

GIST warriors left behind a legacy of struggle & triumph

By Erin Kristoff
LRG Newsletter Editor



Access issues come up often enough in America. Depending on the disease, many times there are agencies or organizations in place to help patients in need overcome these hurdles. Outside of the United States, it is not always easy or even difficult to access treatment for a rare cancer. It can be downright impossible. Factors like cost, patient population, and bureaucratic red tape can lead to restrictions on a patient's ability to afford or even get a prescription for drugs like Gleevec, Sutent and others.

Vera Krstevski was diagnosed with GIST in August 2007 in her native Macedonia, where the Ministry of Health had not prioritized funding treatment costs for rare diseases like GIST. This created a situation in which most patients are left to find other ways to access life-saving treatment.

She had her first gastrectomy shortly after diagnosis; one year later, she had a recurrence and a second operation. Vera started 400mg of Gleevec in January 2009 and spent two years on the drug, managing to increase her dosage to 800

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Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

February 2012 In memory of Janice Aubert, Vera Krstevski, Sally Smith, Vol 13, No. 1
Edward Sauer & Janet Rowe

Genetic markers of progression in GISTS and their significance

By Maria Debiec-Rychter
Catholic University of Leuven
LRG Research Team Member
With an introduction by Jerry Call,
LRG Science Director

Today there are four major methods of determining risk of recurrence after initial surgery. These methods are pretty good at identifying low-risk and high-risk tumors. However, there is a fairly large group that fall between low-risk and high-risk. Those with so-called "moderate" or "intermediate" risk tumors are faced with the decision of whether or not to take Gleevec. New guidelines exist that recommend taking Gleevec for at least three years, with many experts advocating longer periods for high-risk patients.

Gleevec is an outstanding drug and a



DEBIEC_RYCHTER

lifeline for the majority of GIST patients. However, it does have side-effects and these can be significant for some patients. In addition, like all cancer treatments, it is expensive. Thus it is extremely de-

sirable to find better methods to determine which patients need to take Gleevec and which patients are essentially "cured" by surgery and don't need to take Gleevec. In this issue of the LRG newsletter, LRG Research Team member, Dr. Maria Debiec-Rychter de-

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The 2011 Executive Director's Report

By Norman Scherzer
LRG Executive Director

The Life Raft Group is coming up on our ten year anniversary. The truth is, we've been around longer than that, since 2000 and the early days of Gleevec, when we were just a handful of patients and caregivers trying to make sense of this strange, new world and help each other as best we could.



SCHERZER

But in 2002, the LRG made a conscious decision to become a formal organization and help not just other each other, but every GIST patient we could find. We started out with a simple goal, to ensure no one would ever face GIST alone. We were focused on survival and educating people about Gleevec and newer drugs coming down the pipe-

line. Everything was new and scary and we had so much to say and do.

As the years have passed our goals have evolved, we climbed out of the back seat and took the wheel by launching a major research initiative to find the cure for GIST; we grew our education and support by rolling out websites, bigger and better newsletters, educational videos, a clinical trials database...I could go on.

We're bigger, our goals are bigger, our

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One Life Rafter chooses a unique way to show support

By William Sumas
LRG Program Associate

Last month, the Life Raft Group took a giant step towards launching the Mike Matthews Legacy Society and planned giving program. Ray Montague, a dedicated Board Member and Treasurer of the Life Raft Group, pledged an incredible \$100,000 bequest in memory of his son, Jonathan, in an effort to jumpstart the program.

Ray joined the LRG in December of 2002 after Jonathan lost his battle to pediatric GIST earlier that year. Since joining, Ray's commitment and support in the struggle to find a cure has been unyielding. In 2007, Ray joined the LRG Board of Directors, giving him the opportunity to broaden the range of his involvement. Of particular importance is the role he plays in promoting numerous pediatric GIST initiatives. These efforts include sponsoring two National Institute of Health (NIH) dinners as well as hosting a pediatric GIST family weekend. His most recent decision to support our planned giving program will enable GIST patients to receive expert care in the future while preserving Jonathan's memory.

Planned Giving is a method of supporting organizations and/or charities that gives the individual a variety of choices when considering estate planning. Planned gifts are beneficial to the donor because they allow the individual to make larger gifts than they normally would be able to while still meeting their current economic needs. The establishment of a planned giving program will

allow the Life Raft Group to engage in long-term financial planning knowing that resources will be available in the future.

The LRG Planned Giving Program was named in honor of Mike Matthews, a Life Raft Group founding member and GIST patient whose story has been a source of inspiration not only for the Life Raft Group, but for cancer patients



Ray Montague, pictured at the June 2011 NIH Clinic, where he sponsored a dinner for the children and parents attending, with LRG Program Director, Tricia McAleer (left) & Maribeth Olt.

everywhere. Mike was devoted to his family, a respected man in his community, and a loving friend.

Mike passed away in 2004 while waiting for a trial that would not come in time. His friends at Purcells Cove Social Club decided to throw him a "Going Away" Party. At this party, Mike asked his wife to dance; everyone in the room knew it was their last. LRG Executive Director, Norman Scherzer was present for this solemn and touching moment and pledged that the LRG would not rest until we live in a world where no man had to ask his wife for one last dance.



Mike Matthews with his grandson.

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 Life Raft Group chose to honor

Mike's memory and the lives of all those who have lost their battle to GIST by establishing this fund and ensuring that their legacy will live on.

To learn more about the Mike Matthews Legacy Society and planned giving please call Christine Schaumburg, the Life Raft Group's Director of Development, at 973-837-9092 x116.

You can also read more about Mike's story in the July 2004 issue of the LRG newsletter.

Congrats to BOD member Marietta Robinson on Obama nomination!

By Jennie Kim

LRG Program Associate

Recently, President Obama nominated our Life Raft Group Board Member Marietta Robinson to join the Consumer Product Safety Commission (CPSC). The Commission ensures the safety of over 15,000 domestic consumer products, particularly those of children's.

Marietta has expressed how honored she is for the nomination and hopes for a quick confirmation from the Senate. Once confirmed she will



ROBINSON

be the fifth member of the commission, giving leverage to the Democrats once again since Democrat Thomas H. Moore's absence, according to the *Washington Post*. Moore left

the commission evenly divided between Democrats and Republicans, which caused consequent disagreements and obstacles for the CPSC.

As a lawyer of 33



years, Marietta has worked with various law firms and is well known in Michigan's political sphere as a successful member of the legal community. Her persistent devotion to the LRG Board provides GIST patients, families, and caregivers hope for a cure.

She continues the legacy of her husband of twenty-eight years, the accomplished James K. Robinson who sadly lost his battle to GIST in August 2010, as she remains committed to the cause of the LRG.

The LRG would like to offer a big congratulations to Marietta on this prestigious nomination!

LRG introduces GIST Day of Learning in Miami

By Tricia McAleer

LRG Program Director

The Life Raft Group is launching a new program called GIST Day of Learning.

In response to the requests of previous attendees of our biennial meeting, Life Fest, for more opportunities like this, we have created a one-day program full of education and support for people who have GIST and their caregivers.

By hosting these events regionally throughout the year at different cancer centers we hope to make it easier for people to attend. Since we will also be hosting Life Fest this year in Las Vegas in early November we are only hosting one GIST Day of Learning event in 2012 in Miami, Fla.

For our inaugural event, we are very excited to work with Dr. Jonathan Trent and the University of Miami's Sylvester Comprehensive Cancer Center. The



event will be held in the Miami Beach area on May 19, 2012. We will be sending out details about the exact location as soon as they are available. This event will be free for GISTers and their families to attend. You can register by going to www.liferaftgroup.org/gdol.html

For many of you who may not know about these types of meetings, it was almost ten years ago in Cambridge, Mass. when the first educational event was held for people facing a newly defined cancer called GIST. That event

grew into what we now call Life Fest. Life Fest has been held in different cities every other year since then. People attend from all over the world to gain a better understanding of their disease, the latest updates on GIST treatment and gain support

from other people who are facing the same obstacles they are. Life Fest is our favorite event because even though our bond is through cancer, it is still a joyous event overflowing with support and hope for a cure.

About Dr. Trent

Jonathan C. Trent, MD, PhD is the Co-Director of the Musculoskeletal Center, Director of the Sarcoma Medical Research Program and professor of medi-

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GIST Research: Articles on the Science of GIST

OCT-1 study shows promise for some CML patients: could there be benefit for GIST?

By Pete Knox

LRG Special Projects Coordinator

An Australian study of newly diagnosed CML patients concentrated on OCT-1 activity as a predictor of molecular response and progression-free survival (PFS) treated with imatinib. The study, entitled, “Chronic phase chronic myeloid leukemia patients with low OCT-1 activity randomized to high dose imatinib achieve better responses, and lower failure rates, than those randomized to standard dose”, is slated to be published in *Haematologica* in an upcoming issue, and was made available ahead of print as an early release paper (doi: 10.3324/haematol.2011.056457). The study looked at patients who were taking either 400 mg or 800 mg of imatinib daily and attempted to see if levels of OCT-1 activity had any predictive value. For a highly detailed discussion of the relationship between OCT-1 levels and imatinib uptake for CML patients, please see the article “Suboptimal response in CML linked to Gleevec uptake into leukemia cells” written by LRG Science Director, Jerry Call from the February 2008 edition of the LRG newsletter.

OCT-1 (Organic Cation Transporter 1) is a protein that is responsible for transporting imatinib into the target BCR-ABL positive cells (tumor cells). BCR-ABL is the oncogene that causes CML, and mutations in BCR-ABL are the primary means by which a CML patient becomes resistant to imatinib.

Major Metabolic Response (MMR) differed significantly among patients with low and high OCT-1 activity levels, with high OCT-1 level patients seeing markedly better results. The significance of this difference did not extend to patients with varying OCT-1 levels that were on a high dose (800 mg) of imatinib. In

Table 1: Relationship between imatinib dosage and OCT-1 activity

Imatinib Dose	OCT-1 activity level	Rate of MMR (24 months)	Statistically Significant? (compared to same dose & different OCT-1 levels)
Low (400 mg/day)	High	100% of patients	YES (p<0.001)
Low (400 mg/day)	Low	57% of patients	YES (p<0.001)
High (800 mg/day)	High	95% of patients	NO (p=0.073)
High (800 mg/day)	Low	68% of patients	NO (p=0.073)

Table above adapted from data presented in: White DL, Radich J, Soverini S, Saunders VA, Frede A, Dang P, Cilloni D, Lin P, Mongay L, Woodman R, Manley P, Slader C, Kim DW, Pane F, Martinelli G, Saglio G, and Hughes TP. Chronic phase chronic myeloid leukemia patients with low OCT-1 activity randomised to high-dose imatinib achieve better responses, and lower failure rates, than those randomized to standard-dose. *Haematologica*. 2011; 96:xxx doi:10.3324/haematol.2011.056457

The findings of the study were of some interest for CML patients, but also should serve as a prompt for discussion and perhaps a call for further research for GIST. A relationship between

imatinib dosage and OCT-1 activity was found for some patients but not for others, as Table 1 shows. (Also see accompanying Figure 1 (page 10) for information about response over time.)

Thus, for patients on low dose (400 mg) imatinib, the rate of Ma-

addition, the researchers looked at trough plasma levels and their relationship to rate of MMR, and found that those patients who had both low trough imatinib levels (defined as <1200 ng/ml) and low levels of OCT-1 activity achieved the lowest rates of MMR (47%) when compared to the other patients in the study, and this difference was statistically significant (p=0.009). In addition, this group also had the highest rate of imatinib failure, a finding that

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First LRG jewelry party is a success

By William Sumas
LRG Program Associate

This holiday season, the Life Raft Group hosted its very first jewelry party in collaboration with our dedicated volunteer photographer Kim Tallau. Kim and her husband Steve joined the Life Raft Group in 2009 when Steve was diagnosed with GIST. They have remained proactive within the GIST com-

munity and play important roles in fund-raising for the Life Raft Group.

On December 13, 2011, local Life Raft Group members and our corporate neighbors browsed through an array of designer jewelry provided by *Touchstone Crystals Jewelry*-a member of the prestigious *Swarovski Group*. The LRG conference room was temporarily transformed into a winter wonderland as shoppers searched for gifts for their loved ones. For those unable to attend,

an online shop was made available for the duration of the month. Overall, the event was a definite success, donating 15 percent of all purchases to the Life Raft Group while spreading the word about GIST to our neighbors. Congratulations to LRG supporter Paula Stover, winner of the eloquent *Inspire Necklace*!



Thank you for your support!

The Life Raft Group wishes to thank all of our members who participated in this year's Holiday Campaign. Though it is still underway (look for final results in the next newsletter), this important campaign has raised over \$47,000 to support our patient education & support, advocacy, and research to find a cure GIST. In addition, this yearly fundraiser has become vital in raising awareness about GIST.



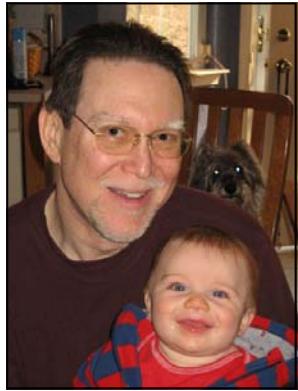
This year, we chose the lighthouse as our theme as a symbol for hope and survival. GIST survivors throughout the world depend on us to move forward in our quest to cure GIST and help those living with it until then.

It's not too late! You can still send out cards to your family, friends, neighbors and colleagues. Remember, you are not only raising funds to help fight GIST, you are raising much-needed awareness about this disease.

GISTER's daughter holds third annual ball for GIST

By Julie Cramer

GIST has had a profound impact on my life even though I am not a patient myself. My father, Mark Becker, bravely fought his battle with GIST for 12 years before he died in 2009. Research and clinical trials are the two things that kept my dad alive long enough to see both of his daughters graduate high school and college, get married and have children. Though my children will never get to know him, I continue to feel that I need to



Mark, with his grandson, Cole.

do something to help people who are still fighting with this disease.

The GIST Benefit Ball is an opportunity for GIST patients from all walks of life to gather with other

patients and supporters to enjoy a fun evening while supporting a fantastic cause.

Please join us next month at the third GIST Benefit Ball which will be held on February 18, 2012 at the Rittenhouse Ballroom in Philadelphia from 7pm to 10pm. There will be casino gambling (for prizes), silent and Chinese auctions, live entertainment, an art auction, and much



Lots of fun was had at last year's GIST Benefit Ball.

more—all to benefit Fox Chase Cancer Center in Philadelphia!

Visit our website, www.gistbenefitball.weebly.com to purchase tickets or for more information. Use discount code "survivor" at checkout to get a special deal!

Did you Know?

In April 2011, AROG Pharmaceuticals initiated a phase II trial of crenolanib (CP-868,596) for GIST patients with PDGFRA-D842V mutation. The current status of the trial was presented at CTOS 2011, and includes data regarding a metabolic response that was observed in a patient. The trial is currently ongoing at Fox Chase Cancer

Center (Principal Investigator (PI): Dr. Margaret von-Mehren) and Oregon Health Sciences University (PI: Dr. Michael Heinrich). To ensure that crenolanib is not given to the patients at a sub-optimal dose, AROG has escalated the current dose by approximately 1.7 fold. Also, in an effort to provide therapeutic benefit to a maximum number

of patients, AROG has increased the sample size and also allowed the patients that had discontinued from the study to re-enroll in the study at the higher dose. Currently available drugs like imatinib and sunitinib have no activity against the PDGFRA-D842V mutated GIST. AROG is hopeful that crenolanib will help provide therapeutic benefits to these patients that currently have no treatment.



GDOL

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cine at the University of Miami Sylvester Comprehensive Cancer Center.

Dr. Trent recently transferred to Miami after leaving his position as an assistant professor of medicine in the Department of Sarcoma Medical Oncology at The University of Texas, MD Anderson Cancer Center in Houston, Texas. Dr. Trent has published numerous abstracts and research articles in leading journals, as well as book chapters, and is a frequently requested lecturer. He is the chief editor of the sarcoma section of Current Opinions in Oncology and on the editorial board of The Chinese Journal of Clinical Oncology, Rare Tumors, and Translational Medicine as well as a journal reviewer on a number of journals, including Nature Medicine, Lancet, Cancer, Clinical Cancer Research, and Cancer Research. His clinical interests focus on GIST patient care, clinical trials and translational research. The excellence of his GIST clinical team led to his recognition as the 2010 GIST Physician of the Year by the Life Raft Group. He is the principal investigator, as well as a collaborator, on several ongoing clinical trials that are examining the use of kinase inhibitors alone and in combination with novel drugs in patients with primary and metastatic GIST. He is a principle investigator of the ongoing GIST registry and is credited with several



TRENT

breakthroughs in GIST that stemmed from his 5-year NIH K-23 GIST research grant. Dr. Trent earned his undergraduate degree in chemistry at South-eastern Oklahoma State University and his MD and PhD in cancer biology from The University of Texas Health Science Center. He completed an internship and

residency in internal medicine at The University of Texas Health Science Center, and a fellowship in medical oncology at The University of Texas, MD Anderson Cancer Center while serving as chief fellow. Dr. Trent is board certified in internal medicine and medical oncology.

GIST Day of Learning-Tentative Agenda Sunday May 19, 2012



8:00 am	Breakfast & Mingling
9:00-10:15 am	GIST: The Basics Overview of history, biology, and treatments
10:15-10:30 am	Coffee Break
10:30-11:30 am	Managing Side Effects
11:30 am-12:30 pm	Clinical Trials Explained and Explored
12:30-1:30 pm	Lunch, Roundtable Discussion: How can we (the physicians & the LRG) better serve the GIST community?
1:30-2:15 pm	Plasma & Mutational Analysis: Important Tools for Managing Your Treatment
2:15-3:00 pm	Nutrition
3:00-3:15 pm	Coffee Break
3:15-4:00 pm	Surgery & Other Options
4:00-5:00 pm	Q&A with Experts
6:30 pm	Dinner

Retired horse trainer seeks to “Harness a Cure” through Dover Downs fundraiser

By Christine Schaumburg
LRG Development Director

Twelve years ago, Life Rafter Bobby Kinsey began his own battle against GIST. Since then, he has helped countless people with GIST across the world. Most of you know Bobby as an LRG member who posts advice and words of encouragement in our email community. Now, Bobby has decided that he wants to do more to help fight this cancer.

A retired horse trainer and former record-holding

lead driver in harness racing, Bobby continues to groom horses at the Dover Downs in Delaware. He is combining his passion for harness racing with his determination to find a cure for GIST. On March 25, 2012, Bobby will host a fund-

raiser at the Dover Downs, *Harness a Cure*, to support the LRG’s research efforts.

Planning is underway; please email Christine for more information: [cschaumburg @liferaftgroup.org](mailto:cschaumburg@liferaftgroup.org).



Right after his second GIST surgery, Bobby broke records with his three-year old “Delaware Sire Stake Filly”. He is picture second from right with his family and Dover Downs officials.

Swiss pathologist wins the 2011 GIST prize

The following is an excerpt from a press release distributed by the Swiss GIST Group.

Berne, Switzerland 29 November 2011 – The GIST Group Switzerland awarded its Science Prize for the second time. This year’s recipient was Prof. Stephan Dirnhofer, who won the prize for his important work on the pathogenesis of GIST at the University of Basel’s Institute of Pathology. Dr. Michael Montemurro and Helga Meier Schnorf, who made the documentary “Living with GIST”, won the Special Recognition Award.

The Gastrointestinal Stromal Tumors (GIST) Patient Support Group, the GIST Group Switzerland, awarded its Science Prize for the second time. This year’s recipient of the GIST prize, which is worth 10,000 Swiss francs, is

Dr. Stephan Dirnhofer, Deputy Head of the Institute of Pathology at the University of Basel. The prize was conferred



DIRNHOFER

for his publication “Frequency, phenotype, and genotype of minute gastrointestinal stromal tumors in the stomach: an autopsy study”, published this year in the journal Human Pathology. The award ceremony took place on the 24 November at the semiannual meeting of the Swiss Group for Clinical Cancer Research (SAKK), held in Basel.

The jury, headed by Dr. Urs Metzger, voted unanimously in favor of this decision. GIST is a very rare cancer of the gastrointestinal tract that occurs in 10–15 people per one million

2011

From Page 1

community is bigger. But we've never forgotten where we began; we are increasing our reach to ensure that amongst everything else—no one faces GIST alone.

And we are still as dedicated as ever to *survival*. We have just chosen to imagine a future without GIST—without cancer.

Maybe that's why it's so hard to write these reports, because I would rather be looking ahead, not behind. But as I said before and must always remind myself, where you're going depends a whole lot on where you've been.

Advocacy

One of the many things the LRG expanded in 2011 was our advocacy efforts. From the early days of helping patients with access issues on a one-on-one basis and reporting on trends we saw in dosage and survival, the LRG has now become an active presence in making change. We still helped patient's access drugs; we just did it more often and in some cases, in new ways.

Alianza GIST, our Latin American patient group alliance, met (as a formal organization) for the first time in Brazil and committed itself to helping patients in this region become better informed about the disease and its treatments as well as get better access to life-saving drugs.

We put this into effect by creating the first event for "Best Practices in Latin America", which we held in collaboration with the Max Foundation at the American Society of Clinical Oncology (ASCO) conference in June and brought American & Latin American physicians together with others to study abnormal GIST cases in the region.

We also took a stand on counterfeit and substandard treatment, which



Representatives of 12 Latin American countries were joined by patients in Brazil.

plagues much of the world, but especially Latin America, by creating a petition and asking the community to stand with us.

Another goal that we have had for years is the routinizing of mutational and plasma testing. In 2011, we took this further than we ever have by first reestablishing free plasma testing through TDM Pharmaceutical Research, when Novartis was no longer able to support the program. Second, we launched a major survey, targeting both patients and doctors, which aimed to find the root causes for lack of participation in these tests and how we can make it better.

Patient Support & Education

I'm constantly amazed at how much our support & education efforts have grown. The ever-changing technological world we find ourselves in continues to come up with new and innovative ways to reach people.

While laying the groundwork for new technology, like a fresh, more interactive website and mobile apps, the LRG reached further and further out. Though

we wish there were no need for it, we increased our patient crisis counseling efforts and plan to make these better in the new year.

We also not only expanded our US local groups, but we began efforts to keep our local

group leaders more engaged and well-informed in order to increase the benefit from those meetings.

In a similar vein, we created a formal Physician Outreach program, with a goal to reach more patients, especially those who might not be able to find us on the internet, through their doctors.

Additionally, after the tragic loss of LRG member, Bill Buchanan, the LRG was able to honor his last wishes and establish a local support group at John Stroger Hospital a county hospital in Cook County, Illinois, where patients sometimes don't have access to the internet to learn more about their disease and often have trouble even getting to appointments.

We also reached more patients by getting out of New Jersey! This year, the LRG had its first professional booth at ASCO in Chicago, where we raised awareness about GIST and the Life Raft Group by connecting with oncologists, pharmaceutical representatives and other patient groups from all over the world.

Moreover, we made a fairly simple, but nonetheless brilliant, decision to hire long-time LRG member and very vocal email poster, Janeen Ryan on a part-time basis.

Bringing Janeen on board has helped us support, assist and comfort more patients. We began as a handful of friends trying to help each other and with Janeen and the rest of the committed staff's help, as large as we become, we will still always feel that way.

This year we saw a new member, Dave Safford, join the LRG and throw himself into supporting the cause by joining the Board and hosting a fantastic piano con-



Our very first "pro" ASCO booth!

RISK

From Page 1

scribes three new genomic-based methods that appear to significantly outperform current methods of risk assessment:

- CINSARC
- AURKA expression
- Genomic Index

One of these methods, the CINSARC method, appears to have broader applicability to the wider sarcoma community as well. Importantly, the DNA CGHarray technique performed by Dr. Debiec-Rychter and colleagues can be performed from paraffin-embedded tumor tissue, the type of tissue that is already available/existing for most GIST patients.

GISTs are heterogeneous tumors in terms of location, histology, molecular profile and prognosis. Although mutations of *KIT* or *PDGFRA* are early and most likely initiating tumorigenic events in GISTs, increasing evidence suggest that clinical behavior of GISTs are influenced by accumulation of other genomic/chromosomal alterations (Figure 1). Like in most tumors, a number of chromosomal changes occur during the progression of GIST from low risk to metastatic (Wozniak et al., 2007). By cytogenetic analysis approximately two-thirds of GISTs demonstrate either total (monosomy) or partial loss of chromo-

some 14q. Loss of the long arm of chromosome 22 is observed in approximately 50 percent of GISTS. Loss of 1p and 15q are common and often coexisting, with higher frequency in high risk GISTS. Losses on chromosomes 1p, 9p (which harbors tumor suppressor genes *CDKN2A* and *B*), 9q, 10, 11p and 13q, and gains or amplifications on chromosomes 5p, 3q, 8q, and 17q are associated with malignant behavior (Figure 2*).

Traditional methods of karyotyping have enabled rough analysis of chromosomal aberrations, but are imprecise and low-throughput. To map chromosomal changes with superior precision, researchers have turned to oligonucleotide-based comparative genomic hybridization (DNA array-CGH) (Figure 3*). By DNA array-CGH analysis, it was found that benign (more commonly referred to as very low- to low-risk) GISTS had a mean number of 2.6 aberrations per sample; malignant primary GISTs had a mean number of 7.5 aberrations per tumor, whereas the mean number of aberrations per metastatic GIST was 9 (El-Rifai et al., 2000; Wozniak et al., 2007). Genes targeted by these chromosomal changes and their contribution to clinical progression of GISTs are only partially known.

Alteration in DNA copy number is one of the many ways in which gene expression and function of

Glossary

Sarcoma: Malignant tumor originating from mesenchymal type of cells.

Karyotype: A picture of all the chromosomes from an individual's cells. This is a test used to check for chromosome abnormalities. A picture of a person's chromosomes is created by staining the chromosomes with a special dye, photographing them through a microscope and arranging them in pairs. It gives information about the number of chromosomes, the structure of their chromosomes and the sex of the individual. The normal human karyotypes contain 22 pairs of autosomal chromosomes and 1 pair of sex chromosomes. Short arm of chromosome is named *p* and long arm *q*.

Deletions: The loss of genetic material. The deletion can be heterozygous (copy number of 1) or homozygous (copy number of 0). Deletions in tumor cells may represent the inactivation of a tumor suppressor gene, and may have diagnostic, prognostic, or therapeutic implications.

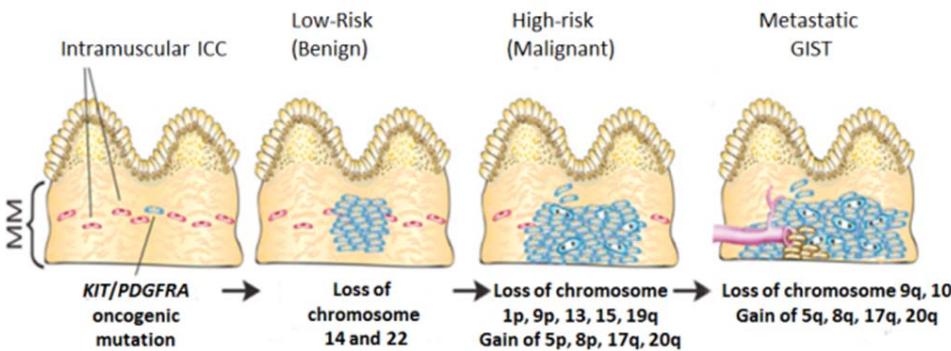
Gains: A copy number gain represents the gain of genetic material. If the gain is of just one additional copy of a segment of DNA, it is called a duplication. If there is one extra copy of an entire chromosome, it may be called a trisomy. When seen in tumor cells, they may have diagnostic, prognostic, or therapeutic implications.

Amplifications: Technically, an amplification is a type of copy number gain in which there is a copy number 10. In the context of cancer biology, amplifications are often seen in oncogenes. This could indicate a worse prognosis, help categorize the tumor, or indicate drug eligibility.

Array comparative genomic hybridization: DNA array comparative genomic hybridization (DNA array-CGH) is an efficient approach to scanning the entire genome for alterations in DNA copy number.



Figure 1



GIST progression is a multistep process that involves tumor initiation, progression, and metastasis. A malignant GIST develops as a result of an acquired mutation in *KIT* or *PDGFRA* & a series of sequential genomic abnormalities.

cancer cells may be modified. In the past, several efforts have been made to establish biologic differences at the levels of gene expression profiles according to tumor's *KIT/PDGFR α* genotypes, their anatomic site of origin and histopathologic grade of malignancy (low-risk vs. intermediate vs. high-risk), based on the whole-genome expression profiling of heterogeneous cohorts of GISTS (Rubin et al., 2001; Antonescu et al., 2004; Ylipää et al., 2011). A variety of genes encoding oncogenes, tumor suppressors, proteins involved in cell

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OCT-1

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was also statistically significant ($p<0.001$).

White and colleagues have provided a much better picture of which CML patients might benefit from a higher dose of Gleevec. Using a combination of OCT-1 activity, imatinib plasma levels and imatinib dose, they were able demonstrate that those with low OCT-1 activity (2/3 of patients), adjusting dose for patients with low plasma levels could significantly improve results.

The findings of this study are important for CML patients, but also raise a few questions for the GIST community to consider as well. While OCT-1 activity levels were not correlated with MMR for all CML patients, they were a good predictor of outcomes for one particular subset of patients: those on a low dose of imatinib that had high levels of OCT-1 activity fared much better than those on the same dose with low levels of activity. For these patients, knowing the levels of OCT-1 activity is an important factor that, in the

Figure 1

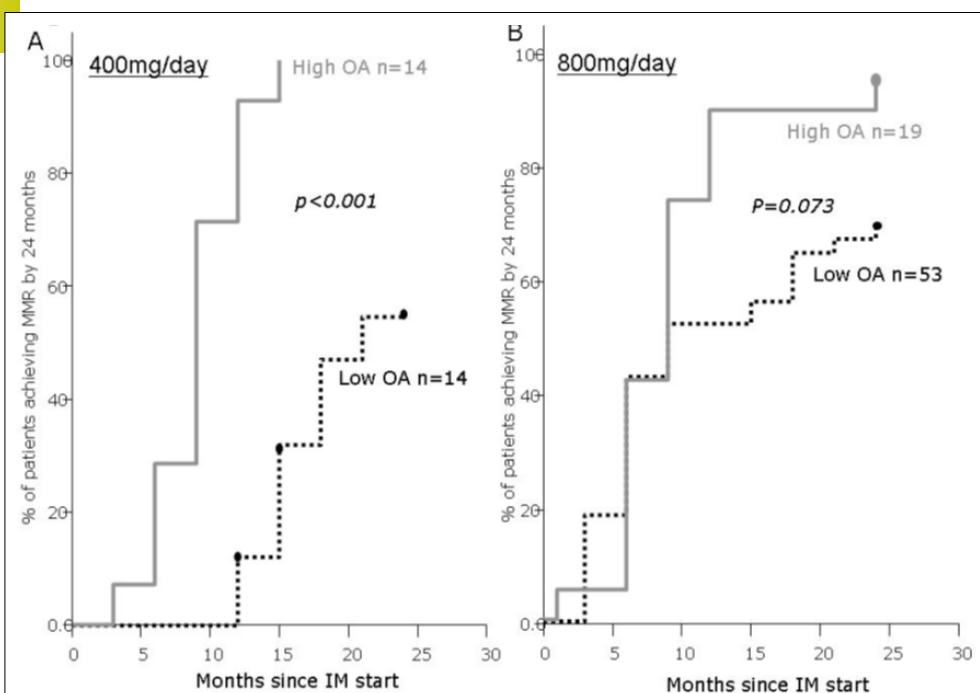


Chart taken from:

White DL, Radich J, Soverini S, Saunders VA, Frede A, Dang P, Cilloni D, Lin P, Mongay L, Woodman R, Manley P, Slader C, Kim DW, Pane F, Martinelli G, Saglio G, and Hughes TP. Chronic phase chronic myeloid leukemia patients with low OCT-1 activity randomised to high-dose imatinib achieve better responses, and lower failure rates, than those randomized to standard-dose. *Haematologica*. 2011; 96:xxx doi:10.3324/haematol.2011.056457

words of the researchers, “provides a valuable prognostic tool to determine the

up-front dose of imatinib in newly diagnosed chronic phase chronic myeloid leukemia patients.” In summary, for CML patients, this test may become extremely important in the future.

The question then, is what about GIST patients? Would testing for OCT-1 activity levels be just as beneficial? Is there a similar relationship between these levels, Imatinib dose, and progression-free survival? What about the role of plasma levels for imatinib and OCT-1 activity? At this point, there are no definitive answers to these questions. While CML and GIST do have their similarities, there are of course differences as well, and it is possible that OCT-1 plays a different role in each disease.

One fundamental difference has to do with drugs available beyond the first line of treatment. CML pa-



Did you See?

Some of you may have seen this picture before, but we just couldn't resist posting when LRG member Nina Johns forwarded it to us.

Nina found this while site seeing in Oregon during her first trip to see Dr. Blanke, when he was at Oregon Health & Science University.

She saw it as her husband passed by and yelled for him to stop. They backed up, turned around and she got a picture with the sign.

What a coincidence!



See OCT-1, Page 14

RISK

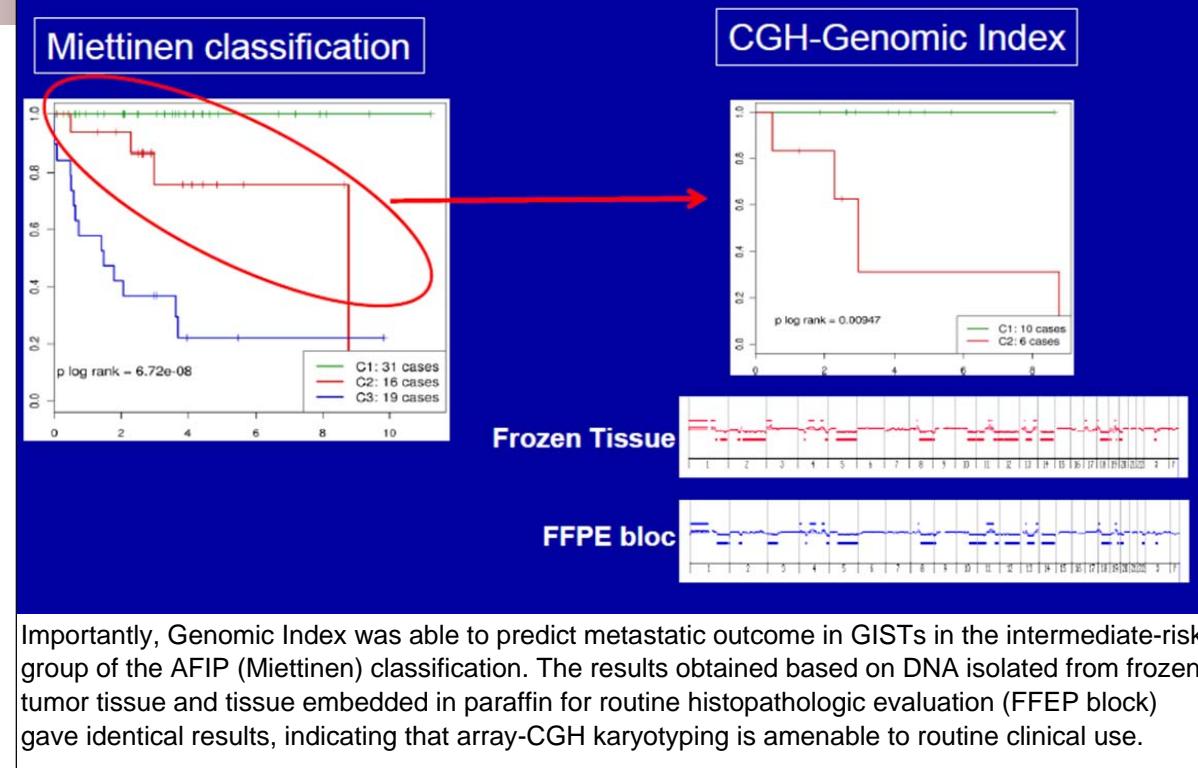
From Page 9

cycle progressions, and proteins involved in the control of cell motility have been found to be aberrantly expressed and/or amplified in GISTs.

In most expression profiling studies in sarcomas, the purpose has been to identify new diagnostic markers or to obtain better understanding of sarcoma pathogenesis. Only a few studies to date have tried to correlate expression profiles with the outcome of the disease. Recently, using a new methodological

approach, Dr. Fredric Chibon and co-workers from the Bergonie Institute (France) have performed integrated genomic and expression profiling analysis of a large set of different sarcoma types, including 32 GISTs (Chibon et al., 2010). By analysing expression profiles according to genome complexity (reflected by the number of chromosomal aberrations in a given tumour) and tumor's histological grade (established by routine histopathological criteria), the researchers were able to identify a prognostic gene expression signature. This signature includes 67 genes involved with cell division (mitosis), chromosome management and, ultimately, genomic stability as a predictor of metastatic potential. The authors proposed the use of this system, which they termed CINSARC (Complexity INdex in SARcomas), as an adjunct to the current histologic grading system. Based on the system the tumors could be divided into two CINSARC classes of "good" or "poor" prognosis. The results were compelling as the authors showed that CINSARC is more sensitive in assigning risk group

Figure 6



than currently used procedures and can be applied to many tumor types including GISTs. Subsequently, through the collaborative efforts between French and Belgian sarcoma groups, these results were confirmed and extended by a more recent study, in which DNA array-CGH and expression profiling analysis was performed on 67 primary untreated GISTs (Lagarde et al., 2011). As a result not only the value of CINSARC signatures was validated (Figure 4*) but also several important correlates were found. Firstly, the gene whose expression was most strongly associated with metastasis was AURKA (which maps to chromosome 20q), even though the AURKA locus was not amplified. Secondly, the deletion of the p16 (CDKN2A) and retinoblastoma (RBI) genes were identified, and these were mutually exclusive and likely causal events leading to increased AURKA and CINSARC gene expression, to chromosome rearrangement and ultimately to metastasis. In addition, the so-called Genomic Index that integrates the number and type of DNA copy number alterations was established. This in-

dex is a strong prognostic factor in GISTs (Figure 5*). The CINSARC class, level of AURKA expression and Genomic Index all outperform the currently used histopathologic grading system in determining the prognosis of patients with GISTs.

GISTs are the most frequent mesenchymal tumors of the gastrointestinal tract and are among the rare tumors to benefit from a targeted therapy. Thus, the development of a method for GIST prognostication has become essential for the proper clinical management of GIST patients, especially in the context of adjuvant treatment, where many patients are exposed to drug while only a small proportion will likely benefit from such treatment. In the past, many pathological criteria based on tumor site, tumor size, cell type, degree of necrosis and mitotic rate have been proposed for predicting the outcome of patients with GISTs. A consensus grading scheme based on tumor size and mitotic count was proposed by the US National Institutes of Health (NIH) in 2001 to estimate the prognosis

2011

From Page 8

cert. Long-time member and Pediatric GIST survivor, Jason DeLorenzo, who has always struggled with GIST complications, ran an entire marathon this year to support GIST research.

New or just arrived, I consider every GIST survivor my friend and I am immensely proud of all they have achieved.

Research

In 2011, the LRG made several strides in the search for a cure.

We sustained our support and participation in endeavors like the NIH Pediatric & Wildtype GIST Clinic which continues to make discoveries in the understanding of this rare subset of GIST.

We were honored to present a poster and a paper on the relationship between Gleevec dosage and long-term survival at the prestigious Connective Tissue Oncology Society (CTOS) conference in November. We've come a long way from a small group of dedicated patients looking for trends in treatments and practices.

This year, we also saw the first progress report of our D-Day initiative.



DeLorenzo is tired but still smiling at the end of the marathon.

This research project was the result of years of knowledge building, and bringing together the best in their fields to consider and plan every next step. As I've said before, a perfect storm created this effort. The funding arrived just as costs for vital tests lowered and the research team had gained enough knowledge and resources to make a strong push for the cure.

I for one was terribly excited to see what they came up with and the results were better than I expected.

Our team identified several new mutations besides KIT in its Sequencing group; an important gene-critical for GIST cell survival- was identified by the Gene Knock-Down group, as well as more relevant targets and resistance

factors; our Drug Screening group, which was created to fast-track effective treatments for patients in need while the lengthier process of finding the cure is underway, found several drugs which could potentially inhibit GIST growth. All of these discoveries are now being vetted by our Validation group and very soon I hope to have even more progress to report.

Perhaps, it is more than preferring to look forward. Perhaps the brighter the future looks, the harder it is to look back.

When we do, we are reminded of how far we still need to go. We lost friends this year- people like Richard Palmer, Dan Cunningham, Rachel Tate and Butch Eller- who supported us as we supported them. It's easy to let these heartbreaks discourage you and rob you of hope.

But in those moments, all I need do is look around at Anita Getler, who is celebrating her six-year cancerversary this month; Tim Mansfield, who has passed 17 years, Floyd Pothoven, Marina Symcox, Tania Stutman and Paula Vettel—Anita, my wife of 50 years, 18 of which have been spent living with GIST.

Devoted wife, mother & grandmother passes

Devoated wife, mother and grandmother, Sally Grahl Smith, 73, married Brack K. Smith, Sr. on June 13, 1959 and passed away Thursday, December 8, 2011 at her home after 52 years of marriage.

Born in Laurinburg, NC, she was a daughter of the late William H. Grahl, Sr and Clara Mae Ballard Grahl. She graduated from Welcome High School in 1956 and then from Greenville General School of Nursing in 1959. She was a homemaker and a member of Rock Springs Baptist Church.

Surviving in addition to her husband are a daughter, VaughnDe K. Peterson and her husband, Terry ; two sons, Brack Kirk Smith, Jr. and his wife Sharon J. and Carl A. Smith; a sister, Kay Johnson ; a brother, William H. Grahl, Jr. and his wife, Brenda ; 6 Grandchildren, Stephanie Gorss, Matthew and Sarah Peterson, Cameron and Megan Smith and Kelsey Smith.

In addition to her parents, she was preceded in death by a brother-in-law, Leroy C. Johnson. Condolences may be expressed online at www.robinsonfuneralhomes.com.

Mark your calendars!

- The GIST Benefit Ball, hosted by Julie Cramer (Page 5) will be held on **February 18**.
- The next Cook County meeting will be held on **March 3** from 1-3 PM. Please email Jim Hughes at tjhughes43@comcast.net for details.
- The LRG researchers are meeting in Belgium, **March 18-23**.
- "Harness a Cure" (Page 7) is set for **March 25**. Details coming soon!
- Alianza GIST's next meeting is scheduled for **March 26-28**. Email srothschild@liferaftgroup.org for info,
- GIST Day of Learning (Page 3) in Miami, Fla. Will be held on **May 19**. Contact the LRG for information. Look out for Life Fest 2012 in Las Vegas in the beginning of November. More details to come!

WARRIORS

From Page 1

mg (after discovering an exon 9 mutation) through perseverance and donations from generous friends and patients (You can read more about this story in our April 2010 newsletter issue).

Eventually Vera was shifted to Sutent and then on to other drugs when the progression continued. Though she tried tremendously to get ahead the disease, Vera passed away peacefully on December 17, 2011.

It may seem as if for the duration of her illness, she knew only struggle and financial hardship, and that may be true. However, through the exhaustive endeavors of Vera and her family, collaboration with the CML community, talks with health authorities and a huge media campaign to create more awareness about access, Gleevec was put on the treatment reimbursement list and future GIST & CML patients have been left with the gift of access to a life-saving drug.

What Vera and her devoted son, Dejan inspired in Macedonian GISTers and non-GISTers alike was nothing short of a miracle.

"The GIST & CML communities in Macedonia really came together. What they were able to do was an inspiration to patient advocates everywhere," said LRG Global Relations Director, Sara Rothschild, who worked with closely with Dejan on this campaign, "The passion and the steadfastness that Dejan had for saving his mother motivated me as I



KRSTEVSKI

goes on."

continued working with the global GIST community." Dejan, too, is not done yet, "We have another fight ahead of us that will be much harder, putting Sutent on the reimbursement list. We have already started [working] together with RCC patients that are also affected by lack of access to Sutent. The fight

Rafael Becerra was never highlighted in our newsletter, but he was well known in the GIST community and widely loved by all who knew him.

He started out like many GIST patients, faced with a diagnosis they were not prepared for. After his initial surgery, he continued his normal life, but in

his spare time he began to study his disease, to learn what treatments were available and how to manage the side-effects they produce. In a relatively short amount of time, Rafa, as he was known to his friends and colleagues, accomplished much.

In his comings and goings to treatment appointments, Rafa began to meet other people who had the same disease, like Rafael Vega. Together, they decided to create the Colombian GIST Foundation

(www.fundaciongistcolombia.org), for the purpose of educating and informing patients and medical providers and raising awareness about treatments and side-effects management.

Never tiring, "The Rafaels" and

mined empirically, but generate a large intermediate-risk group (approximately 25% of patients) for which adjuvant imatinib is controversial because the real metastatic risk is poorly defined. As mentioned above, high Genomic Index determined by array-CGH can identify poor prognosis patients in the group classified as intermediate-risk by the AFIP classification. (Figure 6) Array-CGH technique is already used in pathology laboratories using formalin-

Fundacion GIST Colombia joined other Latin American countries to form Alianza GIST, an alliance aimed at improving the knowledge base and standards of care for all Latin American GIST patients.

In the course of his various duties in Colombia and Latin America as a whole, including visiting the homes of every GIST patient who joined his organization, Rafa's progression began to spread and overcome his GIST treatment in the summer of 2011 and he passed away on December 8, but as his brother, Jairo, said in a final note on Rafa's blog, "He left a legacy of struggle, perseverance and positivism against the adverse circumstances that life presents to us."

This is obvious from Dr. Vega's beautiful eulogy to Rafa, where he proudly announced, "Rafa was the first GIST patient in Latin America to persuade the Social Security office in Colombia to get medicine approved for his GIST treatment, which was not yet approved in the world. He was an example for all patients with cancer."

Alianza GIST Coordinator, Vicky Osio once said, "Although it is terrible; GIST has allowed us to know people as exceptional as Rafael Becerra."

As for Rafa, he chose the way he would approach life and even death when he announced to his brother, "I will leave the day that I have to, not before."

It will never be fair to lose GIST warriors like Vera & Rafa, but the GIST community can take comfort in the lasting gifts they left for us.

The world will not be the same without them, but it is forever changed thanks to them.

fixed paraffin-embedded samples. Genomic array-CGH profiling could therefore be a powerful tool to manage imatinib therapy for intermediate-risk GIST patients.

**Due to the length restrictions of a newsletter such as this, we were forced to remove some information from Dr. Debiec-Rychter's article. You can find more figures and a full list of references on our E-News site, www.gistnews.org.*

RISK

From Page 11

of GIST patients. In 2006, the Armed Forces Institute of Pathology (AFIP) proposed an updated system taking into account also tumor location (Miettinen and Lasota, 2006). Both systems are based on histopathological assessment of tumor aggressiveness. Cut-off values defining risk groups have been deter-

HAPPY CANCER-VERSARY TO ANITA GETLER!

This month, LRG member Anita Getler (pictured below with her grand-daughter Oriannah) will be celebrating two important days. Her birthday is on February 5, followed closely by her cancer-versary on February 14. Valentine's Day &

GIST? That doesn't seem to go together, but Miss Anita never stops smiling...

"Wow! It's hard to believe all this time has passed since my diagnosis with GIST and I have been truly blessed to be cancer-free and dancing with NED for six years now! I even had the joy of another grandchild, Mariellah, born this past June....very thrilling for me and my family to celebrate another new life joining us!"

My wish is to find a cure for GIST and all other cancers this year so we can all relax a little bit, but in the meantime always live life to the fullest and enjoy each day!"

Congratulations Anita....
and Happy Birthday!



OCT-1

From Page 10

tients that don't respond well to imatinib have second and third line drugs that are very effective for most patients. While GIST patients do have treatment options beyond imatinib, and they are effective for some patients, they are not as effective for as broad a group as with CML. Because of this, resistance is a bigger issue for GIST patients, who do not have as many broadly effective drugs beyond the first-line to fall back on, and for most patients, is extremely hard to overcome once it has developed. Thus, the best approach may be to try to prevent resistance before it happens, as opposed to trying to reverse it when it occurs. Further research into which patients need a higher dose (or plasma level) of imatinib is one of the most promising ways to prevent resistance, and this study may help provide some clues to help drive that research.

The only way to determine the role of OCT-1 is to conduct further research, both on GIST tumors, to get a

general understanding of what role OCT-1 may play, and through clinical trials, to see if there is any correlation between these levels, plasma levels of imatinib, and increased survival among GIST patients. A collaborative effort may be the

best approach, with GIST researchers working with their CML counterparts to augment existing research and help determine if additional research can be conducted that would directly benefit GIST patients .

Janice loved life & family

Janice Garrison Aubert, 76, of Spencer, died December 21, 2011. Born January 2, 1935 in Pond Creek to William and Maxine Garrison, Janice loved life and family, especially her grandchildren.

Janice was preceded in death by her parents; sister, Billie Rerrick; and grandson, Mike Bastianelli. She is survived, by husband, Ray Aubert of Spencer; children:

Nancy West of Coraopolis, PA; Don West

of Oklahoma City; and Paul West of Dammam, Saudi Arabia; stepson, Marty Aubert of Oklahoma City; seven grandchildren and four great-grandchildren.

The family would like to thank Hospice Quality Care for their loving care during Janice's final weeks.

In lieu of flowers, please send donations to The Life Raft Group, which is working to find a cure for G.I.S.T., a rare form of cancer, at 155 US Hwy. 46, Ste. 202, Wayne, NJ 07470, or www.liferaftgroup.org



SWISS

From Page 7

inhabitants per year. In their investigation, the authors discovered a so-called mini-GIST in 2.9 percent of the cases studied, i.e. in 17 of 579 autopsies. This is still well below the rate of 20–30 percent that has been published by other authors in smaller-scale studies. Together with the extensive molecular genetic investigations, these findings provide important insights into the molecular mechanisms leading to GIST. The jury was impressed not only by the indisputable quality of the work submitted but also by Prof. Dirnhofer's commitment to the study of this rare disease. In the past seven years, he has published ten papers on this topic that are listed in Medline, eight of them containing original research. GIST is a sarcoma, a group of malignant tumors that occur in connective tissue, bones and muscles. As a non-profit organization, SAKK also conducts studies on such rare forms of cancer.

Film makers win Special Recognition Prize

A second award, the Special Recognition Prize, was conferred on Helga Meier Schnorf and Dr. Michael Montemurro



Winners again: (From left to right) Dr. Dirnhofer, Helga Meier Schnorf, Dr. Montemurro and Mrs Heiniger (a patient who played a major role in the film)

of the GIST Group Switzerland for their documentary "Living with GIST". "The film strikes a delicate balance between appealing to the emotions and conveying information and focuses on delivering a message about a difficult topic. It neither wrings the heartstrings and nor becomes bogged down in technical details. The film succeeds in maintaining this quality for 50 minutes," said Urs Metzger on behalf of the jury. Using patient histories from real life, "Living with GIST" impressively illustrates the path from the correct diagnosis to therapy and dealing with the disease and with cancer. It also throws light on the worldwide network of patients and phys-

sicians and their cooperation across medical disciplines and in research. Yet the patient is always the focal point of the documentary.

"Living with GIST" won the EDI 2011 Silver Medal just a few days ago. EDI is the Swiss prize awarded to the best advertising, industrial and corporate films and is sponsored by the Swiss Federal Department of Home Affairs.

Show the LRG some love!

Valentine's Day is coming up, a perfect time for your friends and family to show GISTers some love!



Please send out your Holiday Fundraising Campaign note cards. All donations go directly to support patients & GIST research (You can read more about this year's campaign on page 5).

You can also go to www.acureisinourreach.org, upload a photo (you and your sweetie, perhaps?) and tell the world what a cure would mean to you. Won't you be our valentine?

The first steps towards finding a cure for GIST can start with you!

If you or your loved one has had their tumor removed, you are eligible to participate in the GIST Collaborative Tissue Bank (GCTB). As an added benefit, we also offer free mutational testing with participation. Contact the LRG at 973-837-9092 to learn about GCTB, and how you can help find a cure for GIST.

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