



LIFE RAFT GROUP

October 2012

In memory of Melvin (Skip) Cook, Joy Davis, Joe Delalat, David Finkelstein, Richard Fosbrink, Jennifer Locke, Harald Pederson, Michael Shorb and Joan Smalec

Vol 13, No. 5

'Night to Fight Cancer' event raises almost \$90,000 total

By Lisa Hart

LRG Assistant Development Director

New developments seen in Pediatric-Like GIST

By Jerry Call
LRG Science Director

For many years, wild-type GIST tumors were a mystery. In 2007, Barbara Pasini, J. Aidan Carney, Constantine Stratakis and colleagues identified the first mutations in pediatric GIST tumors in a protein called succinate dehydrogenase (SDH). Coding (instructions) for making the SDH protein is contained in four subunits (genes), SDHA, SDHB, SHDC and SDHD. The group, led by Constantine Stratakis, initially reported

mutations in three of the four subunits; SDHB, SHDC and SDHD. SHDA remained a mystery.



WAGNER

Mutational analysis of SDHA has not been performed very often because of its complex structure with 15 exons and the presence of three pseudogenes (a non-functional gene with a similar, but not identical DNA sequence). Recently several groups have undertak-

The ninth annual poker tournament, now known as the "Night to Fight Cancer" to benefit The Life Raft Group's research programs was held at Midtown Loft on September 13, 2012.

Board President Jerry Cudzil once again hosted this successful event to raise money and awareness so that someday soon we can have a cure.



CHAN

Jerry began hosting this important event in 2004 after his father-in-law and good friend, Bill Roth, was diagnosed with the disease. Unfortunately, Bill lost his battle with GIST but Jerry continues to fight

Register for Life Fest!
See Page 7

See PEDIATRIC, Page 11

See NIGHT, Page 10

Janeen's tips for surviving caregiving

By Janeen Ryan
LRG Outreach Coordinator

Caring for someone suffering from an illness is hard, there's no other way to put it. Most of the time it gets easier but in the beginning right after a surgery, it can be very emotionally draining and frightening. Caring for someone you love is even more so as there is an emotional

connection, a deep desire to alleviate the pain and suffering we see in the eyes of the person whose bedside we are hovering over. There are no books for that, no class you can take with a test afterward to let you know you are capable of doing this and no pass - fail exam to study later so you get



RYAN

the parts right that you may have missed. Caregiving is more of a learn-as-you-go event. I say event because, that is what we call the times in our lives that change us. Events bring out joy, tears, happiness, or pain. "Events" that we look back on and just know that we are different for having experienced them. Caregiving is like that. It changes us. Not only for the moment that we are providing it, but, down to the very core

See CAREGIVING, Page 8

What court considered on Affordable Care Act

By Diana Nieves
LRG Executive Assistant

On Thursday, June 28, the U.S. Supreme Court upheld the constitutionality of the Affordable Care Act (ACA), a landmark law enacted in 2010 to improve the health of all Americans and control health care costs. The ACA provisions include:

—Minimum essential coverage, requiring individuals to have a minimum essential coverage or pay a penalty (a.k.a. individual mandate or individual responsibility).

—Medicaid Expansion (2014), extends coverage to individuals with incomes below 133 percent (plus an additional 5 percent standard disregard) of federal poverty level.

There were four issues considered by the Court as discussed by the American Public Health Association, Network for Public Health Law, and School of Public Health and Health Services at George Washington University on a July 5, 2012, webinar.

Does the Anti-Injunction Act bar



challenge to the minimum coverage provision's penalty until it goes into effect in January 2014? The shared responsibility payment imposed to those who forgo health insurance is described as a penalty, and Congress deliberately did not use the word "tax". The purpose of the payment requirement is to give individuals an incentive to have minimum coverage, not to raise revenue.

The ACA describes many other exactions it creates as taxes. The penalty is not one of them. "In distinguishing penalties from taxes, the Court has explained that if the concept of penalty means anything, it means punishment for an

unlawful act or omission. While the individual mandate clearly aims to induce the purchase of health insurance, it need not be read to declare that failing to do so is unlawful. Neither the Act nor any other law attaches negative legal consequences to not buying health insurance, beyond requiring a payment to the IRS."

Does Congress have the power under the Constitution to enact the minimum essential coverage provision un-

Some ACA Provisions

- Working families are protected from losing their health care or being forced into bankruptcy when a family member gets sick or is in an accident.
- Young adults can stay on parents' insurance until age 26.
- Insurance companies can't exclude people with preexisting conditions, rescind coverage, or discriminate on a condition or disability.
- States may still obtain permission to offer Medicaid-covered community based services.
- Basic Health Plan option will be available.
- Requirements that health plans cover substance use disorder treatment.
- Provisions for reasonable break times for nursing mothers in the workplace.
- Programs to improve oral health.
- Provisions increasing Medicare and Medicaid coverage of preventive services.
- Once fully implanted, the law will slow health care premium growth rates, adding another \$2,000 to family savings by 2019.
- The law is expected to reduce the deficit by \$127 billion from 2012 to 2021.

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.html or by sending a **check** to:

The Life Raft Group
155 US Highway 46, Suite 202
Wayne, NJ 07470

Disclaimer

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

Please advise Erin Kristoff, the Communications Director, at ekristoff@liferaftgroup.org of any errors.

der the Commerce and Necessary and Proper Clauses? Congress does not have the power to regulate inactivity, which is what the failure to purchase insurance is. The Necessary and Proper Clauses only authorizes actions to be taken in furtherance of a constitutional power. The individual mandate does not regulate existing commercial activity. It instead compels individuals to become active in commerce by purchasing a product, on the ground that their failure to do so affects interstate commerce.

Does the mandatory Medicaid expansion impermissibly coerce the States into continuing their participation in the Medicaid program? The Medicaid expansion is part of the larger

See ACA, Page 7

Research Articles on the Science of GIST

Masitinib, other trials presented at ASCO

By **Jim Hughes**

LRG Clinical Trials Coordinator

Advanced First-Line Patients

1. *Masitinib Phase 2 & 3*

Two posters were presented by principal investigators in the Phase 2 and 3 trials of masitinib for the treatment of newly diagnosed GIST patients.

Axel Le Cesne, MD at Institut Gustave Roussy, Villejuif, France, presented a five-year update of the Phase 2 masitinib trial. Patients with newly diagnosed inoperable GIST received 7.5 mg/kg/day. No prior imatinib therapy was allowed. Objectives included response rates, progression-free survival (PFS) and overall survival (OS). Thirty patients were admitted to the study. Mutation analysis was reported for 19 of the 30 patients. Median PFS was 41 months and median OS was 65 months. Five patients had prolonged response. Of these, two had a partial response and three a complete response. Exon 11 patients tended to have better response. There was no imatinib comparison arm, but these results compared favorably with results reported for the Phase 3 imatinib trial in the United States.

One caution is that there were no exon 9 patients reported in the mutation analysis so the number on trial is unknown. Adverse events were reported as mild with the most common being asthenia (87 percent), diarrhea (57 percent), eyelid edema (57 percent), nausea (47 percent), muscle spasm (43 percent) and rash (37 percent). The authors state that

adverse events occur mainly during the first year and that there is good long term tolerance after that. They also conclude that the results support the Phase 3 comparison with imatinib for first-line treatment of GIST.

In another poster, Antione Adenis, MD from Centre Oscar Lambret, Lille, France, reported the outline of the Phase 3 trial comparing masitinib with imatinib for newly diagnosed GIST patients. Dr. Adenis presented data showing that masitinib is the most selective

kinase inhibitor under development or already approved.

If kinase inhibitors were like rifles shooting at targets, masitinib has a very tight pattern centered on c-KIT like kinases whereas sunitinib

looks more like a shotgun pattern with hits all over the kinase family target. This more focused approach is expected to result in fewer side-effects. The trial randomizes patients in a 1:1 ratio to 7.5 mg/kg/day masitinib or imatinib 400 mg or 600 mg. Patients remain on assigned drug until either progressive disease by RECIST or discontinuation due to toxicity.

Patients who have exon 9 mutations and who are considering this trial should be aware that the most effective dose in preventing primary resistance in Exon 9 has been 800 mg. Cross-over from imatinib to masitinib is not permitted. It is assumed that patients who fail masitinib will have access to imatinib outside the trial. There are 222 patients planned. As of May 23, 2012, 117 patients had been accrued worldwide in Western Europe, Hungary, Lebanon, Thailand and the United States.

From the poster, we learned one thing about this trial that sets it apart from other GIST trials to date. The primary

objective measurement is progression-free survival. However, the trial design is not *superior* PFS. The design is a “non-inferiority hypothesis (85% power using a 95% two-sided confidence interval of the hazard ratios.)”

That is a bit complicated. First, this does not mean that masitinib is necessarily inferior to imatinib first-line in advanced GIST but that the trial can continue even though the intermediate results do not show superior PFS for masitinib. (The poster reported that the Data Review Committee did review the trial results as of May and approved continuing the trial.) In the end, masitinib can succeed if through the final trial results it can be assured that 95 percent of the time it delivers 85 percent or better PFS compared to imatinib.

The second important measure in this setting will be side-effects. Masitinib can succeed as inferior at avoiding progression but at the same time superior in toxicity. Secondary endpoints include “Quality of life assessment” analysis, which will be watched closely in future trial reports. It is important to note that nilotinib did not succeed in a Phase 3 superiority trial design against imatinib. At the same time it was widely reported that patients experienced fewer side-effects on nilotinib. Now, one can only speculate if nilotinib would have succeeded in a non-inferior design. Non-inferiority trials are uncommon but can have important non-PFS endpoints in different settings. Lower costs to deliver, easier to distribute and administer (think oral versus IV) and reduced follow-up care are important everywhere but especially in the low-income countries where they can mean the difference between treatable and non-treatable on a large scale. This can be a learning experience and hopefully we will learn more as the



LRG research team efforts compare well to a bigger and costlier project

By Phil Avila

LRG Newsletter Editor

And Jerry Call

LRG Science Director

How does a \$2 million-a-year cancer research effort with a team of nine scientists keep pace with a \$100 million-a-year project with a team of 200? Pretty well, it turns out.

With the Cancer Genome Atlas project in the news lately—the *New York Times* recently reported on progress in its colon cancer work—we decided to compare some of its data with that of the Life Raft Group’s Research Team and its *D-Day Project*. Our research focuses on GIST.

Here’s what we found:

—Both groups have performed next genera-

tion sequencing including whole genome sequencing and exome sequencing. With much greater funding, the colon cancer project has sequenced about six times as many samples (although more are being planned in GIST).

—Both groups have performed extensive supporting screens, including DNA copy number changes and expression arrays. The colon cancer project has also performed promoter methylation screens, and the LRG Research Team is in the process of doing so. The LRG sponsored a grant to gather/extract human Interstitial Cells of Cajal (ICCs) to act as normal controls for a future methylation screen and expanded its team to include Dr. Tamas Ordog of the Mayo

Clinic to help get this done. ICCs are the pacemaker cells of the GI tract.

—The *D-day project* also sponsored two major initiatives that were not included in the colon cancer project. These included functional screens to evaluate the importance of individual genes in GIST tumors (11,000 gene knockdown, Kinase panel knockdown, phosphatases knockdown and proteases knockdown) and a drug-screening program that tested more than 200 different drugs.

—Both projects worked with the Broad Institute to perform their screens.

More Reports to Come

The colon cancer report by the Cancer Genome Atlas project will be fol-

lowed by findings on its efforts in lung and breast cancers and acute myeloid leukemia later this year. The sweeping project is being financed by

two govern-

ment agencies, the National Cancer Institute and the National Human Genome Research Institute.

In contrast, the LRG’s research works toward finding a cure for GIST, which many consider to be a model cancer for researchers because many of its mechanisms are being uncovered.

The *Times* article, by Gina Kolata, explained the importance of the research: “Scientists increasingly see cancer as a genetic disease defined not so much by where it starts — colon, liver, brain, breast — but by genetic aberrations that are its Achilles’ heel. And with a detailed understanding of which genetic changes make a cancer grow and thrive, they say they can figure out how

best to mount an attack.”

For example, mutations in the BRAF gene were identified in some cases of colon cancer and have also been found to play a role in some cases of

‘The Life Raft Group has revolutionized the way we do research by relieving traditional barriers to collaboration and encouraging a group dynamic ... it is a game-changer.’

GIST.

The LRG Research Team is led by Dr. Jonathan Fletcher of Brigham & Women’s Hospital and Harvard University. Team members update their strategic plan annually and share information with each other at quarterly meetings. Their *Pathway to a Cure* research plan was launched in 2006, and four years later the *D-Day Project* was initiated.

The *D-Day Project* takes a four-pronged approach to finding a cure for GIST, emphasizing sequencing, gene knockdowns, drug screening and validation studies. This is what makes it distinct from the Cancer Genome Atlas project.

The focus is on finding a cure. Team member Dr. Brian Rubin of the Cleveland Clinic puts it this way, “The Life Raft Group has revolutionized the way we do research by relieving traditional barriers to collaboration and encouraging a group dynamic... This type of focused collaboration would not happen without the funding of the Life Raft Group ... (it) is a game changer for patients with GIST.”



The LRG Research Team

Research Articles on the Science of GIST

New immunotherapy approach advances

By Jerry Call
LRG Science Director

According to a story in the *New York Times* by Katie Thomas, Novartis and the University of Pennsylvania (Penn) recently entered into a research and licensing agreement estimated to be worth \$20 million. The partnership is intended to study and bring to market a new approach being developed at Penn that uses immunotherapy to fight cancer.

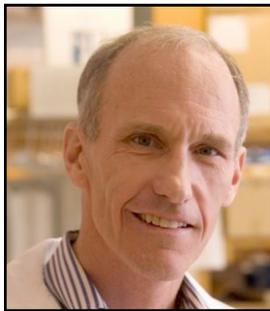
So far, in a very small trial of three chronic lymphocytic leukemia patients, two of the three patients had complete responses ongoing at more than 12 months and one patient had a partial response lasting for seven months. One of the complete responses was recently reported in the *New England Journal of Medicine*.

The new treatment uses T cells, a type of immune cell that are taken from the patient's body, genetically modified and then re-infused into the patient. These modified T cells are called chimeric antigen receptor (CAR) T cells. In previous trials with these modified T cells, tumor responses have been modest and they did not persist for long enough after being re-introduced into the patient. Using this second generation CAR T cell, Dr. Carl June and his colleagues at Penn obtained long-lasting persistence once the cells were re-introduced.

Under the agreement, Novartis will contribute \$20 million to build the Center for Advanced Cellular Therapies at Penn. This center will be devoted to the development of the new therapy. Novartis will get an exclusive worldwide license to the technology while Penn will

receive royalty payments.

The Novartis/Penn deal is the most recent success in the war on cancer using immunotherapy and the three CLL responses are among the most dramatic. Attempts to use immunotherapy against cancer date back well over a hundred years. The history of immunotherapy during those 100+ years is one of low response rates, but long response times in the few patients that did respond. In addition, it has a history of working better in patients with small tumor volumes and not as well with patients with large, bulky tumors. And while there is a perception among patients that since it's "natural", immunotherapy must be less toxic than chemotherapy, that is not always the case as immunotherapy can often have



JUNE

significant side effects. The dramatic responses obtained by the Penn team and the willingness to invest a substantial amount of funding into developing the technology may indicate that immunotherapy may be turning a corner on the way to becoming a mainstream therapy.

Other recent, but perhaps less dramatic successes include the FDA approval of Yervoy for melanoma and Provenge for prostate cancer. Both of these therapies resulted in an improved overall survival of about four months for patients. Yervoy (generic name ipilimumab) is a CTLA-4 inhibitor that increases the effectiveness of T cells. Provenge uses a different mechanism; it attempts to increase the effectiveness of another type of immune cell, the dendritic cell.

What was most interesting about the results of Yervoy in melanoma is not the fact that it increased survival by four months, but the fact that a small percentage of patients, perhaps 10 to 15 percent had very long-lasting responses.

Of even more interest for GIST patients, several teams of researchers are working on combining immunotherapy with targeted therapy and have published their results. This has led to clinical trials, including a new trial combining dasatinib (a KIT inhibitor approved for CML) with Yervoy that just started at Memorial Sloan-Kettering Cancer Center (MSKCC) in New York, led by Dr. Ron DeMatteo and Dr. Richard Carvajal.

Given the recent successes in immunotherapy and the potential for combining immunotherapy with targeted therapy, the Life Raft Group is exploring opportunities to facilitate collaboration and increase funding for groups that are working in the field.

ASCO

From Page 3

results of this trial are available.

There were a number of posters reporting retrospective analysis of subjects that can impact GIST management. The subjects were grouped around surgery and imatinib therapy.

2. Surgery

The role of surgical cytoreduction before imatinib therapy in patients with advanced GIST. Hojung an, MD of Division of Medical Oncology, Asan Medical Center, Seoul, South Korea.

In this poster reporting results of an analysis in Korean patients treated from 2001 to 2010 the authors conclude that tumor burden on diagnosis is an independent predictor of survival after imatinib therapy. Although patients who had cytoreduction tended to have less progression the authors also conclude that surgery before starting imatinib in newly diagnosed advanced GIST does not significantly benefit prognosis. Notably, the group of patients having surgery was small (35) compared

See ASCO, Page 12

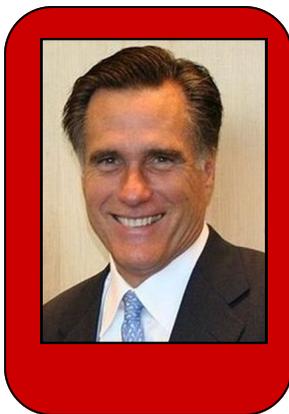
Countdown to Election Day



With the 2012 presidential election fast approaching, we take a look at the candidates' positions on healthcare.

While President Barack Obama defends the Affordable Care Act, which he calls a major achievement of his first term, Republican candidate Mitt Romney has called for a repeal of the law. Romney has recently eased off a bit from that position by saying he would keep some elements of the ACA.

Here we present some of the candidates' stances as compiled by the AARP. The LRG does not take a stance in the Election, but those interested in more detail can go to www.aarp.com or the candidates' websites.



Mitt Romney

'I will not allow Medicare to become a voucher program that leaves seniors at the mercy of the insurance industry, with a shrinking benefit to pay for rising costs.'

'Give people a stake in what the cost of insurance is going to be ... Co-insurance, where people pay a share of the bill, that makes a difference.'



Barack Obama

He supports limited rules to bar insurers from denying coverage to those with preexisting conditions when they have had coverage for a specified period of time.

Among key provisions he advanced are a requirement that nearly all Americans obtain health coverage and bans on preexisting condition exclusions.

He opposes the health law's expansion of Medicaid coverage to as many as 17 million people.

He supports the notion that wealthier seniors should pay more toward their health coverage and lower-income seniors should receive a higher subsidy.

He advanced a proposal for a refundable tax credit to help small businesses buy health insurance for their employees.

He opposes Republican proposals to turn Medicaid into a block grant for states.

Mark a milestone with the LRG at Life Fest 2012

There's still time to make a contribution to the LRG's Tenth anniversary commemorative book that will be distributed at *Life Fest 2012: Celebrating 10 Years of Dedication*.

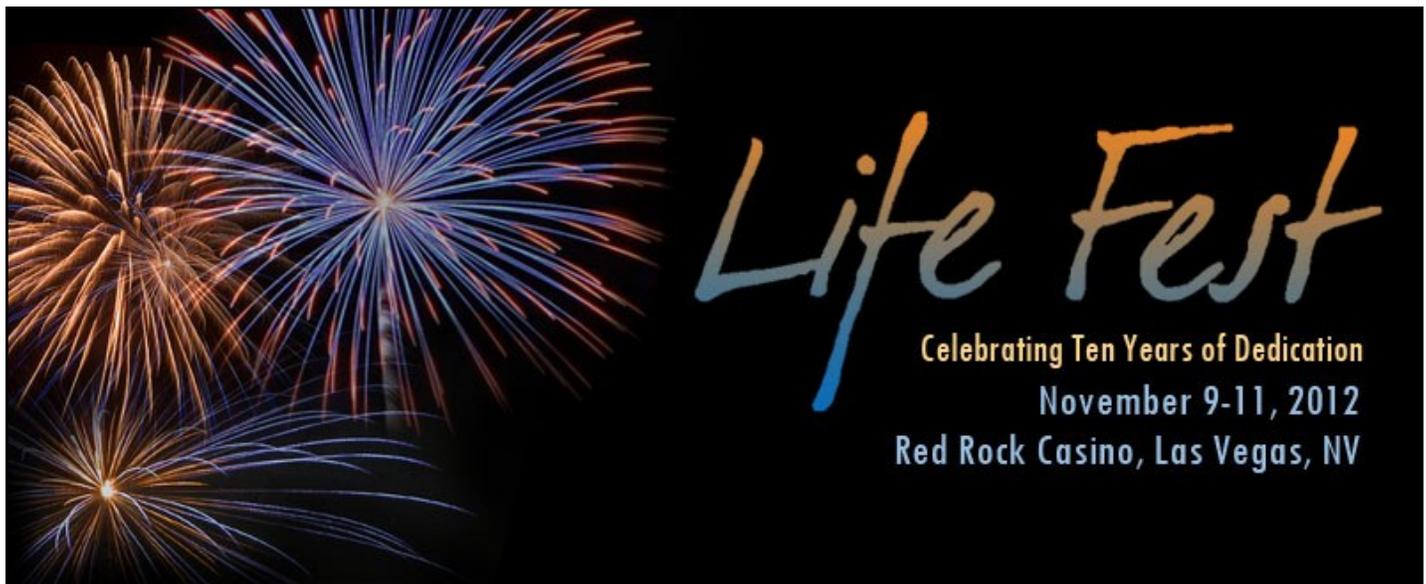
Just click on the Mark a Milestone button on our Life Fest page at www.liferaftgroup.org/members_lifest.html.

You can add photos, favorite moments, or expres-

sions of appreciation to those who have helped you on your journey with GIST.

If you haven't registered yet for Life Fest, there's still time for that, too.

The three-day event will be held November 9 to 11 at the Red Rock Casino in Las Vegas. You may want to call us at 973-837-9092 for more information about registering.



ACA

From Page 2

ACA and is the only way for states to cover low income people. Medicaid has grown to the point where states cannot afford to decline the expansion and lose all federal Medicaid funds. Potential loss of all Medicaid funding is too onerous a condition. The Medicaid expansion “accomplishes a shift in kind, not merely degree. The original program was designed to cover medical services for four particular categories of the needy: the disabled, the blind, the elderly, and needy families with dependent children.”

“Under the Affordable Care Act, Medicaid is transformed into a program to meet the health care needs of the entire nonelderly population with income below 133 percent of the poverty level.”

If unconstitutional, can the mini-

num coverage requirement be severed from the remainder of the Act?

Congress can offer funds under the ACA to expand availability of health care, and require that States accepting such funds comply with the conditions on their use. Congress is not free to penalize States that CHOOSE NOT to participate in that new program by taking away their existing Medicaid funding.

Other challenges that are being discussed and reviewed include: contraception coverage requirement (employers claiming violation of religious freedom), independent payment advisory board (created to monitor Medicare spending), and challenges based on invasion of privacy, interference with medical autonomy, and usurping legislative authority. In the news recently, it was questioned

whether ACA is a “job killer” in that it will reduce the amount of labor used in the economy by about 800,000 jobs. Some low-wage jobs might be lost due to workers choosing to retire earlier or work part-time for they will no longer be dependent on employers for their health care safety net. ACA is modeled under the Massachusetts mandated health insurance law, an act providing access to affordable, quality, and accountable health care. To learn more about Massachusetts law visit: <http://www.lawlib.state.ma.us/subject/about/healthinsurance.html>.

Coming soon: A look at how the Affordable Care Act and other factors such as FDA policies are affecting patient access to off-label drugs such as Votrient.

CAREGIVING

From Page 1

of our being. It brings with it a sense of responsibility for the well-being and even the very life of another person.

These changes can bring about extreme emotions in both the caregiver and the person he or she is caring for. Sometimes we forget that not only is our loved one affected by their illness, they are also affected by the knowledge that someone else's life is altered. This can bring depression, anger, resentment, even fury to either or both people involved.

You must remember that as a caregiver, you are not only responsible for the needs of

another but, yourself as well. Putting yourself last in line for needs being met is a natural response but one you should try to resist. If you burn out or get sick, you're not doing anyone any good and you might end up needing a caregiver yourself.

What I am going to attempt to do is give some real life insight and some useful pointers to assist in alleviating some of the more unpleasant side effects of caring for a loved one.

In the beginning, many people say, "I can't do this, I'm not strong enough" while others say, "This is going to be easy".

The first group usually feels that they will not be up to the task— they have a fear of making a mistake, a fear of doing something wrong, a fear of causing further damage to an already sick person. It is natural to feel that way. If you make a mistake at work, you can be reprimanded, no big deal. If you make a mistake with caregiving, someone can be injured or worse. At least that is what that little voice inside your head tells you. It's far from the truth but a valid concern nonetheless.

The second group is the one in for the bigger surprise. As easy as you think it is going to be, you end up wishing it were only as hard as you originally thought. Caregiving, for the most part, is

more than making it to doctors appointments on time and hand-holding. That is a big part of it, but it goes so much deeper. There are physical responsibilities, emotional responsibilities, plus all the regular day-to-day errands.

What I want to help you with is finding the balance, the balance between caregiving and taking care of your own needs. To be able to receive care yourself, sometimes *from* yourself I think is

just as important as learning to care for your loved one. There will be times when you have to

take yourself out of the caregiver mode and decompress. You might do this by taking that friend up on an offer of "If there's ever anything I can do...". Friends say this all the time don't they? Well, call one of them and say, "Remember when you were asking if you could help?"

Then ask them if they could sit with your loved one while you go out to run some errands.

If you want to go get your nails done or get a pedicure, go to the driving range and hit some balls, you should go! Taking care of yourself is not selfish; you *must* take care of yourself mentally as well as physically. Otherwise, how will you be able to continue caring for your loved one?

Men and women cope in different ways. In my experience women are social—we talk to each other, we cry together, we laugh together, and we lean on each other for support. Men are more visual; watching a ball game on TV will sometimes calm the nerves (Don't ask me why). Alone time is important for both sexes, so are friendships, and keeping as close to the old schedules as possible. If you used to go to Thursday

night bowling then keep that up; if you used to go out with the girls on Tuesdays, make arrangements for someone to come relieve you. You need that time, and your loved one just might like the change of company too. Don't take it personally but not many people can be cooped up for hours or days, even weeks at a time with one person and not get cabin fever.

At the very least your loved one will know that they are not a burden and that they are not keeping you from living your life and enjoying the company of your friends. This is a huge cause of guilt for a person who depends on another. Fear that they are a burden, that they've ruined your life, can eat away at the best of relationships. Sometimes resentment can begin to form on both sides. I don't care how much you love that person, if you allow your life to be completely centered on him or her, I guarantee you something will have to give. It's better to keep it from happening in the first place. Remember to take

a break if at all possible. One of the most important things to think of, and most often overlooked, is your support group. Who are they? Relatives, friends, church

members, neighbors, these are all rich sources of assistance. The more you have the better. As soon as possible, invite everyone over (or out to coffee) to discuss this very thing. Chances are they are truly hoping to be of some help, they just don't know what you need. So tell them. People *want* to help, they just need some guidance as to what to do. Provide them with suggestions.

Maybe someone can come by to read from a favorite book, and someone else can pick up the dry cleaning, another friend might be counted upon to sit with your loved one so you can just get out of

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Don't take it personally but not many people can be cooped up for hours or days, even weeks at a time with one person and not get cabin fever.

CAREGIVING

From Page 8

the house for a while.

This is a good time to discuss the situation. Chances are, they are wondering but won't ask, people are curious to know what exactly is going on. It's not morbid to be curious, it's human nature. Tell them about the cancer or illness. Tell them what you know, tell them about the operation, talk about your fears, just tell them whatever you are comfortable discussing. I recommend getting the correct information out there so there are no misunderstandings.

This would also be a good time to tell them that even though you know their heart is in the right place, to please refrain from regaling you with stories of their own family members with cancer. This was a problem I faced quite often. As soon as anyone at work found out my husband had cancer they just couldn't wait to tell me about their aunt or uncle or father who had cancer too. I learned to stop them right there and tell them "I know you have a story, but, please understand how much I'm dealing with right now, can we talk about this another time?"

Ten Caregiving Tips

1. **Straws:** Drinking straws are very helpful to keep around and make it much easier to drink if sitting up is difficult. A rubber band around the top of a water bottle keeps the straw from sinking down into the bottle if you loop the last twist around the straw.

2. **Variety:** Keep various juices on hand as many people recovering from surgery need to keep hydrated and water just isn't on the list of things that appeal. There are flavored drops available at many grocery stores that make plain water more palatable.

3. **Night sweats:** If pain medications are in use, profuse sweating is sometimes an issue. Changing the sheets can be very difficult on a daily basis and for me it was every few hours. I suggest bed liners, these can be purchased in medical supply stores but your local pet supply has the same thing for house training puppies. I know it sounds strange but the large size works great.

4. **Dressing comfortably:** Oversized T-shirts makes dressing and undressing much easier, larger arm holes and roominess are more comfortable while recuperating. It's also easier to get at drains and bandages when they need attention. I cut up the back of the shirt from the hem almost to the collar, leaving the back open makes changing clothes much easier.

5. **Keeping busy:** An entertainment pack is good for all ages: crossword puzzles, a deck of cards, a CD of favorite music, a back scratcher. I kept a basket of things by the bed and later by the couch so my husband didn't need to ask for every single thing he wanted. And don't forget to put the remote within reach!

6. **Small portions:** Staying hydrated is very difficult when you don't feel like drinking, especially if your loved one is on a chemo drug they can become dehydrated very easily. Handing them a large bottle of water to them may be overwhelming. I suggest four ounces of water in a small cup offered every half hour to 45 minutes. It's an easy amount to drink, and over a day, more water will be consumed than from large glasses or water bottles.

7. **Lists:** Keeping an up-to-date list of medications, doses, and schedules is very helpful. Especially in the beginning, it takes the worry out of what to give when and if there is more than one

caregiver, a check box sheet is helpful in keeping track of what has been taken so accidental double dosing is not an issue.

8. **Pill Box:** Pharmacies offer all kinds of pill boxes, I recommend the large seven day box with four sections, morning, afternoon, evening and bedtime sections, which help keep pills straight and you can see what is needed at a glance.

9. **Peace of mind:** Another item that is of great value is a baby monitor. Being able to hear when you are needed is necessary and having the freedom to go about your daily routine is priceless. They are designed to pick up the slightest sound from an infant so all a person has to do is whisper your name and you can hear it clearly. Some of the newer ones even have a video feature for constant monitoring of whatever the camera is pointed towards. Being able to know exactly when your presence is required provides peace of mind and it keeps you from running down the hall every 10 minutes to check. Some people like to use a bell but if an ill person, or you, have a headache well, let's just say bells tend to get dropped (or thrown) never to be seen again.

10. **Special diets:** Many people recovering from surgery have special diets: find out what the doctor recommends. For other people, certain dietary needs will be required. If there are none, go out and buy some of those small packaged frozen meals. I know it sounds terrible but anyone recovering from surgery rarely wants to eat much at first. Packaged meals are also, for the most part, of much higher quality than they used to be but watch out for high sodium content. The kitchen has always been my favorite area of the house, for me cooking was my "down time". If you hate it (or can't cook) then by all means, cheat.

Once you get into a routine, don't forget to take time out for you. Go for a walk, read a book, or, ask someone to take over for a while. It does not mean you are weak; it does not mean that you don't care. Taking a break is a necessary means of staying healthy.

Join the Mike Matthews Legacy Society

You can plan for your future while supporting the Life Raft Group's programs and research through a charitable gift. Planned gifts enable the Life Raft Group to engage in long-term financial planning knowing that resources will be available in the future. If you wish to discuss your planned giving options, please call our Director of Development, Christine Schaumburg, at 973.837.9092 ext. 116.



NIGHT

From Page 1

on to help others impacted by GIST.

“I am so grateful for the support shown to the Life Raft Group by our friends year after year. They bring a great enthusiasm to this event whether they are playing or spectators. This is one of my favorite nights of the Year,” Jerry says. Over 150 players and guests participated in the Night to Fight Cancer to bring in almost \$90,000 for LRG.

The competition came down to three individuals: Shirley Chan, Richard Taddania and Robert Fitzpatrick. Richard Taddania went home with the championship, a \$10,000 seat to the World Series of Poker in Las Vegas next summer. Coming in second and third place were Robert Fitzpatrick and Shirley Chan. Congratulations to all of the winners and participants.

A special thank you goes out to our corporate sponsors, especially our Diamond Sponsor, **Bank of America Merrill Lynch**, which donated \$10,000. Our Club Sponsors were the Phoenix Foundation, which donated \$5,000 on behalf of Phoenix Partners Group; and Morgan Stanley, which donated \$4,000. Investors Bank and The Seaport Group both donated \$1,000 towards the event. Thank you to Sobel & Co, Hansen & Ryan, and IDT for their corporate donations and all of the attendees for their gener-



A dealer oversees the action

ous gifts. In addition, our friend, Lyon Carter III, was our beverage sponsor once again while Kim Tallau of Innovative Images donated her professional photography services.

We look forward to everyone joining us next year for our 10th Anniversary celebration of Jerry Cudzil’s Night to Fight Cancer. For more information on how to get on the mailing list for next year’s event, email us at wsumas@liferaftgroup.org, or visit our Facebook page at www.facebook.com/NighttoFightCancerLRG.



From left, Winners Robert Fitzpatrick, Richard Taddania, Shirley Chan and Board President Jerry Cudzil. Taddania took home the championship.

Mark your calendars!

- The French GIST Conference is scheduled for **October 6** at the Hôtel Mercure Château Perrache in Lyon.
- The fifth annual GIST Cancer Research Fund: Walk for a Cure will be held **October 21** at Lake Almaden Park in San Jose, California.
- **November 9-11** the LRG will hold Life Fest 2012: Celebrating 10 Years of Dedication at the Red Rock Casino in Las Vegas.
- The Connective Tissue Oncology Society will host its annual conference in Prague **November 14-17**.
- Faster Cures will hold its Partnering for Cures conference **November 28-30** in New York City.



Cancer research funds restored in New Jersey after advocacy

Following advocacy efforts by the Life Raft Group and eight other cancer organizations, New Jersey restored \$1 million in funding for the NJ Commission on Cancer Research in the FY 2013 budget.

NJ State Senator Diane Allen, a cancer survivor representing the 7th Legislative District, sponsored the resolution, stating “I know that cancer research saves lives every single day.”

The LRG wishes to thank NJ Governor Chris Christie and the lawmakers who supported this important cancer initiative.

With state budgets under pressure, let us know if funding is jeopardized in your state, so we can advocate on your behalf. Contact Christine Schaumburg at 973.837.9092, ext. 116.

PEDIATRIC

From Page 1

en the challenge of sequencing SDHA. Most recently, Dr. Andrew Wagner, Dr. Jason Hornick and colleagues (Dana-Farber Cancer Institute) reported that SHDA mutations were found in 27 percent of a group of 33 tumors with known deficiencies in SDH.

Researchers have known for a few years now that the SDH protein does not function correctly in *all* pediatric-like GIST tumors. This is true whether or not the researchers could find a mutation in the tumor. Researchers



HORNICK

noted that applying a stain for the SDHB protein could reliably identify GISTs with defective SDH proteins. GISTs that had a defective SDH protein would stain negative for SDHB. A positive SDHB stain meant the SDH protein was okay and that the patient did not have pediatric-like GIST. As a result, it has recently been suggested that this type of GIST should be called “SDH-deficient GIST”.

While a negative SDHB stain could classify a GIST as SDH-deficient, it did not necessarily mean that a mutation would be found in one of the subunits and it did not offer any clues as to which subunit might have a mutation. In their recent paper, Wagner and colleagues found that adding another stain to the testing, SDHA, could help zero in on where to check for mutations. They found that about one quarter (27 percent) of the SDHB negative tumors that they tested also stained negative for SDHA. In addition, a negative SDHA stain correctly predicted that a mutation would be found in the hard to sequence SDHA subunit. As a result, an immunohistochemistry test (stain) for SDHA can be used to predict which patients should be screened for SDHA mutations.

Importantly, normal tissue was available for testing in six of the nine patients (four female and five male) and SHDA mutations were also found in the normal tissue, indicating that these GISTs may

be familial, although none of the patients had a family history of GIST or paraganglioma. The authors noted that “Furthermore, no patients with germline SDHA mutations and both GIST and paraganglioma have yet been reported (in contrast to the Carney–Stratakis syndrome with germline mutations in SDHB, SDHC, or SDHD). The same SDHA mutations reported in paragangliomas have also been identified at a low rate in healthy donors; it therefore seems likely that there is a low penetration of both GISTs and paragangliomas in patients with germline SDHA mutations. Until additional follow-up and complete family history are obtained on a larger cohort of patients with SDHA-mutant GISTs, the familial implications of identifying a germline SDHA mutation remain somewhat uncertain.”

Wagner and colleagues noted that the prevalence of SDHA mutations in their cohort suggests that SDHA mutations are likely to be more common than SDHB, SDHC or SDHD mutations and that taken together, the various studies suggest that, to date, about 35 percent to 40 percent of SDH-deficient GISTs contain some type of SDH mutation. They note the possibility of further mutations or other defects being found in the future.

Although we don’t have a list of facilities that offer complete SDH mutational testing, we would note that the Knight Cancer Institute, at Oregon Health Sciences University (OHSU) offers a 23 gene mutation panel that will test for all of the known SDH mutations as well as BRAF, KRAS, NRAS and NF1. Also included are mutations for SDHAF1 and SDHAF2 (mutations found in paragangliomas, but not yet in GIST).

IGF1R overexpression limited to SDH deficient GIST

In the last few years, overexpression of IGF1R has been noted in some wildtype GISTs, but not others and has not been noted in GISTs with KIT or PDGFRA mutations. A new clinical trial recently opened for wildtype GISTs with an IG-

FR1R inhibitor.

Several recent papers shed light on which wildtype GISTs might have overexpression of IGF1R and thus might be candidates for therapies with IGF1R inhibitors. The first paper found IGF1R overexpression in 71 of 80 SDH-deficient GISTs (pediatric-like GISTs), but in only nine of 625 (1%) of GISTs with normal SDH expression (typical of adult-type GISTs). This paper was the result of work done at the National Cancer Institute (NCI). The authors included 2012 GIST Hall of Fame inductees (November, 2012) Dr. Jerzy Lasota, and Dr. Markku Miettinen; as well as the former Pediatric GIST Clinical Coordinator, Dr. Su Young Kim; the Head of the Molecular Oncology Section at the NCI, Dr. Lee Helman; and Zengfeng Wang PhD of the National Institutes of Health. This paper suggests that IGF1R overexpression may be limited to pediatric-like wildtype GIST.

In a smaller report of eight SDH deficient GISTs, three NF1 GISTs and 40 unselected GISTs, all eight SDH deficient GISTs overexpressed IGF1R and none of the NF1 GISTs did. Of the 40 unselected GISTs, five turned out to be wild-type and two of those proved to be both SDH deficient and to overexpress IGF1R. The remaining three SDH positive wild-type GISTs did not overexpress IGF1R.

Sutent Survey

The Life Raft Group has been conducting a survey on Sutent dosing, looking at standard dosing vs. continuous dosing.

If you take Sutent and haven't had a chance to participate in the survey yet, please do so at the following link:

<http://tinyurl.com/d2v4rox>

Results will be compiled into a report in a future edition of our newsletter.

Thank you for participating!

ASCO

From Page 5

to those who did not (235).

Outcomes of multivisceral resection of gastric gastrointestinal stromal tumors. Sabha Ganai, MD University of Chicago Medical Center, Chicago, Illinois. Here the authors report that patients with larger tumors tend to have more than one organ (multi-visceral) involved in their surgery. The history of patients at the University of Chicago indicates that these patients have significantly earlier progression and lower proportion of survival at three years post-surgery. They note that the 73 patients analyzed from 2001 to 2007 in this study represent a wide range of presentations (clinical heterogeneity) and that GIST management practice patterns changed over this time.

Neoadjuvant treatment of locally advanced GIST: Results of APOLLON, a prospective, open label Phase II study in KIT- or PDG-FRA-positive tumors. Peter Hohenberger, MD Mannheim University Medical Center, Mannheim, Germany.

This discussion poster presented the results of a Phase 2 trial in Austria and Germany sponsored by the Technische Universität München. The trial started in 2005. Forty-one patients with locally advanced primary GIST (clinically non-metastatic) were given imatinib for six months followed immediately by surgery. Many of these patients were judged inoperable or requiring multi-visceral resection upon at the outset of treatment. Multi-visceral resection is multi-organ surgery i.e. surgery impacting stomach and spleen or other organ combinations. The primary endpoints were PFS at one and five years. Secondary endpoints included the rate of organ-preserving surgery. The study concluded that “Neoadjuvant therapy with imatinib 400mg/day for six months is safe and downsizes tumors significantly. Firstline multivisceral resection of primary GIST should no longer be the standard of care.” In the United States the National Comprehensive

Cancer Network (NCCN) guidelines currently caution that complex multivisceral resection should be avoided in primary GIST and suggest perioperative imatinib therapy treatment with a multidisciplinary team approach.

The chart with this article (Figure 1) was prepared from data in the poster. It shows the greatest improvement for initially inoperable patients 93 percent of whom could eventually have surgery. Significant improvements in morbidity were also seen for patients who initially required either multi-visceral resection or full organ removal.

Dr. Hohenberger compares his study to a similar RTOG study in the US. In both studies of mostly high risk patients five-year PFS was over 56 percent, while OS was over 77 percent. These results are described as promising since both studies took place in the era before adjuvant therapy was fully adopted. These studies are small. Ideally they will be repeated under the latest guidelines for GIST management. It would be helpful to see outcomes by mutation type and with longer adjuvant therapy.

3. Imatinib therapy

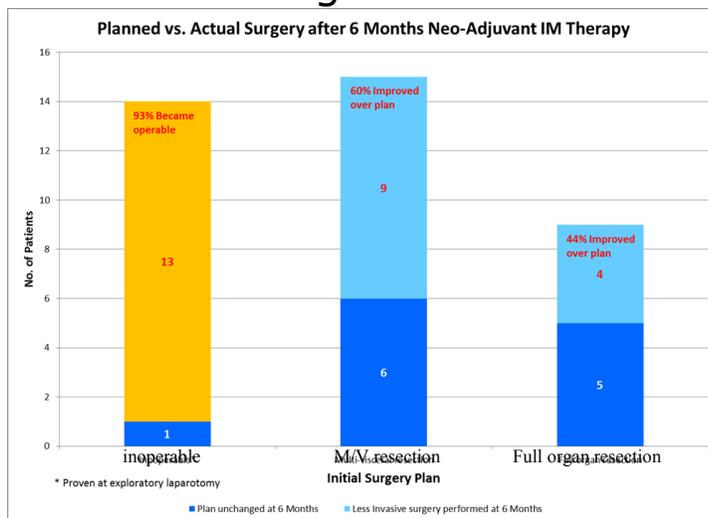
Pharmacokinetics of escalated dose of imatinib in patients with advanced gastrointestinal stromal tumors. Changhoon Yoo Asan Medical Center, University of Ulsan College of Medicine, Seoul, South Korea

This poster is a retrospective study of 66 advanced Korean patients who from 2008 to 2011 experienced resistance on 400 mg imatinib and in-

creased dosage to 800 mg. Imatinib minimum concentration levels (Cmin) were taken at 400mg and after escalating the dose to 800 mg. The absolute and percent changes in blood levels as well as tumor response were measured. The authors conclude that “Imatinib Cmin at 800 mg and the percent change of Imatinib Cmin were not associated with response and survival outcomes.”

This report differs significantly from other studies of Imatinib Pharmacokinetics (PK) (often referred to as imatinib blood levels or trough levels). It studies PK in patients who have already experienced progression. Most studies to date have looked at PK in recently diagnosed advanced patients who have not progressed and for whom the question is “would management of PK help avoid progression.” So the results

Figure 1



of this study are not necessarily applicable to the pre-resistance setting.

This study included a relatively high ratio of KIT exon 9 GIST patients (28 percent) who do not respond as well to 400 mg imatinib. Exon 9 patients typically experience a better initial response to higher dose (800 mg) than to lower dose (400 mg) imatinib. However in this exon 9 enriched cohort, where one

See ASCO, Page 13

ASCO

From Page 12

would expect to see some survival improvement attributable to overcoming primary resistance there was none reported. One possible reason may be the distribution of Cmin values reported for these patients at the lower 400 mg dose. The distribution indicates many patients were already at 1,100 ng/ml Cmin or higher before starting imatinib 800 mg. If this is true then a lower rate of response might be expected in these patients. The lack of response noted in the results might therefore be questioned on these bases.

In additional findings, the authors highlight the correlation between body surface area and Cmin levels at 800 mg. An association was also found between severe toxicities and percent change of imatinib Cmin following dose escalation. In conclusion they suggest that monitoring of imatinib Cmin might help to predict or manage toxicity induced by escalated dose of imatinib.

Observational/Retrospective reports with potential impact on GIST management.

Diagnosis and initial evaluation of patients with gastrointestinal stromal tumor (GIST): An observational study of 1,226 patients. Dr. Jonathan Trent University of Miami Sylvester Comprehensive Cancer Center, Miami, FL.

There were 1,226 patients accrued between January 2005 and December 2010. During this period GIST management practices changed significantly. Twelve-month adjuvant IM treatment began as an accepted practice in June 2007 and was FDA-approved in December 2008. A third or more patients entered the ReGISTry study before adjuvant treatment was accepted. Thirty-six month adjuvant treatment was accepted standard after June 2011. The ReGISTry data now represents more a window on past treatment practices. As an example, in this update only 8 percent of patients accrued are reported to have had mutation analysis. More recent patient series show a higher percent of patients in the

U.S. are receiving mutation analysis after 2009.

The data highlighted in this poster (Figure 2) concerned the mix of specialties diagnosing and then managing GIST. Surgeons are primary at diagnosis, while medical oncologists are primary for management after diagnosis. The data points out the importance of a multi-disciplinary team approach to managing GIST.

Characteristics of gastrointestinal stromal tumor (GIST) patients receiving short-term versus long-term imatinib (IM) adjuvant therapy: A chart review analysis.

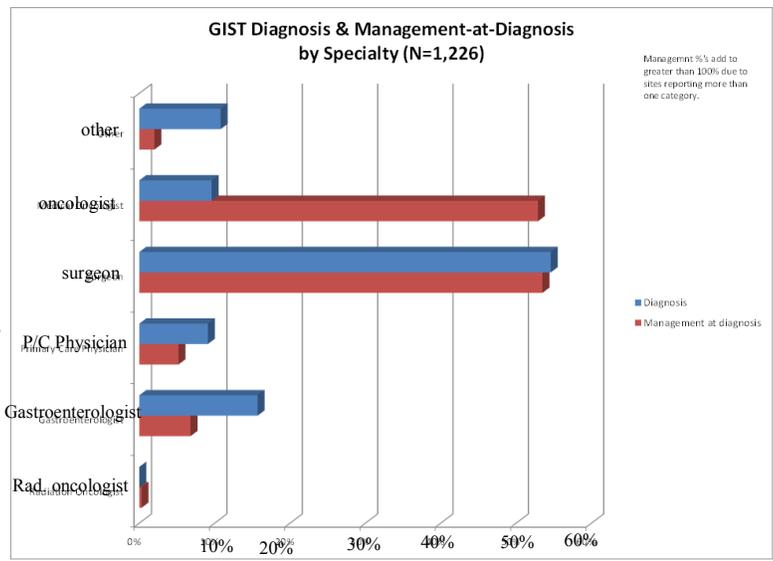
Annie Guerin Analysis Group, Inc., Boston, MA

The authors of this study included analysts at Analysis Group a healthcare consulting service, employees of Novartis Pharmaceuticals and Anthony Conley, MD of Moffitt Cancer Center in Tampa, Florida. A second consulting firm (All Global) was used to contact oncologists in the United States who were recruited to use their physician administered on-line patient chart reviews. Three hundred twenty physicians contributed data. Of these, 98 percent were hematologists/oncologists or medical oncologists. Only four self-described as sarcoma specialists, while 22 percent were in institutions and 77 percent were in private practice. Most were in small to intermediate-sized practices (two to nine physicians).

Data was collected on 819 GIST

patients who underwent surgery as primary treatment after December 19, 2008, the date one-year adjuvant imatinib treatment was approved by the

Figure 2



FDA. The patient data was divided into two groups: a short term group—those treated continuously with imatinib for six to 12 months following surgery (n=411), and a long term group—those treated with imatinib continuously for at least 24 months (n=408). Data was collected on patient, physician and clinical outcome characteristics.

Findings included:

- Patients in the long-term group tended to be higher risk.

- Patients in the short-term group had more co-morbidity (cardiovascular and ischemic heart disease)

- Despite the higher risk characteristics of the long-term group the study found that:

- Imatinib use over an extended period of time was associated with lower recurrence rates and lower mortality rates

- After controlling for confounding factors the risk of recurrence was 4.67 times and the risk of mortality was 3.74 times higher in the short term versus the long term.

Chicago chapter celebrates 10th anniversary

By Jim Hughes

LRG Clinical Trials Coordinator

The Chicago-area GIST Patient group first met on September 17, 2002.

According to Dick Kinzig, organizer of the original group, “Six Life Rafter, two spouses and a daughter were able to make the meeting.” Since 2002 the group has been meeting three times a year at Wellness Place in Inverness, Illinois, 30 miles northwest of Chicago. Patients from all over the Chicago area including Central Illinois, NW Indiana, and Wisconsin have attended over the years.

On September 8, 2012, a Ten Year Celebration accompanied the regular meeting. Twenty-six attended including 14 patients. Of the six original patients at the first meeting, three are still with the group. Dick Kinzig and Paula Vettel attended the tenth meeting with their spouses Phil and Sue, respectively. Original members Bob (patient) and Jeannie Book still live in Indianapolis but did not make the celebration. Champagne and cake were served.

The memorial list for Chicago-area



At left, the first meeting of the Illinois chapter of the Life Raft Group brought together, from left first row, Phil and Paula Vettel, Nancy Welsh, Jeannie Book; in back, Tricia Brasen with her mother, Pat, Dick Kinzig, Carol Berres and Bob Book.

Above, the 10th anniversary celebration, with Dick and Sue Kinzig, Paula and Phil Vettel, Elaine Rys, Margi Hughes, Nestor and Beth Sanchez, Lucy Madsen, Stan and Carmen Drab, Leigh Borland, Dean and Carrie Coppe, Robert and Janet Sholiton, Maria and Frank Stariha, Kathy and Kip Bishop, and Jennifer Moore. One person asked not to be identified.



GIST patients includes over 30 members who either attended or were invited to attend. It includes Carol Berres, Pat Novicki and Nancy Hughes Welsh who were at that first meeting but who are no longer with us having lost their fight with GIST.

That same weekend the Bill Buchanan Chapter of the LRG at Cook County Hospital met in Chicago. Thirteen attended the meeting. Dr. Michael Mullan presented an overview of the GIST

ReGISTry, an observational study that included 40 Cook County GIST patients. Dr. Thomas Lad, Oncology and Dr. Harry Richter, Surgical Oncology also attended.

The Bill Buchanan Chapter was made possible by the efforts of the late Bill Buchanan, a longtime Chicago chapter member whose wishes led to a flurry of donations to that made it possible for the group to find a home at Cook County Hospital.

Richard Fosbrink passes away

Richard A. Fosbrink, 68, of South Connellsville, went to walk with his Lord in the church triumphant on Wednesday, May 2, 2012, surrounded by the love and care of his family and friends.

He was born October 25, 1943 in Connellsville a son of the late Clyde 'Zeke' and Katherine Opal Martin Fosbrink who both passed away in 2002.

Richard was a graduate of Connellsville High School with the Class of 1961.

He was a South Connellsville Borough Council member, a member of the Albright United Methodist Church where he sang in the chancel choir, a member of the South Connellsville Rod and Gun Club, a lifetime member of the NRA, and former Assistant Scoutmaster with Boy Scout Troop 111.

Richard served his country in the U.S. Army, worked at National Tube, Fruehauf, Anchor Glass Container, and was deputy constable before his retirement in 1999.

In his spare time, Richard enjoyed working in his woodshop and was active in trap shooting league. He also enjoyed singing and giving belly rubs to his spe-

cial cats, Jack and Daisy.

In addition to his parents, Richard was preceded by an infant brother Charles.

Left to cherish his memory are his loving

wife of 46 years Elaine Dienes Fosbrink, and a daughter Donna Fosbrink both of South Connellsville; a son Richard L. Fosbrink of Detroit, Mich., formerly of Pittsburgh; his brothers, Bruce Fosbrink of Connellsville and Larry Fosbrink and wife Sally of Uniontown; a special cousin Bobby Deaver and wife Amy of Connellsville and several cousins and many good friends.

The family wishes to thank the staff of Excelsa Health and Hospice Care and Highlands Hospital, Dr. Al Saadi, Dr. Oppy, Dr. Morcos, and the many wonderful friends and neighbors who kindly helped in his courageous battle with cancer.



Michael Shorb, California poet

Michael Shorb, dearly beloved husband of Judith Grogan-Shorb, passed away on August 8, 2012, from a very rare cancer.

Born October 29, 1943, he was the son of the late Robert Shorb and Helen Thisted Shorb; brother to the late Beverly Gonzales and Paul Shorb. His other brothers and sisters: Jan Jupp, Myrna Todd, Keith Shorb, Nadine Morris, Bill Shorb and Glen Shorb.

Michael was a poet and was published in over 100 poetry magazines and poetry anthologies.

Donations may be made in memory of him to The Life Raft Group, 155 US Hwy 46, Ste 202, Wayne, NJ 09470.



History of Laughter By Michael Shorb

The woman's voice was trapped inside the River Kronos, it clung to silt and fish glide, moth in torrential distance.

It was Old Winter himself who intervened, fishing the stiff voice out.

You owe me, he said, half your love poured on stones.

We'll call it laughter.

Melvin 'Skip' Cook, Navy veteran

Melvin H. "Skip" Cook, age 76, of Brecksville, Ohio, passed away at his home surrounded by his loving family on Tuesday, August 28, 2012.

He was a Navy veteran and beloved husband of Joanne (nee Deeter); loving father of Diane Landoll (Richard) and David; step father of Tim Harbison (Lori) and Wendy Herbert (Ron); grandfather of DJ, Peter, Katie, Rose, Logan, Diana and Erin; brother of



the late Elaine Zerkle; and friend of many.

Skip was an Eagle Scout, 32nd degree Mason, and the retired owner/operator of Cook Bonding and Manufacturing Company, Cleveland. Memorials may be forwarded to the Shriners Hospitals for Children, 2900 Rocky River Drive, Tampa, FL 33607 and/or Hospice of the Western Reserve, 17876 St. Clair Avenue, Cleveland, OH 44110-2602.

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