigilance and for careful documentation of their cases." Joensuu said their findings parallel those of another research group in Austria (later published in the *Journal of Clinical Oncology*). The Austrian scientists reviewed patients taking sunitinib or another anticancer drug, sorafenib (Nexavar). Joensuu noted that "cardiac adverse events with sorafenib seem similar to those related to sunitinib."

"Patients treated with sunitinib need careful monitoring, not only for hand-foot syndrome and other well-established adverse effects, but also for thyroid and cardiac function. Although data are limited and more research is needed, sunitinib might be at least as cardiotoxic as [the breast cancer drug trastuzumab (Herceptin)]."

"Longitudinal monitoring of LVEF is standard practice in breast-cancer patients treated with trastuzumab. Such monitoring and an electrocardiogram also seem indicated in patients treated with sunitinib. Patients with coronary artery disease, severe heart disease, or previous treatment with anthracyclines may be at particularly high risk of cardiac failure and possibly cardiac infarction during sunitinib therapy and will need close follow-up. Sunitinib-related hypertension should be treated promptly," Joensuu concluded.

"As a result of their experiences with Sutent, Stanford Cancer Center has developed a monitoring program similar to the one suggested by Dr. Joensuu for all of their patients on Sutent. This program exceeds the monitoring requirements recommended in the Sutent prescribing information which currently say (in part)

See SUTENT, Page 14

Gowdy played many roles: nurse, quilter, volunteer, wife and friend

Berthe (Maurice) Gowdy, 80, of Hudson, died Wed. Jan. 21, 2009 at the Community Hospice House in Merrimack, NH surrounded by her loving family.

Berthe was born in Central Falls, RI on Dec. 22, 1928 daughter of the late Ronaldo and Suzanne (Miller) Maurice. For 57 years she was happily married to Donald Gowdy of Hudson.

Berthe was formerly an RN in Burbank Hospital in Fitchburg, MA. Berthe enjoyed quilting and belonged to the Catholic Daughters of America for over 40 years. She played an active role in the Meals on Wheels program among many other volunteer organizations that she contributed to throughout her life.

Besides her loving husband, Berthe is survived by three sons and three daughters-in-law, Marc and Rebecca Gowdy of South Berwick, ME, Bruce Gowdy and his wife Eve of Oakland, CA and Scott and Michelle Gowdy of Wilmington, NC. Two daughters and a son-in-law, Patricia and Mustafa Malik of Cheverly, MD and Mary Gowdy of Keene, NH. Four brothers, Roland and Onide Maurice, both of New Brunswick, Noel Maurice of Waltham, MA and Ronald Maurice also of New Brunswick. Six sisters, Therese Geneau of Marlboro, MA, Pauline Smith of Quebec, Fernande April of New Brunswick, Norea Maurice of Quebec, Bernette Black of Paris, TX and Blondine Phoebus of British Columbia. Seven grandchildren, Benjamin Gowdy of South Berwick, ME, Stuart Gowdy of Chapel Hill, NC, Alia Malik (active Peace Corps: El Salvador), Jaheed Malik of St. Paul, MN, Alyssa Gowdy of Wilmington, NC, Brendan Gowdy of Las Vegas, NV and Heather Gowdy of Millersville, PA and many nieces, nephews, cousins, and friends.

GOWDY

In lieu of flowers the family has requested that donations be made to the Community Hospice House, 210 Naticook Rd., Merrimack, NH 03054 and/or the LifeRaft Group, 40 Galesi Dr., Wayne, NJ 07470. To send an online message of condolence, sympathy meal or for directions, please visit www.dumontsullivan.com. A tribute video will also be available to view online. The Dumont-Sullivan Funeral Home in Hudson is in charge of arrangements.

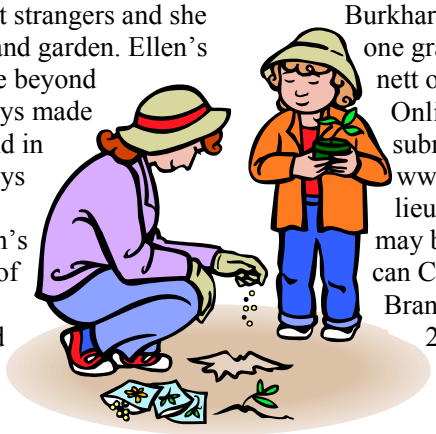
TALENTED MUSICIAN PASSES WITH FAMILY BY HIS SIDE

After a long battle with illness, so courageously fought, Dan Wiseman went to sleep peacefully, on Friday, February 6th, 2009. His very large family will hold him in their hearts always. The world has lost a very special person. No flowers, but donations for GIST (Gastro Intestinal Stromal Tumours Support UK) in Dan's memory can be sent to Alfred Smith Funeral Director, 15 Rowan Road, Streatham, London, SW16 5JE.

You can view an article in the July-August 2005 issue of the newsletter featuring Dan called, "Musicians of the LRG" at www.liferaftgroup.org/newsletters.html

Family and home were Heppler's first loves, gardening and cooking were her passions

Mrs. Ellen Marie Sarko Heppler, 47, of Jamestown, North Carolina, died on December 7, 2008 at her residence. A native of Cuyahoga County, Ohio, she was born on July 9, 1960, a daughter of James A. and Betty Mash Sarko. Ellen's family and home were her first love. She welcomed all into her home and heart and to know Ellen was to love her. She made friends with perfect strangers and she loved to entertain and garden. Ellen's culinary skills were beyond compare. She always made time to help a friend in need, share their joys and bring comfort when needed. Ellen's kindness and love of life will be in our hearts forever. God bless you Ellen.



She leaves behind to cherish her memory, her fiancée, Seth Bennett of the home, mother, Betty Sarko of Brook Park, Ohio, children, Michael of Chicago, Ill., Nicholas of Brook Park, OH, Cody of Louisville, Ky. and Casey of North Olmsted, Ohio, brother, Michael Sarko and wife Debbie of Brook Park, Ohio, sisters, Maribeth Sarko and husband Michael Nichols of Middleburg Heights, Ohio and Kristine Burkhart of Strongsville, Ohio and one grandchild Ava Marie Bennett of Vermillion, Ohio.

Online condolences may be submitted through www.cumbyfuneral.com. In lieu of flowers memorials may be directed to the American Cancer Society, 4-A Oak Branch Drive, Greensboro, NC 27407. Arrangements by Cumby Family Funeral Service in High Point.

GISTers meet at MD Anderson

When Pat George made an appointment to get his blood levels tested at MD Anderson in Houston, Texas, he thought it would be a neat idea to hold an impromptu gathering of GIST patients while he was at it.
He managed to get a few others to join to "catch as catch can" in between appointments. Pictured from left to right: Tosca, Barbara Dore (GSI Board Member), George Logan, John Bissonet & Pat George.

Did you Hear...

THE LRG HAS JUST ADDED FREQENTLY ASKED QUESTIONS IN HEBREW TO WWW.LIFERAFTGROUP.ORG & WWW.GLOBALGIST.NET!

A GIST warrior to very end

The following letter was sent to the LRG email community as well as many of Judi and Lee's friends. Lee Emerson was a remarkable man who is truly missed by all; Judi has been an amazing caregiver and we thought it appropriate to say goodbye to Lee with Judi's own words.

It is with great sadness that another could not slay the dragon called GIST. Lee fought hard, he was calm and steady during the entire battle. He lived with the dragon since July of 2001. He was an athlete; lean and ready, with perseverance and endurance. He tried all the medicines plus radiation but could not hold it at bay.

We were together 29 years this month and worked together side by side in business for 23 of those years. On January 20 he signed the hospice papers. I kept him at home. He called his sons, siblings, and friends. And his sons came and spent time. They said goodbye and cried. Lee failed quickly, the disease shut him down and he was in "limbo" for only a few days. We have lost another warrior to the disease. My passion, my friend and my lover.

Please light a candle and keep up the fight. Hopefully the battle will be longer for our fellow-GISTers which will come from learning more about the Beast.

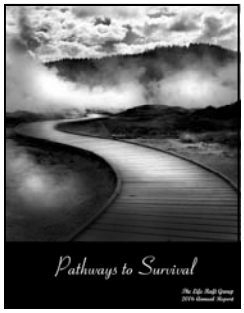
Lee and I send you love, thanks, and hugs for your support.— Judi

Read an article on Judi's caregiver battle at www.liferaftgroup.org/member stories_lifton.html

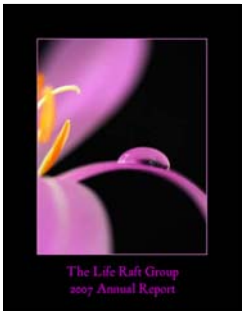
We Want You!

For the past three years, we have used artwork from LRG members as covers of the LRG Annual Report. This year we are asking anyone who would like to submit their own artwork to us at liferaft @liferaftgroup.org. If you have any questions, contact us at (973) 837-9092. Read on for some of the inspiration behind past covers.

This is actually a picture of a wood carving made by Rachel Tate, that has hung in the LRG office since its beginnings.



Mark Thomas donated this piece to the LRG, just before he passed. We chose to honor his photography skill on our cover.



Pediatric GISTer, Rachel Gilbert used photography to lift her spirits. She has become a wonderful artist!

Don't miss out on your opportunity to shine!

SUTENT

From Page 11

"In patients without cardiac risk factors, a baseline evaluation of ejection fraction should be considered". The Stanford protocol would move monitoring of ejection fraction from something that "should be considered at baseline" to routine baseline and periodic monitoring (as well as other monitoring).

All of the patients that experienced a cardiac event in the Schmidinger study (Sutent and Nexavar patients in Austria) recovered after cardiovascular management and no survival difference was noted between patients that experienced a cardiac event versus those that did not. The review of the Dana-Farber patients (Chen et al.) reported that congestive heart failure and left ventricular dysfunction generally responded to withholding sunitinib and medical management of heart-related issues. Stanford (Telli et al.) reported that three of five patients with follow-up cardiac evaluations had persistent left ventricular dysfunction after discontinuation of sunitinib and initiation of standard heart failure therapy.

In an interview with the Life Raft Group, we asked Dr. Witteles, a cardiologist at Stanford, to comment about the type of monitoring he recommends for patients on Sutent. Dr. Witteles recommended:

- Close monitoring of blood pressure
- Treatment of all hypertension **including mild hypertension** (over 140/90 mm Hg).
- Cardiac monitoring at baseline and every three months (previous cardiac risk factors might require closer monitoring).
- For patients with previous heart problems – very close monitoring at a tertiary care center (specialized heart care center).
- Investigational monitoring of biomarkers might include BMP and Troponin

According to Witteles, patients without a previous history of heart problems won't necessarily need to be seen by a cardiologist. The oncologist can order cardiac monitoring tests such as an echocardiogram or a MUGA scan. However, if those tests find abnormalities, then it's time to get a cardiologist involved in the treatment plan.

Pfizer's Commentary

Helping Patients Continue Treatment Through Monitoring For and Managing Cardiovascular Effects

Pfizer is actively supporting and conducting research of cardiovascular events with Sutent including ongoing Phase 3 trials, preclinical research and database analysis. Pfizer is also working closely with leading oncologists and cardiologists on this topic. With these efforts, Pfizer aims to provide physicians and patients with the information and tools to best manage patients being treated with Sutent for their underlying cancer.

Physicians treating patients with GIST are advised to carefully monitor patients with prior cardiac events or with cardiac risk factors for clinical signs and symptoms of congestive heart failure while receiving Sutent. Baseline and periodic evaluations of left ventricular ejection fraction (LVEF) should also be considered while the patient is receiving SUTENT. In patients without cardiac risk factors, a baseline evaluation of ejection fraction should be considered (Sutent Prescribing Information, 2009).

Patients with any questions or concerns should contact their treating physician, or obtain additional information from Pfizer by calling 1-800-TRY-FIRST (1-800-879-3477).

Chicago –area GISTers meet at Wellness Place

WELLNESS PLACE
A CANCER RESOURCE CENTER

Chicago Area GIST patients held a regular get-together January 25 at Wellness Place in Palatine, IL. There were 16 attendees including seven patients from Wisconsin and Illinois. New members included Dwight Beery, Bill Buchanan and Salvador Lazaro. At the beginning of the meeting, greetings were read from those who could not attend. Among those unable to be there were Dick and Sue Kinzig whose daughter, Kathy, passed away in December, a victim of fibrosarcoma. All present extended sympathies.

The agenda included an extended roundtable of personal updates and recent experiences. This was followed by refreshments and a short overview of papers from the November 2008 Connective Tissue Oncology Society meeting (CTOS) and the new clinical trial report card now on the LRG website. The next Chicago-area meeting will be May 3, 2009 at Wellness Place. All Chicago Area GIST patients are welcome to join .

The Life Raft Group

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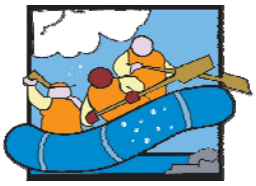

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