

LRG meets in Mexico!

By **Karen Kelley**
LRG Director of Planning

Researchers and staff from the Life Raft Group and representatives from Mexico's science and medical community came together to commit to their mission of improving the survival of gastrointestinal stromal tumor (GIST) patients in Latin America.

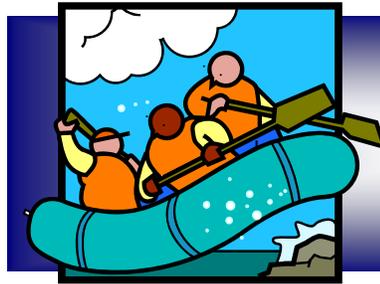
The Latin American GIST Coalition, initiated by the LRG, met during this three-day event February 2 to 4 in Mon-



"Norman and The Rafaels" (Becerra to left and Vega to right) take a moment at the L.A. GIST Coalition meeting.

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Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

April 2010

In memory of Carl Banker, Shawn Vernon, Jennifer Bayles, Fred Weiss, Jeanne Noell & Gloria Richmond

Vol 11, No. 2

Life Fest: Clinician of the Year winner and Tree of Life project

By **Belinda Ehrlich**, LRG Program Associate & **Erin Kristoff**, Newsletter Editor

And the winner is...

After careful consideration, the Life Raft Group has chosen the recipient of the GIST Clinician of the Year award – Dr. Jonathan Trent of MD Anderson Cancer Center.

Dr. Trent, a tissue sarcoma specialist, has received numerous awards for his work in GIST research. He is the principal investigator on many GIST clinical trials and his ongoing trials include examining the use of Gleevec alone and in

combination with novel drugs in patients with metastatic GIST and the combination of imatinib with surgery in resectable GIST.

Dr. Trent has also published many abstracts and research articles in leading journals and is a frequent lecturer on the topic of GIST.

Dr. Trent earned his undergraduate degree in chemistry at Southeastern Oklahoma State University and his M.D. and Ph.D. in cancer biology from The



TRENT

See LIFE FEST, Page 6

Advocates unite to help struggling patients in Macedonia

By **Dejan Krstevski**
& **Sara Rothschild**,
LRG Global Relations Director

Vera Krstevska was born in November 1955 in Skopje, Macedonia. She works in a laboratory of the Institute for Transfusiology with the Clinical Center in Skopje. She is a proud mother of two sons and loving grandmother of four grandsons.

Vera was diagnosed with GIST in August 2007. She had her first gastrectomy with the tumor removed from her intes-



tines. One year later, she had a recurrence in the stomach, intestines and liver. A second operation was successful at removing the tumors from her stomach and intestines, but two cysts remained in her liver. After consultation with her local oncologist and a GIST specialist located in Greece, Vera started 400mg of Gleevec on January 15, 2009.

Vera's case is not much different from other GIST patients. What sets her apart, however, is the country in which she lives and its debilitating health system.

Located in Southeastern Europe, the

See MACEDONIA, Page 7

Researchers collaborate at Monterrey meeting

By Jerry Call

LRG Science Coordinator

The LRG research team continues to investigate a number of key areas. These include research into ways to overcome drug resistance, improve initial response to treatment, clinical trial support, high throughput screening and establishing the basis for moving individual drugs into clinical trials.

Overcoming drug resistance

The general mechanisms of resistance to Gleevec have been fairly well understood since about 2003. During this meeting, further insights were provided about drug resistance to HSPHSP90 inhibitors and additional insights into Wild-type/pediatric GIST signaling with respect to IGF1R. The IGF1R data provides further scientific support for targeting IGF1R in a subset of GIST patients.

New strategies identified by the research team to overcome Gleevec resistance have now entered clinical trials

including the phase II STA-9090 trial (HSPHSP90 inhibitor) and a wide array of PI3K inhibitors (phase I) and IGF1R inhibitors (most in phase I). The phase I trials are not specific to GIST. A phase I trial combining an HDAC inhibitor and imatinib is also close to opening.

Additional resistant GIST cell lines have been developed, including a cell line from Dr. Jonathan Fletcher with loss of PTEN, which is a protein normally responsible for blocking the ability of PI3K to accelerate GIST cell growth and survival. These cells should be useful in understanding the details of how PI3K works in GIST cells and also useful in understanding the most effective ways to target PI3K therapeutically.

Dr. Fletcher reported on both first and second generation HSPHSP90 inhibitors. Reports from the IPI-504 phase III trial indicated high toxicity and treatment-related deaths in medically fragile patients with prior liver resection. First generation ansamycin HSPHSP90 inhibitors such as 17-AAG and IPI-504 are derived from natural compounds and seem to have some liver toxicity (some more than others). Second generation

See RESEARCH, Page 8

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 LRG Research Team meets at Monterrey Tech: Dr. Brian Rubin, Dr. Sebastian Bauer, Dr. Cristina Antonescu, Dr. Matt van de Rijn, Dr. Jonathan Fletcher, Karen Kelley, Norman Scherzer, Dr. Anette Duensing, Dr. Chris Corless, Dr. Maria Debiec-Rychter & Jerry Call

GIST Research: Articles on the Science of GIST

Updates from GI ASCO 2010

By Jerry Call
LRG Science Coordinator

The 2010 Gastrointestinal American Society of Clinical Oncology conference was held January 22-24, 2010 in Orlando, Florida. Several of the abstracts/posters are summarized below.

Risk assessment for tumor recurrence after surgical resection of localized primary gastrointestinal stromal tumor (GIST): North American Intergroup phase III trial ACOSOG Z9001

Abstract # 6

ME. Blackstein et al

Dr. Blackstein (University of Toronto) and colleagues reported on maturing data from the Z9001 adjuvant Gleevec trial. In this trial, 713 patients took either Gleevec or placebo for 12 months. With

a median follow-up of 20 months, the recurrence-free survival (RFS) was 91 percent for the imatinib arm and 74 percent for the placebo arm.

NOTE: This study was unblinded in April 2007. Some patients in the imatinib arm may have continued imatinib after one year (they received imatinib outside of the clinical trial) and some placebo patients were switched over to receive the drug or may have taken the drug after the trial was stopped. Both situations would make interpreting the data more difficult. In spite of this, recurrence is clearly reduced or delayed for patients taking imatinib in the moderate and high risk categories (See Table 1).

Final results from a phase III study of IPI-504 (retaspimycin hydrochloride) versus placebo in patients with gastrointestinal stromal tumors following failure of kinase inhibitor therapies

Abstract # 64

G.D. Demetri et al

This randomized phase III trial was terminated early due to the occurrence of four on-treatment related deaths in the IPI-504 arm. These deaths were considered drug-related and included kidney failure, liver failure, metabolic acidosis and cardiopulmonary arrest. Grade three or four AST or ALT abnormalities (indicates injury/damage to liver cells) were present in three of the four deaths. The authors concluded "...In this heavily pretreated patient population, IPI-504 was not well tolerated at this dose and schedule, and the study was terminated early." IPI-504 continues to be evaluated at lower doses and alternative schedules in other clinical tri-

Table 2: Risk Factors

Risk Factors	Risk
High Mitotic Rate	p<0.0001, Hazard Ratio 11.3
Tumor Size ≥ 5 cm	p<0.0001, Hazard Ratio 2.0
Small Bowel Primary	p=0.02, Hazard Ratio 1.7

NOTE: Risk factor calculations via multivariate analysis. Table adapted from 2010 GI ASCO, abstract #6

als for patients with other forms of cancer.

In an accompanying poster, a relationship between prior liver surgery and safety was noted. Of the six patients on IPI-504 with prior liver surgery, there were three on-study deaths not due to GIST (50%). Of 26 patients on IPI-504 with no prior liver surgery, there was only one on-study death not due to GIST (3.8%). The poster also noted that the patient population in this trial had advanced disease, as evidenced by deaths during the screening period and short progression-free survival in the placebo arm (33 days).

A cross-sectional study of imatinib plasma trough levels in patients with advanced gastrointestinal stromal tumors: Impact of gastrointestinal resection on exposure to imatinib.

Abstract # 161

C. Yoo et al

Dr. Yoo and colleagues from the University of Ulsan College of Medicine and the Asian Medical Center, Seoul, South Korea; report that in a series of 108 GIST patients, higher imatinib levels (Cmin) were correlated with advanced age (p=0.02), low creatinine clearance (p=0.001), low hemoglobin (p=0.01), and albumin concentrations (p<0.001). Imatinib concentrations (Cmin) were also significantly lower in 17 patients with a total or subtotal gastrectomy (937±339 ng/mL) compared to the 75 patients without a gastrectomy

Table 1: Recurrence-free survival

	2 year RFS	
Low Risk tumors (45%)		
Imatinib	98%	p=0.92
Placebo	98%	
Moderate risk tumors (24%)		
Imatinib	98%	p=0.05
Placebo	76%	
High Risk tumors (31%)		
Imatinib	77%	p<0.0001
Placebo	41%	

NOTE: Risk determined according to the Miettinen (Sem Diagn Pathol 2006) criteria. See www.liferaftgroup.org/gist_diagnosis.html. Table adapted from 2010 GI ASCO, Abstract #6.

This report confirms earlier results that show benefit for adjuvant Gleevec. It is not surprising however, that there is little or no apparent benefit for low risk patients. What is somewhat surprising is that low risk patients make up the largest group in this large series of patients (45%). These preliminary results raise questions about whether low-risk GIST patients need to take adjuvant Gleevec.

GIST-Switzerland Group founded for the support of GIST patients

By Helga Meier Schnorf

On January 14, 2010 the GIST-Switzerland Group was founded in accordance with the provisions of the Swiss Civil code. The aim of the association is to support GIST survivors.

As specified by Dr. Metzger during the last Swiss meeting, which was held on April 24, 2009 in Zurich, one of the major concerns of the greatly missed founder, Dr. Ulrich Schnorf, was to avoid the Swiss patient advocacy group — which has been in existence now for eight years— being dependent on one single individual, but rather to ensure its continuity by creating a legal entity. Ulrich carried out the main part of the essential preparatory works for the foundation of this association. Thereafter, Dr. Urs

Metzger and Helga Meier Schnorf implemented all the requirements necessary for this creation. This is due to the strong commitment and essential role of Dr. Metzger in the drafting of the statutes and their adapta-

tion to the requirements of the tax authorities. Advance notice from the tax authorities in Zug has been returned. It assures us that according to these statutes, the tax exemption requirements for a non-profit-making association have been fulfilled. From a legal point of view, the founding of the association was assisted by Mr. Erich Kalt of Schweiger law firm, a lawyer and notary at Zug. Mr. Kalt chaired the founder meeting.

The excellent collaboration with Das Lebenshaus in Germany continues, and not only in the administrative domaine. Ulrich Schnorf would be happy to see that his second life's work, which he worked on so passionately and which he developed, still exists with the same commitment and so much reunited strength.

A few words from the new president, Martin Wettstein

I wish the newly created GIST-Switzerland Group good luck, much enthusiasm and perseverance.

The association is important for all patients suffering from GIST, their fami-



The founding members, pictured from left to right: Mathias Merki, Martin Wettstein, Helga Meier Schnorf, Urs Notter, Dr. Michael Montemurro, Dr. Urs Metzger.

lies, treating physicians and partners in the pharmaceutical industry. Moreover, for me, the treatment of patients suffering from GIST has a particular significance—as it is a model for the treatment of other types of tumours and cancers.

I want to express my great joy in the creation of the association. Thanks to the considerable preparatory works provided by the deceased (and unfortunately himself affected), Dr. Ulrich Schnorf and the selfless continuation of this work by his widow, Mrs. Helga Meier Schnorf, a very invaluable basis for the setting up of a patient organisation was laid with remarkable presence and assuring continuity.

I am taking the opportunity to express my particular thanks for all that. I also want to thank all the founding members, in particular our highly qualified medical consultants, Dr. Urs Metzger and Dr. Michael Montemurro. They give us the courage to take control of this association with the guarantee of professional support along with broad knowledge.

Finally, I would like to thank you for the confidence that you grant to me as first president of the association.



SCHNORF

The GIST-Switzerland Group

Founding members:

Martin Wettstein, President, Meggen
Herbert Blatter, Member, Sion
Helga Meier Schnorf, Member, Zug
Matthias Merki, Member, Basle
Urs Notter, Member, Bürgenstock

Prof. Dr. Urs Metzger, Medical Consultant,
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Over 100 attend 3rd national Italian GIST meeting

By Gabriella Tedone
Associazione Italiana GIST

The Third National Italian Meeting of A.I.G. (Associazione Italiana GIST) was held at Fondazione IRCCS Istituto Nazionale dei Tumori (INT), in Milan on Saturday, February 27, 2010.

For the 99 patients and caregivers attending the meeting, it was a great opportunity to hear lectures by the main Italian GIST experts, learn more about GIST, and share issues and open topics with doctors. Thirteen speakers, various oncologists from INT and the University of Medicine, and six Novartis representatives attended the meeting and participated in the discussion with the audience.

The meeting focused on molecular

genetics, of utmost importance for diagnosis, prognosis and prediction.

Many goals were also achieved. Patients have been well informed about importance of correct diagnosis and about what is requested to perform



GISTers from all over Italy met in Milan on February 27.

See ITALY, Page 9

Getting the "GIST" of gastrointestinal stromal tumours: LRG Canada's first webcast a success

By David Josephy
President, GIST Sarcoma
Life Raft Group Canada

The Life Raft Group has been pioneering the development of GIST online resources since its inception. Life Raft Group Canada relies heavily on the internet to overcome the distance barrier in a country that stretches "from sea to sea to sea" (Atlantic to Pacific to Arctic).

Recently, Life Raft Group Canada hosted its first online learning experience. This interactive webcast was held on March 23, 2010, and it was very successful. Entitled Getting the "GIST" of Gastrointestinal Stromal Tumours, the event reached patients and caregivers across Canada with information about GIST and about Life Raft Group Canada and its upcoming initiatives.



JOSEPHY

Hospital Cancer Centre, shared his expertise on GIST and its treatment, including the recent approval in Canada of Gleevec for adjuvant (post-surgical) treatment of GIST.

After the webcast, Dr. Verma addressed several questions from the live audience. In fact, we ran out of time before he could answer all of the questions that came in.

The presentation is archived at

We were very fortunate to have one of Canada's leading experts in GIST as our key presenter. Dr. Shailendra Verma, Medical Oncologist at the Ottawa



www.liferaftgroup.ca; click on the Getting the "GIST" of Gastrointestinal Stromal Tumours link on our homepage. On behalf of GIST Sarcoma Life Raft Group Canada, I'd like to thank Dr. Verma for sharing his time and expertise. We look forward to holding more webcasts in the future.

Latin American GIST Coalition promotes Monterrey Declaration

By Sara Rothschild

LRG Global Relations Director

An historic event took place after the LRG Research Team meeting (See page 2) from February 2-4, 2010, when a group of cancer patient advocates, called the Latin American GIST Coalition, met for the first time to outline their mission and commitment to promoting the survival of GIST patients in Latin America.

As part of the gathering, the Coalition had an unprecedented meeting with the world's leading GIST researchers who are committed to finding a cure for this rare disease. This encounter with researchers gave the Coalition added inspiration in their endeavor to create a mission to promote survival of GIST

patients through information, education, and strategic networking.

The Coalition gathered in a room lined with flags

representing ten countries across Latin America and the United States. The circle of flags symbolized the unity among the patient community and its belief that change can only be achieved through solidarity.

Important alliances were achieved, including one with the Tecnológico de



The Latin American GIST Coalition meets for the first time in Mexico.

Monterrey, an institution committed to the development of the first center for cancer research in Mexico, and another with The Max Foundation and the Life Raft Group, organizations dedicated to improving the lives and survival rates of

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LIFE FEST

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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. Dr. Trent is board certified in internal medicine and medical oncology.

LRG members were asked to nominate



Butch Eller, pictured here with LRG staffer, Tricia McAleer at a GIST gathering in NJ.

whom they believe to be the best doctor or nurse. The winner receives the award on Saturday, June 26 at the Hyatt Regency in Jersey City, New Jersey.

Long-time LRG member and 7-year cancer survivor Butch Eller's nomination was chosen as the winning entry due to his admiration and dedication to Dr. Trent. Not only did he write about Dr. Trent's merits, but he faxed over 20 of Dr. Trent's research articles to the LRG office as evidence! Butch has also won a free trip to Life Fest to present the award to Dr. Trent himself.

Tree of Life

As a part of Life Fest 2010, the LRG is also asking members to contribute to the Tree of Life project.

The Tree of Life is a wonderful oppor-

tunity to show your appreciation for all the good things that you have experienced since your GIST diagnosis. This is your chance to tell the world just what this time has meant to you. Trips you've taken, anniversaries celebrated, births of grandchildren, degrees finally earned... whatever events you've been alive to experience since your diagnosis can be a part of your Tree of Life.

For those with a loved one that has passed on, don't feel as though you can't participate. Feel free to fill out a Tree on his or her behalf. Creating your Tree is fun and easy. Simply go to www.liferaftgroup.org/members_lifest.html for a detailed list of instructions.

The Tree of Life is a creative way to "count your blessings." Show the world all you've done as a GIST survivor!

The deadline for contributing to the Tree of Life has also been extended to May 15, we urge you to take advantage and participate today.



Want to honor someone special in the GIST community at Life Fest? Purchase space in the Life Fest Commemorative Program. You can:

- Remember a loved-one
- Thank a doctor or caregiver
- Show support for a local LRG group
- Show support to the GIST community
- Say whatever you want!

Go to www.liferaftgroup.org/lifest_sponsorship.php for more info.

MACEDONIA

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Republic of Macedonia is one of the successor states of the former Yugoslavia. Macedonia has a public health insurance system in which most treatments, operations, and general care are covered by the government with little cost shared by the patient.

There is, however, a gap in the system—in particular for rare disease patients. The Ministry of Health has not prioritized funding treatment costs for rare diseases, like GIST and CML; therefore, most patients are left to find other ways to access life-saving treatment.

After a few tragic patient cases and coordinated outreach efforts among the Macedonian GIST, CML and rare disease communities, the Ministry of Health approved a program in 2009 to fund the treatment of rare diseases.

Although this seems like a triumph, a year has passed and the implementation of this program has yet to begin due to budgetary constraints, as well as an acceptance of information about how new treatments such as Gleevec can provide longer progression-free survival and better quality lives.

With the help of the Life Raft Group and other international advocacy groups such as European Cancer Patient Coalition (ECPC), an aggressive letter-writing campaign was initiated. It urged the Macedonian Minister of Health to advocate that Gleevec be covered by the Health Fund. The international CML and GIST communities also partnered together on behalf of Macedonian patients to advocate for access to life-saving treatment.

Over the past year, in conjunction with the letter-writing campaign, individual patients and the Macedonian Society of CML Patients (to which the GIST patients belong) have organized aggressive media campaigns to increase awareness to the public about the problems they have encountered. Numerous meetings have been held with officials in the Ministry of Health and the Health Fund. Promises were made, yet no positive results have been achieved.

As of today, people like Vera are still awaiting a positive response from the health authorities, but problems accessing treatment are becoming more serious for patients like Vera.

Through the Life Raft Group, Vera was able to find a GIST specialist, Dr. Ioannis Boukovinas, who has proven to be very experienced, professional and helpful in regard to the management of Vera's disease. Through the LRG e-mail community & Dr. Boukovinas, Vera also found information about mutational and plasma testing and discovered that she had an Exon 9 mutation for which her doctor recommended increasing Gleevec to 800 mg.

Unfortunately, due to the political and financial situation in Macedonia, Vera could not go to a higher dosage and remained at 400 mg. One year since the mutational testing and her start of Gleevec, a CT scan showed a new tumor in her stomach.

With the help of donations, she managed to increase the dosage to 800 mg, but this is not a long-term solution. Plasma testing has verified that imatinib is at therapeutic levels so she hopes for a continued good response to this dosage.

Vera is not the only Macedonian patient feeling financial and medical pressure due to treatment access issues.

**Mail letters to:
The Life Raft Group
Attn: Macedonia
155 US Highway 46,
Suite 202
Wayne, NJ 07470**

In order to keep patients like Vera alive, her family is appealing to the international GIST community to advocate for patients and push the Macedonian health authorities to cover Gleevec treatment in their Health Fund. If you would like to help, please send your letters to the Life Raft Group, who will pass it along to the Ministry of Health.

Note: Dejan Krstevski is Vera's son and has been advocating on her behalf since her diagnosis.

HAPPY CANCER-VERSARY TO KATIE CAMPBELL!



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

Congratulations to Katie Campbell who has been NED (No Evidence of Disease) for two years. With this wonderful news comes a new outlook, "I live everyday to the fullest and take nothing for granted. I have been given a second chance." Katie has used this second chance to help others in the GIST community through the St. Louis GIST Foundation, who are holding a GIST gathering on May 15. Go to www.gistl.org for event information.

RESEARCH

From Page 2

compounds are synthetic and so far have not been shown to have the same liver toxicity. The selective and highly potent second generation HSP90 inhibitor, STA-9090 has entered phase II trials for GIST. A total of four sites are expected to open. Dr.

Fletcher also described new laboratory studies in which GIST therapeutic response to HSP90 inhibitors was maximized by concurrent inhibition of other crucial growth and survival pathways in the GIST cells.

Improving initial response

Several research groups presented data on different ways to improve the initial response to Gleevec. The hope is that if you can increase the number/type of tumor cells killed, then there is a smaller pool for resistant cells to grow from.

One of the central challenges to improving response seems to stem from the fact that tumor cells that are proliferating seem to be easier to kill than those that are not proliferating. The later state is called quiescence. In many cases Gleevec does not kill tumor cells but causes them to become quiescent and thus, harder to kill. Several researches presented data on different methods of attack against these quiescent tumor cells.

Dr. Brian Rubin presented data on autophagy as a consequence of Gleevec therapy and potential methods to overcome it. Autophagy is a cellular process that can lead to cell death, but can also lead to cell survival when the cell is under stress. During autophagy, stressed cells stop proliferating and can adapt their metabolism to stressful states, such as decreased nutrients, allowing cells to evade cell death. Gleevec appears to induce autophagy in some GIST tumor cells and the autophagy prevents tumor cell death. Giving Gleevec and interrupting the autophagy process at the same



LRG Research Team member, Dr. Maria Debiec-Rychter presents her research.

time may result in much greater tumor cell kill rates. Dr. Rubin is also collaborating with the Mayo Clinic in characterizing ICC stem cells and has significantly expanded his mouse models.

Dr. Anette Duensing has previously shown that Gleevec induces quiescence in GIST tumor cells. Her studies are now focused on whether it is possible to revert those quiescent GIST cells into a state in which they can more easily be killed. Novel approaches such as this one are needed to shift the cellular responses to Gleevec toward apoptosis instead of cell cycle arrest to make Gleevec-based therapies more effective with a goal towards a cure.

Recently, working with other members of the LRG research team, including Dr. Sebastian Bauer, Dr. Duensing has shown that bortezomib, an approved proteasome inhibitor, has activity against Gleevec-sensitive and Gleevec-resistant GIST tumor cells. Dr. Duensing and her team identified two modes of action for bortezomib, including stabilization of histone H2AX as well as down-regulation of KIT. These results provide a rationale for clinical trials to test the efficacy of bortezomib in GIST patients. During the meeting, Dr. Duensing provided additional insights into the mechanisms and possible new targets in quiescent GIST cells.

Dr. Sebastian Bauer presented data on other pathways involved in quiescence. In addition, Dr. Bauer is taking the lead in starting a new GIST trial in Germany very soon for Gleevec combined with the LBH589, a HDAC inhibitor made by Novartis. This trial is the result of previous work done by the LRG team, including Dr. Bauer and Dr. Maria Debiec-

Rychter, which showed that LBH589 and other HDAC inhibitors had a significant effect on GIST cells.

On behalf of Dr. Besmer, Dr. Antonescu reported on signaling pathways activated by imatinib. He also reported progress in developing mouse models with double mutations. A careful characterization of these mice is in progress.

Drug screening

Further progress was made for in vitro and in vivo drug screening of mutant KIT oncoproteins including:

- KIT inhibitors
- HSP90 inhibitors
- Combination therapies

Dr. Maria Debiec-Rychter reported on screening with drug combinations in several xenograft models (human tumors from patients implanted into mice).

Clinical support

Dr. Chris Corless presented on behalf of himself and Dr. Mike Heinrich, an update on the Z9001 imatinib adjuvant trials. The Heinrich/Corless labs have provided mutational analysis for the correlative studies of this trial. Some of this data was presented at the 2010 GI



Research Team members have a round table discussion about the day's presentations.

ASCO meeting and will be summarized in another article in this issue of the newsletter (see 2010 GI ASCO).

The Heinrich/Corless team also reported that 40-50 percent of adult wild-type GISTs have high levels of IGF1R expression. Additional analyses of IGF1R related proteins are in progress.

The Heinrich/Corless labs have also screened new potent KIT inhibitors,

ASCO

From Page 3

(1388±656 ng/mL). The authors concluded in part that "...monitoring imatinib plasma levels may be important for patients with low C_{min} levels, especially those who have undergone major gastrectomy."

NOTE: While the optimal concentration of imatinib has not been firmly established, preliminary data found a longer time to progression for patients with plasma levels above 1,100 ng/mL (Demetri et al.). We would also note that while patients with a gastrectomy in this series were found to have lower plasma levels, other series have reported no difference between patients with versus without a gastrectomy.

High frequency of synchronous adenocarcinomas in patients with gastrointestinal stromal tumors

Abstract # 23

B. Garicochea et al

This retrospective study looked at one hundred Brazilian GIST patients treated at two centers. Fourteen percent of these patients were found to have another type of cancer during the treatment planning stage. According to the authors, this rate is much higher than observed in the majority of human cancers. The accompanying GIST was frequently discovered incidentally.

ITALY

From Page 5

and guarantee it and the predictive role of mutational analysis of KIT / PDGFRA.

Dr. M. Pierotti, scientific manager at INT, said molecular medicine is a broad field whose objectives can be summarized in four "Ps": Preventive, Predictive, Personalized, and Participatory Medicine (because of the more and more relevant importance of advocacy groups).

Special topics were presented, including one by Dr. A. Gronchi (surgeon at INT, Milan) on a new European, Australian and New Zealand trial (EORTC62063) evaluating "Surgery of Residual Disease in Patients With Me-

Vietnam vet, Olympic torch-carrier and proud dad passes at age 61

Carl David Banker, age 61, passed away January 29, 2010 after a long battle with GIST. He was born to Bertha Decatur Banker and Paul Comer Banker, in Cheverly, Maryland, on December 24, 1948.

Carl graduated from Nicholas Blackwell High School in Bartlett, TN in 1967. He also attended the University of Tennessee in Martin, TN.

Carl served in the United States Army and fought in Vietnam from 1969-1970 and was stationed in Germany from 1970-1971. He is a decorated Vietnam veteran. Carl worked for General Motors for over 30 years and retired in 2008. He also had the honor of carrying the Olympic Torch in San Diego, CA in 2002.

He is survived by his wife of 34 years, Katherine; four children, Kathy Stephens, of Huntsville, Alabama; son, Richard Banker, his wife, Katherine, and their son, Ian, of Bernalillo, NM; daughter, Karen Collins, her husband, Roy, and their three children, Jonathan, Lau-

ren and Aaron of Woodhaven, MI; son, Carl David, his wife, Monica, and their 2 children, Lance and Kailey of Wesley Chapel, FL.; sister, Patricia Duke, and her husband, Kevin, of Wynne, AR; and best friend of 47 years, Keith Ferrell, of Hernando, MS. In lieu of flowers, a donation to the Research Department (gastric cancer/ GIST) in Carl D. Banker's memory can be made to UNM Cancer Center, Development Office, 1 University of New Mexico, MSC 07-4025, Albuquerque, NM 87131-0001. Carl will be deeply missed by his family and friends.

tastatic Gastrointestinal Stromal Tumor Responding to Imatinib Mesylate"; the second by Dr. D. Morelli (Manager of Laboratory Medicine at INT, Milan) about the starting of the first lab testing the clinical significance of imatinib plasma levels - an observational study in INT evaluating correlations between SNPs, imatinib plasma levels and responsiveness to drug. Patients were especially interested in presentations by Dr. Fausto Catena and Dr. Maria A. Pantaleo. Dr. Catena discussed the surgery of primary and localized disease, open surgery or laparoscopic surgery. Dr. Pantaleo focused on imatinib adjuvant therapy and open issues, such as which patients should be treated, along with dose and duration. She stated that low risk GISTs should not receive adjuvant Gleevec and high



Carl Banker on his "Olympic" journey.

risk GISTs have a strong indication for it. Intermediate risks should be examined case by case, based on Miettinen risk classification with decisions resulting from dynamic and interactive processes. The oncologist has to examine many factors including the patient's expectation, age, concomitant diseases, mutation, site, intermediate risk, surgical procedure and compliance. The clinicians at the meeting were very involved and answered all of the patients' questions regarding side-effects of specific drugs, off label drugs, drug trials and approaches against resistance. Their contribution was greatly appreciated by the audience.

A special thanks to Dr. Paolo Casali, the head of the Sarcoma Dept. at INT, Milan.

Poss meets her mark...and then some!

By Erin Kristoff
LRG Newsletter Editor

When we first reported on Kate Poss' progress in fundraising for the Life Raft Group using the Austin Marathon back in December 2009, we knew she would make her mark.

Starting out with a goal of \$2,620 (100 for every mile she ran, "plus an extra \$20 for that pesky last .2 mile"), Kate exceeded it within six hours. Kate then raised her goal to \$5,000, and blew that out of the water in less than three weeks. Kate set her new goal at \$6,500. Would the tremendous outpouring of support die down? With two months left until the February 14 marathon, Kate's supporters pushed her past the \$6,500 mark and over the \$7,000 mark!

Now all she had to do was run the 26-mile marathon! With determination and a whole lot of spirit, Kate pushed through it and finished the race.

The question then remained, "How does it feel, now that it's over?"

"Amazing," Kate said, "It feels won-

derful."

Kate was doing all this in honor of her dad, John Poss. John was diagnosed with GIST in 2000 and sits on the LRG Board of Directors. "For months, it was the main thing I was focusing on. I thought the fundraising would be the hardest part but it wasn't."

Kate tried not to be shy and reached out to a large range of people for this campaign. While most of her supporters knew the Poss family, many donations came from business and casual acquaintances, filling Kate with an overwhelming sense of pride.

"I was hesitant when I made my list. Then I realized that the worst they could do was delete the email."

For Kate and the LRG, that risk paid off.

But if fundraising wasn't the hardest part, what was? Well, the training of course.

Juggling her training with her demanding job in TV and film production and a holiday season filled with goodies was a handful.

"Trying to fit it in with my work schedule was the hardest part, some-



Kate in the home stretch.

times I was too tired to train but I had to keep going."

But there was an even harder part of the process that Kate didn't see coming,

See MARATHON, Page 14

MONTERREY

From Page 1

terrey, Mexico.

The historic event was attended by LRG Executive Director Norman Scherzer, LRG staff members Jerry Call, Karen Kelley and Sara Rothschild, LRG researchers, patient representatives from nine Latin American countries, and executives and scientists from Monterrey Institute of Technology and Higher Education.

This relationship built upon a foundation that the LRG has in place with top GIST researchers in the United States and Europe.

The hope is to increase access to information, treatment, and advocacy for

Latin American patients and the medical community.

The synergy of these three groups and the exchange of information and experience will hopefully result in expanded research opportunities and action on the



Docs and researchers from the US and Mexico mingle at Monterrey Tech.

part of LRG researchers and Monterrey Tech.

See page 2 for the scientific article about the LRG researchers meeting and progress. See page 6 for a more detailed article about the Latin American GIST Coalition and the issuance of the *Monterrey Declaration*.

Special thanks goes to meeting host Rodrigo Salas, the LRG Mexico liaison and a member of both the LRG Board of Directors and the Monterrey Institute's Board of Directors. Thanks must also go to Monterrey Tech, who provided many meeting support services throughout the week, Synta Pharmaceuticals for support of part of the Research Team meeting, and Novartis Pharmaceuticals for support of the Latin American GIST Coalition meeting.

COALITION

From Page 6

patients with rare cancers worldwide. These alliances will provide a number of resources to help the Coalition identify and reach GIST patients and disseminate information and education into Latin America. Rodrigo

Salas, the Mexican representative of the Coalition, summed up the purpose of the meeting and resulting alliances as “an extraordinary historic event paired with expertise from our partnership organizations to strengthen our efforts at promoting survival of GIST patients.” The meeting reached its climax when the Coalition proudly announced their plan to promote survival of GIST patients,



Maria, Pat & Piga find a moment to discuss Latin American GIST issues.

- 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. which they called the **Monterrey Declaration**, focused on four key principles:

Check out page 13 for more pictures from Mexico, plus the Monterrey Declaration!

dination with the physician community. With its goals in place, the Coalition adjourned to their respective home countries as pro-active members of a new cancer awareness movement, planning to meet again in the near future.

The Latin American GIST Coalition is a partnership of patient advocates from nine Latin American countries. The following Coalition members were present at the Monterrey meeting: Sandra Mesri of Argentina, Vicky Ossio of Bolivia, Dr. Alexandre Sakano of Brazil, Piga Fernandez Kaempffer of Chile, Dr. Rafael Vega of Colombia, Rafael Becerra of Colombia, Michael Josephy of Costa Rica, Alejandro Miranda of the Dominican Republic, Rodrigo Salas of Mexico, Maria Isabel Gomez de Soriano of Venezuela, Norman Scherzer of the Life Raft Group and Pat Garcia-Gonzalez of The Max Foundation.

RESEARCH

From Page 8

some of which target KIT in a different manner than previous KIT inhibitors. Dr. Heinrich and Dr. Corless are also collaborating with a research group from Bologna and at the University of British Columbia on different projects.

New targets

Dr. Cristina Antonescu presented data on a new protein that is overexpressed in GIST. Inhibition of this protein resulted in a decrease in GIST tumor cell proliferation as well as an increase in apoptosis. In addition, this protein is expressed in certain ICC cells, but not in other ICC cells. This may help pinpoint the cells of origin of GIST tumors. This protein represents a new potential target in GIST tumor cells.

High throughput screening

A number of teams are using various high throughput screening techniques to identify new targets in GIST. Dr. Matt van de Rijn is collaborating with three groups on tissue micro-array projects using 3-SEQ technology. These include

the LRG tissue bank project, a project with Brazil (Bacchi) and a project with Norway. The LRG project and the Norway project both have clinical outcome data. Dr. van de Rijn presented some data on the expression of four different proteins in GIST.

Dr. Sebastian Bauer presented proteomic screening data comparing several GIST cell lines. Dr. Anette Duensing, in collaboration with Dr. Brian Rubin, is working on a kinome screen for GIST 882 and GIST-T1 cell lines. The primary and secondary screens for the GIST882 cell line are complete and targets are now being validated, focusing on the 10 most prominent hits. The GIST-T1 screen will be done +/- imatinib.

Dr. Jonathan Fletcher has several high-throughput studies in progress. These include shRNA knockdown of single genes in a GIST-T1 cell line. In this study, individual genes are silenced in individual cells to find the most important genes/targets in GIST. This is in collaboration with the Broad Institute.

In perhaps the most ambitious GIST research project ever, Dr. Fletcher – in conjunction with Dr. George Demetri and Dr. Edward Fox at Dana-Farber Cancer Institute – is also sequencing the entire GIST genome. It was only a few years ago (2003), that the human ge-

nome was first sequenced. The human genome project took 13 years, cost several billion dollars and collaborators weren't labs, they were countries. While the cost of sequencing a genome has come down dramatically, it still costs several hundred thousand dollars. This work is currently underfunded, although considered to be very high priority because it offers hope of identifying additional mutated proteins (analogous to KIT and PDGFRA) that can be targeted by biologically rationale therapies in GIST.

Mark your calendars!

- Dana-Farber will be hosting “Living with GIST – 10 Years of Molecular Targeted Therapy” On **April 9**, call (617) 632-3301 for more info.
 - The Life Raft Group will be having the Grand Opening of our brand new office in Wayne, NJ on **April 22**. RSVP by April 12 to Wendi Swaffield (973.837.9092 ext 102)
 - Colorado will hold its meeting **April 24** at the Aspen Room in Denver. For more information, contact Jerry Call at jcall@liferaftgroup.org.
 - The NJ local group is having a gathering at the new LRG office on **May 1**. For more information, please email Tricia McAleer at tmcaleer@liferaftgroup.org
 - GISTers in the Chicago-area will gather on **May 10**. Email Paula Vettel at paulav2@sbcglobel.net for details.
 - The St. Louis GIST foundation is planning a meeting for **May 15**. For more information, go to www.gistl.org.
- Registration is open for Life Fest 2010 June 25-27!**
Register at www.liferaftgroup.org/members_lifestregistration.html

Life Fest 2010 and our gala event: GIST 2010: A Decade of Difference

It has been a remarkable decade for the GIST community as scientific discovery, medical treatment and drug development have put GIST at the cutting edge of cancer treatment and care. Between 2000 and 2010, GIST has gone from being a misdiagnosed rare cancer, with only a 5% response to treatment, to one of the best understood cancers, where patients can now expect an 85% response to treatment. 2010 marks the tenth anniversary of a breakthrough in GIST treatment as the first group of patients to receive an oral drug to treat metastatic GIST will reach their 10-year survival benchmark.

The Life Raft Group will be celebrating this amazing decade of achievement at **Life Fest** on June 25-27, 2010 at the Hyatt Regency in Jersey City, NJ. On Friday night, June 25th Life Fest will open with a gala event: **GIST 2010—A Decade of Difference**. The evening will feature a look back at the key scientific and medical milestones over the last ten years and a look forward to the most promising treatments and discoveries on the horizon.

For this occasion special recognition will be awarded to a select group from the GIST patient, medical, scientific and pharmaceutical communities who have contributed not only to the understanding and treatment of GIST, but also whose accomplishments have made a difference to the survival of GIST patients. These honorees will be spotlighted for their accomplishments at the gala and inducted into the **GIST Hall of Fame**. The **Humanitarian of the Decade Award**, recognizing the most outstanding accomplishments over the last 10 years will be given jointly to Dr. Daniel Vasella and Dr. George Demetri, (also serving as **Honorary Chair**) for their roles as leaders in GIST research and clinical care, and for personally be-

ing responsible for saving the lives of countless GIST patients. The celebration will continue throughout the course of the weekend with other key awards including **Clinician of the Year** and **Volunteer of the Year**.

A retrospective of GIST scientific discoveries and medical advances as



Dr. Daniel Vasella

Humanitarian of the Decade



Dr. George Demetri

Honorary Chair Humanitarian of the Decade

well as profiles of the Life Fest honorees will be featured in the Life Raft Group's newsletters and communications in the months leading up to Life Fest. The complete GIST historical retrospective and honoree profiles will then be compiled for a special commemorative program that every Life Fest attendee will receive.

The Life Raft Group will be gathering stories from all those who've been involved on the front lines of GIST—patients, family members as well as scientists, doctors and nurses who fight alongside them. These stories of courage, perseverance and determination will be featured throughout Life Fest.

Life Fest will be a celebration of survival and hope and a time to recognize the enormous courage of every patient and family member who has battled and continues to battle GIST. Life Fest will offer the entire GIST community—GIST patients, their friends and family members, GIST medical professionals, researchers and scientists—an opportunity to come together to honor and celebrate the past and to forge a path forward to find a cure.

Event Highlights

GIST 2010 Gala Celebration— Friday, June 25, 2010:

A special night of celebration and recognition with proceeds going to LRG's **Pathway to a Cure** research program:



- **Humanitarian of the Decade:** The last ten years of GIST progress would not have been possible without Dr. Daniel Vasella (Novartis Pharmaceuticals) and Dr. George Demetri, (Dana Farber Cancer Institute), two extraordinary men whose contributions to GIST have saved countless lives.
 - **GIST Hall of Fame:** GIST champions from the scientific, medical, pharmaceutical and patient communities will be honored for their contributions.
 - **10 Year Commemorative Program:** Profiles of the honorees and a history of GIST scientific and medical advancements including profiles of those fighting GIST on the front lines.
- Life Fest—Saturday & Sunday, June 26-27, 2010:**

The world's largest gathering of GIST patients and caregivers with two days of workshops, meetings and presentations and recognition for the GIST community, including:

- **Volunteer of the Year:** The LRG will recognize one volunteer for outstanding service.
- **GIST Clinician of the Year:** A patient-driven contest to select a GIST Clinician who has gone beyond the call of duty (Please see page 1 for our winner)
- **Tree of Life:** A pictorial opportunity for GIST patients to display the good things (including special trips, new grandchildren, etc.) that have happened to them since diagnosis because of the advancements in treatments.
- **Workshops** (partial list) include GIST Treatment Overview, Drug Developments, Clinical Trial Update, and Side Effects Management.

The Latin American GIST Coalition meets in Mexico!

Monterrey Declaration

Latin American GIST Coalition

February 3, 2010

Mission	Misión
We are a Coalition committed to promoting the survival of GIST patients in Latin America	Somos una alianza comprometida para la sobrevivencia de pacientes con GIST en Latinoamérica
Goals	Objetivos
<ul style="list-style-type: none"> To improve the knowledge of patients and physicians To increase access to adequate treatment and resources To support local patient organizations, including the creation of new ones To encourage collaboration and coordination with the physician community 	<ul style="list-style-type: none"> Mejorar el conocimiento de pacientes y medicos Aumentar el acceso a tratamiento y recursos adecuados Apoyar a organizaciones locales de pacientes incluyendo la creación de nuevos grupos Promover la colaboración y coordinación con la comunidad médica



Dr. Alexandre Sakano, Piga Fernandez and Vicky Ossio are all smiles for the camera.



Rodrigo Salas & LRG staffer, Sara Rothschild caught the smiling bug too.



LRG researcher, Dr. Matt van de Rijn & Dr. Rafael Vega have a meeting of the minds.

Michael Josephy = Michael Josephy - Costa Rica
PAT = PAT GARCIA GONZALEZ, The Max Foundation, US
ROSA = RAFAEL VEGA FUNDACION GIST COLOMBIA
Uilma Angulo = Uilma Angulo Fundacion gist Colombia
SANDRA MASRI = SANDRA MASRI Fundacion gist ARGENTINA
MARIA ISABEL GOMEZ = MARIA ISABEL GOMEZ ASAPHE, VENEZUELA
Alejandro Miranda = Alejandro Miranda L FUNDACION UN PASO MAX Rep Dominicana
RAFAEL BECERRA = RAFAEL BECERRA - FUNDACION GIST COLOMBIA
Rodrigo Salas → Rodrigo Salas → Monterrey, Mexico
Norman J. Scherzer → Norman J. Scherzer The Life Raft Group
Piga Fernandez → Piga Fernandez → CHILE
ALEXANDRE SAKANO = ALEXANDRE SAKANO - BRASIL
VIRGINIA OSSIO = VIRGINIA OSSIO - LRG EN LATINOAMERICA



The gang's all here! From left to right (Sitting): Sara Rothschild, Claudia Zambrano, Maria-Isabel Gomez, Rodrigo Salas, Karen Kelley, Norman Scherzer, Rafael Vega & Monica Rivera. (Standing) Roberto Arzaba, Vicky Ossio, Eduardo Guzman, Ian Davies, Rafael Becerra, Alejandro Miranda, Pat Garcia, Alexandre Sakano, Piga Fernandez, Julio Madi, Sandr Masri, Michael Josephy, Vilma Angulo, Matt van de Rijn & Jose Ramos

Brave GIST fighter and dedicated wife and mother passes

Jenn was born in Salt Lake City (SLC) on December 13, 1967, to Wayne Sanford Young and Louise Goodworth Young. She lived in Poughkeepsie, NY, until she was nine years old. In 1977, Jenn moved with her family from New York to Gilroy, CA, where she lived until she graduated from Gilroy High School in 1986. Jenn attended Brigham Young University (BYU) in Provo, UT, before serving eighteen months as a full-time volunteer missionary in the Florida Fort Lauderdale Mission of the Church of Jesus Christ of Latter-day Saints (LDS or “Mormon” Church). She returned to BYU after her mission and graduated in 1993 with a Bachelor of Arts in Graphic Design and a minor in Outdoor Recreation. Jenn met David Bayles in January of 1993, and the two were married in December in the Oakland California Temple of the LDS Church. During their marriage, Jenn pursued a Masters degree at the University of Utah in Recreation Therapy while the couple lived in Salt Lake City from 1997 to April 1998. In the summer of 1998, the couple returned to live in Provo and Jenn gave birth to Mitchell Young Bayles in August. The family moved to Henefer, UT, in 2000

and Jenn gave birth to Zachary Calvin Bayles in January 2001. The family moved to La Crescenta, California, about one month later.

Jenn was diagnosed with GIST in 2002. She fought the cancer bravely, enduring numerous surgeries and chemotherapies, including until very recently. Nevertheless, Jenn served La Crescenta Elementary School, where Mitchell Bayles and Zachary still attend, and the LDS Church, continuously and faithfully throughout her fight against cancer. In February 2008, Jenn received an Honorary Service Award from the La Crescenta Elementary PTA for her help in the classroom, with the school Foundation, the book fair, and for leading the “Meet the Masters” art program. During her tenure in the art program, Jenn led numerous assemblies for the student body wearing costumes related to the artist or subject art work and dedicated countless hours instructing the docents and preparing materials for the projects. Jenn always served in the

Church as a “visiting teacher” and, in addition, accepted every “call to serve,” including as the advisor to the 16-18 year old young women’s group under two different presidents, as a girl’s camp counselor, as a Cub Scout Den and Webelos leader and also in the church “nursery.” Jenn showed us it is possible to serve faithfully while suffering life’s hardships gracefully.

Jenn is survived by David, Mitch and Zach Bayles, of La Crescenta, parents Wayne and Louise Young and grandmother Leda Young (born January of 1910) all of Gilroy, CA, sister Suzanne Aughenbaugh (Mark) of Hawaii, sisters Rachel Riley (David) and Deborah Hart (Ben), brothers Stephen (Patty), Darroll (Shara), and Mark (Brittney) all of Utah, sister Rebecca Amesbury (Brian) of Spokane, Washington, her in-laws Calvin and Marilyn Bayles and their family (pretty much all) of La Crescenta, and 40+ adoring “Young” and “Bayles” nieces and nephews.



Jenn Bayles, with her sons, Zach & Mitch.

MARATHON

From Page 10

“Writing down my dad’s story for the first time, and other’s reading it, made me realize what a miracle it all was.”

That realization motivated her to succeed, despite any difficulty she might have faced, “Don’t ever give up. My father was told to give up and he didn’t.”

After a cantaloupe-sized tumor was discovered on his stomach, John was told to go home to die. But after talking his way into an early Gleevec trial, John’s tumor shrank. Ten years later, he is still going strong.

And when Kate Poss finished that last pesky .2 of a mile? John was waiting for her with a big sign, a big smile and a bigger hug.



John gives his daughter a big hug at the finish line.



Kate Bowie, friend and photographer snaps a shot of the pair with “the sign”.

Be prepared when traveling with cancer

By Matthew Mattioli
LRG Office Manager

Recently, an article by Diane Stresing was published on the popular coping website, CarePages.com, about traveling with cancer. With Life Fest coming up in a few months, we thought it worthwhile to share some of the tips and suggestions cancer patients should consider while planning a trip.

•**Consult with your doctor.**

The doctor will be able to discuss restrictions and best travel times between treatments. Some patients cannot tolerate pressure

changes when flying, so driving or taking a train may be suggested.

•**Collect important information.**

Ask your doctor or pharmacist for a letter outlining all of your prescriptions and what they are for. If you have an implant that may set off a security metal detector, get a letter for that as well. If traveling abroad, a letter translated into the language spoken in that country could be useful. Get a list of medical facilities in the area you will be traveling to. Talk to your insurance company before your trip to find out any limitations in care.

•**Be prepared.** Pack extra medication that you think you will need, and keep

your prescriptions in their original containers. Medication should always be packed in your carry-on so they are easily accessible during travel. If your current health requires it, bring a facemask to prevent germs. Whether a cancer patient or not, get all required vaccinations. Make a post-travel appointment with your doctor to discuss anything out of the ordinary that might have happened on your trip. Although you may not need to keep it, having the appointment scheduled will bring peace-of-mind.

Check out <http://www.carepages.com/cancer/cancer-and-travel-precautions.html> for more information.

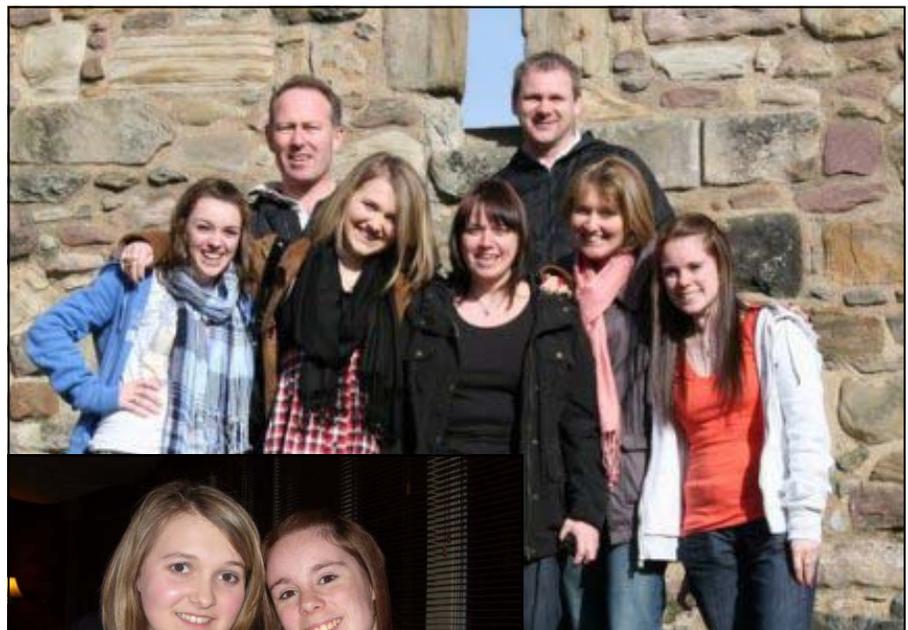


Young GISTers cross country lines to get together

My name is Stacey McAully and for those of you who don't know I was the first pediatric diagnosis of GISTs in Scotland. I have had 2 serious surgeries and was on Gleevec for 3 years. Now I am currently GIST free but have many pulmonary chondromas and an esophageal leiomyoma. My family recently got in contact with another GISTer in England and we met up for the first time.

We did some sight-seeing in Edinburgh and enjoyed eating out. Amongst all the fun we knew there was something that brought us all together. GISTs. We spoke about our experiences and what we all knew about this rare cancer. We got on exceptionally well and hope to meet up again soon.

We have also started to make plans to raise awareness of GISTs together in the UK. Hopefully some of our plans will work out and soon it will be as well known as other cancers. We hope to raise money for research.



GISTers unite: (Top) The whole group takes a picture at Edinburgh Castle. (Left) Young GISTers, Pippa and Stacey.

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