

<http://www.gistsupport.org>

Fall 2008

Volume 1, Issue 2

Special points of interest:

- Dr. Su Young Kim on next Pediatric NIH clinic
- Upcoming clinical trials
- GSI's activities
- Members' tips on where to stay
- Healing through Music
- Come join in!

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Novel Action IPI-504 Infinity trial

The drug IPI-504 (retaspimycin) has moved from a Phase I trial to a Phase III registration trial. ("Registration" means the manufacturer, Infinity, intends to seek FDA approval after this trial.) Infinity anticipates there will be around 26 trial sites in the US and Canada, and 50 globally. You can see details for this RING Trial (Retaspimycin in GIST) at the dedicated website www.ringtrial.com/

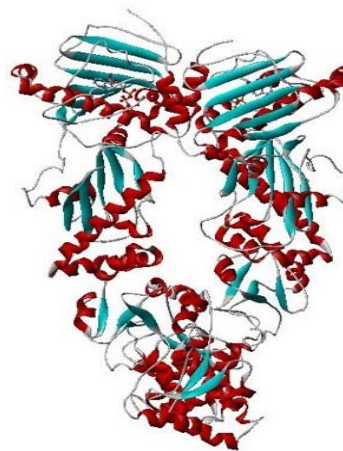
Compared to tyrosine kinase inhibitors such as Gleevec and Sutent, retaspimycin has a novel mechanism of action: it inhibits heat shock protein 90 (Hsp90), a chaperone protein. This difference means that retaspimycin's action is not thwarted by the resistance caused by secondary mutations (which affects TK inhibitors).

Chaperone protein

Hsp90 is one of a class of chaperone proteins, which normally are in close physical contact with other proteins, helping them maintain their shape to perform their normal functions. This helps cancer cells to survive in spite of their genetic defects. So if Hsp 90 is inhibited, cancer cells become more vulnerable and more likely to die. For more details see the [GSI website](http://www.gsi.org).

The placebo problem

In this trial, patients will be randomized to receive either IPI-504 (retaspimycin hydrochloride) or placebo intravenously two times a week for two consecutive weeks, followed by a week of rest.



Heat shock protein 90

Those troubled by the chance of being given the placebo might consider that patients will receive MRI or CT scans on week 2, 5, and 8 for the first 8 weeks and then every 6 weeks afterwards. Therefore, progression on placebo should be detected quickly, allowing the patient to switch to the IPI-504 arm of the trial.

Phase I results

The previous Phase I trial in metastatic patients with imatinib and sunitinib resistance showed that "patients with GIST (n=36), who were heavily pre-treated, experienced a 70% (n=25) overall disease control rate, with 3% (n=1) Partial Response and 67% (n=24) Stable Disease at six weeks.

Estimated median progression-free survival for these patients was 12 weeks. IPI-504 was generally well-tolerated.

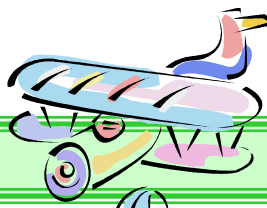
The most common side effects observed to date in the study were fatigue, headache and nausea.



You can see the June 2008 ASCO presentation about the Phase I trial of retaspimycin at [this link](http://www.gsi.org). Or go to:

<http://www.ringtrial.com/pdfs/ASCO-2008-Wagner-IPI-504-GIST-Phase-1-5.31.2008.pdf>

XL820 in Phase II trial



OSI-930 in Phase I

Results from two clinical trials are reported in the 20th EORTC-NCI-AACR Symposium on Molecular Targets and Cancer Therapeutics, from Geneva Switzerland 21-24 Oct 2008.

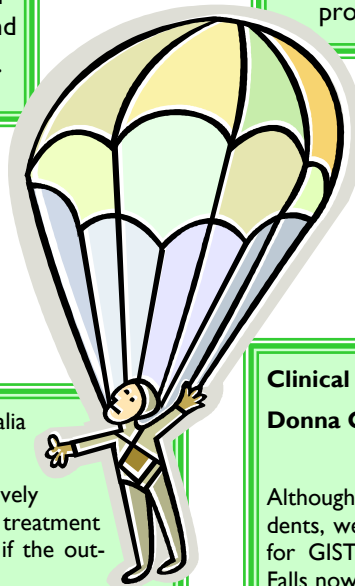
The first is a **Phase II study of the KIT inhibitor XL 820 in patients with advanced GIST, resistant or intolerant of imatinib and /or sunitinib.** XL820 is an orally bio available, small molecule inhibitor of both wild-type and mutationally-activated KIT, VEGFR2 and PDGFR. Mutations in KIT, particularly in the juxtamembrane domain, are common in GIST. XL820 potentially inhibits both the ATP-binding region and activation loop classes of resistance mutations, which are associated with sunitinib resistance.

So far, the study shows XL820 is generally well tolerated and appears to have biological activity in patients with advanced GIST; decreased FDG_PET activity was observed in 4/7 evaluable patients at 4 weeks; 2 partial responses by Choi criteria were observed and follow-up continues. This trial is no longer recruiting.

The second study concerns a **Phase I trial with OSI-930, a multi-targeted oral tyrosine kinase inhibitor (TKI)**

A multicenter phase I study of continuous oral OSI-930 administered to patients with advanced solid tumours. 35 patients were enrolled in the escalation phase (10 had GIST) . All GIST patients had PET studies. Initial patient disease data before and after administration of OSI-930 (days 2 and 22) available at submission demonstrate significant changes in tumour vascularity with good correlations for tumour shrinkage on CT evaluation. Decreases in plasma sVEGFR2 levels were also observed.

OSI-930 has been well tolerated with promising anti-tumour activity.



The Register Trial Dr. Jayesh Desai Australia

This is a Phase II, open label, multicentre study which selectively fast-tracks Wild Type or exon 9 GIST patients through the treatment paradigm compared to their exon 11 counterparts., to see if the outcome can be improved.

All patients will start with 400 mg imatinib dosing, for 6 weeks, and exon 11 patients remain on this dose until progression. Meanwhile all exon 9 and wild type patients, and exon 11 patients who have had progression will be given 600 mg imatinib for 2 weeks, then 800 mg. For all patients on 800 mg imatinib, If progression occurs again, then treatment will switch to 800 mg nilotinib (Tasgina),

Dr Desai, who is the PI of this trial, was a pioneer of Sutent at Dana Farber

<http://www.gicancer.org.au/trials/development/REGISTER.html>

Clinical Trials- What You Need To Know Donna Capps

Although Montana has fewer than a million residents, we have great Cancer care, although not for GIST. Sletten Cancer institute in Great Falls now offers the cyber knife. Our state-wide group, Cancer Family Network has created a forum that gets professionals to write information to help families affected by cancer.

The Montana Cancer Consortium, made up of cancer doctors throughout the state has written a series of mini essays explaining the complicated CLINICAL TRIALS process. For anyone considering joining a trial, these essays should clear up a lot of questions on the trials process.

With CFN's ok, I have put them on the WIKI

Upcoming Trials —Marina Symcox



Comparing 800 mg Gleevec versus 37.5 mg Sutent Or 800mg Nilotinib

For those patients who have been taking 400 mg Gleevec and now need new treatment options, there are two studies in the offing which are going to compare the efficacy of Gleevec 800 mg versus newer treatments. One will compare 800

mg Novartis' drug Nilotinib versus 800 mg Gleevec in patients who are resistant to 400 mg Gleevec by RECIST measurements. This study is "not yet recruiting" but is estimated to start in December 2008 and end in December 2011. The health authority listing below indicates the trial will run in various countries, where 200 patients will be recruited..

<http://www.clinicaltrials.gov/ct2/show/NCT00751036?term=nilotinib&rank=3>

There is a similar trial by Pfizer that compares 800 mg Gleevec versus 37.5 mg Sutent for patients who are resistant to 400 mg Gleevec, currently recruiting.

<http://www.clinicaltrials.gov/ct/show/NCT00372567?order=14>

It may be difficult to enrol US patients, because it is easier for them to go onto higher dose Gleevec or Sutent or off label Nilotinib or off label Sorafenib with their local oncologists if 400 mg Gleevec stops working. But, in other countries that may not

have made available these options (800 mg Gleevec or Sutent or off label Nilotinib), accrual should be easier. So we need to think globally when we consider the patient pool and what might motivate a patient to enrol in a trial.

In an ideal world it would be interesting to see a three way trial that directly compares 800 mg Gleevec, 37.5 mg Sutent, and 800 mg Nilotinib, all in the same trial, along with cross over to another treatment arm should the first drug stop working.

The intent would not be to show one drug is superior to another--these are all outstanding and important drugs, but rather that each drug has different properties and side effect profiles.

Hence, a particular drug may work better than another against a certain subtype of GIST, or certain KIT/PDGFR mutations. When a drug is used may also matter, because each drug tends to leave behind its own unique "footprint" of resistant secondary mutations. So using Nilotinib after Sutent may have a different efficacy profile than using Nilotinib before Sutent, just for example.

Both this second line of defence phase III Nilotinib trial and the Pfizer second

line of defence phase III Sutent trial have mutational analysis as part of the study. Hence, the question can be answered in part if certain subtypes of GIST respond better to a particular drug.

But we won't have a direct three way comparison.

Surgery Pre-Resistance? A Randomized Trial

There is a forthcoming EORTC adjuvant surgical study trial in Europe and Australia to show whether patients with metastatic disease benefit from surgery. Although there have been some anecdotal style studies of what happens if responding metastatic disease is removed before resistance, these were not RANDOMIZED trials. The conclusion of these reports was that surgery to remove metastatic disease while it was responding to Gleevec and before resistance improved overall survival.

However, it could be that those patients who were good candidates for surgery had less widespread disease in the first place, so surgery itself was not the cause for the observed benefits, but rather the fact that surgery was not performed on patients with more widespread disease.

The study will assess the impact of adjuvant surgery on progression-free survival time in patients with GIST who have experienced complete response, partial response or stable disease following 6 - 12 months of treatment with imatinib. Patients will be randomized to receive surgery plus imatinib or imatinib alone .

See GSI website: Surgery for Metastatic GIST

www.gistsupport.org/treatments/surgery/surgery-for-metastatic-gist.php

For a comprehensive overview of which clinical trials are available, see

www.gistsupport.org/treatments/clinical-trials.php

The GSI telephone number is: 215-340-9374



The GSI dedicated telephone number to the EmergingMed clinical trials referral service is:

866-729-1340

or link » EmergingMed

www.gistsupport.org/treatments/clinical-trials/emerging-med-contacts.php



Update on the Pediatric and wildtype GIST Clinic at the NIH

Su Young Kim MD PhD

The National Institutes of Health was proud to host the 1st Pediatric GIST clinic this past summer. The inaugural clinic was very successful, thanks to the many people who volunteered their time for this endeavor. This included the participation of doctors from across the nation, healthcare providers at the NIH who provided their expertise in a variety of fields, patient advocates who contributed valuably to our discussions, but most importantly, the patients and families who took the time and the effort to travel to the NIH to attend.



Post-clinic surveys showed that the most informative aspect of the clinic was the opportunity for patients to ask specific questions relating to their care to the panel of doctors in attendance. Although appointment times were limited, our suggestion that patients come prepared with a list of questions that they wished to ask, in order of importance, allowed us to address the most pressing issues.



Age range increased
Based on this change, the age range of the participants in the second clinic has increased. To date, we received 14 requests to participate in the 2nd Pediatric and wildtype GIST clinic at the NIH on January 21st and 22nd 2009. We extended invitations to 12 patients, and we have extended provisional invitations to the other two patients. Our philosophy is that children with GIST represent a very rare population and deserve foremost consideration. Therefore, we will continue to prioritize registration for younger patients. Anyone who was diagnosed prior to the age of 18 who wishes to attend, will be guaranteed a spot in the January 2009 clinic.

The post-clinic surveys also mentioned that there were too few opportunities to interact socially with other participants. Part of this problem was due to the short duration of stay at the NIH, combined with a very hectic appointment schedule. To alleviate the frenzy of a day too busy, we are now requesting that clinic patients arrive Tuesday evening.

Timetable

Beginning on Wednesday, following a brief introduction session, patients will see a NIH physician for a history and physical examination, followed by meetings with a wide range of specialists, if requested. Wednesday evening will be the official welcome to the NIH, with the introduction of patients and families and medical specialists.

The goal of the Pediatric GIST clinic was to obtain as much information as possible from younger patients with GIST. We were very successful in fulfilling this objective, again thanks to the enormous amount of work that patients and their families performed to send us their medical records. What we found was that the fourteen patients who attended the inaugural clinic were very diverse in all aspects of their medical histories.

Dedicated website

A summary of our findings will be presented at the Connective Tissue Oncology Society (CTOS) meeting in London on November 14th 2009. These results will also be available via our website, www.pediatricgist.cancer.gov. The design and contents of the website are progressing nicely. Our hope is to present complex clinical and research material using language that anyone will be able to understand without the need of a dictionary. The projected opening of this website is December 1st 2008.

Pediatric AND wildtype GIST

There will be many changes for the forthcoming 2nd Pediatric and wildtype GIST clinic at the NIH. The first is the change in the title from "Pediatric GIST" to "Pediatric and wildtype GIST". This is based on the finding that almost all young patients do not have mutations in the genes KIT or PDGFRA, therefore termed wildtype. A percentage of older individuals are also wildtype, and it is our belief that older wildtype GIST patients may resemble patients with Pediatric GIST.

This will be followed by the second Pediatric and wildtype GIST lecture, given by one of the physicians in attendance. During and after dinner, we will provide a more structured environment in order to foster interactions with other patients.

On Thursday, patients will have the opportunity to ask questions to the panel of physicians. Throughout the day, they will also have the option of attending a host of seminars that address other aspects of cancer, including alternative/complementary approaches, recreational/art therapy, relaxation techniques, nutritional tips and others.

Please register

The NIH Pediatric and wildtype GIST clinic encourages everyone with pediatric or wildtype GIST to contact the NIH and register for subsequent clinics (ncipediatricgist@nih.mail.gov). By attending these clinics, patients will help advance basic science and clinical research for GIST. Your information and medical history will add to a valuable database that acts as the foundation for continued advances in Pediatric GIST.

Su Young Kim, MD PhD

Pediatric GIST Clinic Coordinator
Pediatric Oncology Branch
National Cancer Institute
National Institutes of Health

**Dr Kim addresses 1st
Pediatric GIST clinic**



Safe Surfing by Barry Codron

I was devastated by my sister Deanne's contracting cancer (GIST) several years ago. I'm the big brother and I am not supposed to let anything bad happen to my baby sister!

I felt, as I'm sure everyone in a similar situation feels, completely helpless. Of course I did all the things I could think of...researching various aspects and treatments, visiting with her and accompanying her to some appointments when my brother-in-law, a commercial pilot, had to be working out of town. But I could not really do anything for her, and that made me feel horrible.

Much of my research was already done for me by the GIST Support Group. It gave me insight into the disease and into the minds of the victims/survivors and their families. And I knew Dee Dee was ex-



tremely thankful for the wonderful people that comprise the organization. I wanted to do something (anything) tangible, so I offered to write a monthly newsletter for GSI. Julie Royster and Marina Symcox were eager to have me do that, so there you have it.

A labor of love

I try to write something useful for the members each month AND I try to enjoy doing it. A labor of love wouldn't be too much of a stretch to describe the effort.

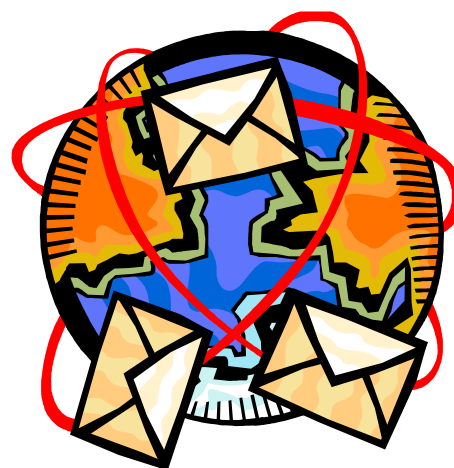
All of Barry's newsletters are available from the GSI website at:

www.gistsupport.org/learning-center/computers-and-internet-surfing.php

GSI's Mail Team Sends GIST Pamphlets

When people write in to request copies of our educational brochure on GIST (see <http://www.gistsupport.org/educational-materials/gist-brochure.php>), the volunteers who take care of answering are Linda Hughes and Sherri Janousky. They divided the country to divvy up the mailings: Linda (in Oregon) handles requests from west of the Mississippi, while Sherri (in Chicago) takes care of eastern requests. When foreign requests arrive, requiring a trip to the Post Office, Linda handles all those.

Can you take some educational tri-folds to your doctor or clinic? If so, write gsi@gistsupport.org and the mail team will send you as many as needed. Many thanks to Sherri and Linda!



Kath Kimball's Cookbook—order now!

Kath has been preparing a cookbook to raise money for GIST research using recipes garnered from friends and fellow GIST patients. The cookbook has 200 recipes (including two of Fla. Bob's favorites). The recipes include a variety of dishes; some meatless main dishes for those who don't like meat; some sugar-free desserts for diabetics; and some fat-free or low fat main dishes, sides, and desserts for those who are health conscious and/or trying to lose weight; there are also some recipes for those trying to gain weight.

The cookbooks cost \$12 each and \$3 for shipping. They will be ready by mid-December and will make a nice gift for Christmas.

All profits from the cookbook will be donated to Dr. Trent at M.D. Anderson to go towards GIST research.

You can contact Kathy at katharine_kimball@hotmail.com for further information or to order your copies now. Checks or money orders should be made out to Katharine Kimball, with 'Cookbook' in the memo field and mailed to Kath Kimball

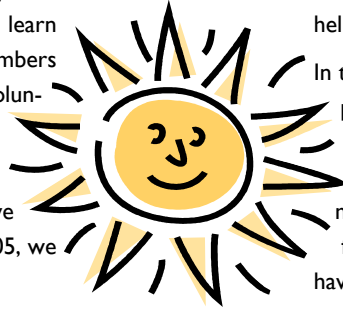
P.O. Box 636, Somerset, TX 78069.

Anyone coming new to GSI will have been welcomed by one of a volunteer team of Greeters. I originally joined GSI because my father had GIST and I wanted to learn everything I could about it. When the founding members were looking to have a welcoming committee, I volunteered.

When I was asked to be the main contact to welcome new members, I was honored. Since we started the welcoming committee on March 23, 2005, we have welcomed 1245 people!

I have since lost my father and many friends, but I chose to stay and help others who are facing this rare cancer.

I continue to help ease the minds of those newly diagnosed. You see we not only welcome people to the support group, we welcome them into our lives. When they



This is my opportunity to bring a smile to somebody's day,

are first diagnosed with GIST, we are the first to reach out and let them know they are not alone and we are here to help them.

In this crazy world we live in, it's nice to know that there are people out there to help you through difficult times. They say "people come into your life for a reason, a season or a lifetime." Some we help, support and guide, and they move on with their lives. With others we form life long friendships to help us grow and build on the lessons we have learned.

So you see, greeting people is very rewarding. I look forward to hearing from those I have reached out to.

The other members of the Greeters committee are shown in the feature boxes below and on the next page...

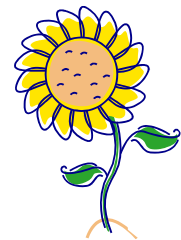
Since March 23, 2005, we have welcomed 1245 people!

Jeni Bullard lives in Michigan with her husband and 2 sons. Jeni was diagnosed at the age of 26. She is currently living with NED (no evidence of disease). Jeni is caring and compassionate and loves helping others

Minnie Broas lives in Colorado with her husband and her son. Minnie is an inspiration to all that know her. She was diagnosed in 2004. Minnie is currently in hospice, please keep her and her family in your prayers.

Jani DeHart was a mother, wife, sister and friend. She was a special needs teacher who loved her students and loved life. Unfortunately, she lost her battle to GIST in September 2006. She is missed by all who knew her.

Maura Cesarini was diagnosed with GIST in July 2002 at the age of 33. Maura and her husband are the proud parents of 2 beautiful girls. Maura continues to help those affected by GIST.



Jeni Bullard—Greeter since 2007

Every morning I start my day with a cup of coffee and my computer. My first click is my email. I am looking for something important.

You may think I am anticipating a love letter or even dreading a bank statement or hoping to start my day with a joke. You would be wrong.

When I go searching I am hoping to see a "newbie" from Leeann South. This is my opportunity to bring a smile to somebody's day, my opportunity to offer a ray of hope in a desperate situation.



Being a greeter for GSI has brought purpose and joy into my mornings.



There is a quote by Abraham Lincoln that says "To ease another's heartache is To forget one's own" I find this to be true for me. I remember those first days of my diagnoses. I can still feel the despair and heartbreak deep in my chest. I can still taste the fear and anger in the back of my throat. I can also remember

wealth of knowledge I received when I found GSI. There was not an official welcoming committee in 2005 but I had Bev, Marina, Lee Ann and Leeann, Julie and a host of others guiding me from the darkness.

As a greeter I have had the opportunity to make friends that have enriched my life and I hope that I have lit a few torches of my own to lead others out of the dark.

I cannot begin to explain the impact some of these "newbies" have had on my life both the ones who are still in my daily emails as well as those who have lost the battle with GIST. I have learned that every person deals with cancer differently, I have learned that not every person has the support from their family and friends that I am blessed with. I have learned that sometimes people need to talk about anything but cancer!

So I owe all my newbies a great big thank you for giving my mind someone to worry about besides me. Also for teaching me so much about a life I am often too busy to notice is flying by.

Phone Pals—Nea Paquet



As we have added so many new people recently, I am not sure if everyone is aware of a volunteer group that GSI makes available. GSI has a phone line for individuals who may want additional information, and may, or may not have computer access. Some Gisters don't have computer access, or don't feel comfortable using a computer. We offer to provide a "phone pal".

When a call comes in, the information is forwarded to me, and I try to get as much information as possible about the individual desiring a call. Where they live, age, NED, medication, diagnosis, etc.

I send out a broadcast to the phone pal volunteers. That way the volunteers will know if they may be a "match".

We spend a great deal of time talking to people on the telephone on a daily basis. The GSI telephone number is:

215-340-9374

Most general cancer support groups do not have more than one person with GIST, and as we know, GIST is different from most cancers.

Our volunteers are carers or have GIST themselves, but we don't have a large pool. So sometimes the individual will call when there is really no perfectly matching volunteer ...but the individual is relieved to have found a person that has been touched by GIST.

Often we can help them get set up on GSI, since there is so much more assistance on line.

If any of you have an interest (and aren't already a volunteer), let me know. We only receive a few requests for a phone pal, and you may only end up with one phone pal a yearso it isn't too time consuming.

I appreciate all of you out there, and the phone pals we currently have.

Thanks! neapaquet@hotmail.com

Vince Luce is a cancer survivor. He was diagnosed in 2001. Vince has learned how read his own CT scans! Vince is a greeter and a phone pal.



Leeann South joined GSI because her father was diagnosed with GIST in May 2003. Even though her father passed away in February 2006, she continues to help those diagnosed with GIST. She enjoys corresponding with new members and helping them navigate the site. She is also a phone pal as well as a greeter.

The BedLounge

I have to sleep propped up ever since my partial gastrectomy, much more propped than a typical bed wedge can do for me. It is to the point where I am much more comfortable in the recliner than in the bed.

I have been searching for a year, for something that would provide me the "recliner effect" - while in the bed.

I found something called the BEDLOUNGE. It is expensive, but for me to be back in the bed like normal where my hubby is....it is worth the expense !!

I wanted to share what I found, in case someone else might need one too !

Wendi Kempf



www.bedlounge.com

CTF Team Does Portland Marathon - Pat Soul

I completed my first marathon, at the ripe young age of 68. I am going on 52 months NED, after my GIST surgery. I also have Neurofibromatosis, (NF1) for short. I live in Los Angeles, and went to Portland Or., to walk/run the marathon with members from my CTF (Children's Tumor Foundation) support group where people with NF can talk.

I had registered as a runner, so I was separated from my team mates at the start, but did manage to find them later. I can't begin to describe the feeling of actually being at the start of a marathon instead of watching it on TV.

With only 10 miles to go, I felt I had it made, especially having to deal with the rain pouring off my cap. I just looked up and said "never have I deserved anything so much, as the medal that is waiting for me at the finish line" So, I just concentrated on getting to the end and not counting how many miles to the finish line.

One bad part, I got stuck over 10 mins., waiting for a train to go by. I hope they fix that problem before the next marathon.

The train passed and I decided to run the rest of it to make up for lost time, about 2 miles or so. I finally saw the finish chute and blew through feeling like a champ. They wrapped the space blanket around

One thing I forgot to mention was that we raised over \$50,000 for the CTF !

It started out with overcast skies for the first few miles, and then came the rain. I was surprised at how good I felt through most of it, and the refreshment tables every few miles gave us what we needed to stay hydrated. One of my favorite parts when we went over the St. John's Bridge.



I had to run that part, because it reminded me of when I ran across the Golden Gate Bridge back in the 80s, and my adrenaline had kicked in....

This was at about the 15 mile mark.

Pat, Bea, Julie, and Pete

me and handed me my medal. This was after 8 hrs, but I had walked most of it, and had to deal with trains and traffic. Next year I plan to run it!

Now for anyone that thinks they are too old to do it, there was a remarkable lady named Mavis, who I saw interviewed during the 1983 L.A. Marathon, and she was in her 80s. Now I was looking at the Portland Marathon result book, and saw that she ran it many times, even at 90 years old, so never say never.....

BTW my GIST was a result of my NF1.

Anyone wanting to know more about NF can go to www.ctf.org or www.nf.org

How A GSI logo and a bike ride found a Doctor Mike Nutile

At the recent bike event for sarcoma awareness sponsored by JHO I was wearing a T-shirt with an iron-on GSI logo. I have to tell you all now, attending this event was divine intervention. Although I like my present oncologist, it is a learn as we go proposition and neither she nor my surgeon know each other.

I was always praying to find a team here like many of you have...

At the bike ride, one of the doctors approached my wife and introduced herself "Hi, my name is Dr. Katherine Thornton from Johns Hopkins Sidney Kimmel Cancer Center... I'm a GIST Specialist on the Sarcoma Team"...

I overheard the intro and I had to catch my breath... did I hear what I thought? My wife looked at me with a smile... then back at the Doctor... and back at me... and we both knew God had a hand in what had just transpired.

I walked over and introduced myself and we talked for a few minutes before the start of the bike event. The whole time I was riding

I could barely contain my joy.

At the end of the event we agreed that I would schedule an appointment with her that very week.

She assured me she was in regular contact with the teams at DF and MSKCC and shared information with them regularly. It turns out she came to Johns Hopkins University (JHU) from New York as an assistant Professor of Oncology with clinical interests in soft tissue sarcoma of adults and GIST.

JHU recently formed a multidisciplinary team of experts covering GIST which is why I was unable to find them when I was diagnosed back in April of 07.

WOW!! and only 10 miles from my house.



Where to Stay in Boston—for Dana Farber

Tips from GSI members



Steve S writes: When going to Dana Farber in Boston the subway system is good enough that staying very near the clinic and hospital (Brigham and Women's) isn't really necessary.

When I had my first surgery, my wife stayed at the Holiday Inn on Beacon St in Brookline. It's easy walking distance, about 6 blocks, from the Clinic. The Hotel also runs a shuttle if needed. The folks at the Holiday Inn were great about letting her check out for a night or two, storing our stuff (for free!) and letting her check back in for a couple nights.

The hotel is about a half block long with an interior garden area that runs the length of the building. We stayed there during my early recuperation and the enclosed heated garden area gave me a place to walk. They also have laundry facilities. The hospital rate was about \$110.00/night plus tax and underground car park-

Vicky V writes: In Boston we stayed at 463 Beacon, an old house converted into "hotel" rooms. It reminded us of a bed & breakfast, minus the breakfast. Very reasonable.

The room we stayed in had a mini kitchen (sink, fridge & microwave, plus plates & silverware). It is about 2 miles from Dana Farber. We took public transportation and walked. www.463beacon.com/



Nancy in CA writes: On the main/lobby floor at Dana Farber there is a lovely resource library with helpful staff and a big coat closet--large enough to store a small carry-on.

The hospital doesn't have a checkroom, so until I discovered this secret closet I was wheeling my suitcase and winter coat from one building to another a half dozen times per visit!

The second wonderful thing about the resource library is that they have two or three computers that almost nobody uses.

So if you are stuck there for a few days prior to surgery or are nervously awaiting the results of scans, it's a wonderful way of keeping in touch with loved ones.

More details and places can be seen in the wiki!
http://gistsupport.medsshelf.org/Places_to_stay_near_major_GIST_centers

New York - visiting MSKCC

Hope Lodge, created by the American Cancer Society, has 61 guest suits. All lodging and support services, are offered free of charge for cancer patients and their families. The Cancer Society partners with major cancer centers in New York City to identify patients with greatest need. Reservation requests are made through medical treatment providers. For more information, contact the American Cancer Society : <http://www.cancer.org/docroot/subsite/hopelodge/locations.asp>

If you contact the MSKCC Social Work Dept. (Phone 212-639-7020) they will mail or fax you their list of housing options. From Becky B

Finally don't forget Joe's house for nationwide places to stay near cancer treatment centres

<http://www.joeshouse.org/>



The cost of parking your car in NYC can really add up. We parked our car in the Path rail line garage in Jersey City much cheaper than parking in Manhattan. PATH is a rail system that runs between Manhattan and New Jersey.

Here is the PATH train link:

www.panynj.gov/CommutingTravel/path/html/

From there the train ride takes about 45 minutes and is quite affordable. Once in Manhattan, you could take a taxi or the NYC subway to where you will be staying. On release from the hospital, you could take a taxi from MSKCC back to the PATH train. From Becky B

Brad writes: My family and I used the YMCA on 63rd St when we visit MSKCC. It was basic but clean, friendly and priced very economically. Tel: (212) 875 4100

Where to stay in — Portland (visiting OHSU)

Donna writes: OHSU gets FREE rooms at major hotels donated from the hotels to them through the Cancer Society. You have to contact the OHSU social worker, with as much notice as possible. I do not have the name of the current person to contact, but I am sure you could call the dept of Hematology or Dr. Heinrich's office and ask who it is now.

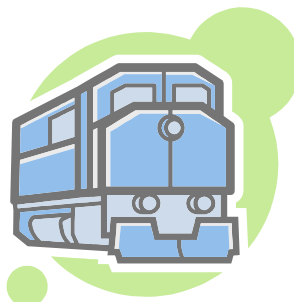
When we went there, to see Dr. B, they were very helpful. After paying for plane fares and rental cars, it was nice to get a place to

Portland's transit system ROCKS!

Portland has one of the best transit systems I've encountered. Cheap and fast.

They also have a most excellent trip planner online at www.trimet.org. You just type in where you are when, and where you're going and it spits out the quickest route, the route with the least walking between stops, the most scenic route, the route that includes stops at a micro brewery and pizza ... (OK, I'm getting silly now). Seriously, it's great.

Richard P.



Amtrak to the rescue

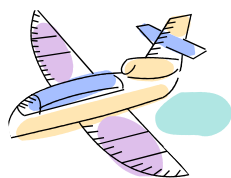
Travelling from Kalispell, Montana I rarely have the opportunity to fly at a rate I can afford. We are at the end of the line. I looked into the train and found a round trip for \$189. The train stops in Portland and I'm looking into a shuttle. I would not be able to travel to OHSU if it were not for Amtrak.

Dirk M



OHSU gets FREE rooms at major hotels donated from the hotels to them through the Cancer Society. You have to contact the OHSU social worker, with as much notice as possible. Call the dept of Hematology or Dr. Heinrich's office and ask for the contact number. When you discuss lodgings be sure to mention whether you have a car or need to be near the free transport system.

Donna



Corporate Angels try to arrange free air transportation for cancer patients travelling to treatment using the empty seats on corporate jets.

<http://www.corpangelnetwork.org/>

Phone 914 328 1313



Continental has a free flight program for patients called Continental Care Force.

The phone number is 281-261-6626.

United Airlines has a program that will give one set of tickets per year.

The Cancer Society can put you in touch with the people that can get the tickets.

800-296-1217 or 800-227-2345.



Houston - visiting MDA

Pat G. always stays at laQuinta Motel on Buffalo Speedway, which he says offers extreme courtesy to MDA Patients.

MDA Patients are ALWAYS provided set-aside rooms at the regular rate, microwave oven and fridge available on request. The usual courtesy shuttle and breakfast are standard. Tel: (713) 668 8082

John says: We always stay at Rotary House at MDA because the price is good approx \$95- \$100 per night. Very competitive and very nice hotel. Location could not be closer and you can get to any of your appointments in about 10 mins just by walking across the skybridges. Food is also good albeit a little expensive but certainly no more so than any other hotel.

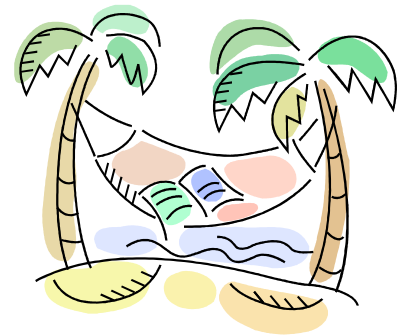
Los Angeles—visiting UCLA

We always stay at the Tiverton House because it's reasonable and there is free shuttle to the UCLA medical facilities but they were booked so we had to scramble to find something else.

We decided on Embassy Suites in El Segundo - right next to LAX but I have to tell you - we NEVER heard an airplane. The hotel was awesome - 2 room suite, underground parking, FREE cooked to order breakfast and happy hour everyday. They also gave each of us a little bag with 2 bottles of cold water - nice touch.

The front desk also has a huge list of all types of restaurants. We ate good, trust me!!!

And the beach was just a mile down the road! It is actually at the end of the runways at LAX so you could look up and feel like you could touch the planes as they took off - kind of cool.



We also drove into Marina del Rey - very short drive from UCLA and had a great day just being tourists and walking on the beach.

The hotel is only 13 miles from UCLA but the traffic is awful in the AM - a 30 minute journey can take an hour, be warned!!

Embassy Suites Phone number: (310) 640-3600

Mary L-B

Have you seen our WICKED Wiki?



Have you had a chance to look through the GSI WIKI lately??

Accessed 45,000 times!

Since it was created in January 2007, the wiki has received over 45,000 visits.

The number of daily visits continues to rise steadily.

Most visitors come from search engines such as Google, but many come from the GSI main website and from the community email archives or their own email. Most people come to the wiki directly to a sub-page..

We are constantly striving to update and add to all of the information. So if you have any information that you want to add, but do not feel comfortable doing so yourself, please e-mail me, and I will add it for you. If you have any suggestions for something you would like to see in the WIKI, please suggest that, too.

In the past month the wiki has received 4,179 visits with an average of 140 visits per day.

In the last 4 months the most popular pages are

1. Main_Page 4,746 visits
2. Sore_mouth 762
3. Muscle_Cramps 689
4. Elevated_Liver_Enzymes 652
5. Anemia 612
6. Doctors_and_Clinics_for_GIST 590

However, the pages that are viewed the most often fluctuate over time, so many others not found here are also viewed regularly

Donna Capps and the WIKI team bbr950@aol.com

Golf Tourney in Honor of Brad Clark—Bonita Springs



The first fund-raising golf tournament ever to be held in Bonita Springs, Florida is to be held in honor of GSI's Operating Committee member, Brad Clark, on December 7th at the BS Colony Golf Course. 115 contestants have entered the competition against each other, hoping to raise a sum in the region of \$9,000.

New Bonita Springs YMCA

Brad has tirelessly supported his community in Bonita Springs throughout the past 15 years. Among other things he has served on the Foundation Board of the Florida Gulf Coast University and their finance committee, supported the Rotary Club, and most notably was Chair at the YMCA through the two years it

took to raise \$7 million to build the new Bonita Springs YMCA, completed in 2005.

Time to give a little back

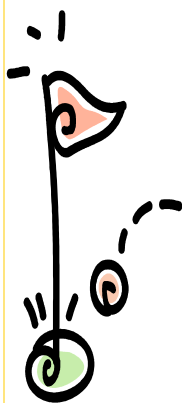
In recognition of Brad's unflagging work for his community, his friend Chip Greenwood has organized this Golf Tournament in Brad's honor, saying: "It is time that our community gives a little back and helps Brad and his battle with GIST with this fundraiser."

Bonita Springs YMCA



The Bob Spiegel Second Opinion Fund

Barbara Doré



Brad Clark has generously asked that the proceeds from the Golf Tourney held in his honor should go to help other GIST patients directly. With Brad's experience of needing to travel to get expert advice and treatment far from home, he asked if the fund could help other patients who find themselves in a similar situation of needing to travel and being unable to due to costs that insurance will not pay.

As a result GSI's Operating Committee is setting up a fund intending to help patients who need to travel for second opinions and treatments, all too often a necessity for those battling this disease, and a cost seldom covered by insurance.

One time \$500

This fund will provide a one time reimbursement grant of up to \$500 to help defray some of the expenses a patient might incur in seeking a second opinion in search of the best advice or treatment for their

Page 12 GIST.

All details including a list of eligible expenses will be available on the website, and when the fund is set up it will be announced via the list and on the website. People who would like to donate to keep the fund going will be able to do so.

In memory of Bob

Originally we were not sure what to call this fund, but with Bob's passing we could not think of a better name than the Bob Spiegel Second Opinion Travel and Treatment Fund, not only to honor Bob but to also exemplify the fund's compassionate and caring intent.

We talked this over with Bob's family and subsequently voted unanimously to approve this initiative.



Brad Clark and his wife Karen

Healing Through Music

Fla Bob Bob Spiegel

There are rare people who endear themselves to others because of their remarkable compassion and caring.

Combine this with an utterly amazing sense of humour and impeccable journalistic skills and someone called Bob Spiegel appears. One in a million....



16 STARS, 4 COUNTRIES AND COUNTING FOR HEALING THROUGH MUSIC

While classical music, easy listening and jazz are running 1-2-3 on the request list, GSI's "Healing Through Music" program has reached and touched many States in the US and the countries of Canada, Australia, and the Indonesian island of Riad.

California leads the list of requests by far, and the variations of the requests are interesting. Some requests have been quite unique, especially the listener who asked for 'Hawaiian Hymns', admitting she knew it was a 'long shot'. So far we've been able to fulfil all requests 'tho we have to go back to the drawing board for the hymn request, but we'll do it. All in all, about 100 CDs have been dispatched from the GSI library, most of them donated by friends, other listers, and some musicians who are the featured artists themselves. Central Florida pianist Lenny Wilson authorized the duplication of his non-commercially produced CD 'All By Myself', a great 'easy listening' album.

Bob wrote the above article and mailed it to the newsletter just days before he so unexpectedly died. He will be greatly missed for his active list participation, wonderful sense of humor and his work with the GSI Operating Committee. Rebeca Porto is continuing the work he started—Healing Through Music.

Check out <http://www.gistsupport.org/gsi-community/healing-through-music.php>

An adventurous sort .. before rule changes turned him off them .. Bob took a ride (drove) a retired, detuned former Rusty Wallace driven Winston Cup NASCAR Stock car on a Super Speedway.



His sense of adventure followed him last year when he took a ride in the belly (front gunners nose bubble too) of a vintage World War II bomber.



He was looking for a similar school with open wheel, open cockpit Sprint Cars .. so he could take a ride in one of those brutal, fire breathing, over powered beasts... USA

GSI - A Celebration of Community

by Lee Ann Lamb, Co-Manager



Volunteers are the heart and soul of GIST Support International—as a grass roots community everyone is a valued participant. Some want to get more involved in one of the various committees that keep GSI running, others just post on a daily basis their stories, questions and support.

We have highlighted some of these committees in this issue of the newsletter. Other committees that we haven't highlighted this time are the Web, Science, and Pediatric Committees. The first three committees form the crux of keeping all the detailed medical information current and up to date, which are crucial to patients as they manage their disease and treatment. Also not mentioned is the List Manager, who keeps the list of members up to date and makes sure they get access to the online listserv for emails.

When GSI was started in 2002, an important goal was to try to form a unique patient group comprised of volunteers. It is so much easier to turn a patient group into a business with full time employees running the operation. We wanted to make GSI more personal than that, while also keeping up with timely scientific and medical news. We wanted to retain the family feeling for our group, but yet gain professional respect from the scientific and medical community for our ability to pass along this very

Fresh ideas and volunteers are always welcome!

technical information on both the listserv and the website. This has not been an easy task, but the fact that we have grown to be the largest GIST patient group in the world is testimony that our goals are being met

Most of GSI's projects come from ideas within the GSI community. They are implemented **by** the community **for** the community, to further our mission of support and education for anyone interested in GIST.

GSI is run entirely by volunteers !

Email: gsi@gistsupport.org

Lee Ann Lamb Co-Manager

Marina Symcox, PhD Co-Manager

Ginger Sawyer Treasurer

Joan Marie Hayno Secretary

Yvonne Blixt List Manager

Donna Capps Wiki Team

Barbara Doré Newsletter Editor

Bradley Clark Newsletter

Bill Davis Newsletter

Phyllis Gay Pediatric Coordinator

Julie Royster, PhD Science Comm.

LeeAnn South Greeting Comm.

Nea Paquet Phone Pals

Rebeca Porto Healing thru Music

Fresh ideas and volunteers are always welcomed to take an active part in the organization—just let us know if you are interested, and choose your role.

