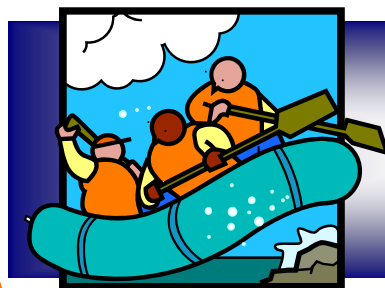


The patient's dilemma: Where should I donate my GIST tissue?



Battling gastrointestinal stromal tumor



LIFE RAFT GROUP

August 2009

In memory of Mark Becker, Kitty Katt Kimbell, Renate Croll, James Kwok, Jack Dear & Jacqui Bromberg

Vol 10, No. 7

By Marisa Bolognese
LRG Director of Planning & Development

Researchers say GIST Collaborative Tissue Bank is designed so there's enough tissue for everyone

The fact is GIST is a rare disease and as a result researchers simply do not have enough tissue samples to do the research needed to find a cure. "Too many

people are still dying because we do not have a complete understanding of the disease, the causes of resistance or how to overcome it," exclaimed Dr. Matt van de Rijn and Dr. Rob West of Stanford University School of Medicine, "Individual researchers at single universities just cannot get enough GIST tissue samples from patients at those institutions."



VAN DE RIJN

Many patients are aware that their tissue is vital to research, but they often face the dilemma of how or where to donate their tissue. Patients are pulled in many directions, often solicited by multiple researchers and institutions. It's difficult to have to choose between a hospital where one receives clinical care and a renowned scientist at another research institution. Patients are not always aware that their donated tissue will likely not be shared between institutions. That could mean having to choose between different expert researchers.

On the other side of the fence, individual researchers often have access to very small numbers of samples and these are usually not associated with detailed clinical information. Competition and a

Please go to page 4 for a very special note from Jacqui Bromberg

See TISSUE, Page 9

Researcher update in Pediatric GIST

By Dr. Cristina Antonescu
Memorial Sloan-Kettering Cancer Center
LRG Research Team

When we first started working on pediatric GIST more than five years ago, our initial observations suggested a homogenous clinical and genetic subset, with predilection for females, gastric location and wild-type genotype¹. Subsequent analysis of additional patients expanded this view, revealing that up to one third of cases may occur in males, whose tumors

may arise in the small bowel and harbor activating *KIT/PDGFR*A mutations². In addition, with longer follow-up, it became clear that some pediatric patients eventually develop secondary neoplasms diagnostic for Carney's triad, obscuring the distinction from the more common form of pediatric GIST. Furthermore, when applying genomic approaches, it became clear that GIST in young adults (defined as older than 18-



ANTONESCU

year of age) is a heterogeneous disease, most of them resembling the adult counterpart, although rare cases of young females with multifocal gastric disease may be documented in this age group².

One additional level of complexity was brought by the overlapping attributes between pediatric and adult wild-type GIST. As demonstrated by us and others, the adult and pediatric wild-type tumors lack the typical genomic alterations, showing mainly a diploid phenotype (Figure 1)³. While loss of 14q and 22q occur frequently and non-randomly in both benign and malignant KIT-

See PEDIATRIC, Page 12



Save the Date! Life Fest 2010 will be held in the New York City-area June 25-27!

Impressive turnout for sixth annual Swiss GIST patient group meeting

By Cindy Meier

(Cousin of Helga Meier Schnorf, LRG member)

On April 24, 2009, approximately 85 GIST patients, caregivers, GIST health care experts, Life Raft Country liaison reps from Italy and Germany, and representatives from the pharmaceutical industry, gathered in Zurich, Switzerland for the sixth time. Switzerland is a small country (population of 7.58 million) which shares four national languages and distinct regional/cultural differences within its own borders. The sheer size of the gathering reflected the high level of interest clearly demonstrating that there is a need to continue hosting meetings of this kind in the future.

All those who were in attendance had been informed via the website that Dr. Ulrich Schnorf had passed away on March 15, 2009 (refer to the April 2009 issue of the LRG newsletter for the obituary). As the founding father of the Swiss GIST support group, Ueli's concern until the very end of his life was to ensure that this meeting went forward. He committed the few brief days between two prolonged hospital stays to making final preparations for this meeting. Ueli's perseverance and commitment were illustrated and appreciated throughout the day. Many tributes were delivered posthumously to honor the man who had dedicated a significant portion of the past eight years of his life

supporting fellow GISTers.

What motivates someone to attend such a meeting? The answer will remain consistent throughout time:

- Obtain the latest medical information on GIST, treatment successes/failures, future options
- Share the human/personal side of having GIST, relate experiences, receive and provide comfort, and acknowledge fears and concerns.

Everyone came to the meeting with expectations and overall, the participants and organizers were not disappointed.



MONTEMURRO



BAUER

Ueli's widow, Helga Meier Schnorf made sure that the organization of the meeting was completed to a high standard and Markus Wartenberg (Director of "Das Lebenshaus" Germany) stepped into Ueli's shoes as the moderator (a difficult act to follow and which he did brilliantly).

The panel of speakers was truly impressive (please refer to www.gastrointestinal-stromatutoren.com for details on individual presentations).

Dr. Stephan Dirnhofer (University of Basel), Dr. Nicolas Widmer (CHUV, Lausanne), Dr. Michael Montemurro (CHUV, Lausanne), Dr. Sebastian Bauer (University of Essen, Germany) all made outstanding, informative pres-



Attendees listen to presentations by GIST specialists.

The Life Raft Group

Who are we, what do we do?

The Life Raft Group (LRG) directs research to find a cure for a rare cancer and help those affected through support and advocacy until we do.

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

How to help

Donations to The Life Raft Group, a 501(c)(3) nonprofit organization, are tax deductible in the United States.

You can donate by **credit card** at www.liferaftgroup.org/donate.htm or by sending a **check** to:

The Life Raft Group
40 Galesi Dr., Suite 19
Wayne, NJ 07470

Disclaimer

We are patients and caregivers, not doctors. Information shared is not a substitute for discussion with your doctor.

Please advise Erin Kristoff, the Newsletter Editor, at ekristoff@liferaftgroup.org of any errors.

entations throughout the day. Representatives from Novartis Pharma SA, Switzerland and Pfizer SA, Switzerland were also present. Bristol Myers Squibb SA, Switzerland was unable to attend but expressed an interest in discussing continued
Markus Wartenberg and Helga Schnorf.



August 2009 clinical trials update


By **Jim Hughes**
Clinical Trials Coordinator

This month we have added a Phase I trial of Vorinostat and Bortezomib at the Carbone Cancer Center, at the University of Wisconsin, Madison. This trial was reported at the American Society of Clinical Oncologists conference in June. Bortezomib is a proteasome inhibitor. This class of drugs has been identified as having potential therapeutic application in GIST. Three GIST patients have entered this trial. So far, researchers report that the best response has been a short

term stable. We will be watching this trial for additional reports.

Additional sites have been added to the Nilotinib versus Imatinib Phase III first-line trial ongoing worldwide. There are 75 sites listed, of which 30 are recruiting. Two of these are in City of Hope Hospital in California and MD Anderson in Texas. This trial is for newly diagnosed and recurrent patients who have not had prior Sutent or Gleevec therapy except with Gleevec for adjuvant use.

The sites for the SF1126 Phase I trial have been updated to include Emory University in Atlanta, as well as Scottsdale, Tucson and Indianapolis.



Please remember that the clinical trial listing can now be found as a "Clinical Trials Bulletin" sent separately each month. You can find this bulletin at: <http://www.liferaftgroup.org/docs/ClinicalTrials/Aug2009.pdf>

Blay appointed new EORTC president

By **Estelle Lecoindre**
President, A.F.P.G. Ensemble
Contre le GIST

I'm really proud and honored to inform you that Dr. Jean-Yves Blay (Centre Léon Bérard à Lyon, France) has just been appointed as the new President of the European Organization for the Research and Treatment of Cancer (EORTC) for three years, thus succeeding to Dr. Martine Piccart from Belgium.

As a brief historical note, the EORTC was founded in 1962 as an international organization by eminent oncologists working in the European and Swiss cancer research institutes. Its very first name was "GECA" for "Groupe Européen de Chimiothérapie Anticancéreuse" (Anticancer Chemotherapy European Group) and then became the EORTC in 1968.

The main missions of the EORTC are (Source: www.eortc.be):

- To develop, conduct, coordinate, and stimulate translational and clinical research in Europe to improve the man-

agement of cancer and related problems by increasing survival but also patient quality of life.



BLAY

to develop innovative and efficient drugs.

- To facilitate the passage of experimental discoveries into state-of-the-art treatments by keeping to a minimum the time lapse between the discovery of new anti-cancer agents and the implementation of their therapeutic benefit for patients with cancer.

- To improve the standards of cancer treatment in Europe, through the evaluation of innovative drugs and new regimens.

- To establish more effective

therapeutic strategies, using drugs already commercially available, or surgery and radiotherapy.

Dr. Jean-Yves Blay is the fifteenth President of the EORTC and the third French one to be appointed since 1962.

He is also the President of the French Sarcoma Group (GSF-GETO) and Coordinator of the European Network of Excellence "CONTICANET", dedicated to connective tissue cancers.

Famous for his human values, strong will and motivation, Dr. Jean-Yves Blay is a key figure in the world of oncology. Therefore, there is no doubt his presidency will leave an indelible imprint in the domain of European cancer research and more specifically in the field of rare cancers.

We send him all our wishes of success in these new responsibilities.



An open letter from Jacqui Bromberg

On August 3, 2009, 22 year-old, pediatric GIST patient, Jacqui Bromberg passed away. She left this note, which she wrote at age 17, just after she was diagnosed.

To all those that I love:

I will miss you more than anything

*But I will come visit and watch all you beautiful people
and take care of you*

I was sent here to meet and love every one of you

Whenever times get tough

You know I am only a prayer away

Love you more than words

Jacqui



GIST & CML patient reps from all over the world meet in Lisbon for Patient Summit

The following is excerpted from a Novartis Pharmaceuticals' news release:

The 7th annual international "New Horizons Conference for Organisations Representing People with CML or GIST" was held this year in Lisbon, Portugal from June 26 to 28. Sponsored by Novartis and held for the seventh year, the conference once again demonstrated the value of bringing together patient advocacy groups from around the world to share their ideas and experiences and to get latest updates from medical professionals. The conference featured 30 hours of presentations from a dedicated and enthusiastic faculty of various disciplines and stakeholder groups.

Where the first New Horizons meeting in 2003 had only 28 advocates, this year's conference welcomed a record 126 advocates from 49 different countries in Europe, North America, Australia, Asia, Africa and Latin America.

Norman Scherzer, Executive Director of the Life Raft Group declared "The conference has become an incubator for new organisations from around the world".

With cancer set to be a global epidemic and the leading cause of death in the near future, and with rare cancers making up around 95 % of all known cancer types, then meeting of representatives of rare cancer patient groups in the CML and GIST space has demonstrated how much can be achieved by active advocacy, international collaboration and mutual training.

Special consideration was given to the concerns of growing advocacy groups and their need to establish legitimacy, trust and credibility through good governance. Presentations from larger advocacy groups such as the Rarer Cancers Forum UK and Sarcoma Patients EuroNet (SPAEN) demonstrated how a bigger collective voice can exact better services from providers and enable groups to support and help one another,

improve access to clinical trials and to develop the leverage necessary to campaign at policy level for the best possible care for people with rare cancers.

"Global communication is really important" commented Markus Wartenberg, Executive Director of "Das Lebenshaus". "The inappropriate management of rare cancers has an enormous cost. Inefficient trials waste money and time. Patient advocacy groups and physicians must work together to generate more efficient and rapid results". Judith Robinson from the GIST support UK added: "Rare cancer sufferers are isolated and there is a psychological benefit as well as a clinical benefit in being able to share information as well as to help find experts and even other patients".

Patient groups were given the opportunity to present their advocacy initiatives during interactive best practice workshops on a wide range of topics. Whilst the GIST Collaborative Tissue Bank and

From the mailbox...



Samuel takes a picture in front of a poster he made displaying LRG educational materials.

To whom it may concern,

Hi my name is Samuel Richmond. I am in grade 4 at U.S.D.S. Bathurst Campus. I was assigned a project about a charity that touched my heart. I chose your charity because my grandmother, Gloria Richmond has cancer. For my fundraiser I had a ministick tournament, mini-basketball and the class had and made snow cones. Inside this envelope there is a cheque supporting your charity and pictures of my lesson. The Life Raft Group really touched my heart.

Sincerely,
Samuel Richmond.

A changing of the guard for the Chicago Life Raft Group

By Erin Kristoff
LRG Newsletter Editor

After many years of faithful service to his fellow GIST patients, LRG member, Dick Kinzig is stepping down as the Chicago-area Local Group Coordinator.

Dick was the first LRG member to start a local group and under his watchful and diligent eye, the Chicago group has grown from just six people at its first



A photo of Chicago-area GISTers meeting in May 2009.

meeting to ten times that today.

Dick has always strived to bring informative speakers to every meeting, as well as provide support to any GIST patient who needs it. Yet when Dick was presented with the Allan Tobes Volunteer of the Year Award at Life Fest 2008, he had this to say, "I'm humbled, because I don't really think I played that big a part."

Replacing him as leader is Paula Vettel, long-time member of the LRG. She has been a part of the Chicago group since its first meeting in 2002. She is also an LRG Science Team member who represented us at the 2008 American Society of Clinical Oncologists conference. Paula has also written articles for the LRG newsletter, and recently, she



VETTEL

and her husband Phil were organizers and hosts for the City Excursion during Life Fest 2008.

According to fellow Chicago group member, Jim Hughes, who assists with local meetings, "Paula will bring added perspective

and energy to the Chicago GIST patient group."

Paula, herself, is excited and hopeful, "I'm honored to be able to serve the LRG, eager to get started, and hope I can do as good a job as Dick did!"

To view a video of Dick receiving his award at Life Fest 2008, go to www.liferaftgroup.org/video_lf08_awards.html.



Dick Kinzig receiving a Volunteer of the Year award at Life Fest 2008.

ACCESS Act to be reintroduced in Congress

In April (“Abigail case denied: Court rules against patients' right to choose”) & September 2008 (“How long must dying patients wait for justice?”), the LRG reported on the use of drugs on a compassionate-use basis for patients with terminal disease.

The Access, Compassion, Care and Ethics for Seriously Ill Patients Act



(ACCESS) is the fruit of the labors of the people mentioned in these articles. After being introduced in 2005 and again in 2008, the Act will once again be

read in Congress.

The LRG would like to encourage everyone to read up on the ACCESS Act and voice your support on Capitol Hill. You can easily do this at the top of the website: www.abigail-alliance.org.

Both of the aforementioned LRG articles can be found at www.liferaftgroup.org/advocacy.html.

Spanish GISTers meet in Madrid



GIST survivors and caregivers gathered from Spanish-speaking countries all over the world on June 24 in Madrid.

New Canadian group meet for 1st time!

GIST Sarcoma Life Raft Group Canada hosted a gathering at the Plaza 500 Hotel in Vancouver, Canada on Monday evening, June 29.

This was the first time that the Canadian group has held an event on the west coast.

Dr. Charles Blanke, Systemic Therapy Provincial Program Leader at the B.C. Cancer Agency, an oncologist and researcher with many years of experience in GIST therapy, spoke to an appreciative audience of about a dozen interested GIST patients and caregivers.



BLANKE

Did you Know...

In phase III trials, low white blood cell counts were often associated with a better response to Gleevec.

According to the Gleevec prescribing information (www.pharma.us.novartis.com/product/pi/pdf/gleevec_tabs.pdf) for GIST patients on 400 mg:

If the ANC (absolute neutrophil count) falls below 1.0 and/or platelets falls below 50:

1. Stop Gleevec until ANC >1.5 and platelets >75
2. Resume treatment with Gleevec at the original starting dose of 400 mg



3. If recurrence of ANC <1.0 and/or platelets <50, repeat step 1 and resume Gleevec at a reduced dose of 300 mg

One theory suggests that low counts may have something to do with how Gleevec is distributed in the body. Another possibility is that the patient may just be getting

more drug into their system than the average person. This can be checked and monitored over time with Gleevec plasma testing and the LRG encourages plasma testing.



Drug prices influencing doctor's decisions

By **Leigh Matano**
LRG Volunteer

Oncologists across the nation are attempting to come to terms with the enormous expense of cancer drugs, some of which can cost up to 100,000 dollars a year per patient. Normally, physicians write prescriptions for patients to bring to a pharmacy. On the other hand, oncologists must personally buy all their drugs because most of the treatments for their patients occur in their office. The doctor is then repaid by the patients, which usually means their insurance companies since the price of drugs are so high.

According to a Wall Street Journal article "Pricey Drugs Put Squeeze on Doctors" by Marilyn Chase, doctors are on the line to pay for these expensive drugs until they are reimbursed, which could normally be anywhere from days to months. Even more troubling to oncologists, patients can sometimes not afford their co-pays, which can easily amount to the thousands of dollars. Insurance companies are also becoming less reliable, sometimes denying or delaying payments to doctors as a result of the economy.

Drug companies often charge a very high price for their products to compensate for the millions to billions of dollars it takes to test and bring a drug to market. Cancer care is a big cost for the United States, estimated by the National Institutes of Health to have cost the nation 72 billion dollars in 2004 and 89 billion dollars in 2007.

As a result of the extreme drug costs, oncologists have begun to take the patient's financial situation and health condition into consideration. Many doctors may not mention or may discourage the use of expensive drugs if they know it will be a burden on the patient financially.

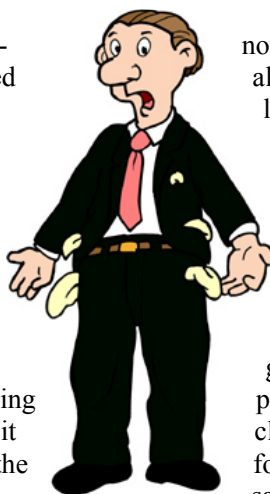
Other nations have already begun to consider a similar process, particularly in Great Britain, where the benefits are

weighed against the costs before the treatment is approved for the National Health Service to pay for them.

Oncologists in the United States are put between a rock and a hard place. Many are concerned that pushing a cheaper treatment that could possibly fail may result in liability issues and are unsure about discussing options of greater cost since it may put too much strain on the patient's expenses.

To combat decreasing profit, some doctors have had to make personal and patient cuts or to borrow money to keep themselves in business.

Chemotherapy and targeted drugs used to make a nice profit for oncologists. However, with the influx of more expensive cancer drugs, and congressional regulation with the Medicare Modernization Act, doctors have been limited on how much they could markup the prices on their treatments, thus limiting their profit. This is especially true for intrave-



nous drugs. Oncologists are only allowed to markup these particular drugs six percent, and since intravenous drugs have become such a big player in new cancer treatments, this has severely hurt the business.

Another problem for oncologists is financial aid programs. Filing for their programs can take weeks and occupies staff time. Some companies claim to have an efficient system for aid, such as Genentech, who says that they have whittled

down the paperwork to just one form for the doctor and another for the patient to fill out.

When the insurance companies aren't paying, and the patients aren't paying, the practices are the ones who suffer as costs are detracting from doctor's incomes. More and more have had to go into debt to keep their businesses afloat.

Ultimately, the patients will be the ones to suffer when their oncologist goes out of business or they have to pay an expensive bill.

June NIH clinic another success!



You can view Dr. Stratakis' presentation, "Genetic Syndromes Associated with KIT or PDGFR Non-Mutant Pediatric GISTs" at <http://videocast.nih.gov/PastEvents.asp>. Scroll until you find June 17.

The clinic kicked off with an informative presentation by Dr. Constantine Stratakis of the National Institutes of Health (top left). Besides receiving excellent care, the clinic also held opportunities for doctors and patients to mingle, like Jeni Bullard, Dr. Jonathan Trent of MD Anderson & Jason DeLorenzo (top right). The waiting room also got a little crazy with expressions of love from semi-newlyweds Meredith & Brad (bottom left) and not-so-much-love from Gordon & Betty (bottom right).

(We kid, they're old friends!)

NJ/NY GISTers meet!



On June 14, GISTers gathered from all over the New York/New Jersey area at the home of LRG Executive Director, Norman Scherzer for an informal gathering. A few old friends were delighted to see each other again, as well as welcome new friends into the fold. Pictured clockwise from center: Norman Scherzer & Anne Pacifico share a moment; GCRF founder Tania Stutman, Marc Wasserman & Pat Bonda-Swenson talk over snacks; NJ Group Leader Anita Getler & LRG staffer Sara Rothschild discuss local group issues; the group gathers for a photo; Isadore & Jonell Lenglet smile for the camera; LRG staffer Tricia McAleer & Butch Eller interrupt their discussion for a quick pose; Jay Goldsamt is all smiles on a beautiful day, Long-time LRG members, Joan Fitzgerald & Anita Scherzer get together for a hug.

Did you see read the July 2009 GIST Link?

If you missed it, check out www.gistnews.org and read LRG Clinical Trials Coordinator, Jim Hughes' coverage of presentations given by top GIST specialists like (pictured left to right) Drs. Chris Corless (Oregon Health & Science University), Suzanne George (Dana Farber Cancer Institute) & Jonathan Fletcher (Brigham & Women's Hospital).



TISSUE

From Page 1

reluctance to share, extend beyond the tissue to the resulting scientific data as well, so key findings can take years to reach scientists, a loss of precious time in the hunt for a cure.

With no system in place to share tissue or data, link clinical histories or coordinate research efforts, what can patients and researchers do to ensure that precious GIST tissue will be put to the best use possible? In a word, collaborate.

Twelve of the world's leading GIST scientists have done just that.

Recently, they joined together with the Life Raft Group to design a system that allows for timely, coordinated and effective tissue dissemination and data sharing. Aptly named the GIST Collaborative Tissue Bank, it is a true partnership between the patients whose lives are at stake and the researchers who have dedicated their lives to finding a cure.

Dr. van de Rijn, project leader of the GIST Collaborative Tissue Bank explained, "This is a unique opportunity to establish a tissue bank of GIST samples with associated detailed clinical information. The GIST Collaborative Tissue Bank would link the extensive databank that has been maintained by the LRG of clinical data volunteered by their patient members, with the research initiatives that are performed by the members of the research team." Dr. Jonathan Fletcher, a world-renowned GIST expert at Brigham & Women's Hospital, and a tissue bank member agrees, "The GIST Collaborative Tissue Bank will support and maximize a wide range of research opportunities and will enhance the collaborations among the group of researchers supported by the Life Raft Group and with researchers outside this consortium. This tissue bank will permit research teams, in unprecedented manner, to evaluate drug targets and drug resistance mechanisms in large numbers of GISTs."

One of the keys to designing a system

that would promote tissue sharing is the use of paraffin-based tissue, as opposed to fresh frozen tissue. According to Dr. Fletcher, "The availability of fresh frozen material has (and always will be) a major limiting factor in many studies and the hope is that the existence of a tissue bank that contains many samples of paraffin-embedded material may al-



FLETCHER

low researchers to study many more cases." As Dr. van de Rijn notes, "while only some tissue samples are frozen and maintained by a small number of academic institutions, **all** surgical specimens are preserved as paraffin blocks," making them easier to obtain throughout a patient's treatment. Because

paraffin blocks do not require special storing or handling conditions—as is the case with frozen tissue—Dr. van de Rijn considers it to be a very efficient way of sharing samples with other researchers and "ideal" for research. Dr. van de Rijn emphasized how vital it is to obtain as many samples as possible.

Under the GIST Collaborative Tissue Bank system, patients would request that the hospitals where they had surgery send paraffin blocks from these surgical procedures to the LRG. There the specimens will be de-identified and labeled with a code that **allows the specimen to be linked with clinical information without revealing the identity of the patient.** This enables the researcher to access critical patient information without violating federal privacy regulations.

Subsequently, the paraffin blocks will be sent to Drs. van de Rijn and West at Stanford University where small core samples of material will be removed from each block for dissemination to researchers and for storage at Stanford. The tissue blocks will then be returned to the hospital pathology departments. The data obtained from studies conducted by the researchers who receive tissue through the GIST Collaborative Tissue Bank will be correlated and

linked to the patient's clinical outcome data and other data regarding the treatment of the patient to investigate many issues related to finding a curing including identifying novel therapeutic targets. Stanford University's TMA website will serve as the data host (<http://tma.stanford.edu>).

The GIST Collaborative Tissue Bank has thus created a true win/win situation for patients and researchers. It has been designed to maximize the use of rare

GIST Patients:

How you can contribute tissue to research to help find a cure

Contact the Pathology Departments at the hospitals where you had surgery. Ask them to send your paraffin tissue blocks, with the accompanying surgical pathology reports, to the GIST Collaborative Tissue Bank, c/o The Life Raft Group.

Review and confirm your GIST medical history. Contact the LRG Patient Registry to review your record. If you are not currently enrolled in the registry, go to www.liferaftgroup.org/members_application.php

For more information visit www.liferaftgroup.org/research_tissue.html or call the LRG at 973-837-9092.

tissue for researchers through a system of sharing and yet preserve the vital tissue for future use by the patient—meeting everyone's needs. Researchers can now cease competing for tissue and instead collaborate on productive scientific investigation. It relieves patients of having to agonize over which researcher

SUMMIT

From Page 4

Patient Registry, the Life Raft Group outlined its initiatives to partner with GIST researchers by sharing patients' tissue and data for GIST research. Other subjects, such as the benefits of alternative therapies like osteopathy to relieve Imatinib treatment side effects, and the use of psychological support as short-term crisis therapy, generated much interest and discussion.

Of note this year was a new focus upon the basic and urgent needs of cancer patients in poorer countries. Presentations from India and Columbia highlighted the challenges faced by patients in the developing world with low quality copies and counterfeit medicines. These drugs are often government sanctioned, despite the lack of quality control or bioequivalence studies. "I wish we could be in place where there were other choices" explained Viji Venkatesh of the Max Foundation India "We keep hoping that things will change. In the end, we all, both physicians and advocates want what is best for the patient". Bureaucratic hurdles can make patient activism extremely difficult in developing countries. Advocates discussed the need to become more vocal about quality patient care and highlighted the role that international advocacy groups can play in helping patients in developing countries, such as by petitioning world health organisations to address the societal costs of substandard care.

The pharmacokinetics of Imatinib continues to be of great relevance to CML and GIST patients. GIST advocates were shown important study results on correlation of imatinib plasma level and clinical outcome, and plasma level testing as a tool in imatinib dose optimisation and GIST management. Shown were as well case studies on the benefits of adjuvant Imatinib for intermediate or high risk GISTs.

Another challenge facing advocacy groups is the issue of adherence. Poor adherence can have a considerable effect on drug response and the development of resistance, particularly in adjuvant

therapy. Despite the obvious that cancer is a serious disease, a presentation of the ADAGIO study assessing compliance in CML therapy has shown the concerns are justified. "Over time, adherence to oral cancer therapies is a problem that is becoming more and more significant" observed Jan Geissler, Co-Moderator of the CML Advocates Network.

"Treatment is not the only priority patients have in life. Patients cannot solve their problem of non-adherence by themselves" said Estelle Lecoite, Director of the patient group "Ensemble contre le GIST" in her presentation about meeting challenge adherence. Methods to improve adherence are more and more becoming an integral part of good clinical practice. In a lively and interactive discussion, advocates discussed the issue of adherence, often drawing from their personal experiences.

Various insights into solving the problem were offered, ranging from simply changing the Imatinib packaging from a 10-day to a 7-day format, to outlining the ways patient advocacy groups can work to educate both health care professionals and the patients about this subject.

Both CML and GIST advocates were united in their call for advocacy groups to become more active in creating a sense of urgency in promoting patient interests. "Chronic cancer care does

not have the same priority as infectious disease care, said Markus Wartenberg "and this can result in delays in research and improvements for patients. In turn, rare cancers do not receive as much attention as more common ones". Nikos Dedes, from the European AIDS Treatment Group, encouraged advocate groups to use the example of AIDS advocacy to work to build credibility and influence through strategic partnerships. "Joining together has created a significant movement for change in our community" he said, while Sandy Craine of the CML support group UK added "tough current economic times mean that rare cancer groups must join together to demand that research is taken up. We have a voice and should exercise our power as citizens". As only one example, the participants learned about the call to action (www.rarecancers.eu) which is currently collecting signatures to create awareness and political action about what needs to be done for rare cancers.

GIST Gathering

Gastrointestinal Stromal Tumor Saturday, November 1 • 8 a.m. – 1 p.m.

Patients and caregivers come and join us for our second St. Louis GIST (Gastrointestinal Stromal Tumor) Gathering

SATURDAY, NOVEMBER 1ST
8 AM – 1 PM
Brown Room in Steinberg Building
Barnes-Jewish Hospital north

Join us for a day to meet others who are facing the same health concerns as you and your caregivers.

- Hear keynote speaker Benjamin Tan, MD present on medical treatments, clinical studies and future drugs.
- Extended Q&A with a physician, a nurse practitioner and a pharmacist to field disease management questions.

Please register by Friday, October 17, 2008.

TO REGISTER: call 800-600-3606.

PARKING: For FREE CONFERENCE PARKING in the North Garage, bring in your parking ticket with you.



Sponsored by Siteman Cancer Center

Barnes-Jewish Hospital north
 4950 Parkview Place
 St. Louis, MO 63110

For more information: Visit the GIST St. Louis blog at <http://www.giststlouis.blogspot.com> or call Siteman Cancer Center at 314-362-7844.



SITEMAN CANCER CENTER
BARNES-JEWISH HOSPITAL • ST. LOUIS • UNIVERSITY OF MISSOURI

A National Cancer Institute Comprehensive Cancer Center

BARNES-JEWISH
Hospital

Washington University in St. Louis
School of Medicine

Wakeling sets out as team of one, gets 7 more riders and raises 7x her goal



Ali (far right), with two of her fellow Team GIST members at the finish line of the "Ride to Conquer Cancer" in Seattle, Wash.

On June 19-20, Ali Wakeling and her fellow Team GIST members completed the 260km Ride to Conquer Cancer from Vancouver, British Columbia, in Canada to Seattle, Wash.

After signing up as a team of one with a goal of raising \$5,000 back in October, Ali's efforts have truly been remarkable as she successfully recruited another eight team members who raised a combined total of over \$36,000!

Next year, the team hopes to involve more members of the GIST community from both sides of the border to try and raise greater awareness of GIST, and perhaps plan a social event for GISTers in Seattle on the evening of the race finish.



Becker fought bravely for 12 years

Mark R. Becker, July 6, 2009, of Deptford, NJ. Husband of Janet (nee Levine) Becker. Father of Stephanie Levitt and Julie Cramer. Father-in-law of Brian Levitt and Michael Cramer. Son of Jacqueline and the late Arnold Becker. Brother of Susan Evans and Ronald (Lisa Anderson) Becker. Grandfather of Cole and Elle Cramer.

Mark fought cancer for over 12 years with courage and ferocity. His determination and strength will be remembered by all who know him. Part of his personal story, "Treatments, trials and trails, oh my" but life must go on" can be found at http://www.liferaftgroup.org/member_stories/index.html

Mark was a passionate

motorcyclist who also enjoyed photography, bow hunting, computers and physical fitness. He was a member of the National Harley Assoc., Camden County Harley Davidson HOGS, the Life Raft Group and Gist Support International. He loved his grandchildren and played with them every opportunity he had. He was a successful graphic designer and photographer throughout his career.



Mark, with his grandson, Cole.

Mark graduated from Trenton State College and attended the School of Visual Arts in New York, NY. Mark had cancer but was never defined by this disease. He did all he could to live as full a life as possible despite the physical limitations that would hold back so many other people. Mark will be deeply and sadly missed by his family,



Mark & Janet Becker

friends and work associates.

Contributions in Mark's memory may be made to www.Gistbenefitball.org - Raising Funds and Awareness for Gastrointestinal Stromal Tumor, 43 Holly Park Dr., Tabernacle, NJ 08088.

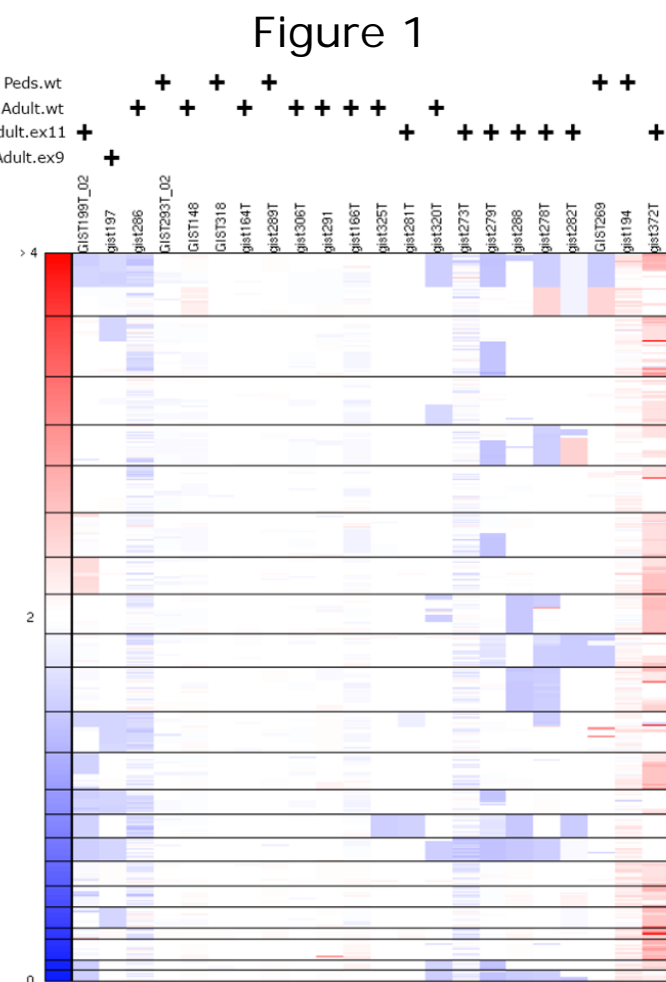
You can view a slideshow of Mark in Wellsboro, Penn at <http://www.youtube.com/watch?v=qOzs48t7yl4>

PEDIATRIC

From Page 1

mutated GIST, suggesting early molecular events, the absence of these genetic events in wild-type GIST suggest alternative pathways of tumor progression. Similar findings were also demonstrated by comparative genomic hybridization (CGH) technique used to analyze three Carney's triad patients⁴. The authors showed absence of the non-random 14q and 22q losses, characteristic of their sporadic counterpart, irrespective of site and biological grade. Furthermore, similar to wild type adult GIST patients, where clinical responses to imatinib are sparse and short-lived, pediatric GIST patients are consistently refractory to imatinib therapy. *In vitro* experiments concur with these clinical observations, showing an inferior degree of proliferation inhibition when treating Ba/F3 cells expressing wild type KIT with imatinib, as compared to nilotinib². For all the above reasons, at the joint initiative of the Life Raft Group and the National Institutes of Health, a pediatric and wild-type adult GIST clinic was created to gather more insight on the similarities and difference between these two rare subsets. The initial response after the first three meetings was outstanding, the clinics being fully booked with patients from across the United States and Europe. Participating GIST clinicians and scientists were involved in a critical review of the clinical findings and management recommendations, as well as initiate a comprehensive tissue collection and data registry.

Because of their rarity, pediatric GISTs may pose significant challenges for the practicing surgical pathologist. Based on our experience, misdiagnoses may occur when limited biopsy material



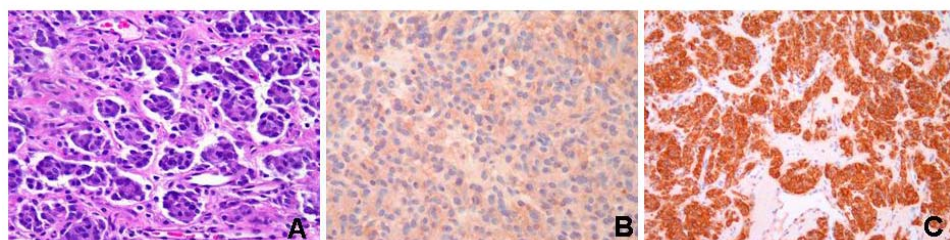
is available, composed of a proliferation of small undifferentiated cells. The differential diagnoses may then be restricted to entities considered in the family of small blue round cell tumors, such as Ewing sarcoma/Peripheral Neuroectodermal Tumor (PNET) or small-cell carcinoma. Neuroectodermal-type rosettes may be seen in pediatric as well as Carney's triad GIST, and should not imply by itself a diagnosis of Ewing sarcoma/PNET (Figure 2A). Furthermore, the immunohistochemical marker that is commonly expressed in Ewing sarcoma tumors (i.e. CD99), is hardly specific, being expressed in a variety of alterna-

tive diagnoses (Figure 2B). The diagnosis of primary Ewing sarcoma of the gastrointestinal tract is extraordinarily rare, and such diagnosis should be confirmed by molecular studies and identification of the *EWS-ETS* fusion transcript. It is our opinion that such challenging cases should be sent for expert pathology review, in large cancer centers with extensive experience in both pediatric and sarcoma pathology. After a correct diagnosis is rendered (diffuse and strong reactivity for CD117, Figure 2C), these patients should be referred for staging and management to sarcoma multidisciplinary teams in centers dedicated to pediatric

GIST care.

If the pathologic criteria to define risk of malignancy in adult GIST are well established and confirmed by multiple studies (i.e. tumor size, mitotic activity), these factors are not reliable in predicting behavior in pediatric GIST. These patients frequently present with multiple nodules within the stomach, and thus the largest tumor dimension cannot be easily defined. Furthermore, a wide range in proliferation index can be detected between patients and even among multiple tumors from the same patient. Our experience is consistent with that of Miettinen⁵, who noted that some pediatric patients with GIST developed metastasis despite being classified as low risk by criteria established in adult GIST. These findings suggest that GISTs in children are unpredictable, being more prone to metastasis than comparable gastric tumors in adults. Secondly, the biology of pediatric GIST appears to be more indo-

Figure 2



See PEDIATRIC, Page 14

SWISS

From Page 4

assistance to the group.

Overall, it was clearly demonstrated that there are various new treatments in the pipeline and the next eight to twelve months should provide some additional options for GIST patients. The creation of a legal not-for-profit entity (association) for the Swiss GIST support group is currently in the works and will hopefully come to fruition later this year. The newly updated website (thanks to Vito Mediavilla) has also been launched.



SCHNORF

Dr. Urs Metzger, Ueli's long term friend and surgeon, announced during his poignant closing remarks, that he would fulfil his final promise to Ueli to continue his work. He will be assisted in his task by Dr. Michael Montemurro with additional help from Markus Wartenberg. Dr. Metzger also promised to support Helga Meier Schnorf in founding the GIST support group association. Metzger will provide all this assistance despite an extremely demanding workload as Chief of Surgery and Medical Director of the Triemli Hospital in Zurich. Helga Meier Schnorf will run the administrative side of the group. Most of the pharmaceutical companies have informally pledged their continued financial support to the group.

No organization should rely solely on one individual to function effectively. Ueli built, as a true Swiss, a solid foundation for the GIST support group. He has left in place all the necessary tools to allow his mission to grow and succeed without him. Ueli would have been proud on April 24 to experience the great turnout and to observe how smoothly everything ran. Perhaps most significantly, to see the validation of how worthwhile his personal efforts have been and how essential, once again, the meeting was for his fellow GISTers.

Renate Croll , 65, loved the beach

After a courageous fight with cancer, Renate Croll, 65, of Millersburg, died June 17, 2009, at the home of her daughter in Pensacola, Fla.

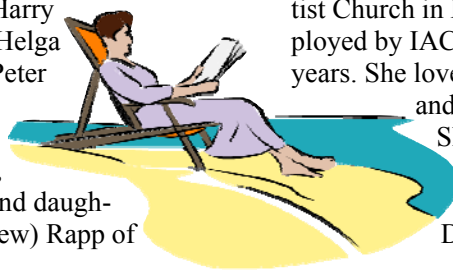
She was born Sept. 7, 1943, to the late Martha (Schubert) Haschke in Muensterberg, Germany.

Renate is survived by siblings, Guenter (Else) Schubert, Harry (Erna) Schubert, Helga (Aldo) Verdura, Peter (Anita) Schubert and Ulrich (Elvira) Schubert, all of Germany; and daughters, Sharil (Andrew) Rapp of

Pensacola, Fla., Donna (Tim) Miller of Millersburg, and Darlene (Bob) Lint of Killbuck; grandchildren, Sheena, Andrew, Jeremy, Chaz, Brant, Jordan, Blaire, Makena and Braxton; and great-grandchildren, Jaden, Xander and Noah, which she adored.

She was a member of Northside Baptist Church in Millersburg and was employed by IAC in Holmesville for 24 years. She loved to vacation at the beach and read.

She was preceded in death by her mother and sons, Michael Haschke and Danney Croll Jr.



Congratulations Dr. Brian Rubin!



Dr. Brian Rubin of the Cleveland Clinic and LRG Research Team, last month welcomed a little girl, Bree, into the world. She weighed 7lbs 13 oz and both mother and child are doing just fine. Brian recently sent us a picture of Bree in her LRG onesie. Isn't she adorable?

TISSUE

From Page 9

or institution to donate tissue to, so that one donation will now reach the world's leading scientists. Patients gain peace of mind that their tissue will be used effectively and efficiently in a multiple of scientific studies at the same time, expediting the search for a cure.

"Being able to do something to help find a cure for my disease gives me hope that a cure will be found faster," says Anne Pacifico, one of the first GIST patients to donate tissue to the project. "I'd much rather that my tissue is put to good use by scientists than just sit in a

file. Research is our best hope and I want to be part of it." Dr. van de Rijn and Dr. West concur with Anne, "We recognize that being able to combine tissue, clinical data and broad expertise of researchers is extremely valuable in the search for a cure. Although we cannot predict the future, we expect to accelerate scientific breakthroughs and treatment developments."

To view a webcast given by Drs. van de Rijn and West on the GIST Collaborative Tissue Bank, go to www.liferaftgroup.org/library_videos.html#tissue

PEDIATRIC

From Page 12

lent than the adult counterpart, with long-term survival even in the presence of metastatic disease and without kinase inhibition therapy. Among the 12 pediatric patients with more than 6 months follow-up, all except two (83%) developed metastatic disease². In spite of such a high metastatic rate, only one patient has died so far, 138 months after initial diagnosis.

Carney's triad is a rare non-hereditary condition affecting young females, being characterized by two or more lesions, including GIST, pulmonary chondroma and extra-adrenal paraganglioma. The multifocal occurrence of the individual components of Carney's triad suggests a genetic predisposition; however there is no evidence that the disorder is inherited. Less recognized, is the association of miscellaneous congenital malforma-

tions in a subset of Carney's triad patients, which have not been described in GIST patients outside this syndromic setting⁴. More recently it was recognized that the autosomal dominant inheritance of the dyad "paraganglioma and gastric GIST", or "Carney-Stratakis syndrome" (CSS), represents a separate condition which affects both males and females and lacks the association with pulmonary chondromas⁶. Mutations of the genes coding for succinate dehydrogenase subunits, typically associated with familial paragangliomas, are most likely implicated in the pathogenesis of CSS⁷.

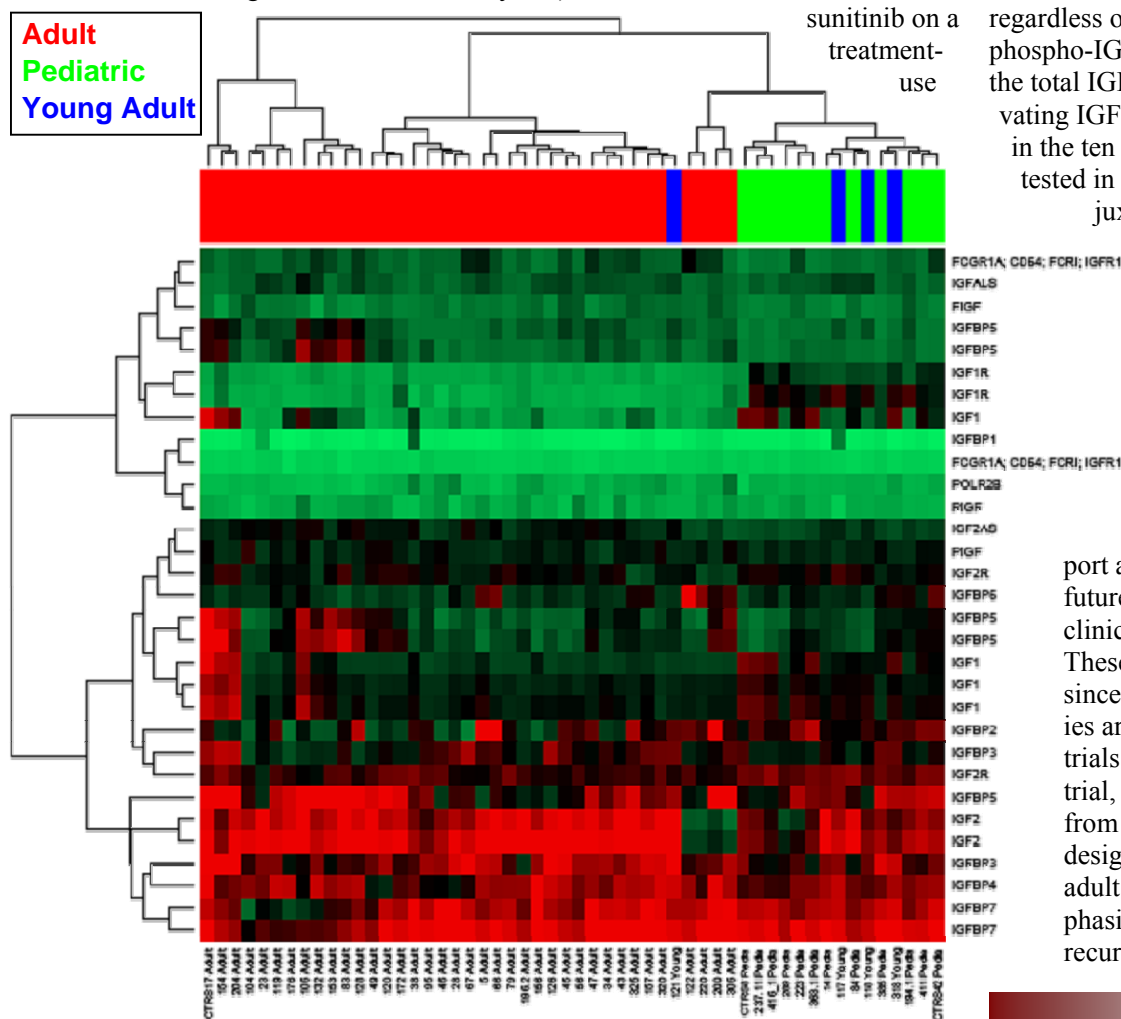
As adult patients with wild-type GIST are among those achieving the most sustained clinical benefit on sunitinib therapy, the possibility of similar clinical efficacy in the pediatric age group remained in question. Recently, Janeway et al.⁸ investigated this hypothesis on seven pediatric patients (aged 10-17 years) with advanced GIST treated with

protocol, after failing imatinib. Their findings revealed a partial response in one patient, stable disease in five patients and disease progression in one patient. Thus six of seven patients showed benefit from sunitinib therapy for an average of 15 months, without significant toxicity.

More recently, an interesting bio-marker was depicted as a potential therapeutic target in pediatric GIST. Expression profiling identified the presence of IGF1R mRNA (Figure 3) overexpression in pediatric GIST, compared to adult GIST, including the wild-type cases ². Additionally, Tarn and colleagues identified the presence of IGF1R amplification and protein overexpression in both wild-type and pediatric GIST ⁹. Applied immunoblotting and immunohistochemistry revealed that IGF1R was markedly overexpressed in the wild-type compared to mutant GIST. Although biochemical activation of the receptor was noted in all GIST tumors tested, regardless of *KIT* genotype, the levels of phospho-IGF1R did not correlate with the total IGF1R levels. However no activating IGF1R mutations were detected in the ten wild-type GIST tumors tested in any of the exons encoding juxtamembrane and kinases

domains. Combination treatment experiments in GIST cell lines with NVP-AEW541 (an IGF1R inhibitor) and imatinib induced an additive strong cytotoxicity response. Follow-up studies are needed to confirm these initial results to support a solid scientific basis for future design of IGF1R-targeted clinical trials.

These results are highly relevant since a number of IGF1R antibodies are now available in clinical trials. Specifically, the SARC001 trial, using the IGF1R antibody from Roche Pharmaceuticals, was designed targeting pediatric and adult sarcomas, with specific emphasis on tumors characterized by recurrent chromosomal translocat-



PEDIATRIC

From Page 15

tions. In keeping with these findings, the first pediatric GIST patient has been enrolled on an IGF1R-antibody protocol, after failing sunitinib therapy, with clinical response to be investigated.

References

1. Prakash S, Sarra L, Socci N, et al. Gastrointestinal stromal tumors in children and young adults: a clinicopathologic, molecular, and genomic study of 15 cases and review of the literature. *J Pediatr Hematol Oncol.* 2005;27(4):179-187.
2. Agaram NP, Laquaglia MP, Ustun B, et al. Molecular characterization of pediatric gastrointestinal stromal tumors. *Clin Cancer Res.* 2008;14(10):3204-3215.
3. Janeway KA, Liegl B, Harlow A, et al. Pediatric KIT wild-type and platelet-derived growth factor receptor alpha-wild-type gastrointestinal stromal tumors share KIT activation but not mechanisms of genetic progression with adult gastrointestinal stromal tumors. *Cancer research.* 2007;67(19):9084-9088.
4. Agaimy A, Pelz AF, Corless CL, et al. Epithelioid gastric stromal tumors of the antrum in young females with the Carney triad: a report of three new cases with mutational analysis and comparative genomic hybridization. *Oncol Rep.* 2007;18(1):9-15.
5. Miettinen M, Lasota J, Sobin LH. Gastrointestinal stromal tumors of the stomach in children and young adults: a clinicopathologic, immunohistochemical, and molecular genetic study of 44 cases with long-term follow-up and review of the literature. *The American journal of surgical pathology.* 2005;29(10):1373-1381.
6. Carney JA, Stratakis CA. Familial paraganglioma and gastric stromal sarcoma: a new syndrome distinct from the Carney triad. *Am J Med Genet.* 2002;108(2):132-139.
7. Pasini B, McWhinney SR, Bei T, et al. Clinical and molecular genetics of patients with the Carney-Stratakis syndrome and germline mutations of the genes coding for the succinate dehydrogenase subunits SDHB, SDHC, and SDHD. *Eur J Hum Genet.* 2008;16(1):79-88.
8. Janeway KA, Albritton KH, Van Den Abbeele AD, et al. Sunitinib treatment in pediatric patients with advanced GIST following failure of imatinib. *Pediatr Blood Cancer.* 2009;52(7):767-771.
9. Tarn C, Rink L, Merkel E, et al. Insulin-like growth factor 1 receptor is a potential therapeutic target for gastrointestinal stromal tumors. *Proceedings of the National Academy of Sciences of the United States of America.* 2008;105(24):8387-8392.

You can learn more about Pediatric GIST at www.pediatricgist.org

Mark your calendars!

● Chicago-area GISTers will be meeting at the Wellness Place in Palatine on **September 13**. Please contact Jim Hughes at tjhughes43@comcast.net.

● St. Louis-area GISTers will be meeting **November 1** in St. Louis at the Siteman Cancer Center. For more information, see page 10 for flyer.



Michigan GISTers meet....hey, wait a minute!



We finally got a picture of the May 9 Michigan meeting! Fashionably late and pictured from left to right are: (Standing) Mary (daughter of Mary Welzen), Jim Martin, Mary Welzen, Ellen Rosenthal, David Davis, Sue Severini, Nancy Wahl's mom, Nancy Wahl, Ted Wahl, Lennis Horst, Cara Catallo, and Doug Horst, (Seated) Jim Mills, Gordon Simmons, and Connie Arndt.

Kitty Katt Kimbell passes away at 60

Kitty Katt Kimbell died April 24 at her Tuolumne, Calif. home after a long struggle with cancer and other illnesses. She was 60.

Born in West Springfield, Mass., Mrs. Kimbell moved to California with her family at the age of 12.

She graduated from Marina High School in 1966 and earned her bachelor's and master's degrees at East Kentucky University.

She spent many years drafting and for a time taught math at San Bernardino Community College, but her family said her favorite job and ministry was as a pastor's wife.

She moved to Tuolumne seven years ago when her husband became pastor of Tuolumne United Methodist Church. She was a member of the church, and Tuolumne County Church Women

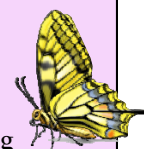
United.

Her family said her interests included attending musicals at Sierra Repertory Theatre, collecting butterflies and attending and leading Bible studies.

She was preceded in death by her father, Bill Katt, in 2007.

She is survived by her mother, Jean Sachs, of Soulsbyville; her husband, Pastor John Kimbell, of Tuolumne; children, the Rev. Shannon Kimbell-Auth and her husband, Michael, of Lakeport, and Kimberle Hill and her husband, Todd, of Riverside; and siblings, Ziggy Katt, of Marble Falls, Texas, and Bob Katt, of Albany, N.Y.

Donations may be made in her name to Tuolumne United Methodist Church, 18851 Cedar St., Tuolumne.



THE LIFE RAFT GROUP

Staff

Executive Director
Director of Operations
Science Coordinator
Director of Planning & Development
Program Coordinator
Assistant Program Coordinator
Administrator
Patient Registry Supervisor
Accounts Manager
Database Manager
Administrative Assistant
Administrative Assistant

Norman Scherzer
Tricia McAleer
Jerry Call
Marisa Bolognese
Sara Rothschild
Erin Kristoff
Karen Heald
Madgda Sarnas
Gale Kenny
Roberto Pazmino
Nicole Burke
Matthew Mattioli

General Counsel
Accounting Firm
Database Consultant
Database Architect
Official Greeter
Fundraising Chairs

Science Team

Volunteers

Thomas Overley
Mackey & Mackey
Steven Rigg
Maria Miller
Gail Mansfield
Marietta Robinson
John Poss
& Gerald Knapp
Jim Hughes
David Josephy
Michael Josephy
Omer Mercier
Rick Ware
Glenn Wishon
Rafael Vega
Paula Vettel

Board of Directors

Executive Committee

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

Directors

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

Contact the Life Raft Group

40 Galesi Drive
Wayne, NJ 07470
Phone: 973-837-9092

Fax: 973-837-9095
Internet: www.liferaftgroup.org
E-mail: liferaft@liferaftgroup.org



Life Raft regional chapters

Alabama	Pat George	patgeorge@bham.rr.com	Minnesota	Sharon Boudreau	redsmb@comcast.net
Alaska	Frank Domurat	patient@oncologyalaska.com	Missouri	Katie Campbell	campbellksoup@hotmail.com
Arizona	Janeen Ryan	tabascocook@yahoo.com	Montana	Donna Capps	BBR950@aol.com
Colorado	Jerry Call	jcall@liferaftgroup.org	Nebraska	Sally Norton	nordeane@cox.net
California	Floyd Pothoven	floyd@fastsemi.com	Nevada	Erik Krauch	erik.krauch@cox.net
Connecticut	Martha Zielinski	john.martha@sbcglobal.net	New Jersey	Anita Getler	acgetler@gmail.com
Florida	Helen Steinnagel	ahjs@sbcglobal.net	New York	Pat Bonda Swenson	pbondaswenson@yahoo.com
Georgia	Skip Ryan	skipryan@tampabay.rr.com	North Carolina	Chuck Korte	pckorte@att.net
Hawaii	Pat Lemeshka	riyank@bellsouth.net	Ohio	Kaye Thompson	tnt.1@sbcglobal.net
Idaho	Richard Palmer	richardpalmer@hawaii.rr.com	Oklahoma	Jane Rowan	jrowan30@aol.com
Illinois	Janet Conley	jkonley73@cablone.net	Oregon	Gail Mansfield	timothy.mansfield1@verizon.net
Indiana	Robert Book	rjkinz@aol.com	Pennsylvania	Kimberly Trout	musikwithkim@yahoo.com
Iowa	Barbara Kepple	kepbjk@aol.com	Rhode Island	Susan Farmer	sfarmer10@cox.net
Louisiana	Jackie Welsh	jackie.welsh@mms.gov	South Carolina	Al Boyle	captboo@windstream.net
Maine	Jodi Merry	merryhillacres@hotmail.com	Tennessee	Alice Sulkowski	sulkowskiab@msha.com
Maryland	Bonnie Emerson	bteensey2@hotmail.com	Texas	Kerry Hammett	hammett@uthscsa.edu
Massachusetts	Maura Cesarini	mauracesarini@hotmail.com	Virginia	Sally Jackson	spjackson@cox.net
Michigan	Ellen Rosenthal	ebrosenthal@comcast.net	Washington	Deanne Snodgrass	g-d-snodgrass@comcast.net
			Wisconsin	Rick Ware	rkwelwood@yahoo.com

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

Australia	Katharine Kimball	katharine_kimball@hotmail.com	Malaysia	Yong Choo Sian	ycspj2005@yahoo.com
Belgium	Kris Heyman	kh@contactgroepgist.be	Mexico	Rodrigo Salas	rsalas@maprex.com.mx
Bolivia	Virginia Ossio	vossiop@gmail.com	Netherlands	Contactgroep GIST	bestuur@contactgroepgist.nl
Brazil	Alexandre Sakano	alexandre@sakano.com.br	Norway	Odd Andreas Tofteng	oddandreas@yahoo.com
Canada	David Josephy	djosephy@uoguelph.ca	Pakistan	Muhammad Shahid Rafique	rsr_srs@yahoo.com
Chile	Piga Fernández	piga.fernandez@gmail.com	Poland	Stan Kulisz	listy@gist.pl
China	Ruijia Mu	mu_ruijia@yahoo.com	Romania	Simona Ene	si_mi_ene@yahoo.com
Colombia	Rafael Vega	ravega63@yahoo.es	Russia	Tanya Soldak	soldak@rpix.org
Costa Rica	Michael Josephy	mjosephy@gmail.com	Samoa	John Galuvao	leasii@gmail.com
Cyprus	George Constantinou	george@gnora.com	Saudi Arabia	Mohamed-Elbagir Ahmed	mohamedelbagir@live.com
Dominican Republic	Alejandro Miranda	ma.689.1215@gmail.com	Scotland	Helena Koumbouzis	hkoumbouzis@yahoo.com
France	Estelle LeCointe	info@ensemblecontrelegist.org	Singapore	Robert Richardson	jambo@pacific.net.sg
Germany	Markus Wartenberg	wartenberg@lebenshauspost.org	South Korea	Changhoon Lee	chlee@mobismiami.com
Greece	George Constantinou	george@gnora.com	Spain	Maria Teresa Jimenez Salado	mariateresa.jimenezsalado@telefonica.es
Hungary	Tünde Kazda	cmkgist@cmlgist.hu	Sudan	Mohamed-Elbagir Ahmed	mohamedelbagir@live.com
Iran	Negar Amirfarhad	negaraf@sympatico.ca	Switzerland	Helga Schnorf	ulrich.schnorf@bluewin.ch
Ireland	Carol Jones	roycal-re-gist@hotmail.com	Thailand	Kittikhun Pornpakakul	kittikun_p@yahoo.com
Israel	Avi Zigdon	zigdona@gmail.com	Turkey	Haver Tanbay	tanbay@tanbay.net
Italy	Anna Costato	anna.costato@virgilio.it	U.K.	Judith Robinson	Judith@ndrobinson.plus.com
Japan	Sumito Nishidate	euic@mbj.nifty.com	Uruguay	Fabrizio Martilotta	fabrizio.martilotta@gmail.com
Jordan	Mohammed Milhem	mohammed-milhem@uiowa.edu	Venezuela	María Isabel Gómez	asaphe_venezuela@yahoo.com
Kenya	Francis Kariuki	bridgestone@coopenya.com			
Lithuania	Virginija Zukauskienė	virginija.starkute@gmail.com			