

LIFE RAFT GROUP

10 years

2002-2012

battling gastrointestinal stromal tumor

April 2013

In memory of
Bob Bridgewater, Buddy Coats, Larry Ryan,
Larry Weaver, & David Wicker

Vol. 14, No.2

GIST specialists give support at Miami GIST Day of Learning

By **Gale M. Kenny**
LRG Program Associate

GIST Day of Learning (GDOL), a free event, was held at the University of Miami on Saturday, March 23. Sponsored through the generous support of Bayer, Novartis and Genentech, this event is the second in a series of seminars focusing on the education and support of GIST patients and their families.

The event marked a continuing collaboration between the LRG and Jonathan C. Trent, M.D., PhD, a GIST specialist and Professor of Medicine at the University of Miami Sylvester Cancer Center. Over 40 patients, caregivers and volunteers gathered to learn, forge new friendships, and consult with some of the foremost GIST authorities in the region.

Although those in attendance came primarily from Florida, we were excited to greet attendees from Alaska, Australia, Tennessee and Georgia! Because of feedback from last year's event, old and new friends were given extra time to mingle. Many were meeting other GIST patients for the

LRG research team meets in New Jersey

By **Jerry Call**
LRG Science Director

In 2006, the Life Raft Group initiated a strategic research plan – *Pathway to a Cure* – that emphasized cooperation, coordination and accountability and brought together some of the finest GIST researchers in the world. Utilizing four years of garnered expertise, the Research Team morphed into *Project D-Day* a four-pronged approach to finding the cure involving Sequencing, Gene Knockdown, Drug Screening and Validation.



Brian Rubin, Sebastian Bauer, Jerry Call, Chris Corless, & Jonathan Fletcher

with at least one in-person meeting per year. This year, the team held its in-person meeting at the LRG office in New Jersey March 22-24, 2013.

Attending research team members were Drs. Maria-Debiec Rychter, Anette Duensing, Jonathan Fletcher, Matt van de Rijn, Christopher Corless, Brian Rubin, and Sebastian Bauer. The LRG was represented by Norman Scherzer, Jerry Call and Roger Campbell. Objectives for the meeting were to report progress on

Research Team projects as well as to discuss future directions and unmet

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The Team meets four times a year,

Who's laughing now? Actress Mo Collins uses humor in her battle with GIST

By **Erin Kristoff**
LRG Communications Director



Mo Collins

Mo Collins is not your typical actress/comedienne, because Mo Collins is a GIST survivor.

Born Maureen Collins and nicknamed Mo by her high school theater teacher, she

never realized that the passion she felt for making people laugh – which many have witnessed on Mad TV, Parks & Recreation, or movies like "The 40-Year Old Virgin" – would be the tool to battle cancer.

Mo was diagnosed in spring 2011 by a stroke of luck when she happened to notice an odd lump in her abdomen.

"I would have done nothing about it. I was 44, feeling healthy, everything was going great for me, but my fiancé, Alex said, 'You need to get it checked out.'"

Alex's insistence paid off. She had a primary GIST tumor in her duodenum

and was lucky to find a doctor who knew enough to know that she needed to see a specialist.

After being given neoadjuvant Gleevec to shrink the 6 cm tumor, Mo went in for surgery that December. "The hardest thing for me then was that we didn't know going in what kind of surgery I would have. I was prepared for a possible Whipple. It's a whole lot to swallow, but that's when you really find out what you're made of."

After surgery Mo was given great news, a Whipple was not needed and

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Stivarga becomes first FDA-approved third-line drug treatment for GIST

By Phil Avila

LRG Newsletter Editor

The Food and Drug Administration, in a much-anticipated announcement for Gastrointestinal Stromal Tumor patients, approved Bayer Pharmaceutical's drug, Stivarga, for use as a third-line treatment for advanced GIST in February.

Stivarga (regorafenib) is a multi-kinase inhibitor that blocks several enzymes that promote cancer growth. It is now the only FDA-approved third-line treatment for patients who find that the first-line treatment, Novartis Pharmaceutical's drug, Gleevec, and the second-line treatment, Pfizer's drug, Sutent, are no longer effective in battling GIST.

"This announcement by the FDA is great news for advanced GIST patients," said Norman Scherzer, executive director of The Life Raft Group. "It means they now have a new option for treatment until our Research Team finds a cure."

Stivarga was reviewed under the FDA's priority review program, which provides an expedited six-month review for drugs that may provide safe and effective therapy when no satisfactory alternative therapy exists, or offer significant

Approval of Stivarga was based on the results of a large multinational trial that recruited GIST patients very quickly, requiring only eight months to enroll nearly 200 GIST patients. Importantly, benefit was seen in multiple subtypes of GIST.



The primary endpoint of the trial was progression-free survival (PFS). The median PFS of patients on Stivarga was 4.8 months compared to 0.9 months for patients on placebo. This PFS time compares favorably with the PFS time of Sutent given as second-line therapy. Because patients that progressed on placebo were allowed to cross over to receive Stivarga, there was no significant differ-

ence in survival between those that started on Stivarga and those that started on placebo.

Among the possible side effects noted in the trial were liver problems, hypertension, hand-foot syndrome, fatigue and diarrhea.

Dr. Michael Heinrich of Oregon Health & Science University, a GIST specialist and member of The Life Raft Group's Research Team, said: "I am excited that Stivarga (regorafenib) has now been approved by the FDA. I have personally seen very good results using the drug to treat patients whose tumors are resistant to Gleevec (imatinib) and Sutent (sunitinib). Besides providing hope and an effective new treatment, the approval of Stivarga will also help encourage other drug companies to continue to develop new drugs to treat GIST."

Richard Pazdur, M.D., director of the Office of Hematology and Oncology Products in the FDA's Center for Drug Evaluation and Research, said Stivarga "provides an important new treatment option for patients with GIST in which other approved drugs are no longer effective."

Last September, the FDA approved Stivarga to treat patients with col-

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/make-a-donation/ 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, LRG Communications Director, at ekristoff@liferaftgroup.org of any errors.



improvement compared to marketed products. The drug was also granted orphan product designation because it is intended to treat a rare disease.

orectal cancer that has progressed after treatment and spread to other parts of the body.

Gleevec received accelerated approval as a first-line treatment in 2002, while Sutent won FDA approval as a second-line treatment in 2006. About 5,000 new cases of GIST are diagnosed each year in the U.S.



Family planning with GIST can be a hard decision

By Phil Avila
LRG Newsletter Editor

Family planning can be one of the hardest decisions patients with GIST make, but for Carolina Ponce Williams the decision was easy.

At high risk for progression, Carolina longed to start a family. So she decided to adopt.

"It was pretty easy for me to decide," she said. "I know adoption is not for everyone. But I had adopted cousins so I knew what to expect."

Her son, Antonio, now 3 years old, "is such an amazing child," she said. She said she thinks about adopting another child everyday, but that will depend on Antonio.

Having her own biological child would have meant going off of her drug Gleevec for a year, a risk she didn't want to take. Her advice to other women: "make sure you investigate it thoroughly."

While there isn't a lot of data on pregnancy and GIST, the prescription information on first-line drug Gleevec clearly warns of risks if a woman stays on Gleevec during pregnancy and advises patients to use a form of birth control. Several studies indicate mixed results for women who stayed on Gleevec during pregnancy, with some babies being born with similar deformities and others without complications.

One of the more comprehensive surveys can be found at bit.ly/imatinibpregnancy.

Novartis Pharmaceuticals, maker of Gleevec, the FDA's approved first line treatment for GIST, and Tasigna, a drug that while not approved for GIST has been taken by some GIST patient, is currently conducting a clinical trial on pregnancy and exposure to those drugs but results won't be ready until at least 2014. See 1.usa.gov/11Smxh0.

Until then, most doctors, like Carolina's, advise patients not to have a baby or go off Gleevec if they are at risk for progression. However, some doctors, with patients with low risk for progression who want to have a baby, work with patients to go off the medication for a year to give birth.

That was the case for April Stephens. She had clean scans for five years before working with her doctor to go off Gleevec to give birth to her daughter, Mary Catherine, who is now five years old and healthy. "I followed all of my doctor's guidelines," she said.

"I wouldn't trade it for anything," April said. It was the first time a pediatric member of the Life Raft Group had a child.

After giving birth in 2007, April went back on 400 mg of Gleevec. In 2011, scans showed progression and she

had another surgery. She is now on 600 mg of Gleevec.

"Women have to weigh the pros and cons," she said.

Barbi Appelquist has thought a lot about family planning and how it affects GIST patients like her. "There are a lot of issues having a baby even in perfect health," she said. These are magnified with GIST. Women, she acknowledged, have different views on contraception and abortion, for example.

"There are still so many unknowns, still so much we don't know about GIST," she said. "Part of you wants to know the answers."

Barbi said she has put off discussing family planning with her husband until she is one-year post-surgery.

Since these issues are so personal in nature, she suggested an email community be created for women of child-bearing age with GIST. "I didn't feel very supported by the general GIST email community," she said.

"I can't imagine what it would be like to be 18 and dealing with these issues," she said. "That's a tough question."

This is the first in a series of articles on family planning and GIST. We will also explore being a mother while on Gleevec and considerations for men with GIST who want to have children. If you'd like to comment for these articles, contact Phil Avila at pa07065@aol.com.



Carolina Williams, her son Antonio, and her husband Terrance



April Stephens, her daughter Mary Catherine and her husband Heath

Pediatric GIST patient welcomes baby boy!



After a long and arduous labor that made the Marine Corps Marathon seem like a 5K, Jill and I are proud to introduce our firstborn son and first child of the DeLorenzo Family, Simon Joseph.

He was born at 6:58am on 3/24/13. 6 lbs. 11oz. 20 inches long. Simon is a wide-eyed, very attentive and curious baby. He unfortunately has a lot of his daddy's features, like bushy eyebrows, pointy ears, and long fingers; but has his mom's chin and nose. So far, what we know is he likes computer screens, and didn't seem to like flash photography. He also likes taking his time after a 29 hour labor. But with a positive and motivated attitude that destroyed all negative stereotypes daddy had about women in childbirth, mother and Simon are doing great.

How to make the most of LRG website

By Jim Napier
LRG Website Manager

As you read in our last newsletter, the Life Raft Group has launched a new website. If you have not already, be sure to visit the new site at liferaftgroup.org for up-to-date news and information about GIST Cancer.

The website uses WordPress, which is widely considered the gold standard of content management systems. It allows the LRG to create content on both pages and posts (aka articles).

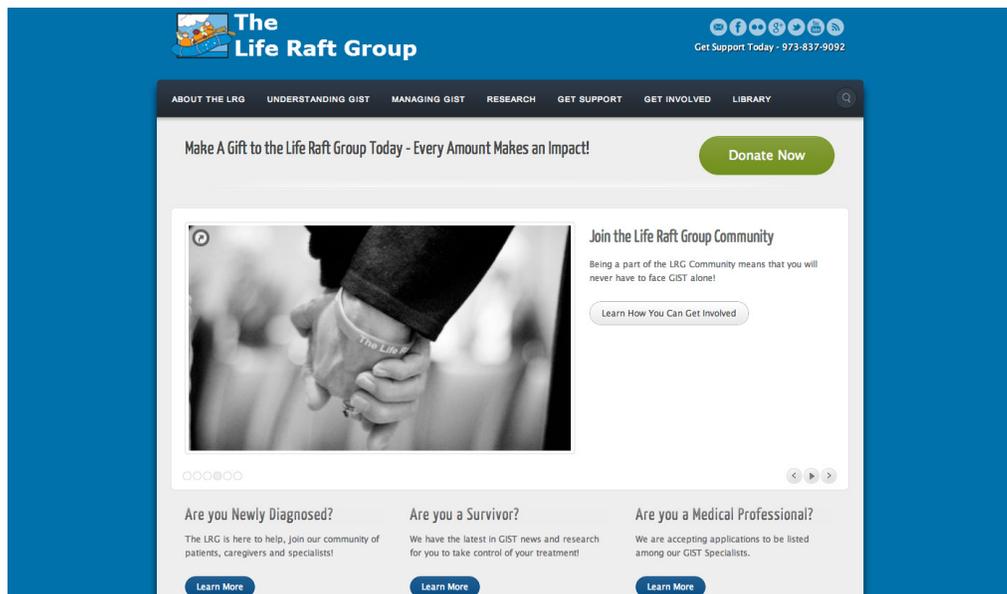
Whether it is the announcement of Stivarga, an update on Clinical Trials, or Janeen's Top Ten Valentine's Day Tips, the LRG is able to share engaging and informative content quickly and easily.

If you have read any of our articles

on the website, you may have noticed two important elements. First, at the bottom of each post, we have sharing options and a comment section. Both are great ways for you the reader to get involved in the conversation and

small box will open up allowing other sharing options including a way to email and print the article.

The comment system that we use is called Disqus, and it is very user friendly. Many sites use this form of comments because it allows you to organize all commenting you may do on the web in one place. Simply type your comment in the open box, and then choose which option to log in with, Facebook, Twitter, Google or Disqus so you can publicly post a comment. If you would rather post anonymously, we offer that option as well.



share these articles with your friends.

For the sharing icons, we feature a Facebook Share, a Twitter Tweet button, a Google + button, and then a button for other sharing options. If you scroll your mouse over the icon, a

article on the site, consider sharing it and leaving us a comment! For more information on how to use these features email Jim Napier at jnapier@liferaftgroup.org.

The next time you are reading an

Pioneer Dan Vasella gave the gift of time

By Erin Kristoff
LRG Communications Director

Recently, LRG Executive Director Norman Scherzer had the opportunity to speak at the retirement celebration for former Novartis CEO and Chairman of the Board, Dr. Dan Vasella in Basel, Switzerland.

As CEO, Dr. Vasella was instrumental in getting Gleevec (then STI-571) to market for a fairly small patient population, but after 25 years at Novartis and Sandoz, he has chosen to step down as Chairman.

There were many illustrious speakers at the event, including a very cheeky speech made by Novartis' architect, Marco Serra, and powerful speeches about Dr. Vasella's

great achievements made by some of his life-long business colleagues and friends. But when Norman took the stage, he kept his speech simple



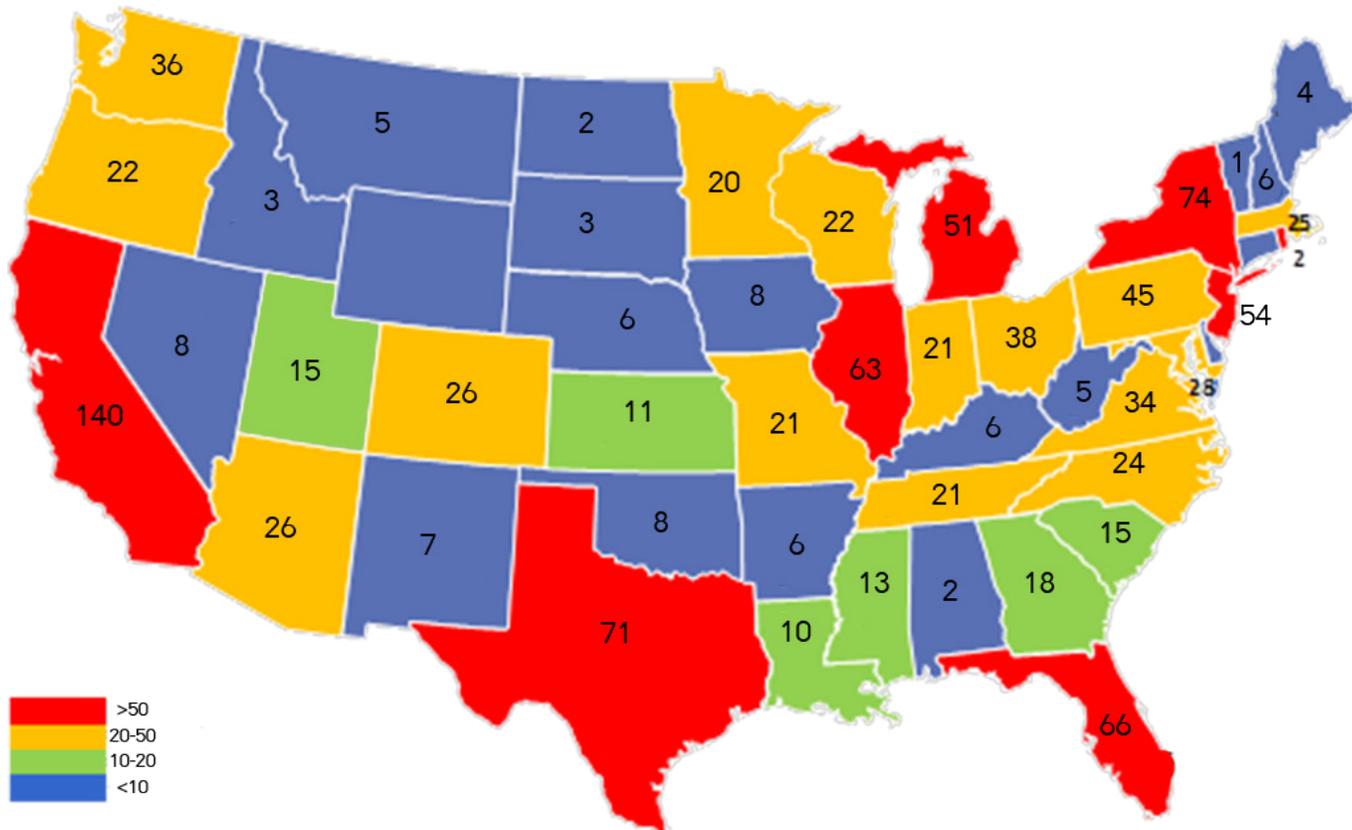
Daniel Vasella, former chairman and CEO of Novartis

by thanking Dan for the gift of time he had given to Norman and his wife, Anita.

He presented Dan a framed clock which also had a picture of Norman, Anita and their seven grandchildren in Disney World. It was a trip Norman had promised his family if Anita became well again, which at that pre-Gleevec time seemed unlikely. Next to the clock and photo were notes written by Norman's children and grandchildren also thanking Dr. Vasella for the gift of many more days with their beloved mother and grandmother.

It was emotional moment for everyone in attendance that day and for Norman and Dan Vasella in particular.

Distribution by State of U.S. GIST Patients in LRG Registry



By Roberto Pazmino
LRG Administrative Director

We have put together a map showing the distribution of patients in the U.S. who are living with GIST in the LRG Patient Registry by state. The map shows how geographically diverse the Patient Registry is, with patients spread throughout the country.

California has the most patients with 140, followed by New York with 74,

Texas with 71, Florida with 66, Illinois with 63, and Michigan with 51. Fifteen other states have 20 or more patients in the Registry. Those states with high numbers of patients range from the East to the West Coast, with many states in between.

The geographical diversity of the Patient Registry makes it a valuable tool for planning events and local meetings and for use in clinical trial recruitment. The Registry is used in conjunction with the LRG's GIST Collaborative Tissue Bank to help

researchers find a cure. We currently have about 1,600 patients in the Registry from all over the world.

We are working on an interactive map showing patients, GIST specialists and treatment facilities that can be searched using multiple criteria.

If you are not already participating in the Patient Registry, you may do so by joining here: liferaftgroup.org/patient-registry/.

LRG Advocates for Cancer Funding in New Jersey

The LRG is continually involved in advocacy efforts to increase government spending on cancer research. We have joined forces with other cancer agencies to once again urge New Jersey Governor Chris Christie and the New Jersey Legislature to restore the \$1 million budget appropriation for cancer research in the state.

Dr. Alison Gammie, a cancer researcher from Princeton University

testified before the Senate Budget Committee last week and the Assembly Budget Committee yesterday to highlight the importance of funding cancer research in New Jersey, and urging the legislature to restore the \$1 million budget appropriation. In a story in the Star Ledger, Dr. Gammie revealed that NJ residents are moving out-of-state for treatment, and states:

"New Jersey risks losing some of its most brilliant citizens, who out of

financial necessity will move to locations such as Texas, North Carolina and Florida — states that have made a significant commitment to financing cancer research."

Last year, joint efforts by the Life Raft Group and several other cancer organizations helped to restore the funding. We hope for the same outcome this year.

Larry Ryan lived to love, loved to live

By Janeen Ryan

LRG Outreach Coordinator

Larry Ryan was born in Brooklyn, New York, on September 25, 1945; he passed from this world into the loving arms of Christ on February 25, 2013. He was holding tight to my hand as he left, to his last breath he tried not to leave me. He put up a valiant battle with GIST for over six years, but he could fight no more.

I met Larry when I was interviewing for a job at a VW dealership. During our interview we talked for an hour and forty-five minutes but only spoke of the job for five or 10. We hit it off like old friends—a spark was ignited that day, and unknown to me for months, Larry said he fell in love that day. For me a special connection was made and Larry became my best friend very quickly. Then he began to ask me out, repeatedly! But I had two children and could not afford to lose my job over an office romance. Nowadays that would be considered a no-no but rules never meant much to Larry. Months later he entered one more time into my office and said, "I just quit my job, you got a promotion to my position, no more excuses, now will you go out with me?" I was so surprised I said, "Of course I will." Heck, I'd marry him! And I did, just seven months later in a tiny chapel in the New Mexico desert.

Larry delighted in spoiling me; little gifts would show up around the house. Flowers, sweet cards, and other thoughtful gestures from him were something I got to enjoy for 15 years. I loved him fully and completely, as did he me. All this showed me I had found my true love, my forever mate, and we both basked in the joy of finding each other. This was a second chance for each of us, and we reveled in the good fortune we felt was a special gift from above.

In December of 2006, Larry began his journey with GIST. He won many battles with the help of The Life Raft Group. Larry overcame seemingly

insurmountable odds several times against this incurable cancer. The diagnosis was terrible—the side effects, the weakness, surgeries.... All of it wore us down. But it also worked as the catalyst that brought the family back together. Larry's children and my own family were able to overcome past issues and band together to form a strong bond that would help to sustain us all over the next six years.

I asked him once if he could change anything, what would it be? He said he'd have taken more golf lessons and completed his pilot's license training. I asked,

wouldn't you choose not to have gotten cancer? He said he didn't choose to get it in the first place, how could he choose not to? Besides, he said, it brought his family back together. . . That's all that mattered.

In 2009, we were losing our house, so we decided to sell everything in it and buy an RV so we could travel! Larry had recovered from his liver surgery and became well enough to travel the country in an RV with me for 18 glorious months. We enjoyed adventures from the Oregon coast (his favorite) to Cape Cod, Massachusetts (my favorite) and everywhere in-between. We were chased by a tornado in Oklahoma, nearly flooded in Wako, Texas. Drove inland by a hurricane on Cape Cod, and treated to the beauty and majesty of watching every change of season known to the U.S.

Larry loved to fish—he tossed his line in the Pacific, the Atlantic, lakes, rivers, and streams, anywhere he could find to enjoy the water and the tug of a fish on his line. I remember once he was sitting by a river in East Texas with his line in the water and I was reading a book nearby. A man approached and asked what Larry expected to catch. Larry said he didn't know, just whatever is in the water. The man

drawled, "Well yer gonna be here fer quite some time, that thar is a drainage ditch." Larry pulled out his line, which was covered with crawdads. He turned to the man and said, "Look there, I caught some hors d'oeuvres for tonight," then proceeded to walk back up the bank, dropping his "hors d'oeuvres" along the way. Oh, how his quick mind amazed me, always one step ahead and quick with a wink.

Dashing our hopes, tumors returned in December 2010. Surgery followed at Dana Farber, but traveling in the RV was no longer possible. Heartbroken, he and I returned home to Arizona in 2011 to be near the support of our family. In June of 2012, he could no longer tolerate oral chemo and entered Hospice.

In 2006, when we first heard the words, "We've found a mass," we were overcome with grief. When the news had sunk in and the tears had dried, Larry looked at me and said, "I feel so sorry for you, the caregiver has the toughest job." Even then he was thinking of me. He had cared for his first wife through her cancer and in the years he fought GIST he sometimes expressed regret that he had not known how to be an advocate for her as I had been for him.

In the last months of his life, Larry told me several times that if I could continue, if I could use the experiences and lessons we'd learned as a team fighting for his life against GIST, then his death would not be in vain. The cancer would not have won, but only served to continue to be the

driving force behind my resolve to help others who are walking the path of surviving this diagnosis. I promised him I would. He wanted his legacy to be the continued support and assistance of GISTers everywhere. It's just like him to be thinking of others at the end of his life, even strangers, only connected by this one

common thread. It shouldn't surprise anyone, as Larry never once asked, "Why me?" He never complained, but often tried to console others who were upset for him. Now he watches over me, my guardian angel, forever perfect— forever my love.



RESEARCH

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needs. It is important to note that the two-day meeting provides a chance to share the progress of each lab in a more detailed manner than is possible any other way. There are some major differences in the way that the LRG Research Team operates compared to traditional research. First, they are not focused on 10 or 20 different cancers; the focus of each lab is on GIST. In addition, the research labs share data on an ongoing basis. This is much different than the traditional model in which researchers operate in more isolation and data is not distributed until the publication cycle is complete. This makes the data a year or more old before it is distributed.



Jonathan Fletcher, Maria Debiec-Rychter, Anette Duensing, & Matt van de Rijn

Highlights from this year's meeting

Dr. Jonathan Fletcher's lab, working with Drs. Suzanne George, George Demetri and colleagues at Dana-Farber Cancer Institute, as well as with Dr. Michael Heinrich at Oregon Health and Science University, has identified resistance mutations (secondary mutations) associated with resistance to Stivarga (regorafenib). Stivarga was approved February 25, 2013 in the United States as a third-line therapy in GIST, and is currently under review for approval in Europe and across the world (Approved in Japan). Some patients benefit from Stivarga for significant periods of time, but the typical duration of benefit (median time before progression) was about five months in the Phase III clinical trial. Guided by recent lab insights, the Boston group is studying approaches that combine Stivarga with other drugs to maximize clinical benefit. One possibility that is being intensively pursued is to sequentially administer Stivarga with a second effective drug in GIST. This plan would require a clinical trial to test the dose and schedule, and to monitor for new or unexpected toxicities that might

develop from giving the two drugs together in sequence. This is an innovative way to try to improve outcomes for patients using all the tools proven effective against this disease.

Dr. Chris Corless, reporting for the Heinrich/Corless labs, reported new data about methylation status of the SDH proteins in pediatric-like GIST (SDH deficient GIST). Mutations in one of the SDH subunits (either SDHA, SDHB, SDHC or SDHD) have been reported in about half of pediatric-like GIST cases. However, all pediatric-like GIST patients seem to have a defective SDH protein. Pediatric-like GIST

patients stain negative (indicating the protein is missing or defective) for the SDHB protein and all other GIST patients stain positive for this protein. A change in methylation has been suggested as a possible aberration in pediatric-like GIST by Dr. Katherine Janeway.

Methylation is an important regulator of which genes are used in a cell. Alterations in DNA methylation are common in a variety of tumors. Alterations include hypermethylation (too much) and hypomethylation (too little). One consequence of hypermethylation can include silencing of tumor suppressor genes. Several drugs are available that target hypermethylation in cancer. At this time, it is unknown if these drugs would be appropriate for SDH-deficient tumors (or a subset of them).

Dr. Corless noted a change in methylation for a small group of pediatric-like GIST. Additional research is

needed on more cases. In order to do this, wildtype samples from the LRG tissue bank will be studied; but more cases are needed. Wildtype patients that are not currently participating in the tissue bank are welcome to participate in this research. See the Life Raft Group website for details about how to participate in the LRG tissue bank and LRG GIST Patient Registry.

In other SDH-related news, LRG Research Team member Dr. Brian Rubin has managed to locate a SDH deficient paraganglioma cell line. He is currently working on access to that cell line. A recent study in a yeast model of cells with SDH deficient suggested several drugs that might be effective in cells with these deficiencies. The paraganglioma cell line, if available, should allow for further drug testing in a cell line that more closely resembles the GISTs and paragangliomas that occur in patients. As reported at the meeting, technology to detect very small bits of DNA that are circulating in plasma is getting better. In theory, this technology could be used to identify GIST patients at risk of relapse due to resistance or after surgery or adjuvant therapy from a simple blood draw. Plans were made to start looking at the logistical requirements for incorporating plasma collection into the LRG tissue bank.

In summary, LRG research team members are continuing to examine all possible avenues in their search for a cure for GIST. The research mentioned here, which represents a small part of the data reported in the meeting, directly affects particular subsets of patients with GIST, such as those who would benefit from combination therapies and those with specific mutation types. It also bene-



Some of the research team members at dinner with LRG Executive Director, Norman Scherzer

fits the GIST community as a whole, however, as lessons learned may be transferrable to other subtypes, and every approach eliminated helps us narrow our focus and ultimately find the correct one.

GDOL

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first time, and expressed feeling both inspiration and optimism from this experience.

Contributing to the tremendous success of the event were the GIST professionals who all displayed an exemplary spirit of giving and dedication for the benefit of this unique community of patients. We are thankful to the University of Miami for providing the venue, and wish to acknowledge their team of specialists, who are leaders in providing excellence in GIST diagnosis, management and awareness.

Dr. Trent, whose cooperation has made GDOL possible, is the Co-Director of the Musculoskeletal Center, Director of the Sarcoma Medical Research Program, and Professor at the University of Miami (UM). His practice is located at the Sylvester Comprehensive Care Center. Outstanding in his field, his research findings on GIST have been presented in several esteemed medical publications. In addition to facilitating the meeting, he shared his vast knowledge in "GIST Overview" and spoke on "Clinical Trials Explained and Explored."

Alan S. Livingstone M.D., FACS, is Professor and Chairman of the Lucille and DeWitt Daughtry Department of Surgery at the University Of Miami Miller School Of Medicine, where he maintains a busy surgical practice in addition to an active involvement in translational research for a variety of cancers. He is the author of numerous books, book chapters, peer reviewed surgical periodicals, has lectured world-wide and has a prime interest in educating the medical students and residents at UM. His presentation on "Surgery and Other Options" was enormously informative, and offered a variety of slides from actual surgical resections on advanced GIST tumors. It is without question that Dr. Livingstone sets the standard in advanced surgical expertise; having recently

completed a number of resections for GIST patients previously deemed inoperable by outside facilities.

Lunch was combined with "A Roundtable Discussion on Side Effects", an important topic led by Elizabeth Fontao, MS, and PA-C. Ms. Fontao, a licensed and certified Physician Assistant, has extensive experience in oncology, and currently dedicates much of her time to sarcoma and GIST. She works in concert with Dr. Trent at the Sylvester Comprehensive Cancer Center, where she is responsible for

patient chemo and immune therapy support, side effect management and follow-up care. The format of this segment bolstered the participation of the attendees and individual side effect woes were brought up and addressed.

A lecture on "Pathology and Role of Mutations in GIST Treatments" was presented by Andrew E. Rosenberg, M.D.,

Chief of Anatomic Pathology, Director of Bone and Soft Tissue Service and Professor of Pathology at the University of Miami Sylvester Comprehensive Care Center. Dr. Rosenberg has published extensively and actively consults for the College of American Pathologists and The American Joint Commission on Cancer, serves on several Editorial Boards and has been an invited lecturer at local and international medical conferences. His slides and accompanying information offered a comprehensive explanation of what GIST looks like under a microscope.

He further underscored the crucial role mutational testing has in directing a course of treatment, and recommended this be determined for every GIST that is diagnosed.

"Clinical Trials Explained and Explored" was discussed by Dr. Trent. After a review of the trials across the United States, Dr. Trent discussed the importance of these efforts in identifying new medications for GIST. Fourth and fifth-line drugs are currently being sought and there is a great need for GIST patient participation.

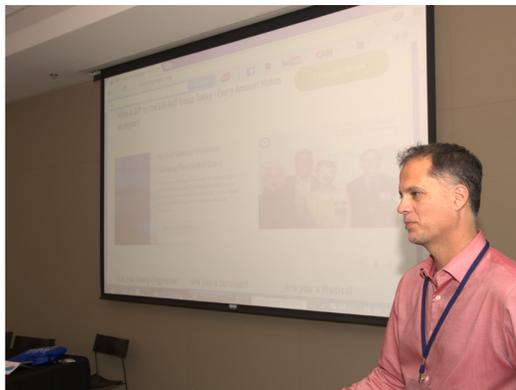
This event was a result of many people from various locations working together, and we wish to extend our gratitude to all who offered their time and talent. We would like to send a special thank you to Alice Sulkowski, R.D., C.D.E. A nutritionist, a GIST survivor, and a longtime LRG friend, Alice provided handouts on "Nutrition and GIST" for all our attendees. She works at Mountain States Health Alliance in Johnson City, Tennessee.

We also wish to acknowledge with gratitude our sponsors, Bayer, Genentech and Novartis for their generous support of the meeting. In addition we extend a befitting thank you to Dr. Derek Naten, Kristen Alleque and

Richard Proctor from Bayer for their attendance and unwavering support for our educational events.

Pictures from the event were courtesy of our volunteer photographer Don Edgar of DL Photography based in Miami. Don is double thanked, as this is the second GDOL event he worked for us and we are truly appreciative.

It was our good fortune to locate Phillip Lwiza, a Miami-based Videographer to offer his discerning eye and equipment in the recording of this event. Thank you both for providing your photographic perspective to this important meeting.



Dr. Jonathan Trent presenting at GIST Day of Learning in Miami, Fla.



Dr. Rosenberg giving his presentation at GIST Day of Learning in Miami, Fla.

Mo Collins

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they had extracted the tumor with clear margins. "That had to be the greatest moment of my life when I first woke from surgery and they told me I had plan A, which was the good plan. There was nothing in my life before that could compare to that feeling."

Now, Mo is over a year NED and keeping a positive outlook on life despite GIST, partially because she has seen first-hand the negative effects fear & worry can have on a body. Within the month before starting treatment, Mo's fear and anxiety over her cancer diagnosis dominated her life.

"Within the month before I started treatment, my tumor started growing so fast that it increased from five cm to six cm and I realized the power of fear. I realized I had to find a way to not be afraid. Fear is something that we create."

Now Mo is using the power of positive thinking each and every day, "I talk to myself a lot. I tell myself that it's just a cell—I diminutize it. Nutrition and exercise keep me above my fear. They build my armor. I feel like I'm winning. I say, 'This is good for me; there's no way cancer can get through this.'"

Mo believes that the battle against GIST is fought not just with treatments and surgeries but within yourself, "You've got to stay happy. You need to stay mentally on top of this. That's where the battle is truly won. I'll do everything I can to stay on top of it, I'll do the things I need to get

positive and then I feel better."

However, life for Mo isn't always a walk in the park. Mo, like most GIS-



Mo Collins, as Joan Callamezzo planking on "Parks and Recreation"

Ters, struggles with side-effects like fatigue and edema of the eyes, which can make her look worn down and drunk-looking. For an actress it can be a particular challenge, "I call them my fetal pig eyes. For me to audition and go on camera, it takes a whole different kind of mental strength."

In fact, her recurring role as Joan Callamezzo on NBC's Parks & Recreation has been a blessing in disguise. "Joan has been a drunk lately so it's kind of a relief."

Besides Parks & Recreation, Mo has been doing a lot of voice work, which can be a safe haven of sorts, "I can sit and do it and not be tired!"

While fatigue is a big problem for her, in typical Mo-fashion she's battling it

by staying fit.

"What I started to do is bench pressing. It takes 10-15 minutes, and my sweet Alex trains me. When I'm done I'm not physically exhausted, I'm not run down, I'm strong. I've never been able to do a pushup and now I do three sets of them post-GIST! I like that it makes me feel strong."

But it's her passion for laughter that is her biggest weapon against GIST, "My gift here on this planet is that I'm a story-teller and a funny person. I need to do it. I need to get up there and laugh and I need other people to laugh with me. It's kind of selfish actually."

But Mo is using this gift in a very selfless way by organizing a comedy fundraiser for the Life Raft Group and GIST research. Bravely coming out as a cancer survivor in a tough business, Mo is using her diagnosis experience to try to increase GIST awareness so that no patient goes to a doctor that doesn't know what GIST is.

"I want to go have fun. I need this for me.

But we need money for research. This is part of what I'm supposed to do—talk about it, laugh about it, and shed some light on it so that others who don't understand GIST may come to understand it because of the humor."

**"NUTRITION AND EXERCISE
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THEY BUILD MY ARMOR.
I FEEL LIKE I'M WINNING.
I SAY, 'THIS IS GOOD FOR
ME: THERE'S NO WAY
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THIS.'"**

Help the LRG in the search for a cure!

Wildtype GIST tissue is needed for a current LRG Research Team project. This project, briefly described on page 7, will look at SDH methylation status in wildtype GISTs. If you or a loved one are a wildtype GIST patient, please help the LRG Research Team in its search for the cure by donating your tissue. See the LRG website for instructions on joining the LRG Tissue Bank and GIST Patient Registry or call (973) 837-9092 or email us at liferaft@liferaftgroup.org for assistance. The process is easy—the tissue required is taken from an existing paraffin block held in your hospital, so no new biopsy is required.

Note: We are always looking to add more tissue to our Tissue Bank, so regardless of type, if you are thinking of ways to support research, please consider donating your tissue today.

'Buddy' Coats Jr. passes away

Clarence Charles "Buddy" Coats Jr., 65, of Jeffersonville, Indiana, died Sunday, April 22, 2012, at his home. He was buried in Walnut Ridge Cemetery.

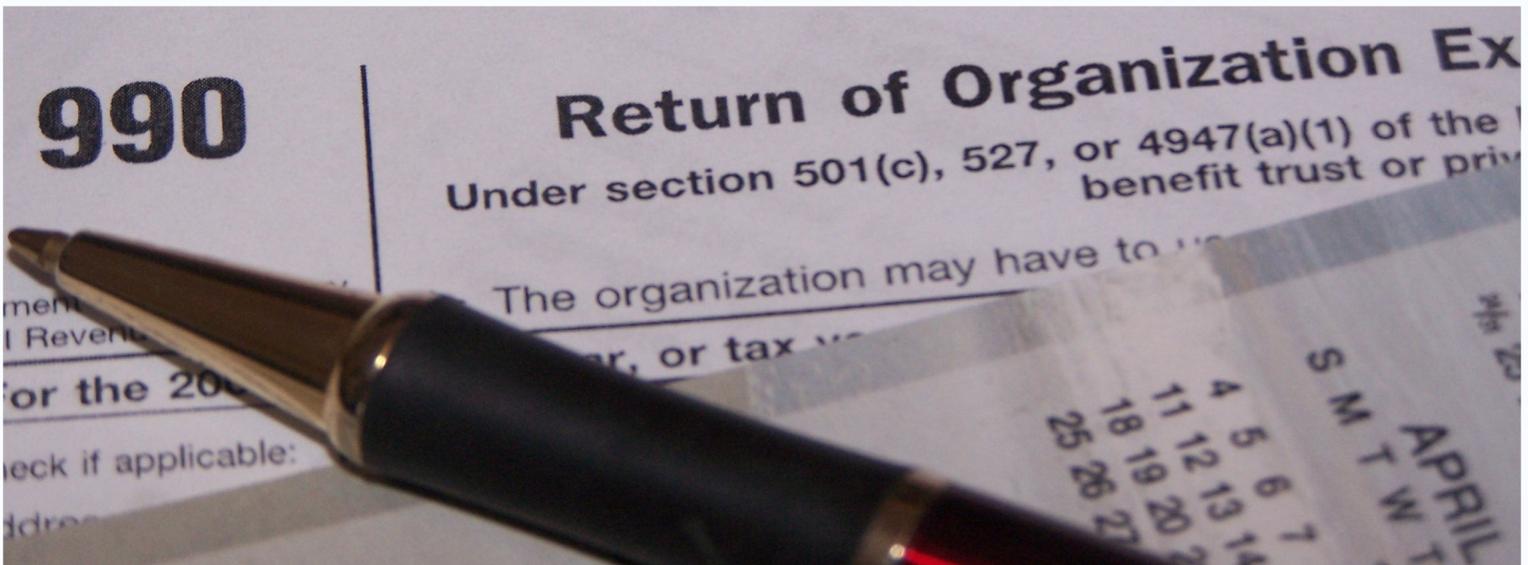
He was born June 3, 1946, to the late Bud and Dorothy Coats. He was a 1964 graduate of Jeffersonville High School and received his master's

degree in education from Indiana University. He was a retired school teacher, a member of Southeast Christian Church, Jeffersonville Masonic Lodge 340, Scottish Rite, and served on the West Clark School Board.

He is survived by his loving wife, Denise Coats; a son, Clarence "Buddy" Coats III and wife, Melinda, of

Henryville; grandchildren, Bryce and Brandon Romig and Xavier, Zerach, and Zidon Coats, of Henryville; and stepdaughter, Kara Hennis and husband, Jeff, of Jeffersonville. He was preceded in death by his daughter, Faith Michelle Romig, and parents, Clarence Sr. and Dorothy Coats. Expression of sympathy may be made to Kosair Charities.

Audit report gives glimpse into priorities



By Roberto Pazmino
Administrative Director

Every year, the Life Raft Group's financial statements are audited, providing a glimpse into the priorities of the organization. Audited results for 2012 will be received soon.

Operating expenses are broken down between program services, which include research, family services, advocacy, and information and education; fundraising, and operational expenses such as management of the nonprofit. These financial statements are the responsibility of the organization's management.

Audits must be conducted in accordance with auditing standards generally accepted in the United States

of America, those standards require that the auditor plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation.

In every audit one specific section is the contributions audit, all contributions including unconditional promise to give, are recorded as made. All contributions are available for unrestricted use unless specifically restricted by the donor. Cost of providing the organization's programs, management and fundraising activities are separately summarized in the

statements of functional expenses.

Last year expenses distribution percentages were as follows:

Program Services:
Research 76%
Family Services 4%
Advocacy 4%
Information and Education 8%
Management & General 4%
Fundraising 4%

The 990 also documents the tremendous amount of time our volunteers give to help the GIST community.

We will be posting our 2012 audited results on our website as soon as they are completed.

You can see our budget philosophy and all previously filed 990 at liferaftgroup.org/budget-and-operating-philosophy/

Bulgarian GIST group increases reach

By Juliana Popova
GIST Alliance for Patients-Bulgaria

My name is Juliana Popova and I'm the chairperson of the Bulgarian support group for people with GIST - "GIST Alliance for Patients-Bulgaria".

Our organization was founded in January 2012. All patients can contact us by e-mail at info@gist-bg.com or by phone at: +359 888 585 366; +359 889 242 228. We have already done some activities, such as creating a website, www.gist-bg.com/, making

some leaflets with useful information, providing psychological support for people with GIST and assisting them in obtaining the appropriate treatment.

In June 2012, the first national meeting of GIST patients in Bulgaria was held in Sofia. In December, we started a training seminar about different conditions in our treatment.

The number of GIST patients on treatment is constantly increasing, and now there are more than 80. There is no clinical register for GIST patients in Bulgaria, so my information may not be exact.

Our organization is a member of SPAEN (www.sarcoma-patients.eu/) and we attended the SPAEN Annual Conference in November 2012, when we presented GIST Alliance for Patients -Bulgaria. Also received an invitation to attend the New Horizon GIST Conference in Miami this year.

At present, I'm trying to reach more GISTers (I'm in touch with about 40), to continue with the training seminars, and to help establish a center for GIST treatment. The local problems in Bulgaria are quite different. For example, here the Gleevec patent has expired and the first generic imatinib is coming.

Around the World...Chile Edition



Piga Fernandez, the LRG's global relations coordinator, participated in an activity called "I have cancer, ...lets talk" organized by Red Chile Cancer, a coalition of cancer patient groups in Chile. The main objective was to let people know the reality of GIST patients in Chile and create awareness of the need that different types of cancer are covered by the health systems.



Joel Salazar, a Chilean GIST patient, is running marathons to raise awareness of the need for GIST to be codified and approved as a pathology by the health system in Chile.

Carol Heller to be local leader in Eastern Pennsylvania

Carol Heller will be working with Jeff Bernstein to cover the state of Pennsylvania as local group leaders. She is very excited to help and hold meetings, and will be handling the eastern region of the state.

Carol can be reached at cheller01@comcast.net.



LRG CALENDAR

GDOL Chicago
May 5th 2013

ASCO
May 31st-June 4th 2013

New Horizons
June 5th-7th 2013

Alianza GIST
June 7th-9th 2013

for details about the events check out liferaftgroup.org/events

NIH
June 26th-28th 2013

Night to Fight Cancer
September 12th 2013

The Art of the Cure Gala
November 7th 2013

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Life Raft regional chapters: Find your reps info at liferaftgroup.org/find-a-support-group/

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Barbara Kepple	North Carolina Chuck Korte	Wisconsin Rick Ware

Life Raft country liasons: Learn more about the Global GIST Network c& find contact info for your rep at www.globalgistnetwork.com

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