

Dating with GIST: who, what, when, and just plain how?

By Erin Kristoff
LRG Newsletter Editor

Valentine's Day is coming up and that's a time of strong feelings. Sure there are those who pass by this holiday without a backward glance but for the most part you'll see the world turn upside down for one day. Peek inside a classroom and you'll see little girls desperately hoping for a lacey heart made of construction paper. On any city street you'll find people of all ages forking over hard-earned cash for bushels of roses and daisies and lilies. You'll even notice the Anti-Valentine's day crowd. With a box of chocolates in hand, Valentine's is a particularly hard day for them.

In honor of this tempestuous day, we've put together an article on dating. As if it wasn't already a perilous mine-

See **DATING**, Page 11

Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

February 2011

In memory of Reuven Haifi, David Brandis, Rick Sorg, Silvio Manzanares, Glen Banks, Marek Szczesny, Robert David, Ron De Wit, David McCormick & Butch Eller

Vol 12, No. 1

D842V gets its moment in the spotlight

By Jerry Call
LRG Science Coordinator

The Gleevec for GIST story continues to remain one of the most successful stories in oncology. What could be better than a drug that works in 85 percent of patients? As great as this story is, there is room for improvement. Half of the patients on Gleevec for metastatic disease will progress in the first two years and 15 percent of patients are resistant to Gleevec right away or within the first six

months of treatment. AROG Pharmaceuticals may have an option for a few of those patients.

About five percent of GIST patients have a mutation that is completely resistant to Gleevec and to the second-line drug, Sutent. It is the D842V mutation that occurs in exon 18 of the PDGFRA



CALL

See **D842V**, Page 10

2010 Executive Director's Report

By Norman J. Scherzer
LRG Executive Director

The year 2010 was a bitter-sweet year built upon extreme highs and lows.

This year we celebrated a decade of treatment with Gleevec and Sutent, commemorated by an extraordinary gathering at our Life Fest weekend in New Jersey that brought ten year GIST survivors together with family and friends and with the clinicians, researchers and pharmaceutical companies that were responsible for this medical milestone. Lumina-ries of the GIST medical world were



SCHERZER

inducted into the GIST Hall of Fame; Drs. Demetri and Vasella were honored with Humanitarian of the Decade Awards; Dr. Trent was honored with the Clinician of the Year Award and hundreds of GIST patients and their families were honored for countless acts of kindness and of courage. (You can read more about Life Fest 2010 at www.liferaftgroup.org/members_lifest.html)

On the research front, the critical work of the Life Raft Group's research team was dramatically expanded due to a very generous donation by a Dutch patient helping to create "Project D Day". This project seeks to accelerate research into the cure by creating teams focused on the following areas: Se-



Dr. Demetri receives an award at Life Fest 2010 from GISTer, John Poss.

quencing, Gene Knock-down, Drug Screening and Validation. We believe this strategy is our best hope for finding the cure. (Read more about Project D Day in our October 2010 newsletter issue: www.liferaftgroup.org/gist_news/archive/issue/39-october-2010) In addition to our ongoing international networking and support, a Latin American coalition, Alianza GIST, was created at the first meet-

ing of Latin American GIST patient advocates from ten countries held in Monterrey, Mexico. This alliance is focused

See **DIRECTOR**, Page 7

Healthcare 2011 and Beyond: Did the donut hole get a little smaller?

By Diana Nieves
LRG Program Associate

A new year always brings changes. The only thing constant in the world is change. Being informed is one of the greatest ways to help alleviate confusion and stress during times of change, and can empower you to make the best decisions for you and your family. Below is a brief but straight-to-the-point description of Medicare in 2011. Subsequent LRG newsletters will cover various issues on healthcare, especially prescription drugs and how you can receive the help you need and deserve.

What Is Medicare?

Medicare is health insurance for people 65 or older, people under 65 with certain disabilities and anyone at any age with End-Stage Renal Disease (ESRD) (permanent kidney failure requiring dialysis or a kidney transplant). Medicare has different parts to help cover specific services.

Medicare Part A - is Hospital Insurance that helps cover inpatient care in hospitals and ies, hospice, and home health care.

Medicare Part B - is Medical Insurance that helps cover doctors' services, hospital outpatient care, home health care and some preventive services.

Medicare Part C (Medicare Advantage Plan) - is another Medicare health plan (like an HMO or PPO) choice you may have which are offered by private companies approved by Medicare. If you join a Medicare Advantage Plan, the plan will provide all of your Part A and Part B coverage. Medicare Advantage Plans may offer extra coverage, such as vision, hearing, dental, and/or health and

wellness programs. Most of them include Medicare prescription drug coverage (Part D see below). Medicare pays a fixed amount for your care every month to the companies offering Medicare Advantage Plans. These companies can charge different out-of-pocket costs and have different rules for how you get services (like whether you need a referral to see a specialist, etc.). These rules can change each year.

Medicare Part D (Medicare Prescription Drug Coverage) – is a prescription drug option run by Medicare-approved private insurance companies. Part D helps cover and/or lower the cost of prescription drugs. This coverage can help protect you against higher costs in the future. Each plan can vary in cost and drugs covered. Two ways to get Medicare prescription drug coverage are through

1. Medicare Prescription Drug plans, or
2. Medicare Advantage Plans or other Medicare Health Plans

To join a Medicare Prescription Drug (Part D) Plan you must have Medicare Part A **OR** Part B. To join a Medicare Advantage Plan (Part C) you must have Medicare Part A **AND** Part B. If you have limited income and resources, you may qualify for extra help to pay for Medicare prescription drug coverage. You may also get help from your state.

CHANGE in 2011

Most Medicare drug plans have a coverage gap (also called the Donut Hole) which means that after you and your drug plan have spent a certain amount of money for covered drugs you will then have to pay the costs out of pocket for your prescriptions up to a yearly limit. Enrollees are responsible for paying 100 percent of their prescription drug costs when they hit the donut hole. In the past enrollees paid full price for their prescription drugs but in 2011 enrollees in

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
155 US Highway 46, Suite 202
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.

the donut hole receive a 50 percent discount on covered brand name prescription drugs.

Yes you read it correctly. **YOUR PRESCRIPTIONS (if they are covered brand name prescription drugs) WILL BE HALF PRICE WHEN YOU HIT THE DONUT HOLE** your yearly deductible plus your coinsurance or copayments and what you pay in the donut hole all count towards the total out of pocket yearly limit. The limit doesn't include the drug plan premium you pay or what you pay for drugs that aren't covered. This is extremely important for you to consider when calculating your overall yearly costs, making a decision

GIST Research: Articles on the Science of GIST

February 2011 clinical trials update

By **Jim Hughes**

LRG Clinical Trials Coordinator

Bayer initiates a randomized Phase III trial of Regorafenib in GIST: On January 10, 2011 Bayer Healthcare in Berlin, Germany announced the initiation of a randomized phase III trial of Regorafenib (BAY 73-4506) for Gastrointestinal Stromal Tumor patients. This is a third-line trial for patients who have failed both Gleevec and Sutent.

Dr. George Demetri at Dana Farber Cancer Institute (DFCI) in Boston heads the steering committee for the trial and is quoted in the press announcement released by Bayer:



DEMETRI

“This Phase III trial was designed based upon strong signals of clinical activity seen in an academically-designed, non-randomized, single-arm Phase II trial in GIST patients whose

disease had exhausted all standard treatment options.”

However, the results of the Phase II Regorafenib trial in GIST have not yet been published.

The trial description indicates that subjects who have had “prior treatment with any other vascular endothelial growth factor receptor (VEGFR) inhibitor” are not allowed. Other VEGFR inhibitors used in GIST include Nexavar and less commonly, Votrient. Representatives from Bayer have verified that this requirement excludes GIST patients who have had prior Nexavar or Votrient treatment.

The Regorafenib Phase III trial is described as a randomized, double-blind comparison of two arms (or patient groups) assigned on a 2:1 basis. In a double-blind trial neither the patients nor the trial clinicians will know which group an individual patient is assigned to. Sixty-six percent of patients will be



randomly assigned to the active group and will receive 160 mg Regorafenib. Thirty-three percent of patients will initially receive only an inactive placebo. Patients entering the trial will then have a two out of three chance of receiving the active drug.

Patients who experience progression during the trial will be subsequently “unblinded”. At unblinding both the patient and the clinician will find out if the patient is receiving Regorafenib or placebo. Patients who are unblinded and who are on placebo will be given the option to cross-over to the active group and receive Regorafenib. The trial protocol description indicates that patients in both groups will be treated in 28 day cycles with patients on treatment for 21 days then off treatment for seven days. Patients will be evaluated by CT or MRI every four weeks for the first three months or cycles. The RECIST criteria

See TRIALS, Page 13

Masitinib Phase II Trial Reports Benefit in New GISTs

By **Jim Hughes**

LRG Clinical Trials Coordinator

At the American Society of Clinical Oncology Gastrointestinal (GI ASCO) Symposium January 20, 2011, researchers reported progression-free and overall survival benefit in newly diagnosed advanced GIST patients in an ongoing Masitinib (AB1010) Phase II trial in France.

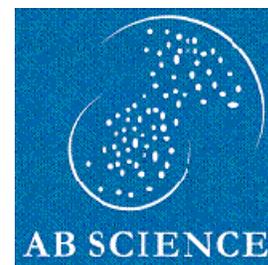
Dr. Jean-Yves Blay at Centre Léon Bérard,

Lyon, France, a noted GIST researcher



and current president of the European Organization for Research and Treatment of Cancer (EORTC), presented the poster for the team that represented six centers in France and the manufacturer, AB Science in Paris.

Masitinib, an inhibitor of KIT, PDGFR, FGFR3 and Lyn/FAK has shown increased potency against common primary GIST mutations in the lab. The phase II trial was designed to evaluate the efficacy and safety of oral Masitinib. From June 2005 to April 2007, 30 advanced GIST patients who had not received any prior drug were recruited. Nine patients are still under treatment.



Global GIST Network adds new GIST representative

Sweden
Susanna Allgurun Neikter
 gist.sverige@gmail.com

See MASITINIB, Page 14

Fight or flight: A chance encounter in the sky compels one GISTer to do her part

By **Piga Fernandez**
Alianza GIST
Chile Representative

My journey as a cancer fighter began fourteen years ago during a routine gynecological checkup in December 1995, when a recto-vaginal septum tumor was detected. After a large resection of the tumor, which was classified as leiomyosarcoma, a round of radiation therapy followed.

Four years later, in 1999, I had a local recurrence that was again resected and as the surrounding tissue had been damaged by the previous radiation; a temporal colostomy was required, followed by a post-operative brachytherapy treatment.

Until that time, I trusted my attending physician, but the following year (2000), when a new cancer recurrence surfaced, he failed to give it any significance, which led me to seek a second opinion

as I lost faith in him and did not feel he provided the support and care I needed... I don't know, maybe he thought the battle was lost, something that I could not let enter my mind.

The oncologist I consulted later left in me a huge impression, as he approached my case with commitment and empathy. He asked for a few days to study my medical chart and requested more specific tests, which confirmed how far off base my previous physician had been. The new diagnosis was "local recurrence with hepatic metastasis." This again required surgery to resect the tumor and a permanent colostomy. A month later, I underwent a hepatectomy to resect three metastatic nodules.

In 2002, two more nodules were detected in the liver, but this time a resection was impossible due to their location. Again, my oncologist took a few days to study this new development and to consult with other specialists in the United States. He then discussed with



Piga (center) with Dr. Alexander Sakano (left) and Vicky Ossio (right) at the first meeting of Alianza GIST.

me what he felt was my only chance, a treatment with a new drug that was been used in chronic myeloid leukemia (CML) and which, depending on the results of immunohistochemical tests, could be a valuable treatment option for me. Waiting for the results of the tests was extremely difficult. I was facing the

See PIGA, Page 9

Latin American GIST Coalition, new challenges on the horizon for 2010

By **Vicky Ossio**
Latin American Liaison

The year 2010 is gone, an important year for the Latin American GIST Coalition. In 2010 the Monterrey Declaration was signed, during the first summit meeting of the group. The group had the privilege of meeting the LRG research team, who works on a daily basis to find the cure for GIST.

The year 2010 was also the year of the creation of more localized groups, such as Argentina, Chile, Colombia and Nica-



OSSIO

ragua, among others. Last year also brought new challenges in different countries related to the access of second-line drugs for GIST. We had some cases of patients, who after becoming resistant to Glivec, were prescribed Sutent or Tasigna. This has put into evidence the difficulty in accessing these new types of drugs, either through the social health system or through private insurance. Our representatives in these countries are facing an



uphill task to access these new drugs. This fact also demonstrated the lack of adequate treatment for GIST in almost all countries in the region. There are few countries that have a team of doctors who treat this disease in an integral way

See ALIANZA, Page 12

NORD Hosts Forum for FDA Commissioner and Patient Leaders

WASHINGTON, January 21, 2011— Food and Drug Commissioner Dr. Margaret Hamburg today conducted an unusual one-on-one dialogue with leaders of approximately 60 patient organizations at a forum hosted by the National Organization for Rare Disorders (NORD).

NORD organized the meeting so that Dr. Hamburg could share with the patient advocates her vision for FDA and hear directly from them their hopes, needs, and concerns.

“I come today to ask for your help, your guidance, and your support at this critical moment for FDA,” Dr. Hamburg told the patient leaders. “We welcome and depend upon input from organizations like yours.”

NORD President Peter L. Saltonstall assured the Commissioner that the patient community is eager to be involved

and supportive of efforts to modernize and streamline the development of safe, effective treatments.

Dr. Hamburg said there are three areas she considers essential to position FDA for today’s needs and those of the future:

- to assure that FDA maintains “and earns every day” the trust and confidence of the American people
- to modernize regulatory science to better incorporate scientific advances and
- to address increasing globalization

“Many of the products we regulate today come from outside the country,” she said. “Of the active pharmaceutical ingredients in medical products Americans use, 80 percent come from outside the U.S.”

Dr. Hamburg emphasized the importance of engaging internationally to share scientific data, harmonize the



regulation process, and assure that critical needs of patients and families are being met.

Questions from the patient advocates covered a broad range of topics, including how FDA determines the risk/benefit ratio when considering new products and how it communicates its expectations to those developing new products.

Dr. Hamburg assured the patient representatives that their voices are heard at FDA. She encouraged them to remain active participants in the regulatory process.

“Never underestimate the impact you bring to these issues,” she said.

6th NIH GIST clinic once again successful

On January 19-21, 2011, the National Institutes of Health (NIH) held its sixth Pediatric and Wildtype GIST Clinic. This clinic focuses on a particular subset of GIST survivors that respond differently to current successful drug therapies for GIST. The Clinic serves to research Pediatric and Wild-type GIST as well as provide consultation for these patients from GIST experts who dedicate their time to travel to Bethesda, Md. from all over the country.



“I learned a lot and feel so much better having the NIH team as an additional resource,” said LRG member, Anne Pacifico.

PACIFICO Everyone with Pediatric or Wildtype GIST is encouraged to participate in future clinics. Patients are provided travel and lodging support to attend the clinic within the United States and partial support is provided for international participants. The next clinic is scheduled

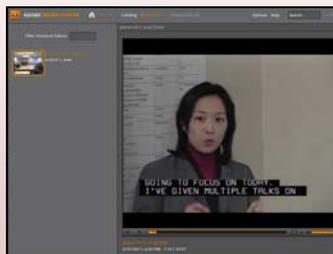
for June 2011.

You may visit the website at www.pediatricgist.cancer.gov. Dr. Su Young Kim, Pediatric GIST Clinic Coordinator, and his team can be reached at ncipediatricgist@nih.mail.gov.

Presented at the NIH Pediatric & Wildtype Clinic: Skin Toxicities in Targeted Therapies by Dr. Heidi H. Kong

To view this presentation go to: <http://videocast.nih.gov/summary.asp?Live=9939>

You can view it on the webpage or download to your computer.



Banks passes at 63



Capt. Glen P. Banks died December 15, 2010 in his Westminster, Maryland home. He was 63 years old.

Raised in New York, Capt. Banks served in the U.S. Navy and sailed on merchant ships during Vietnam

and the First Gulf War. He later worked as an officer on tankers. He eventually joined Puerto Rico Marine Management in 1986, where he sailed for many years.

In 1978 Capt. Banks joined MM&P (Masters, Mates & Pilots) and later got his start in union leadership when he was elected Gulf Port Vice President in 1997. His leading role in the union continued when he was elected to three terms as the union's Secretary-Treasurer.

Friends describe him as generous, caring and as having a great sense of humor. He is also described as a devoted family man, who loved nothing more than spending time with his sons and wife. He is survived by his wife Elizabeth Banks, sons Thomas and Glen Banks and Thomas' wife Vonda.

State of the GIST community: Life Raft Group's patient registry demographics

By Magda Sarnas

Patient Registry Supervisor

As of December 31, 2010 the Life Raft Group's Patient Registry has now accounted for 1,279 cases of GIST. The members of this registry have reported their clinical information to us as it pertains to their treatment of GIST. Of these 1,279 cases, we are here to report some key demographics that will help you understand who is a part of Life Raft Group GIST Community. Please note we are not making any assumptions or generalizations on who has a higher likelihood of contracting GIST based on gender, age or marital status. We would simply like to make everyone aware of certain facts in the GIST community. We look forward to reporting more from

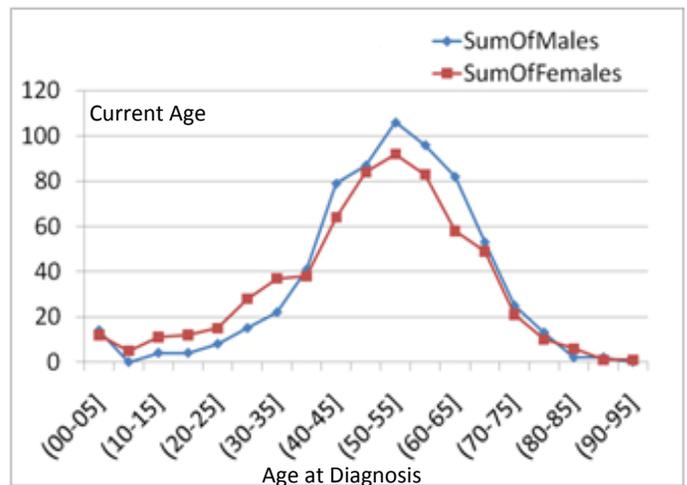
our registry in future newsletters.

We have found that as of December 31, 2010 that the gender make-up of this registry has only a slightly higher number of men than women (Figure 1). Although the majority of cases that have been reported to us under the age of 35 have a higher population of females, males outnumbered females when looking at patients diagnosed at 35 years of age or older.

The marital status of registry has a predominantly high number of patients who are married (Figure 2). The second largest group of patients is single, and third largest group are divorced. When we observed the age at diagnosis of patients (Figure 3), we have a high number of cases who are between the ages of 50 and 55. There are more men than women who are diagnosed in this age group. The youngest case we have in the registry is seven years old

and the oldest case of GIST is 92. Although in the previous chart we see that the most cases of GIST occur at age 50 to 55, we see that there are significantly more women being diagnosed under the

Figure 3: Gender & Age at Diagnosis



age of 35 (Figure 4). Women make up 75 percent of cases who are diagnosed between the ages of five and 18, 65 percent of the ages from 18 to 35 and 46 percent diagnosed at age 35 or above. The high percentage of females diagnosed below the age of 18 is typical of pediatric GIST. The number of females

Figure 1: Gender

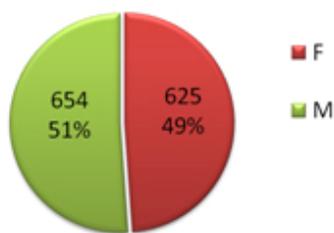


Figure 2: Marital Status

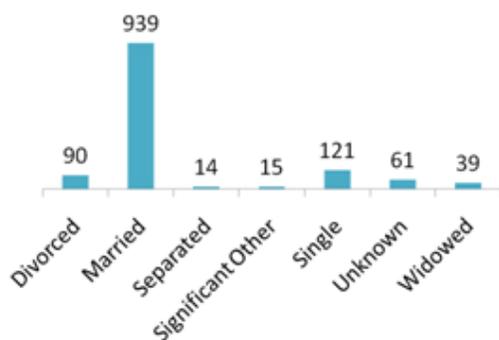
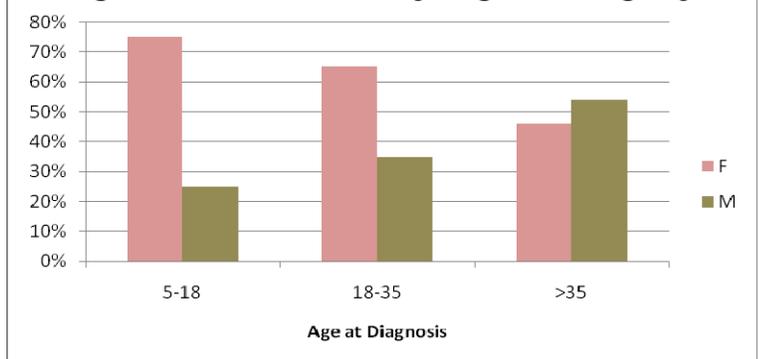


Figure 4: Gender by Age Category



diagnosed between the age of 18 and 35 has a ratio of females to males that is between the younger group and the older group. This may represent a mixed patient population containing both pediatric-type GIST and adult-type GIST.

DIRECTOR

From Page 1

on four key principles facing Latin American patients:

- To improve the knowledge of patients and physicians.
- To increase patient access to adequate treatment and resources.
- To support local patient support organizations, including the creation of new ones.
- To encourage collaboration and coordination with the physician community.

(Learn more about Alianza GIST in our April 2010 newsletter issue:

www.liferaftgroup.org/gist_news/component/zine/issue/38-april-2010)

While these initiatives were taking front row, we continued to improve our patient registry and tissue bank, to expand our educational, outreach and advocacy efforts and to provide one-on-one consultation to patients and oncologists seeking treatment options.

Perhaps the most poignant statement of the year was delivered at the Life Fest Meeting by Dr. Jonathan Fletcher, the head of our research team:

“In Dallas, we (the LRG research team) were asked by Norman to get up on the platform in front of this incredible group and say we were going to cure GIST and I was concerned with saying this because we can’t cure it...but, I am delighted to say and in a clean conscience, four years later, that our understanding of GIST has grown such in the last four years that **now we can stand up on this stage and say with determination and conviction that we are going to cure GIST.**”

However, we cannot dwell only on the year’s highlights. In spite of these successes, many GIST patients continued to endure disease progression and too many continued to die because they ran out of treatment options

Even more frustrating were those GIST patients who died because they



The first seeds of Alianza GIST were planted in Monterrey, Mexico.

could not access treatment or because medical providers failed to use current knowledge appropriately.

The sad irony is that we could dramatically increase the survival rate of GIST patents simply by using what we currently know and without the introduction of a single new drug. Yes, we patient advocates do know that in a perfect medical world all knowledge would be created by randomized double blind clinical trials, reported in prestigious medical journals and provided with the seal of approval of oversight agencies like the United States Food and Drug Administration (FDA). But the reality of rare cancers such as GIST is that not everything can be investigated by such clinical trials and in the interim we really do have to use what we currently know to try to stay alive.

As my “New Year’s Resolution”, I would like to tackle some pressing questions with the help of the medical and GIST community.

To oncologists: Tests are currently available to determine the mutational status of GIST patients; these tests have been available for over eight years. About 15 percent of GIST patients will have an exon 9 mutation and clinical trials have shown that patients with exon 9 mutations receive far more benefit from a higher dose of Gleevec. **Why are so few GIST patients in the United States receiving such mutational tests?**

To the US FDA: Gleevec has been clearly demonstrated to shrink tumors, both primary and metastatic. If you administer Gleevec for a few months prior to surgery for a primary tumor, you are likely to shrink the tumor and make it easier for the surgeon to remove it and just as importantly, doctors can ascertain whether the cancer is responsive to Gleevec should there be recurrence fol-

lowing surgery. **Can we accept this without a randomized clinical trials requirement, particularly when such a trial is unlikely to happen?**

To the pharmaceutical companies: The LRG accepts that drug companies must make a profit and must navigate the complicated clinical trial process to do that. But there is not necessarily a conflict between good science and good business.

- The current clinical trial criteria for evaluating whether a drug is effective against GIST are called RECIST. Many GIST specialists and respected members of the medical community have commented that it is outdated and misleading. **Why is the more relevant CHOI criterion or just plain disease stability not being used?**
- Including mutational testing within your protocol may mean that you will find that some mutations respond to your drug while others do not. **Why are you not routinely including this testing when, as a result, what may have become a clinical trial failure may now become a success?**
- A number of pharmaceutical companies have begun consulting with patient advocacy organizations in order to garner help designing more effective clinical trials. **Why isn’t this common practice?**

It may seem as if I’m coming down a bit hard on the medical community. But in order to make 2011 a better year than 2010, we owe it to ourselves to push the boundaries of convention—to focus not on what is familiar, but what is right.

It is the patients, caregivers and advocacy groups who must stand by and watch our friends leave this world. If we know something is wrong, we owe it to their memories’ to try and make it right.



FLETCHER

He never met a stranger, only friends: Beloved LRG member passes at 66

Robert “Butch” W. Eller, age 66 of Pennsville, NJ, passed into heaven on Wednesday, January 19, 2011 at his residence surrounded by his “Little Darlin” and wife, Jeanie, and loving son, Ryan, as well as family and close friends. Butch was diagnosed with the rare cancer (GIST) Gastro-Intestinal Stromal Tumor in November of 2003.



Butch and Jeanie pose in the “raft” at Life Fest 2010.

Born on September 1, 1944, to the late Bertha “Sis” Keen Eller, Butch was a lifelong resident of Pennsville. He graduated from Pennsville Memorial High School with the class of 1963 he enlisted and served in the US Navy from 1963-1967, a veteran during the Viet Nam War era. He also served with the US Army Reserve and the Delaware Air National Guard retiring as a Staff Sergeant from the US Air Force in 2004.

Butch worked for his brother-in-law, Stu Stephens (deceased), for three years at Stephens Plumbing & Heating and continued as needed for many years afterwards. In 1970 Butch joined the Pennsville Township Police Department as a Patrolman. In 1975 he was assigned to the Detective Division, was promoted to Detective Sergeant in 1976, and was promoted to the rank of Lieutenant in 1989. In April 1994, Butch was named Chief of Police of the Pennsville Police Department, which was his life long goal achievement, retiring in July 1997 with 27 years of service.

In January 1995, Butch attended the FBI National Academy in Quantico, VA for an eleven week professional course for Advanced Investigative and Management Training for law enforcement officers in executive positions. In March

1995, he was a proud graduate of the 180th session of the FBI National Academy.

Certified in scuba diving Butch, along with friend Ted Vengenock, founded the Salem County Dive Team. He also initiated the “Citizens Police Academy” where township residents got an inside look and understanding of police work through training and classroom instruction.

During his law enforcement career he obtained certification in his Arson Investigation and Fingerprinting. Butch became a New Jersey Certified EMT and he received his degree in Criminal Justice from Salem Community College in 1991. Butch was a long time member and past President of the Fraternal Order of Police (FOP), the South Jersey Police Chief Association and the Retired Police Officer’s Association. At his recommendation, the project on the new FOP building was implemented.

Butch’s other achievements and affiliations include being a member of the Millwright & Machinery Erectors Union - Local 1545 in New Castle, DE, he received his CDL w/Hazmat endorsement. He volunteered as a Little League coach in Pennsville and the Habitat for Humanity in North Fort Myers, FL. Butch, along with his brother Jack, became Master Masons of the Masonic Order Excelsior Penns Grove Lodge #54 F.N.A. Butch also belonged to the Pennsville VFW #1952 and American Legion, the Salem County Sportsman Club, and the Salem County Chapter of the American Red Cross. He was also a member of the Family Motor Coach Association (FMCA) and Jersey Gems Camping Club.

From 1984-2002, Butch owned and operated BJ’s Video Production Service along with his wife. Butch and Jean also co-owned and operated, with his sister Bess and her husband Arthur, the Bay Country Campground in Rock Hall, MD for seven years. During that time he served as Secretary for the Rock Hall Business Association and MD Campground Owners Association. After retirement Butch worked for Ross Fogg Oil Company in Salem, Taylor Construction in Pennsville, Bay Shore Ford Truck Sales in New Castle, DE, and most recently for Lucas Greenhouses in Monroeville, NJ.

Over the last two years Butch was under the care of Dr. Jonathan Trent at MD Anderson Cancer Center in Houston, TX. Dr. Trent and Butch formed a special type of bond that is not typical in your normal doctor/patient relationships, he considered Dr. Trent not only a fantastic caring doctor but a valued friend and mentor. Butch was able to honor Dr. Trent as Clinician of the Year at the Life Raft Convention in June 2010. During the ceremony Dr. Trent turned the tables on Butch presenting him with a true



Butch presents Dr. Trent with the Clinician of the Year award .

PIGA

From Page 4

temporality of life, although filled with great hope and faith, I saw before me a light, a chance to keep on living.

The results were as expected, it was a GIST that reacted to this new drug whose name was unknown to us at the time. The race to learn more about what a GIST was began in earnest and to try to get a hold of this new miracle drug. My surprise in learning that it was precisely Novartis that manufactured this drug was enormous, as just very recently one of my sons had began working for this pharmaceutical company. And so, the network of contacts and generous angels was set in motion.

We learned about the Max Foundation and Novartis Glivec International Patient Assistance Program (GIPAP) program and I applied immediately. For family reasons, I was living some months in Guatemala and some others in Chile during that time, so I was blessed to be accepted to the Guatemalan GIPAP program. I then started my treatment with Glivec, followed by periodic checkups every three months in Guatemala.

The power and magic of the solidarity around me does not cease to amaze me! I remember having received the gift of airplane tickets to travel to my checkups from good people that I didn't even know, and I remember with immense gratitude the support of my family and friends who looked after my children while I was away.

Two years later, already permanently residing in Chile, I entered into the Chilean GIPAP program, which has allowed me until today to continue my treatment with Glivec without interruption and with great success.

Once again and every day, I give thanks to the Lord for the gift of life, for the generosity of Novartis, for the effective and close way the Max Foundation monitors my treatment, for the solidarity of my friends near and far, and for the strength shown by my children and their support throughout this journey, as they are the main reason behind my drive to fight this battle. Thanks to all of them, I

have been able to look at the future with new and hopeful eyes.

Today, I also want to express my heartfelt thanks to the Life Raft Group for their invitation to participate in their Alianza GIST initiative. At this point, the same as Norman, I want to share with you something that happened during my return trip home after participating in the Latin American GIST Coalition planning meeting in Monterrey.

A Uruguayan lady who lives in New York sat beside me on the plane, and just after we had exchanged but a few words, one of those magical moments when two souls connect occurred. She began telling me part of her personal story.

Her husband had passed away two years prior after a battle with cancer. When she was describing to me the development of his illness, it was as if she was narrating my own story... an initial diagnosis, surgeries, radiations, metastasis and, in his case, also chemotherapy. The similarities were uncanny, the big difference was that her husband was dead and I was alive.

So many questions filled my mind! Was he diagnosed properly as was I and therefore received the appropriate treatment? Did he have access to enough information so as to decide whether or not to trust his physician's diagnosis? Could it have been a misdiagnosed GIST? And if so, had it been identified and

treated properly, as in my case, could he still be alive?

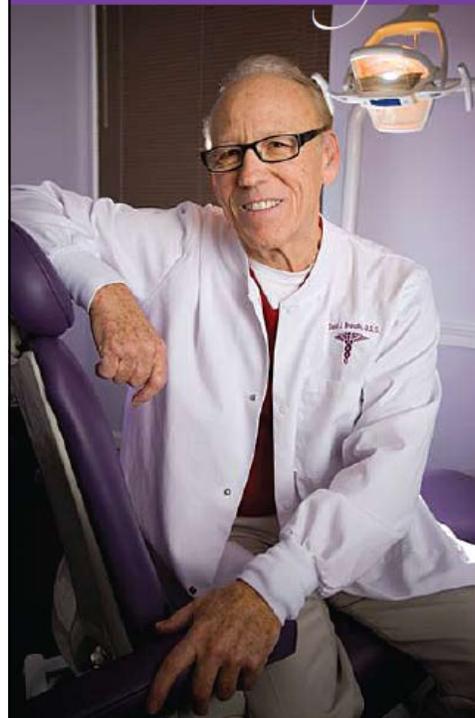
Of course, we will never know the answer to all those questions, but after the Monterrey meeting I felt compelled to return to my country to try to do my bit in the fight against this disease. This conversation further cemented my decision and confirmed the need to provide to physicians the largest amount of information possible related to this rare type of cancer so they can draw upon such information when making a diagnosis.

It also confirmed the need to arm GIST patients with all the wealth of information available so they may better understand what is happening inside their bodies. I need to support them so they never feel alone in this fight for their lives, and in some way, give to others the same gifts I have received during my journey.

DAVID J. BRANDIS, D.D.S.

February 14, 1940 - November 25, 2010

In Loving Memory



For more than 40 years you served people of Springfield, central Illinois and nationally with caring and compassion.

You exemplified the highest of standards and professionalism in cosmetic dentistry.

And you treated your partners, staff and patients like family.

TANYA L. DeSANTO, D.D.S. & JULIE R. NATHANSON, D.D.S.
AND EVERYONE AT PRAIRIE DENTAL GROUP

A legacy. A hero. A friend. Thanks for the memories.

D842V

From Page 1



VON MEHREN



HEINRICH

gene and it represents almost two-thirds of the PDGFRA mutations that occur in GIST.

AROG Pharmaceuticals has announced the start of a new phase II trial specifically for patients with metastatic/advanced GIST who have the D842V mutation (ClinicalTrials.gov Identifier: NCT01243346). The trial is anticipated to open at Fox Chase Cancer Center in Philadelphia, Penn. in April 2011 under

Dr. Meg von Mehren, Dr. von Mehren is the Director of the Sarcoma program at Fox Chase. A second site is planned at Oregon Health & Science University (OHSU) in Portland, Ore. under Dr. Michael Heinrich at the same time. Fox Chase and OHSU were also two of the four sites involved in the very first Gleevec for GIST trials.

This trial will be testing a new drug, Crenolanib (CP-868,596) for the first time in GIST patients. AROG acquired this drug from Pfizer and it has already been through phase I testing.

Mutations in exon 18 occur in a part of the gene that codes for the activation loop of the PDGFRA protein. Activation loop mutations have been a challenge to target. Most tyrosine kinase inhibitors like Gleevec, will only bind to and block their drug targets when the proteins are in an inactive state. Mutations in the activation loop destabilize the protein so that it can't assume the inactive state necessary for drugs like Gleevec to bind to.

PDGFRA D842V kinase has been resistant to Gleevec and Sutent. Crenolanib is able to bind tightly to D842V mutations, blocking the signal that drives this type of GIST. Interestingly,

while Crenolanib potently blocks the D842V mutation and wild-type PDGFRA, it does not inhibit PDGFRA mutations that occur in exon 12 or exon 14. Fortunately, Gleevec effectively inhibits the mutations that occur in these two exons.

Crenolanib is a bit unusual among tyrosine-kinase inhibitors (TKIs). Most of these drugs inhibit at least three and often more kinases, many or most of which do not contribute significantly to the cancers the drugs are treating. This lack of specificity leads to side-effects. Crenolanib is very specific, inhibiting the PDGFRA and PDGFRB receptors and not much else. In phase I trials, the drug has been very tolerable, with nau-

sea being one of the main side-effects. This can be treated with anti-nausea medications like Zofran.

Finding a drug to inhibit the D842V mutation has been a difficult challenge. Matching the right patients to the drug may prove to be an equally difficult predicament. The problem is that the United States is lagging behind when it comes to performing mutational testing. As reported at the 2009 American Society of Clinical Oncologists (ASCO) meeting, only four percent of GIST patients

in the United States have received mutational testing according to an observational registry of GIST patients called the reGISTry (Novartis Pharmaceuticals). This number compares to 60 percent with mutational testing in France and 40 percent to 50 percent in Germany.

Trying to find a patient with a mutation that makes up only five percent of a rare cancer when only four percent of all GIST patients are having testing is like trying to find a needle in a haystack. It may prove challenging to recruit enough patients for even a small trial.

According to Dr. von Mehren, "There is a growing understanding of differences in GIST tumors and response to therapy. At present, the greatest use for mutational testing is consideration of dose escalation of [Gleevec] in patients with exon 9 tumors. Most experts be-

lieve that it is in a patient's best interest to do so, but because of increased toxicity with higher dose therapy, the presence of exon 9 should be documented before escalating the dose. We also have the opportunity to start testing drugs for patients that are not sensitive to [Gleevec] and [Sutent], as in this trial. Because of this, both European and US guidelines recommend mutation testing at the time of diagnosis, primarily for the convenience of obtaining the informa-

	Gleevec (as first-line)	Sutent (as second-line)
KIT		
Exon 9	Intermediate – appears to require higher doses	Good
Exon 11	Good	Poor
PDGFRA		
Exon 12	Good	N/A
Exon 18 - except D842V	Good?	?
Exon 18 - D842V	Resistant	Resistant
Exon 18 - D842Y	Good (lab results)	N/A
Wild-type GIST	Poor to fair	Good

Silvio Manzanares, a tireless entrepreneur and GIST patient

By Maria Teresa Ponce
Nicaragua representative

Silvio Manzanares was a tireless fighter, a man with great courage and optimism, with a brilliant mind, the one who never said no when a doctor ordered a treatment or procedure, always an entrepreneur since he got sick in 2001. He changed the way of earning in life, conforming his job to his new state of mind.

He was always a great creator of new ideas. He was a great engineer, full of projects for his personal life and his work. If something didn't work out, he always did something else until reaching success. He had an excellent sense of humor, which helps us, his family and friends, to remember him with much joy and through many anecdotes, but mainly

with so much love. His 12 years old daughter shows all of these characteristics, facing with strength the loss of her beloved father.

His memories live in our minds. All of those who met him feel his presence. He died knowing that he received so much love and support during the time he was sick. He never felt alone. In his sick bed to the end of his days, he always wanted to help other patients to fight against this terrible beast. Silvio was very thankful for the help given by the Life Raft Group, and found that the LRG really fulfills its mission to give support and advice to patients and caregivers, so they feel they are not alone in their fight against GIST.



A great man is gone, but he will never leave our minds and hearts. At the end, he put himself into God's will, being confident that God would do the best for him and for the rest. He is no longer with us, but he will not suffer anymore, because he is at peace in heaven. Those who stay on earth should not give up in our fight against this cruel disease.

Silvio was a role model, because he always looked for ways to help other patients in his position as Secretary of Fundación Alas de Vidda (an organization in Nicaragua to help patients with GIST and CML).

May God have him in his glory, rest in peace. We will follow the way Silvio confronted life in difficult situations. He never felt defeated by GIST.

DATING

From Page 1

field, it is even further complicated when you are living with cancer.

This article is the first of two parts; part two will be featured in the April 2011 issue.

When dating, people who have had cancer often avoid talking about their illness. At a time when closeness is so important, it might seem risky to draw attention to your problems.

"With GIST, we are lucky that most of us still have the ability to date without the other party having to jump the emotional and mental hurdle of a deformity," states Jason DeLorenzo, Pediatric GIST survivor, "However, what will happen when this person knows that I face my death every day, and life with me will force you to face that reality yourself?"



DELORENZO

The American Cancer Society cautions against keeping

silent for long, "Sometimes you can ignore the cancer for a time. But when a relationship gets serious, silence is not the best plan. If you don't talk about it, cancer can become a secret that will limit your closeness to your partner. A loving partner needs the chance to accept you as you are."

You can avoid rejection by avoiding dating, but then you miss out on the chance to have a happy healthy relationship.

Eric Tan, a young GISTer in Singapore offers, "Ask yourself this question, 'Do I want to have a relationship or not?' If you are unsure or feel negatively about it, then I suggest you find a lot of hobbies (that can last you until old age), pay more attention in building your friendships and be happy for as long as you are alive. However, if the answer is yes, then use GIST as your strength instead to pick up your lazy hand and dial that number and ask out someone for a date!"

For Eric, these words are as much for himself as they are for other GISTers.



Tan, cozying up with some of the LRG ladies during a recent trip to New York.

"I met a girl, we got along real fine, but before we were official, I needed her to know the truth. GIST eventually became the end of the relationship. Did I expect it? Yes. It's just harder when it became a part of reality and I am in this part.

She told me the expected textbook reply: 'What will happen to me if you are gone?' and 'What is going to happen to our kids and I cannot take this kind of pressure.' Surreal isn't it? But who can blame her? From what I saw from her reactions, it must not have been easy for her as well. She was as confused as I was whether this cancer can bring a happy ending."

"Dating with a GIST leads to two major difficulties," says Estelle Lecointe,

Man of God, musician, proud father and husband, McCormick will be missed

Robert David McCormick, 69, formerly of Jacksonville, FL, died at home in Marianna, FL on December 27. Mr.

McCormick was a long-time resident of Marianna, FL, a deacon and member of First Baptist Church where he was active in the music program, having served as director for the handbell choir, was Interim Minister Music for two terms and supply organist for many years.

He was a former member of the GA Sons of Jubal. David was a long time member of the FL Worship Choir. He retired from the FL Baptist Convention serving as Manager at Blue Springs Baptist Assembly in Marianna, FL where he served for over 18 years. He was a

graduate of Norman Junior College in Moultrie, GA and Shorter College in Rome, GA where he received a B.A. degree in Music. He earned a Bachelors of Church Music Degree from Southwestern Baptist Theological Seminary in Ft. Worth, TX.

Employment included Minister of Music, First Baptist Church, Lake City, FL, McCaysville, GA, Buford, GA, North Pompano Baptist Church, Pompano Beach, FL, St. Johns Park Baptist Church, and Hogan Baptist Church in Jacksonville, FL. He taught Sign Language at Chipola College in the Adult Education program, and worked for the Jackson County School Board as an interpreter for the Deaf at Malone School

and Graceville High School. He was organist at St. Luke's Episcopal Church in Marianna for over 12 years.

He is survived by his wife, Carolyn O. McCormick of 44 yrs of marriage; a daughter, Michele McCormick Savery and husband, Gerald Savery Jr. of Jacksonville, FL; a son, Michael S. McCormick and wife, Christy Pittman McCormick, of Kingsland, GA; grandsons, Troy and Kyle Savery of Jacksonville, FL, one granddaughter, Jeanette Savery, and grandsons, Caleb and Casey McCormick, of Kingsland.

In lieu of flowers the family requests that contributions be made to Gideons

International or Covenant Hospice of Marianna.

ALIANZA

From Page 4

(family doctors, gastroenterologists, oncologists, pathologists, radiologists).

We have just too many patients in Latin America who do not receive adequate advice about drug regimens and how to fight side-effects. We have just too many patients in this region, almost all, that do not know their mutation type. This is so important when it comes to defining the type of treatment, the correct drug dosage, the most adequate second-line drug according to the type of mutation, etc.

All of these issues are important. They could make a difference in the rate of survival for GIST. The evidence is clear: Patients in Spanish speaking countries lose the battle before patients in countries where access to information is more likely.

What can we do?

First, we have to realize that GIST is a rare disease and that because of this, most oncologists around the world will never have the chance to see one case of GIST. For the same reason, we should not expect that an oncologist that has one or two patients with GIST will know

much about the disease. This is where we, as patients & caregivers, as an organization, should step in. As an organization, we should reach out to more patients, doctors and health centers in order to help them access information.

As patients and caregivers we should realize that we have to be in charge of our treatment. We have to be in control. This means that we have to use the strength that information gives us, the courage to ask our doctors for the treatment we deserve and ask the insurance companies for the drugs we need, drugs that can extend our lives. We should not be afraid to inform the doctors about the next step.

Second, we can contribute to research in more than one way. To find the cure for a rare disease like GIST, researchers need tissue samples to perform different tests. Donating tissue is easy, and by donating, we will receive at no cost the mutation results.

Jeroen Pit, a Dutch patient who recently donated a large amount of money to the LRG research team commented in the LRG October newsletter: "Why are we so passive? If everyone sits still, not much is going to happen... If GIST cases in the

US range from 5,000 to 10,000 diagnosed a year, and 10,000 people donated just ten dollars a month, we would have 1.2 million dollars a year for GIST research."

This is another powerful way to contribute, by donating small amounts of money. If we as patients cannot afford this, we probably know people that are willing to donate some money for research.

We all want to find the cure. If we cannot donate money, dear friends, let's donate tissue!

The cure is around the corner. Let's start this year by taking action, not by worrying. We all can help.

Did you Know?

If the cost of mutational testing is not covered by your insurance agency, you can have your mutational testing done for **FREE!**

You can do this by participating in the **GIST Collaborative Tissue Bank**. The GIST Collaborative Tissue Bank is a one-of-a-kind tissue bank, where your tumor will help the world's leading GIST researchers search for the cure.

Request more information about the Tissue Bank, by contacting our office. We will send you an instructional package about the program.



TRIALS

From Page 3

will be used to evaluate tumor response or progression. Scans will be reviewed by an independent central facility to confirm status.

Currently, Bayer provides only an email address for patients wishing to inquire about the trial: clinical-trials-contact@bayerhealthcare.com

The LRG will be working with Bayer to better understand how patients with

limited email access can inquire about this trial. In the interim, the LRG will provide contact information in the site listings in our Clinical Trials Database as individual recruiting sites publish trial listings in their local registries. The LRG database listing for this trial can be found at: <http://gistrials.fmgateway.com/iLRG/details.php?Trial=221>

The United States trial listing indicates that one site in Innsbruck, Austria is currently open. Plans are for 70 sites in 17 countries worldwide and 14 states in the United States. Estimated enrollment is 170 patients per the National Institutes of Health listing. We understand that 34 patients have already been accrued.

For additional details and clinical trial site listing that includes sites that are not yet recruiting, see the Clinicaltrials.gov listing at: <http://clinicaltrials.gov/show/NCT01271712>



Michigan GISTers meet!

GISTers from Michigan met on Saturday, January 15 at Caribou Coffee in Royal Oak, Michigan. Pictured standing from left to right are Ron Brandt, Susan Brandt, Ted Wahl, Ellen Rosenthal, Nancy Wahl and Dean Schmitz; seated are Zarina and Abbas Patni. Diane Schmitz is behind the camera!

If you are interested in planning or have recently had a meeting in your area, let us help you spread the word in the LRG newsletter! Email us at liferaft@liferaftgroup.org

CHANGES

From Page 2

about the plan you wish to apply for and what additional assistance you will need if any. This was a shock for most when they went from making co-payments for their drugs to paying 100 percent of the cost. Now enrollees receive a 50 percent discount. So here's the donut hole for 2011:

- You pay the first \$310 of drug costs before your plan starts. This is considered the deductible.
- You pay your copayment and your plan pays its share until the combined total amount (plus your deductible) reaches \$2,840.
- Donut hole - when drug expenditures are between \$2,840 and \$4,550 you will be in the donut hole. Previously, you had to pay the full cost of your prescription drugs but in 2011 you will get a 50 percent discount on covered brand name prescription drugs. You will spend \$1,710

in prescription drugs during your time in the donut hole.

Once you reach \$4,550 in out of pocket expenses for prescription drugs you will receive catastrophic coverage and you only pay a small copayment for each drug until the end of the year.

The above expenses only include the cost of prescription medications. It does not include the monthly premium that you pay to the prescription drug plan, this is still 100 percent your responsibility to pay unless you are receiving some other forms of assistance. And the above details what you will experience each year unless the state you live in or the federal government makes changes to the plan in upcoming years. The plans for Medicare are to phase in additional discounts on the cost of both brand name and generic drugs in upcoming years. By 2020, the changes that will go into effect

Table 1

2010	100%
2011	50%
2020	25%

will close the coverage gap and rather than paying 100 percent of the costs, your responsibility will be 25 percent of the prescription drug costs (Table 1).

Father & husband and long-time LRG member passes away at 72



Marek Szczeny passed away on October 25, 2010. Born on May 5, 1939 in Poland, Marek was an engineer and happily married man for

more than 40 years. He was also the father of two sons, Krzysztof and Bartosz.

His life passed without any serious medical complications until GIST was diagnosed in March 2003. In June 2003, he had resection of a primary tumor located in the large intestine, since then he was on Glivec (2003-2010) and Sutent (2010). He was also a supportive member of the Life Raft Group for the last seven years.

MASITINIB

From Page 3

At four years after initial treatment the overall survival rate is 74 percent. However, the median overall survival has not been reached and patient data continues to be collected.

The results of this trial (Table 1, page 14) compare favorably with the ASCO 2007 report combining the results of the Phase III imatinib trials in the United States and Europe. Those trials compared two daily doses of imatinib, 400 mg and 800 mg. The key differences are an improvement in median progression-free survival (PFS) of over one year and the apparent advantage in overall survival (OS) at four years of 74 percent versus approximately 50 percent for the imatinib trials at relatively the same time point.

The caveats are that the Masitinib Phase II trial has a much smaller patient population than the Imatinib Phase

Table 1: Trial Results

Phase	Drug	Patients	Median PFS	Median OS
2	Masitinib 7.5 mg/kg/day**	30	3.42	Not yet reached*
3	Imatinib 400 mg daily	818	1.58	4.08
3	Imatinib 800 mg daily	822	1.95	4.05

* OS at last report was 74% at four years
 ** For example, a 150 lb person would weigh about 68 kg. (68 X 5mg = 510 mg).

Grade 3/4 Adverse Events

Event	Grade	Frequency
Rash	3	10%
Neutropenia	3	7%
Abdominal Pain	3	7%
Skin Exfoliation	4	3%

III meta-analysis (30 versus 1,640). In addition the confidence limits currently reported for Masitinib median PFS (1.46 - NR) still include the median PFS reported for the imatinib trials (1.58 and 1.95).

Grade 3/4 adverse events reported can be seen in Table 2.

These promising results for the Phase II Masitinib trial support the ongoing randomized Phase III trial comparing Masitinib to Imatinib in the first line for locally advanced or metastatic GIST patients. That trial is currently recruiting patients at seven sites in the United States, 28 sites in France and seven sites in Lebanon. Patients and clinicians can check our trial listing for the latest information about the trial and about Masitinib: <http://gisttrials.fm-gateway.com/iLRG/details.php?Trial=176>

D842V

From Page 10

tion at that time because tissue is readily available. The most recent pathology guidelines now ask for mutation status if it is known; this may help pathologists to request the test more routinely.”

Mutational testing can be done in a number of CLIA (Clinical Laboratory Improvement Amendments) certified labs in the United States. Listed below are some labs that we are aware of that do mutational testing, although not all of them test for PDGFRA mutations.

- Oregon Health & Science University (OHSU), Portland, Ore.
- Fox Chase Cancer Center, Philadelphia, Penn.



JAIN

Salt Lake City, Utah

- Quest Diagnostics

Author’s Note: The leadership team at AROG includes the CEO, Dr. Vinay Jain and the COO, Hemanshu Shah. Dr. Jain, a medical oncologist, founded the largest oncology CME company in the United States and was involved in the

- MD Anderson Cancer Center, Houston, Texas
- Memorial Sloan-Kettering Cancer Center, New York, N.Y.
- Arup Laboratories,

development of several important drugs for lymphomas.

The Life Raft Group’s name symbolizes a life raft in a storm; help when you desperately need it. AROG Pharmaceuticals has thrown out its own life preserver to GIST patients. The biggest question at this time may not be how well it will work, but can anyone find it? How many GIST patients will fail to find that life preserver because they don’t have the guidance that will lead them to it—they don’t have mutational testing.



SHAH

ELLER

From Page 8

Texas cowboy hat and honored him as the GIST Patient of the Year. Dr. Trent was inspired by Butch's determination and positive never give up attitude.

Butch loved life and enjoyed his (so called "retired" years) traveling in his motor home, taking cruises with his crazy friends, going to Myrtle Beach and Florida, and spending time with family and friends. Butch would make friends no matter where he was and would often turn to a stranger and ask, "Where are you from?" During his years battling cancer any negative circumstance in life was "just another little bump in the road" and he was often telling other cancer patients to "never give up!" No matter what the circumstance Butch always remained positive! Butch was an inspiration to many with his smiling face which sometimes could cause an opposite effect.

Butch will be dearly missed by his loving wife of 32 years Jean Elaine Finlaw Eller, his loving son Ryan Thomas Eller, and faithful dog Coop. He was a devoted son to his mother the late Bertha "Sis" Keen Eller. Surviving are his siblings Bess Engle and husband Arthur of Chestertown, MD; William Eller and wife Kae of Eldora, NJ; Nancy Stephens and husband Robert McGuire of Newark, DE; Janet Jeager of Punta Gorda, FL; Patricia Woolbert of Woodstown, NJ; Jack Eller of Hockessin, DE; Linda Poeta and husband Raymond of Cape Coral, FL; and sister-in-law Kay Finlaw Creel and husband Maynard of South Riding, VA. Butch also leaves behind his aunt Ethel Keen Jones, of Georgetown, DE; numerous nieces, nephews, great-nieces, great-nephews, great great nieces and many close friends all over the country will miss him. Predeceased by his Grandpop



The surprise "Patient of the Year" waves his Texas cowboy hat proudly.

Harry Keen, his Uncles Norman Keen and Warren (Steven) Keen (and wife Florence), his Aunt Mildred Keen Layton, brother-in-laws Stuart Stephens and Clarence Woolbert, and his very close friend Charlie Jeker.

Butch also leaves behind a mentor and dear friend "Chief" Thomas A. Dwyer whom he considered his

"FATHER" and who also hired Butch to the Police Department in 1970.

Over the years Butch enjoyed jet skiing, snow skiing, running, scuba diving, golfing, playing rec league softball, tennis, crabbing, eating crabs, gardening, vacationing all over the world, and spending lazy afternoons on his front porch with his Little Darlin' Jean and best 4-legged friend Coop. He enjoyed spending time at their farm on the beautiful Chesapeake Bay in Rock Hall, MD. Butch cherished watching his loving son Ryan's many sporting events, his family gatherings, police department picnics, and many FOP functions. There will be many fond memories of the FOP golf tournaments which were first organized by him in the 1980s and continue today. He was also instrumental in organizing and planning many Super Bowl parties. In lieu of flowers, donations may be made in memory of Butch Eller to the Life Raft Group, which assists GIST Cancer Patients, 155 Rt. 46W, Suite 202, Wayne, NJ 07470, or online at www.liferaftgroup.org/donate.html or to Compassionate Care Hospice Foundation, 11 Independence Way, Newark, DE 19713, or online at www.cchfoundation.net or www.laughreyfuneralhome.com

DATING

From Page 11



LECOINTE

Pediatric GISTer and founder of Ensemble contre le GIST, "The first one being to announce the disease, the second one to explain the induced collateral damages and personal sacrifices. It's very difficult to find the right time to bring these topics in the discussion as these aspects can be very scary for someone who's never faced this kind of situation. If I say it at the very first date, I know by experience I might never see the man again because human nature tends to prefer simplicity rather than what I have to propose.

A big issue in dealing with GIST and dating seems to be timing. If not the first date, then the second? Third? When is the right time to broach the subject?

Cancer.net feels that the talk should occur as your relationship starts to deepen. "The right time to talk to a partner about cancer differs for each person. However, it may help to wait until you and your new partner have developed a mutual level of trust and caring. It is also best to tell a new partner before a relationship becomes serious."

Part two will cover tips on approaching the subject, success stories and new ways to meet people.

Mark your calendars!

- David Safford's Piano Concert for GIST will be held on Valentine's Day, **February 14**.
- On **February 16**, the LRG Board of Directors will be meeting in Tampa, Florida.
- The LRG Research team will also be meeting in Tampa, **February 17-18**.
- The much-anticipated Alianza GIST gathering in Brazil will take place the week of **April 11**.
- The American Society of Clinical Oncologists (ASCO) meeting will be held once again in Chicago, **June 4-8**. If you're there, watch out for the joint Max Foundation-LRG-Monterrey Tech-Alianza GIST project!

THE LIFE RAFT GROUP

Staff

Executive Director
 Science Coordinator
 Program Director
 Global Relations Director
 Communications Coordinator
 Director of Planning
 Administrative Director
 Patient Registry Supervisor
 Accounts Manager
 Office Manager
 Program Associate
 Program Associate
 Program Associate
 Executive Assistant

Norman Scherzer
Jerry Call
Tricia McAleer
Sara Rothschild
Erin Kristoff
Karen Kelley
Roberto Pazmino
Magda Sarnas
Gale Kenny
Matthew Mattioli
Daniela Jorge
Diana Nieves
Jennie Kim
Lisa Pereira

155 US Highway 46, Ste 202
 Wayne, NJ 07470
www.liferaftgroup.org

Volunteers

General Counsel **Thomas Overley**
 Database Consultant **Steven Rigg**
 Official Greeter **Gail Mansfield**
 Latin America Liaison **Vicky Ossio**
 Clinical Trials Coordinator
 Photographer **Jim Hughes**
 Science Team **Kim Tallau**
Tanya DeSanto
Jim Hughes
David Josephy
Michael Josephy
Rick Ware
Rafael Vega
Paula Vettel

Phone: 973-837-9092
 Fax: 973-837-9095
 E-mail: liferaft@liferaftgroup.org

Board of Directors

Executive Committee

Jerry Cudzil, President
Stan Bunn, Past President
Ray Montague, Secretary-Treasurer

Directors

Robert Book **Marietta Robinson**
Mia Byrne **David Safford**
Chris Carley **Rodrigo Salas**
Jim Hughes **Larry Selkovits**
Jerry Knapp **Silvia Steinhilber**
John Poss



Contact the LRG

Life Raft regional chapters

Alabama	Pat George	patgeorge@bham.rr.com	Minnesota	Sharon Boudreau	redsmb@comcast.net
Alaska	Frank Domurat	patient@oncologyalaska.com	Missouri	Katie Campbell	campbellksoup@hotmail.com
Arizona	Janeen Ryan	tabascocook@yahoo.com	Montana	Donna Capps	BBR950@aol.com
Colorado	Anne Bridgewater	babridgewater43@yahoo.com	Nebraska	Sally Norton	nordeane@cox.net
California	Floyd Pothoven	floyd@innovix.com	Nevada	Erik Krauch	erik.krauch@cox.net
Connecticut	Martha Zielinski	john.martha@sbcglobal.net	New Hampshire	Julie Thorne	julierthorne@gmail.com
Delaware	Helen Steinnagel	ahjs@sbcglobal.net	New Jersey	Anita Getler	acgetler@gmail.com
Florida	Cindy Bones	ccalyppo3@comcast.net	New York	Pat Bonda Swenson	pbondaswenson@yahoo.com
Georgia	Skip Ryan	skipryan@tampabay.rr.com	North Carolina	Chuck Korte	pckorte@att.net
Hawaii	Pat Lemeshka	riyank@bellsouth.net	Ohio	Kaye Thompson	tnt.1@sbcglobal.net
Idaho	Richard Palmer	richardpalmer@hawaii.rr.com	Oklahoma	Jane Rowan	jrowan30@aol.com
Illinois	Janet Conley	jkconley104@gmail.com	Oregon	Gail Mansfield	tngman65@gmail.com
Indiana	Paula Vettel	paulav2@sbcglobal.net	Pennsylvania	Kimberly Trout	musikwithkim@yahoo.com
Indiana	Robert Book	RMBBook2@aol.com	Rhode Island	Susan Farmer	sfarmer10@cox.net
Iowa	Barbara Kepple	kepbjk@aol.com	South Carolina	Al Boyle	captboo@windstream.net
Louisiana	Jackie Welsh	jackie.welsh@mms.gov	Tennessee	Alice Sulkowski	sulkowskiab@msha.com
Maine	Jodi Merry	merryhillacres@hotmail.com	Texas	Kerry Hammett	hammett@uthscsa.edu
Maryland	Bonnie Emerson	bteensey2@hotmail.com	Virginia	Sally Jackson	spjackson@cox.net
Massachusetts	Maura Cesarini	mauracesarini@hotmail.com	Washington	Deanne Snodgrass	g-d-snodgrass@comcast.net
Michigan	Ellen Rosenthal	ebrosenthal@comcast.net	Wisconsin	Rick Ware	rkwelwood@yahoo.com

Life Raft country liaisons: Learn more about the Global GIST Network: www.globalgist.org

Argentina	Sandra Mesri	sandramesri@hotmail.com	Macedonia	Dejan Krstevski	krstevski@euromoto.com.mk
Australia	Katharine Kimball	katharine_kimball@hotmail.com	Malaysia	Yong Choo Sian	ycspj2005@yahoo.com
Belgium	Kris Heyman	kh@contactgroepgist.be	Mexico	Rodrigo Salas	rsalas@maprex.com.mx
Bolivia	Virginia Ossio	vossiop@gmail.com	New Zealand	Marie Lagaluga	marielagaluga@xtra.co.nz
Bulgaria	Stefan Mandov	stefan_mandov@abv.bg	Netherlands	Contactgroep GIST	bestuur@contactgroepgist.nl
Brazil	Alexandre Sakano	alexandre@sakano.com.br	Nicaragua	Maria Teresa Ponce	maria.teresa.ponce@aeienergy.com
Canada	David Josephy	djosephy@uoguelph.ca	Norway	Odd Andreas Tofteng	oddandreas@yahoo.com
Chile	Piga Fernández	piga.fernandez@gmail.com	Pakistan	Muhammad Shahid Rafique	rsr_srs@yahoo.com
China	Ruijia Mu	mu_ruijia@yahoo.com	Poland	Stan Kulisz	listy@gist.pl
Colombia	Rafael Vega	ravega63@yahoo.es	Puerto Rico	Gerardo Silva	gsilva@helvetia-pr.com
Costa Rica	Michael Josephy	mjosephy@gmail.com	Romania	Simona Ene	si_mi_ene@yahoo.com
Cyprus	George Constantinou	george@gnora.com	Russia	Tanya Soldak	soldak@rpxi.org
Czech Republic	Jan Pelouchová	janapel@centrum.cz	Samoa	John Galuvao	leasii@gmail.com
Dominican Republic	Alejandro Miranda	alex2@sbt.com.do	Saudi Arabia	Mohamed-Elbagir Ahmed	mohamedelbagir@live.com
Finland	Mirja Vuotilainen	miiri49@gmail.com	Scotland	Helena Koumbouzis	hkoumbouzis@yahoo.com
France	Estelle LeCointe	info@ensemblecontreglist.org	Singapore	Robert Richardson	jambo@pacific.net.sg
Germany	Markus Wartenberg	wartenberg@lebenshauspost.org	South Africa	Jenny Aitken	oaiken@telkomsa.net
Greece	George Constantinou	george@gnora.com	South Korea	Changhoon Lee	chlee@mobismiami.com
Hungary	Tünde Kazda	cmlgist@cmlgist.hu	Spain	Maria Teresa Jimenez Salado	mariateresa.jimenezsalado@telefonica.es
India	Paresh Majmudar	majmudarparesh@indiatimes.com	Sudan	Mohamed-Elbagir Ahmed	mohamedelbagir@live.com
Iran	Negar Amirfarhad	negaraf@sympatico.ca	Sweden	Susanna Allgurun Neikter	gist.sverige@gmail.com
Ireland	Carol Jones	roycal-re-gist@hotmail.com	Switzerland	Helga Schnorf	ulrich.schnorf@bluewin.ch
Israel	Avi Zigdon	zigdona@gmail.com	Thailand	Kittikhun Pornpakakul	kittikun_p@yahoo.com
Italy	Anna Costato	anna.costato@virgilio.it	Turkey	Haver Tanbay	tanbay@tanbay.net
Japan	Sumito Nishidate	eujc@mbj.nifty.com	U.K.	Judith Robinson	Judith@ndrobinson.plus.com
Jordan	Mohammed Milhem	mohammed-milhem@uiowa.edu	Uruguay	Fabrizio Martilotta	fabrizio.martilotta@gmail.com
Kenya	Francis Kariuki	bridgestone@coopkenya.com	Venezuela	María Isabel Gómez	asaphe_venezuela@yahoo.com
Lithuania	Virginija Zukauskienė	virginija.starkute@gmail.com			