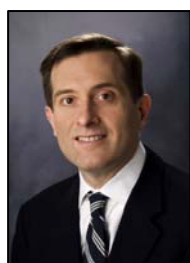


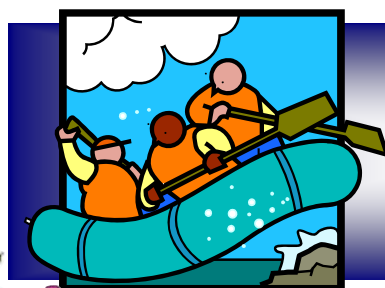
Molecular therapy & surgery combined in GIST

By Dr. Ron DeMatteo
Memorial Sloan Kettering
Cancer Center

For most cancers, the combined use of multiple different types of therapy is the most effective approach. Over the last several years, we have applied this philosophy to GIST. In this article, I will review our current understanding of multimodality therapy for both primary GIST and metastatic GIST. The gold standard of therapy for primary



DEMATTEO



January 2008

In memory of William Fraser, Edward Friedman, Nan Mustard, Judy Earle, Dan Scherban & Ken Lundell

LIFE RAFT GROUP

Vol. 9, No. 1

GIST is surgery. However, despite complete removal of all visible disease, as many as half of patients will develop tumor recurrence. We at Memorial Sloan-Kettering Cancer Center (MSKCC), and others, have found that the likelihood of recurrence depends on several features of the tumor. As with many tumors, size predicts outcome. Patients with tumor size greater than ten centimeters do not do as well as those with smaller tumors. Tumor location is also important. Patients with GIST that

arises in the stomach fare better than those with small intestine GIST. The dominant predictor of recurrence is mitotic rate (the number of dividing tumor cells that the pathologist sees per 50 microscopic fields). Patients with a mitotic rate of less than five have approximately a 20 percent chance of recurrence by five years after surgery compared to an 80 percent chance for those with a higher mitotic rate. The relationship of mutation to recurrence after removal of a primary

See DEMATTEO, Page 6

2007 Executive Director's Report

A look back at 2007 and a look ahead at what is to come in 2008.

By Norman Scherzer
LRG Executive Director

The advent of the New Year is a wonderful opportunity to take stock of what the Life Raft Group has accomplished in 2007, as well as reflect on what has already begun and what we still hope to achieve. It is hard still to list the triumphs and defeats of the last year in this article, when the ultimate defeat, the death of GIST patients, continues to take center stage. But our tradition is to light candles to celebrate the lives of those who have left us and not mourn the past. With the birth of a new year, we look forward to new developments, new precedents, new resources, new treat-

ments and new hope.

A Look Back

We expanded the content and the scope of our informational and educational efforts. Once again, we have raised the bar for scientific content in our monthly newsletters and struggled to maintain a balance between covering coping issues and heroic stories of our members and providing the scientific material that researchers, clinicians and a growing number of patients and caregivers have come to depend upon to keep them informed. We also created new educational materials, including a cutting-edge pamphlet on "Navigating GIST Clinical Trials" and built a new and sophisticated system for tracking these clinical trials. We began a series of



SCHERZER

monthly webcasts featuring experts in clinical care, research and education and archived them in a new onsite webcast library.

We continued to expand the content of our websites and have almost completed our first total redesign and reorganization of the LRG website. We are planning to launch this in a few weeks.

On an ongoing basis, we have counseled patients one-on-one about their options for choosing and accessing treatment and we intervened, on numerous occasions, behind the scenes to overcome obstacles to obtaining life-saving drugs. Our advocacy efforts continued, confronting cutbacks in Medicare and insurance coverage for GIST patient treatment.

As an ongoing special mission we once again tried to bring quality care and coordinated research to the treatment of pediatric GIST patients. We co-sponsored, with the National Institutes

See REFLECTIONS, Page 7

Laura sees pot o' gold, even if no one else can

By Laura Kukucka

This article was reprinted from Laura Kukucka's CarePage with her permission. You can view her CarePage at www.carepages.com. CarePage name: LauraKukucka

My life... My mom and I were out shopping together recently, while Phil was at home working on our attic remodeling. I had been trying to call him for awhile and wasn't getting an answer, and I was starting to get worried. My mom asked why I was so concerned, and without really thinking about it, I told her that I'm just so darn lucky, and I'm afraid my luck will run out eventually and something bad will happen. She gave me the strangest look and said, "You know, those are really odd words coming from a cancer patient." I've had a lot of people over the years who've told me how rotten my luck is. After all, take a glimpse into my world:

☑ I don't have a regular hairdresser, but I bought a Christmas gift for the woman at the James [Cancer Center] who draws my blood every 2 weeks.

☑ I let casual work acquaintances think I'm just weird when I exhibit odd behavior, like walking slowly if I'm in pain or throwing up in the office bathroom if something doesn't agree with me. I hate people feeling sorry for me, and I figure whatever their imagination comes up with, it won't be anything as crazy as the truth (which is that I have no stomach and, according to the PET scanner, "at least 25 hypermetabolic lesions" in my liver).

☑ Along the same lines, I let people think I'm just a non-drinking square,



Laura Kukucka poses with husband, Phil and son, Jake in Disney World.

rather than explaining all the reasons why I don't/can't drink alcohol.

☑ I have a 7-inch scar down the center of my belly that people stare at if I wear a bikini...but it doesn't stop me from wearing them. I'm proud of my battle scar!

☑ When well-meaning people ask me if/when Phil and I are going to have kids, I just nonchalantly respond, "Nah, when you get it right the first time you don't need to have any more..." because it's just so much more socially acceptable than saying, "actually, our health won't allow us to have a baby together and some days it doesn't bother me, but other days it breaks my heart."

☑ I have to take a painkiller every night if I want to sleep in any position other than flat on my back.

☑ Terms like "lymphoproliferative", "hyperplasia" and "duodenum" are second nature to me, and I can explain the difference between "histology", "pathology", "etiology" and "hematology".

☑ I truly no longer remember what it's like to *not* have cancer.

So...I guess I can see where someone might think I drew the short straw in life. But, really? I think I'm one of the



See LUCKY, Page 11

The Life Raft Group

Who are we, what do we do?

The Life Raft Group is an international, Internet-based, non-profit organization offering support through education and research to patients with a rare cancer called GIST (gastrointestinal stromal tumor). The Association of Cancer Online Resources provides the group with several listservs that permit members to communicate via secure e-mail. Many members are being successfully treated with an oral cancer drug Gleevec (Glivec outside the U.S.A.). This molecularly targeted therapy represents a new category of drugs known as signal transduction inhibitors and has been described by the scientific community as the medical model for the treatment of cancer. Several new drugs are now in clinical trials.

How to join

GIST patients and their caregivers may apply for membership free of charge at the Life Raft Group's Web site, www.liferaftgroup.org or by contacting our office directly.

Privacy

Privacy is of paramount concern, and we try to err on the side of privacy. We do not send information that might be considered private to anyone outside the group, including medical professionals. However, this newsletter serves as an outreach and is widely distributed. Hence, all articles are edited to maintain the anonymity of members unless they have granted publication of more information.

How to help

Donations to The Life Raft Group, incorporated in New Jersey, U.S.A., as a 501(c)(3) nonprofit organization, are tax deductible in the United States.

Donations, payable to The Life Raft Group, should be mailed 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. As for the newsletter, every effort to achieve accuracy is made but we are human and errors occur. Please advise the newsletter editor of any errors.

January 2008 clinical trial update

By Jim Hughes

LRG Science Team Member

The following new United States trials were reported in the December 2007 Newsletter as part of the International Clinical Trial Update. They have now been added to the US table and are repeated here for US readers. All contact information is listed in the table below.

XL820 Phase II: Exelixis has announced this trial as currently open in Park Ridge, IL. Plans are also underway to open at Dana-Farber and at UCLA in 2008. This is a Phase II trial for GIST only.

AUY922 Phase I: AUY-922 is an HSP-90 inhibitor manufactured by Novartis. Patients may not have had prior HSP-90 or HDAC inhibitor therapy. Novartis study ID is CAUY922A2101.

Perifosine plus Sorafenib Phase I: Oncology Specialists in Park Ridge, IL has called to inform us they have Phase I Perifosine + Sorafenib. Perifosine is an HDAC inhibitor. Sorafenib inhibits multiple tyrosine kinase targets associated with GIST.

SNX-5422 Phase I: "Safety and Pharmacology of SNX-5422 Mesylate in Subjects With Refractory Solid Tumor

Malignancies" has opened in Nashville, TN and Scottsdale, AZ. SNX-5422 is an HSP-90 inhibitor made by Serenex.

STA-9090 Phase I: STA-9090 is an HSP-90 inhibitor. According to the Synta press release, in preclinical studies, "STA-9090 has shown the ability to inhibit multiple kinases with comparable potency to, and a broader activity profile than specific kinase inhibitors such as Gleevec, Tarceva and Sutent. In addition, STA-9090 has shown potency ten to 100 times greater than the geldanamycin family of Hsp90 inhibitors, as well as activity against a wider range of kinases. In in vivo models, STA-9090 has shown strong efficacy in a wide range of cancer types, including cancers resistant to Gleevec, Tarceva, and Sutent." This open-label Phase I study in patients with solid tumors is designed to identify the maximum tolerated dose of STA-9090 based on a twice-a-week intravenous dosing schedule. In addition to an evaluation of safety and tolerability, patients will be assessed for response rate based on the RECIST criteria. A second Phase I study with an alternative, once-a-week dosing schedule is planned.

XL765 Phase I: Manufacturer Exelixis is sponsoring a Phase I trial of its PI3K and mTOR inhibitor XL765 at two

sites in the United States: Wayne State University, Detroit, Mich. and START, San Antonio, TX.

The following additional updates have been made to the US Trial table:

AMN107 Phase III: H. Lee Moffitt Cancer Center in Tampa, Flor. and MD Anderson in Houston, TX are now open and have been added as sites. Trial number is CAMN107A2201.

IPI504 Phase I: Mount Sinai Hospital in Toronto, Canada has been added as a site. Martin Blackstein, MD is the Principal Investigator.

Sorafenib (BAY 43-9006) Phase II: A new site has been added. Arthur G. James Cancer Hospital and Solove Research Institute at Ohio State University Medical Center, Columbus, Ohio.

BEZ 235 Phase I: Now open at the Sarah Cannon Research Institute in Nashville, Tenn. BEZ235 is a Novartis drug that targets the PI3K tyrosine kinase and indirectly inhibits the downstream targets AKT and mTOR. Also available at the Nevada Cancer Institute in Las Vegas.

KOS1022 Phase I: We were informed in late November that this trial at Colorado University in Aurora, Col. is on hold for toxicity.

Sorafenib (BAY 43-9006, Nexavar)

Sorafenib in treating malignant GIST patients that progressed during or after previous treatment with imatinib and sunitinib

Phase: II
Conditions: GIST
Strategy: Multiple Targets
NCT#: NCT00265798
US Contact: Univ. Of Chicago Cancer Res. Cent., Chicago, IL
Telephone: Clinical Trials Office, 773-834-7424
US Sites: **City of Hope**, Duarte, CA
Warren Chow, MD, 866-434-4673 xt 64215
Cancer Care Specialists, Decatur, IL
James Wade III, MD, 217-876-6617
Onc./Hem. Assoc. of Cent. IL, Peoria, IL
John Kugler, MD, 309-243-3605
Dana-Farber, Boston, MA
Travis Quigley, RN: 617-632-5117
Memorial Sloan-Kettering, New York, NY
David D'Adamo, MD, 212-639-7573
Ohio State Univ., Columbus, OH
Clinical Trials Office, 614-293-4976

Imatinib+Pegylated Interferon-a 2B

A Phase II Study combining targeted therapy with immunotherapy using imatinib + Pegylated Interferon-a 2B in imatinib-naïve GIST patient

Phase: II
Conditions: GIST
Strategy: Kill GIST Cells,
Study #: HCI 22172
US Contact: Univ. of Utah, Salt Lake City, UT
Huntsman Cancer Institute
Candace, 801-581-4477

XL820

Study of XL820 given orally to subjects with solid tumors

Phase: II
Conditions: GIST
Strategy: Multiple targets
NCT#: NCT00570635
US Contact: Christiaan McEwen, 415-337-1754,
christiaan.mcewen@quintiles.com
US Sites: Oncology Specialists, Park Ridge, IL
Kathy Tolzein, RN: 847-268-8200

Perifosine+ Gleevec

Phase II Study of Perifosine Plus Gleevec for Patients With GIST

Phase: II
Conditions: GIST
Strategy: Multiple Targets
NCT#: NCT00455559
US Contact: Online Collaborative Onc. Group
ocogtrials@ocog.net
Telephone: 415-946-2410
US Sites: **Cancer Center at Century City**, Los Angeles, CA
Sant Chawla, MD
Coeur D'Alene, ID
Oncology Specialists, Park Ridge, IL
Kathy Tolzein, RN, 847-268-8200
Grand Rapids, MI
Sayre, PA
MD Anderson, Houston, TX
800-392-1611

Kwart puts pen to paper in plea to patients

By Erin Kristoff
LRG Newsletter Editor

When the Life Raft Group Board of Directors was challenged to raise funds for the LRG Resistance Research project, Arnold Kwart took it as an opportunity to make a difference. Not being part of the business world, he had only past patients to rely on for help. As a leading surgeon in the field of urology, Dr. Kwart helped thousands of patients, whose lives were made better with the intervention of Dr. Kwart.

Kwart knew that the only way he could help the Life Raft Group was to ask his prior patients to help him as he helped them. "I believe in the what the Life Raft Group is doing. I know a lot of people in medicine. [The LRG] is organized so well, they put most hospitals to shame."

After creating a letter that revealed his medical status, hopes and fears to thousands of patients, he and his family sealed over 2,100 envelopes in a massive person-to-person appeal. Having never done something of this nature, Kwart had no idea what kind of response he would get.

The response would prove to be

overwhelming.

Kwart's home and the LRG office were immediately flooded with letters, donations and "Get Well" wishes.

"They wish me well and they miss the opportunity to interact with me as a

doctor and patient and I miss that too."

Dr. Kwart's plea has raised more money for the Life Raft Group than any other fundraising campaign to date. "In this world where everybody has no time

to think about anyone else, they do when you give them an opportunity to do so. Speak from your heart and they respond."

At the end of the year, Dr. Arnold Kwart has already raised a staggering \$90,000! And that number is rapidly climbing.

"I adore my patients and they love me, it's as simple as that."

ARNOLD M. KWART, MD

November 19, 2007

"As a physician, I have devoted my life to helping others, and have continually been inspired by the strength, courage and hope of my patients in the face of disease. Now—as the tables have turned—I have a renewed appreciation for the worry and fear that accompany an incurable illness."



KWART

That is why I'm writing today. I am asking you to join me in supporting the Life Raft Group – the nonprofit, patient support group for GIST – and its sophisticated team of GIST research scientists. In the near future, these researchers believe that GIST may not only be controlled, but eventually cured, by new combinations of highly selected targeted therapies. I am proud to be a board member of this esteemed group.

The Life Raft Group has been an invaluable source of information, support and guidance for me during the past six years. It is deeply committed to ensuring the survival of GIST patients while maintaining their quality of life. While its total research program costs \$1.4 million annually, I believe it's worth it. Now, we have an even greater challenge going.

Until September, all my energies to help my patients can help us by me.

I thank you in advance.

Sincerely,

Arnold Kwart

Arnold Kwart, MD
Board Member, Life Raft Group

PS. For your convenience, I have enclosed a return envelope which is deductible to the extent permitted by law. Please also visit our website for more information.

Dear Dr. Kwart,

Thank you for taking the time to contact me about the Life Raft Group. I was saddened to learn that you are no longer practicing, as I always enjoyed my visits to your office. I'm currently getting my MBA at UNC Chapel Hill and hope to contribute more to your cause once I rejoin the workforce. I hope you are doing well, and Happy Holidays.

– Anonymous

Dear Dr. Kwart,

After 3 prostate surgeries (compliments of Dr. Kwart), open heart surgery, umbilical surgery, etc., etc., I was feeling quite sorry for myself. I stopped as soon as I hear about your situation. I am glad to find that you are fighting hard against this unusual and rare disease.

Your patients and friend,
James Haight

Dear Dr. Kwart,

I hope the enclosed will help the cause.

I received your letter from WHC and want you to know how highly I regarded you as a person and or a doctor. You're the tops!

I will miss seeing you on my visits to your office. You and your family will be in my prayers.

All the best.

Sincerely,
Dan

Dear Dr. Kwart,
Tamar and I were saddened to learn of your illness. We wish you and your family nothing but the best.

Sincerely,
Tamar and Stanley
Rabin

Dear Dr. Kwart:

I marvel at your fighting spirit. Your surgical skill and good cheer certainly got me through the toughest time of my life. God-speed!

Anonymous

From the desk of...

To Whom It May Concern:

I am pleased to make a contribution to the Life Raft Group, in honor of Dr. Arnold Kwart who has been a treasured friend and colleague of mine for over 35 years.

Sincerely,
Martin Lebowitz

LRG webcast success, DeMatteo discusses adjuvant Gleevec

By Sara Rothschild
LRG Program Coordinator

On December 19th, the Life Raft Group held its seventh webcast on “Surgery and Molecular Therapy for GIST.” The presentation was given by Dr. Ronald P. DeMatteo, surgeon at Memorial Sloan-Kettering Cancer Center. Dr. DeMatteo is recognized as an international expert in GIST and is the principal in-



vestigator of two multicenter trials sponsored by the National Cancer Institute and Novartis Pharmaceuticals that are being run through the American College of Surgeons Oncology Group (ASCO). The trials are testing the benefit of adjuvant Gleevec following the resection of primary GIST. Dr. DeMatteo also has National Institutes of Health grant awards to perform correlative studies on tumor specimens from patients on these trials.

DeMatteo discussed some of his work regarding taking Gleevec on an adjuvant basis after surgery. He and his colleagues intend to publish these

findings some time this year in the journal, *Cancer*. His presentation also gave a clear explanation of what surgery entails when a GIST is resected.

If you would like to hear a recording of this presentation, please visit: www.liferaftgroup.org/news_webcasts.html.

Please join us for our next webcast on January 24, 2008 at 12:00 PM EST. “Balancing Your Needs and Your Role as Caregiver” will be presented by Carolyn Messner, DSW, MSW, LCSW-R, BCD, Director of Education & Training with *CancerCare*.

Texas + Poker = winning combination

By Erin Kristoff
LRG Newsletter Editor

John Poss had no idea what would happen when he decided to hold a poker tournament in Texas but he knew he would probably need a lot of help. Enlisting friends like Dale Couch (who agreed to help put the event together on the condition that it be named “The Poss” and Dawn Wolfe of TXL Mortgage, John managed to see his vision through.

On November 7, 2007, the first Texas Poker Tour-

namment was held. Nearly 100 people attended the event, which was held at the Lakeside Country Club.

“The atmosphere was great! Everyone was mingling and having a wonderful time,” said Dawn. The night began with an hour of cocktails and chatting before the tournament kicked off.



Players prepare for an exciting night of cards at the first Texas Poker Tournament for the Life Raft Group.



POSS

prizes.

Many players said they had a wonderful time and were looking forward to another event next year.

Many of John’s friends from out of state came or donated entry fees I if unable to attend. Four hours from the time the first drink was served, the final three were crowned: John Ramsey took third place, Billie Ellis came in second and Tim Welbes finished first. All three received gold coin pieces as



Players (including three Poss family members) smile for the camera. We wonder how many were still smiling by the end of the night?

John Poss would like it known that he begged Dale Couch not to name the poker tournament, “The Poss”. In the interest of professional ethics we thought it was only fair that we share that information with our readership.



DEMATTEO

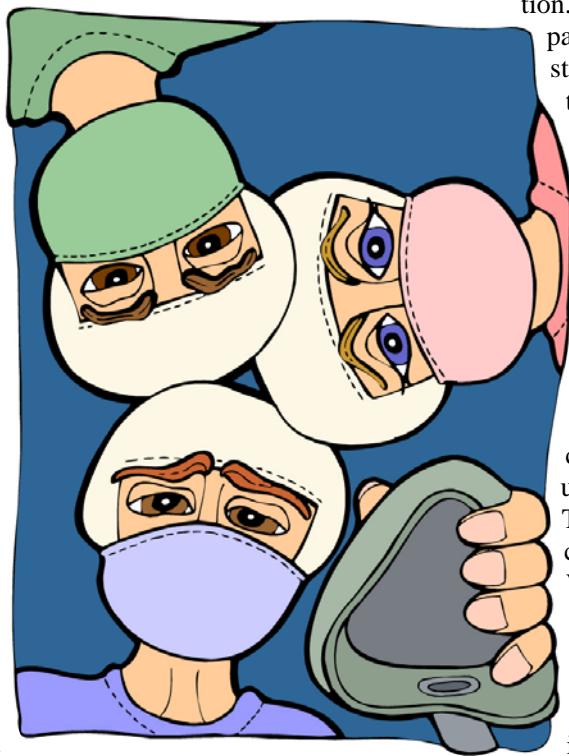
From Page 1

GIST requires further study. However, it appears that patients with exon 11 point mutations or insertions do better than those with KIT exon 11 deletions or a KIT exon 9 mutation. It should be stressed that all these indicators of recurrence have been established in patients who underwent surgery alone and were never treated with imatinib or other tyrosine kinase inhibitors (TKIs) unless they developed recurrence. Risk factors for recurrence may be different in patients who are treated immediately after surgery with TKIs.

To determine whether taking imatinib after removal of a primary GIST can decrease the chances of tumor recurrence, we conducted a phase III clinical trial known as ACOSOG Z9001. In this multicenter trial, patients who had complete removal of a primary GIST were randomized to one year of imatinib (400 mg/day) or one year of placebo. Over 650 patients were enrolled. The trial was stopped prematurely in April 2007 based on the difference in tumor recurrence between the two treatment groups. As outlined in a National Cancer Institute (NCI) press release in April 2007, the chance at one year of developing a recurrence was three percent in the imatinib-treated patients versus 17 percent in the placebo-treated patients. Final analysis of the data is pending and then treatment recommendations will be made. There are several other large trials testing the benefit of adjuvant imatinib. One is led by the Scandinavian Sarcoma Group and is examining one versus three years of adjuvant (i.e., post-operative) imatinib. Another is a European Organization for Research and Treatment of Cancer (EORTC) trial comparing no treatment to two years of imatinib; the goal of this trial is to determine whether overall survival is different. We will not know the results of these trials for at least several years.

The standard therapy for metastatic GIST is TKI therapy. Prior to the era of TKIs, surgery was sometimes used for patients with metastatic GIST because conventional cytotoxic chemotherapy

was so ineffective. In highly selected patients with metastatic GIST, surgery alone resulted in a median survival of approximately two years. We now know that TKIs achieve a median survival of



about five years. The major problem with TKIs is the development of drug resistance, which occurs in half of patients within two years. Consequently, we need new approaches for patients with metastatic GIST. One possibility is that a combination of drugs may prove to be more effective than using one drug alone. This is the case with many other types of cancers. Though another option is to consider using TKIs in combination with surgery for metastatic GIST.

The use of surgery in patients with metastatic GIST who are being treated with TKIs is investigational. The idea is to remove all visible disease whenever possible. This may result in delaying, or possibly even preventing, the development of drug resistance. The hypothesis is that an individual's chance of developing resistance is proportional to the amount of tumor that remains after TKI therapy. MSKCC, and several other centers around the world, has utilized surgery in addition to TKIs in selected patients with metastatic GIST. We have learned that surgery is generally not useful for patients who have multiple tu-

mors that have become resistant to imatinib. If one tumor is resistant, surgery may provide benefit. Patients with non-progressing metastatic GIST have done well with complete tumor resection. However, these are highly selected patients. It is also important to understand that there is risk of complications and even death in performing surgery in these patients who otherwise may have lived several more years on TKIs alone. We need better tools to predict drug resistance to select who should undergo surgery. The only way to prove convincingly that surgery should be used for metastatic GIST is to conduct a scientific clinical trial in which patients are randomized to continue TKI therapy alone or to undergo surgery and then resume TKI therapy. Such a trial is being considered in this country.

We have learned a lot about GIST in the past decade. While surgery is the best therapy for primary GIST and TKIs are the best therapy for metastatic GIST, the optimal multimodality treatment for GIST is yet to be defined. Already, we have discovered that adjuvant imatinib is beneficial in primary GIST and now it is important to define which patients should be treated and for how long. There is certainly theoretical value of surgery, in addition to TKI therapy for metastatic GIST and this area requires further study.

GIST 101

Mitosis is *cell division*.

Using a microscope, a pathologist counts the number of dividing cells per "50 High Powered Fields" (HPF). This tells them

how quickly the tumor is growing.



REFLECTIONS

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of Health (NIH), a major meeting of pediatric GIST medical professionals and patients which has culminated in an agreement with the NIH to host a clinic for pediatric GIST patients starting this coming spring. We will have a lot more to say about this in the near future but suffice it to say that this is a most exciting development to improve the care of our young patients.

On the research front we are a few months away from completing the first two years of our five-year strategic plan to discover and overcome the reasons that GIST patients develop resistance to treatment. To date we have awarded nearly two million dollars to implement this plan, created by our research team. This effort is coordinated by Dr. Jonathan Fletcher at Dana-Farber/Brigham & Women's Hospital and his colleagues: Drs. Cristina Antonescu and Peter Besmer of Memorial Sloan-Kettering Cancer Center, Drs. Chris Corless and Mike Heinrich of Oregon Health & Science University, Dr. Maria Debiec-Rychter of Catholic University in Leuven, Belgium, Dr. Brian Rubin of the Cleveland Clinic and Dr. Matt van de Rijn of Stanford University.

Our research is unique in many ways, including being based upon a coordinated plan of action, a novel grants process that caps indirect costs at 10 percent (instead of typical 60% to 75% rates), and a philosophy that mandates cooperation, collaboration and accountability in place of isolation and competition. In addition, we have created two tissue banks, for adult GIST at Stanford University and Pediatric GIST at Memorial Sloan Kettering.

As a complement to this research strategy we vastly expanded our GIST patient registry by converting our extensive medical information to a dramatically more robust and comprehensive data base format. In the very near future we will be publishing our latest forward-looking analysis of the relationship between Gleevec dosage and survival.

A Look Ahead At Issues Affecting Survival

The core mission of the LRG is survival and it is not yet met. Despite early and dramatic responses to Gleevec in excess of 85 percent, the specter of resistance and an endless roll call of deaths call for a sober assessment of the obstacles that remain to be overcome.

It is simply not enough to recount our many successful projects, virtuous though they may be. GIST patients, like most cancer patients, too frequently pass into the night and do so with a graceful courage marked by a soft silence. We have much to do to achieve our mission.

Our blueprint for ensuring the survival of GIST patients builds upon using existent knowledge as well as further research.

Our research has begun to make progress in identifying the downstream pathways that characterize Gleevec resistance and in finding ways to shut these down. We believe that our strategic planning and coordinated approach to research will provide a pathway to an eventual cure. Our initial objective is to turn GIST into a chronic disease, probably by providing the patient with a cocktail mix of drugs that ensure survival and a high quality of life. The ultimate objective is to find a cure by totally destroying every GIST cancer cell so that the patient will be able to stop taking drugs, avoiding high expenses and inevitable side effects. We will shortly begin our third year of our five-year plan.

Although research must remain the cornerstone of achieving our mission there is much that can be done with what we currently know to improve the chances of survival.

Prescribing the right Gleevec dosage for metastatic GIST patients: The current consensus is to treat metastatic GIST patients with 400mg per day and to cross over to a higher dosage should progression occur. However, it is not at all clear to us that this consensus is always correct. We now know that patients with an exon 9 mutation respond dramatically better to a higher dosage of Gleevec and do rather poorly on a 400mg dosage. For patients with surgi-

cal tissue on file it would seem prudent, if not urgent, that the tissue be tested for genetic mutation and that exon 9 patients be given a higher dose. The situation for other patients, generally those with exon 11 mutations, is less clear and will be the subject of a Life Raft Group study to be released next month.

In addition to routine mutational testing to determine the existence of exon 9 mutations we suggest that routine plasma testing be introduced to attempt to determine the level of Gleevec in the body. There is evidence to suggest that the clearance levels of Gleevec increase over time and some reasonable speculation that this may mean that a starting dosage of 400mg of Gleevec is not sufficient for all patients over time.

Given the efficacy of current treatment options once Gleevec resistance has developed we would submit that currently it may be easier to prevent resistance from developing than trying to reverse it once it occurs.

Adjuvant treatment following surgery for a primary tumor: Although we have data only from one early clinical trial, that data suggests that patients given preventive (adjuvant) treatment, following the successful removal of a primary tumor (i.e. with clear margins), have a lower rate of recurrence, at least in the short term.

Early diagnosis: We have known for some time that the prognosis for



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progression free survival is better for patients with smaller tumors and with lower mitotic rates. It would seem reasonable that the earlier the patient is diagnosed the more likely the tumor would be smaller. Little attention has been paid thus far, to finding ways to promote earlier diagnoses of GIST. A focus of the Life Raft Group's efforts in the coming year will be to provide those doctors most likely to encounter the earliest symptoms of GIST, including family practitioners, internists, gastroenterologists and emergency room physicians, with information designed to raise their index of suspicion.

Accessing Treatment: The cruelest situation for GIST patients is the inability to access available treatments. The two major issues are a lack of knowledge about current treatments, including those in clinical trials, and a combination of logistical and financial obstacles preventing access. As more drugs are approved for the treatment of GIST the likelihood is that more patients will be seen by more inexperienced oncologists, particularly in health settings like the

United States. That reality, combined with a complex number of clinical trials, means that there is an educational need to reach both physicians and patients with the latest treatment and clinical trial information. Making sure that nobody dies because of ignorance, either their own or that of their physician, is the driving force behind the Life Raft Group's educational programs.

The hard reality of logistics and finances often enter the scene after a particular treatment is identified. Gleevec and Sutent, the current Food and Drug Administration-approved drugs for GIST, are expensive. Although both Novartis (maker of Gleevec) and Pfizer (maker of Sutent) have patient assistance programs, they vary widely in different countries and have financial eligibility cutoffs. Forty-seven million Americans live without health insurance and not all qualify for financial assistance for cancer treatment. Accessing clinical trials poses all sorts of obstacles, depending on where they are located (many are in expensive urban areas) and what they require in terms of travel and lodging. Few trials offer assistance for travel and lodging and many United States trial locations have prohibitive financial requirements for international patients.

Accessing treatments through compassionate-use poses yet another set of difficulties and even the best intentioned pharmaceutical companies are no match for the onerous processes required by medical institutions for approving such drug use. Addressing these varied and many issues is a major priority for the Life Raft Group.

Quality Controls: Mistakes are an unfortunate reality in medical care. With relatively new areas such as the rapidly developing diagnosis and treatment of GIST, the lack of quality controls can be particularly problematic. For example, there is currently no reference laboratory for the complex mutational tests GIST patients need. There is no Board Certification for GIST specialists or even the broader area of sarcomas, the family of cancers to which GIST belongs. There is no reference testing for radiologists, including those who rarely see GIST tumors. The Life Raft Group intends to begin addressing quality control issues this year.

Much remains to be done on our pathway to a cure for GIST. The memory of those who have left us sustains us and the urgency of those struggling for survival drives us. I will pose this question once more: If not us, then whom?

Japanese GISTers 'Relay for Life' in September

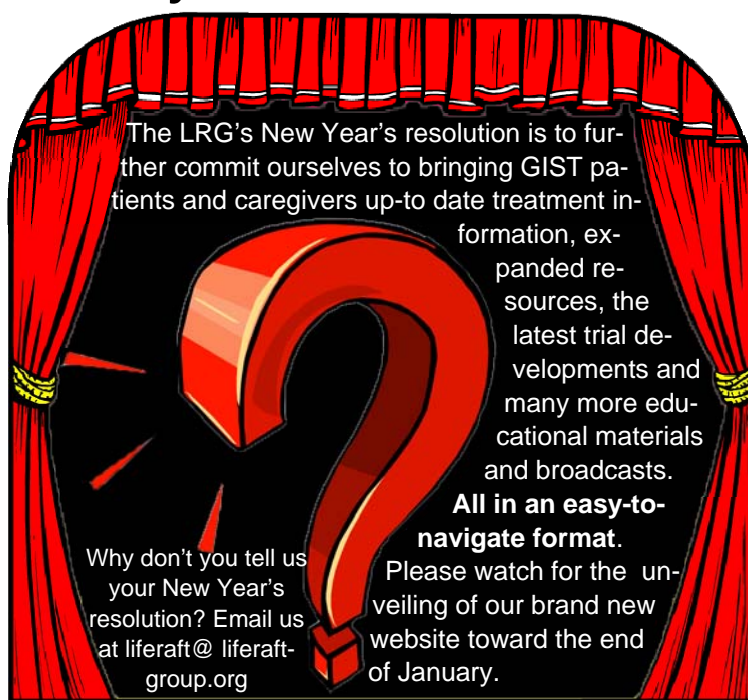


GISTers in Japan showed their commitment to stopping cancer in their lifetime by walking for the American Cancer Society's "Relay for Life" in September 2007 in Ashiya.



The weather was fine, everyone had a wonderful time and felt very uplifted by the event. RFL is scheduled for two Japan locations next year and no one can wait!

What's your New Year's resolution?



TRIALS

From Page 3

AMN107 (nilotinib, Tasigna®)

Efficacy and safety of AMN107 compared to current treatment options in GIST patients who failed imatinib and sunitinib

Phase: III

Conditions: GIST

Strategy: Inhibit KIT (PDGFRA signaling)

NCT#: NCT00471328

US Contact: Novartis

Telephone: 800-340-6843

UCLA, Los Angeles, CA

US Sites: Myung Lee, 310-825-4494

Wash. Cancer Inst., Washington, DC

Jake Paterson, 202-877-5371

Moffitt Cancer Center, Tampa, FL

Bonnie Murray, 813-745-3819

Univ. of Chicago, Chicago, IL

Patient Coordinator, 773-834-7424

Dana-Farber, Boston, MA

Travis Quigley, RN, 617-632-5117

Karmanos Cancer Institute, Detroit, MI

Anne Marie Ferris, 313-576-9373

Washington Univ., St. Louis, MO

Nick Fisher, 314-354-5102

Wake Forest, Winston-Salem, NC

Scarlet Hutchins, RN, 336-713-6915

Fox Chase, Philadelphia, PA

1-800-FOX-CHASE

MD Anderson, Houston, TX

Sylvia Abanto, 713-794-1919

Sunitinib (Sutent) or Imatinib (Gleevec)

Safety and effectiveness of daily dosing with sunitinib or imatinib in GIST patients

Phase: III

Conditions: GIST

Strategy: Multiple Targets

NCT#: NCT00372567

US Contact: Pfizer Clinical Trial Information Service

pfizercancertrials@emergingmed.com

Telephone: 877-369-9753

US Sites: Contact Pfizer

Dana-Farber, Boston, MA

Travis Quigley, RN, 617-632-5117

Doxorubicin and Flavopiridol

Doxorubicin and Flavopiridol in Treating Patients With Metastatic or Recurrent Sarcoma That Cannot Be Removed By Surgery

Phase: I

Conditions: GIST/Sarcoma

Strategy: Inhibits Production of KIT

NCT#: NCT00098579

US Contact: **Memorial Sloan-Kettering**, New York, NY

David R. D'Adamo, MD, PhD

212-639-7573

IPI-504

Safety Study of IPI-504 for GIST or Soft Tissue Sarcoma

Phase: I

Conditions: GIST or Soft Tissue Sarcoma

Strategy: Destroy KIT, (HSP90)

NCT#: NCT00276302

US Sites: **Premiere Oncology**, Scottsdale, AZ

Michael S. Gordon, MD,

480-860-5000

Premiere Oncology, Santa

Monica, CA

Courtney Carmichael, RN,

310-633-8400

Dana-Farber, Boston, MA

Travis Quigley, RN, 617-632-5117

Univ. of Michigan, Ann Arbor, MI

Rashmi Chugh, MD, 734-936-0453

Mt Sinai Hospital, Toronto, CA

Edith Bardi, (416) 586-4800 ext 4795

Perifosine + Sunitinib

Perifosine + sunitinib for patients with advanced cancers

Phase: I

Conditions: GIST/ Renal Cancer

Strategy: Multiple Targets

NCT#: NCT00399152

US Contact: **Online Collaborative Oncology Group**

ocogtrials@ocog.net

Telephone: 415-946-2410

US Sites: Huntsville, AL

Tower Hematology and Onc.,

Beverly Hills, CA

Pomona, CA

Santa Monica, CA

Oncology Specialists, Park Ridge, IL

Kathy Tolzien, RN, 847-268-8200

Kalamazoo, MI

BEZ235

A Phase I/II, multi-center, open-label study of BEZ235, administered orally on continuous daily dosing schedule in adult patients with advanced solid malignancies including patients with advanced breast cancer

Phase: I/II

Conditions: Advanced Solid Malignancies/Adv. Breast Cancer

Strategy: Target KIT Downstream Signaling

US Contact: **Nevada Cancer Inst.**, Las Vegas, NV

Donna Adkins, RN, 702-822-5173

Sarah Cannon Res. Inst., Nashville, TN

Howard Burris, MD, 615-329-7274

KOS-1022

Study of Oral KOS-1022 in patients With advanced solid tumors

Phase: I

Conditions: Advanced Solid Tumors

Strategy: Destroy KIT (HSP90)

Study #: COMIRB 05-0627

US Contact: (ON HOLD)

Sarah Eppers, 720-848-0052

CNF2024

Study of oral CNF2024 in advanced solid tumors

Phase: I

Conditions: Tumors/Lymphoma

Strategy: Destroy KIT, (HSP90)

NCT#: NCT00345189

US Contact: Biogen Idec

oncologyclinicaltrials@biogenidec.com

US Sites: Scottsdale, AZ

New Haven, CT

Cancer Therapy and Res. Center,

San Antonio, TX

Pat O'Rourke, RN, 210-616-5976

AUY922

Phase I-II study to determine the Max Tolerated Dose (MTD) of AUY922 in advanced solid malignancies...

Phase: I

Conditions: Breast Cancer/Solid Malignancies

Strategy: Destroy KIT, Hsp-90

NCT#: NCT00526045

US Contact: Novartis,

Telephone: 1 800 340 6843

US Sites: **UCLA**, Los Angeles, CA

Carolyn Britten, MD, 310-825-5268,

Dana-Farber, Boston, MA

Travis Quigley, RN, 617-632-5117

Stephen Hodi, MD, 617-632-5053

Washington Univ., St. Louis, MO

Paula Fracasso, MD, 314-362-5654

Nevada Cancer Inst., Las Vegas, NV

Sunil Sharma, MD, 702-822-5360

LBH589

A Phase IA, two-arm, multicenter, dose-escalating study of LBH589 administered IV on two dose schedules in adult patients with advanced solid tumors and non-Hodgkin's lymphoma

Phase: I

Conditions: Adv. Solid Tumors / Lymphoma

Strategy: Destroy KIT, Inhibit Cell Cycle, Induce Apoptosis, (HDAC)

US Contact: **Nevada Cancer Institute**, Las Vegas, NV

Donna Adkins, RN

Telephone: 702-822-5173

MP470

MP470 in Treating Patients With Unresectable or Metastatic Solid Tumor or Lymphoma

Phase: I

Conditions: Solid Tumor/Lymphoma

Strategy: Multiple Targets

NCT #: NCT00504205

US Sites: **Virginia Piper Cancer Center**,

Scottsdale, AZ

Raoul Tibes, MD, 480-323-1350

South Texas Accelerated Research Therapeutics,

San Antonio, TX

Anthony Tolcher, MD, 210-593-

5255

TRIALS

From Page 9

XL765

Study of the safety and pharmacokinetics of XL765 in adults with solid tumors

Phase: I
Conditions: Cancer
Strategy: Target KIT downstream signaling
NCT#: NCT 00485719
US Sites: **Karmanos Cancer Institute**, Detroit, MI
Theresa Laeder, 313-576-9386
South Texas Accelerated Research Therapeutics
San Antonio, TX
Gina Mangold, 210-413-3594

XL820

Study of XL820 given orally to subjects with solid tumors

Phase: I
Conditions: Cancer/Solid Tumors
Strategy: Multiple Targets
NCT#: NCT00350831
US Sites: The Cancer Institute of New Jersey, New Brunswick, NJ
Pamela Scott, 732-235-7459
Cancer Therapy and Research Center, San Antonio, TX
Pat O'Rourke, 210-616-5976

STA9090

Phase I trial of STA-9090

Phase: I
Conditions: Solid Tumors
Strategy: Destroy KIT (Hsp-90)
US Sites: **Dana Farber**, Boston, MA
Travis Quigley, RN, 617-632-5117
Geoffrey Shapiro, M.D., 617-632-4942

Perifosine + Sorafenib

Phase I Study of Perifosine + Sorafenib for Patients With Advanced Cancers

Phase: I
Conditions: Renal Cancer/Tumors
Strategy: KIT downstream targets, multiple targets
NCT#: NCT00398814
US Contact: **Online Collaborative Onc. Group**,
Telephone: 415-946-2410
US Sites: Huntsville, AL
Los Angeles, CA
Oncology Specialists, Park Ridge, IL
Kathy Tolzein, RN: 847-268-8200,
Greenville, NC
Nashville, TN
Houston, TX
Vairfax, VA

OSI-930

A Phase I dose escalation study of daily oral OSI-930 in patients with advanced solid tumors

Phase: I
Conditions: Solid Tumors
Strategy: Multiple targets including inhibit KIT (PDGFRA signaling)
NCT#: NCT00513851
US Contact: medical-information@osip.com
Telephone: 800.572.1932, x7821
US Sites: Univ. of Colorado Cancer Center, Aurora, CO
Mary Kay Schultz, 303-266-1740
Dana-Farber, Boston, MA
Travis Quigley, RN, 617-632-5117

SNX-5422

Safety and pharmacology of SNX-5422 e in subjects with refractory solid tumor malignancies

Phase: I
Conditions: Solid Tumor Malignancy
Strategy: Destroy KIT (Hsp-90)
NCT#: NCT 00506805
US Contact: Catherine A. Ross, 919-376-1330, cross@unicorn-pharma.com
US Sites: **TGen Clinical Research Services**
Scottsdale, AZ
Joyce Ingold, RN 480-323-1339
Ramesh Ramanathan, MD
Sarah Cannon Research Institute
Nashville, TN
Howard Burris, MD

Insurance status linked to cancer outcomes

The following is excerpted from a press release regarding an American Cancer Society study.

Atlanta, GA., December 20, 2008— A new report from the American Cancer Society finds substantial evidence that lack of adequate health insurance coverage is associated with less access to care and poorer outcomes for cancer patients. The report finds the uninsured are less likely to receive recommended cancer screening tests, are more likely to be diagnosed with later stage disease, and have lower survival rates than those with private insurance for several cancers. The new findings on stage at diagnosis and survival by insurance status use data from the National Cancer Database (NCDB), a hospital-based registry sponsored by the American College of Surgeons and the American Cancer Society, the only na-

tional registry that collects information on patient insurance status. The report appears in the January/February issue of CA: A Cancer Journal for Clinicians, a peer-reviewed journal of the American Cancer Society.

In 2007, the American Cancer Society launched a nationwide campaign to highlight the role of access to quality care for all Americans. While advances in the prevention, early detection, and treatment of cancer have resulted in an almost 14 percent drop in the death rates from all cancers combined from 1991 to 2004 in the US..., not all segments of the population have benefited equally from this progress. Evidence suggests that some of these differences are related to lack of access to health care. In particular, the lack of health insurance, or inadequate health insurance, appears to be a critical barrier to receipt of appropriate health

care services. The report provides an overview of systems of health insurance in the United States and presents data on the association between health insurance status and screening, stage at diagnosis, and survival for breast and colorectal cancer based on analyses of the National Health Interview Survey (NHIS) and the NCDB. Among the report's findings:

For all cancer sites combined, patients who were uninsured were 1.6 times as likely to die in five years as those with private insurance.

"The truth is that there are gaping holes in our health care safety net and that most of these safety-net services are neither effective nor efficient in providing chronic-disease prevention, detection, or treatment," writes Elmer Huerta, M.D., American Cancer Society president, in an accompanying editorial.

The full press release can be viewed at www.americancancersociety.org



Mustard was friend until very end

Erin "Nan" Mustard, 55, passed away peacefully at her residence in Discovery Bay on Dec. 4, 2007. Nan was the wife of Tim Mustard and had been married for 36 years.

Nan's parents are Adna Palmer of Texas and the late Dud Nelson. She is survived by her children, Nikki and Steve Shipley of Discovery Bay, and Jason and Jo Mustard of Monterey Bay Academy; grandchildren, Keanna Shipley and Timothy Mustard; siblings, David and Sharon Nelson, Joe and Linda Nelson and Dana and Ron Atwood, all of Texas; numerous nieces and nephews.

Nan was born on a plantation in Greenwood, Miss. in 1952. She lived in Tracy for 10 years and was a member of Tracy Seventh Day Adventist Church, of which her husband formerly was a pastor. Nan loved singing, especially in her church choirs. She worked for Discovery Bay Travel and Discovery Appraisal Services. Nan enjoyed traveling, especially trips to Hawaii, and camping in their motor home. She also enjoyed

cooking and received her qualification for cooking in hospitals and nursing homes.

Nan loved time spent with her family, especially with her grandchildren. She was known to help and visit those who suffered from the same cancer she had contracted, even while on vacations with her family. Nan will be remembered as a loving wife, mother, grandmother, sister and a dear friend to many.

A graveside service was held December 7, 2007 at Union Cemetery in Brentwood. Arrangements were handled by Hotchkiss Mortuary in Tracy. Memorial contributions in Nan's name may be made to The Life Raft Group, 40 Galesi Drive, Suite 19, Wayne, NJ 07470, or GSI Group Dana Farber Cancer, Attn: GIST Research/Dr. Demetri, 10 Brookline Place, West Brookline, MA 02445, please indicate on check: GIST Research/Dr. Demetri.



MUSTARD

Community Beat

Let's hear a big congratulations for LRG member, Kerry Hammett who has just recently graduated with a Bachelors of Science in Nursing from the University of



HAMMETT

We have also just learned the good news that pediatric GIST patient and member, Sile Bao has been accepted at the excellent institution, New York University! **Congratulations Sile!**

Texas. Though she has been receiving many job offers, Kerry is taking time off to prepare to pass the State Boards this month.

Good luck Kerry!



BAO

LUCKY

From Page 2

luckiest people I know. Both of my parents are alive and relatively healthy. I have a big, beautiful old house in a bustling urban area that I really like, despite the fact that it gets a little cagey not too far south or east of us. I have a happy, healthy son and I'm married to my soul mate...and despite the fact that we both have cancer, our day-to-day health is pretty good overall. I've got two goofy dogs and a kitty that I adore. I have two sisters whom I couldn't love more, even if we were related by blood rather than marriage. And I have all of you – my friends and family who help me through the rough times. In short, I have so much love in my life that I sometimes feel like I should pinch myself to make



Laura with sisters-in-law, Kathy (the bride) and Tanya.

sure it's real.

I've had periods of good health in my life, but at the time I might have been working in a job I didn't like, or trapped in a relationship that sapped all of my energy. There were many days when I thought that feeling lonely with someone sitting right next to you had to be the worst feeling in the world.

I'm not trying to brag. I'm simply try-



ing to show that I think you can be as happy as you want to be. I could easily choose to focus on all of the bad stuff in my life, and spend my days sulking over my rotten luck. But what would be the point of that? I'd much rather spend my time and energy counting my many blessings! My life...is beautiful.



Mark your calendars!

- The next webcast, "Balancing Your Needs and Your Role as Caregiver", presented by Carolyn Messner, Director of Education & Training with *CancerCare* will be held on January 24, 2008 at 12:00 p.m. EST.
- Look out next month for the updated LRG dosage study.



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