The Life Raft GROUP

June 2013 Vol. 14, Issue. 3

Ensuring no one has to face GIST alone

**Also in this issue**



In Loving Memory: Albert Paul Costa, Ralph Farmer, John Janicki, Marie Lagaluga, Cherie Lufkin Blackett, Edward Martinka Jr., Mohammad Reza Yazdi, Nora Lynn Webb-Winstead

## How 'Next Generation' DNA sequencing is changing the landscape of GIST research and diagnosis

**By Christopher Corless**
LRG Research Team

During the past dozen years gastrointestinal stromal tumors have emerged from oncologic obscurity and reached center-stage in the development of targeted therapies for solid tumors. Tyrosine kinase inhibitors (TKIs) like imatinib, sunitinib, and more recently regorafenib, have proven effective in suppressing the growth of metastatic GIST, allowing patients to live far longer than during the previous era of ineffective chemotherapy. Parallel stories in the treatment of malignant melanoma and non-small cell lung cancer are being played out, with one theme common to all of them: match the right drug to the right mutation, and the tumor will respond well to the treatment. In this article, I will discuss some of the technologies, both standard and new, that are used to identify mutations in tumor DNA.

The two main treatment targets in GISTs are mutations in the KIT and PDGFRA genes, which code for closely related tyrosine kinases, enzymes that are critical to the growth of GIST cells. Shutting down these hyperactive enzymes with TKIs like imatinib causes the cells to stop growing. Some of the arrested cells will go on to die, resulting in tumor shrinkage and improvement to the patient's well being. Based on data from several clin-

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## First GDOL Chicago hits a homerun!

**By Janeen Ryan**
Outreach Coordinator

Our first Chicago GIST Day of Learning was a huge success! Over 50 GISTers and their families gathered for a great day of learning, and sharing experiences. It was wonderful to get to meet so many new people and reconnect with old friends.

Our session on surgical options by Jeffrey Wayne, MD, FACS Associate Professor of Surgery Northwestern University Feinberg School of Medicine, was very informative and included details on options for GIST surgery at Northwestern.

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## We are proud to introduce the new Life Raft Group logo!

The Life Raft GROUP

After ten years as an established non-profit, the Life Raft Group identified a critical need in its public image. While the LRG began as a small group of patients and caregivers offering support and guidance to each other while facing the early Gleevec trials, the LRG has now grown into a multi-million dollar international organization, heavily involved in advocacy work and changing the face of GIST research. While we remain true to our support & education roots, the LRG required branding to reflect our current stature and credibility in the medical field.

For the past several months, the team has been working with graphic designers and industry professionals to create a new logo and brand that would exemplify all of the LRG's core values: Patient Support & Education, Advocacy and Research.

The objective we had before us was to keep that sense of hope when viewing the logo. We were also obliged to keep the oar, which some Public Relations professionals believed represented the Life Raft Group's commitment to action in the original logo. The result of this process is a polished, professional new design that appeals to all of the LRG's audiences.

We have submitted this logo to an Intellectual Property firm (pro bono) to begin the trademark process. In the coming weeks we will slowly be introducing this new logo to the public and creating detailed branding guidelines for its use.

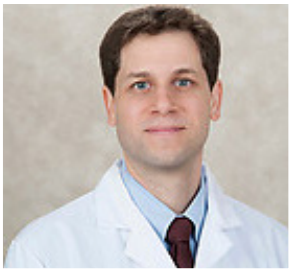
# Combination approach to lead to trial for new patients at MSKCC

**By Phil Avila**
Newsletter Editor

Memorial Sloan-Kettering Cancer Center (MSKCC) is preparing for what it calls "a breakthrough clinical trial" that will test a new drug that uses a MEK inhibitor to target ETV1 in combination with imatinib on a small group of newly diagnosed GIST patients with advanced disease.

We hope to begin recruitment in August, said Dr. William Tap, Section Chief of Sarcoma Oncology at MSKCC. The Phase II trial will be small, with only about 45 participants, and will only have one site at MSKCC in New York City, he said. That's because "we just want to show that this approach works," before recruiting for a larger scale trial, Dr. Tap said. There will be a Phase I portion of the trial to define the Phase II doses of the combination regimen.

The trial is unique because most new GIST clinical trials recruit patients that already have taken imatinib, sunitinib or other drugs and have already developed resistance to those drugs. This trial will try to show that treatment with a combination of imatinib and the MEK inhibitor from the start will be even more effective in combating GIST and will reduce the likelihood of secondary mutations that cause resistance.



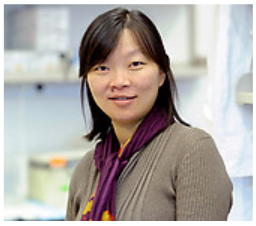
*Dr. William Tap*

Novartis Pharmaceuticals is co-developing the MEK inhibitor, MEK162, with Array Biopharma. MEK162 has been through Phase I trials and recently completed a Phase II trial in NRAS-mutant melanoma.

Dr. Tap said the research that opened the way to this new approach was led by his colleague at MSKCC, Dr. Ping Chi. She was able to show that ETV1, a transcription factor, was essential to the survival of GIST; while it was hard to target ETV1 because it didn't have molecule-binding pockets that could be blocked by drugs, she found a way around this problem by discovering that MEK inhibitors could do that job.

"MEK inhibitors alone doesn't seem to be great, but by doing combination therapy with imatinib we get a dramatic response," Dr. Chi said. ETV1 is a master regulator that is highly expressed in all GISTS.

"Ping's discovery is one of the major discoveries that we have seen in GIST research since the discovery of KIT," Dr. Tap said.



*Dr. Ping Chi*

In 2010, Dr. Chi published a study she led, "ETV1 is a lineage survival factor that cooperates with KIT in gastrointestinal stromal tumours," in Nature.

In a review of the study in Nature, LRG Research Team members Michael Heinrich and Christopher Corless wrote: "Whether the survival of GIST stem/progenitor cells depends on ETV1 is therefore a pertinent question. If so, targeting ETV1 in GISTs may produce the cure that currently eludes KIT inhibitors such as imatinib."

Since 2010, Dr. Chi and her colleagues have been working on a way of finding a practical application for their findings. And now they think they have one.

"We were interested in developing novel approaches to GIST because of the imatinib resistance, and we stumbled upon ETV1, which is a transcription factor," Dr. Chi explained. She said ETV1 plays a role in other cancers, also driving the pathogenic process, but in GIST it is the master regulator in the development of cancer cells. That means it regulates a group of target genes, called the transcriptional targets, which in turn are required for the proper development, specification and survival of a particular cell lineage, such as the Interstitial Cells of Cajal that play a role in GIST.

She said that by conventional thinking, targeting ETV1 was thought to be difficult because it doesn't have the molecule-binding pockets that you could design a drug for. However, she found that the protein stability of ETV1 is controlled by MEK signaling. "So we thought, aha, maybe we could target the signaling pathways. We thought that if we could inhibit the MEK pathway we could destroy the ETV1 protein."

Although using the MEK inhibitor alone didn't produced great results, Dr. Chi said, when they tried using MEK inhibitors in combination with imatinib in vivo "we saw really dramatic responses." Studies in mice have also yielded positive results.

"The hard thing was trying to find the right drug to target this clinically," Dr. Tap said. "That's what Ping and I have been working on for well over a year now. We've spent a lot of time with Novartis (Pharmaceuticals) sharing Ping's data, and they've been very supportive about moving forward with the clinical trial."

Dr. Tap said that while imatinib has been a great drug for GIST, many patients inevitably develop resistance and their tumors begin to grow again.

"We know that their tumors become much more complex on a genetic level, and because of that we often don't see the results we would like to see" in clinical trials for new drugs, Dr. Tap said. "What we're trying to do is bring the combination up front in newly diagnosed patients where we can have the greatest impact."

He said if the small trial "shows this principle works, we'd really like to move it forward into a larger trial."

## Thank you for your contributions to our research efforts

In our last issue, we announced the need for Wildtype GIST tissue for a current LRG Research Team project. The project is looking at SDH methylation status in wildtype GISTs and may provide important information about pediatric-like GISTs.

We'd like to thank all those who contributed. Your response in donating tissue will help us move closer to finding a cure.

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. 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.

# Our decision to enter hospice

**By Janeen Ryan**
Outreach Coordinator

I've been thinking a lot about writing this article. The last thing I want to do is cause worry or pain to anyone reading this. Then I thought of all the people who could possibly benefit in the future from knowing ahead of time what we didn't know at the time we needed to know it. This is for anyone facing end of life issues, for any family member, with any illness, who can benefit from learning about hospice before the need arises. So here we are, talking about a delicate subject from the point of view of someone having recently lived it. If you ever had a pang of fear when hearing the word "hospice" I hope our story will dispel that fear.

*"Knowing we had this option, that it doesn't have to be a permanent situation, greatly relieved us both."*

Our decision began when my husband Larry had reached a point where the options for treating his cancer were not bearable. He was diagnosed in December 2006 with GIST, a 26 cm tumor on his small intestine, metastatic to his liver and omentum. By June 2012 his body would no longer tolerate any medications. A mild heart attack, his third, put him in the hospital where it became clear his body was just not strong enough to continue the targeted oral chemotherapy. He'd had five surgeries, three heart attacks and 17 hospitalizations. Larry had already been on Gleevec, Sutent, Tasigna, and Nexavar, then back to Sutent.

I was of course furiously looking for the next option. Different drugs, off label, combinations - anything to keep going. When we discussed what the trial options were, Larry said he didn't want to travel; it made him ill to be in a car for long periods of time. The answer was no, just like that. It took a while for me to let that sink in. I'd been working so hard, for so long, toward getting him better, that coming to grips with doing nothing was foreign to me. I'm sure you know what I'm talking about. Most people have considered stopping treatment at one time or another, each for their own reason but the transition is somewhat the same.

Still in the hospital and with a rehab facility seeming to be our only option, a nurse asked if we'd like to speak with a hospice representative. Now, the first thing that popped into my head was "No!" To me, hospice was where you go to die. I railed against that idea, but she was gentle and suggested we just hear what the hospice nurse had to say. So we agreed to listen.

A kind and soft-spoken woman came by later and introduced herself as a retired nurse who now worked for the hospital as a hospice entry counselor. Looking back I can only seem to remember what she didn't say, more than what she did. She did tell us we would have a home care nurse that would stop by to check on Larry, but she didn't say how often. She did tell us they would coordinate his medications with a doctor. She didn't tell us our doctor would no longer be Larry's prescribing physician. There was talk of home visits, assistance 24/7 and comfort care. The one most profound point was that entering Hospice equated to not fighting the disease anymore. No more chemo drugs, no more scans, no more blood work (hospice does draw blood if there is a need to see what may be causing discomfort.) No more doctor visits!

It was such an ordeal getting Larry into the car and driving him to a doctor that this was the one thing we saw as a positive during that first consultation. The medical end of his care would come to him. He could use his energy for trips to the lake, feeding the ducks and building birdhouses.

I should say we did not agree right away, still not completely understanding the full scope of what Larry was facing. We were not quite ready to make a decision. So we talked a lot, or I should say, I talked. I spoke to family and got their views on stopping treatment. Everybody seemed to be onboard with understanding that further chemo treatment was just not a viable option and quite frankly, in his weakened condition, we felt it may even shorten his life instead of extending it. In hindsight, we all agree that this was true.

Up to this point I had made every important decision regarding my husband's care and treatment, but this was not my decision to make. I could not, and would not, try to influence him to do anything he might not want to do. So, we talked some more. I told him he needed to tell me what he wanted. I needed to hear the truth; now was not the time to be thinking of me anymore. He had to think of himself and what he wanted, and he needed to tell me and the kids. Larry has four children, two boys and two girls who were desperately hoping for him to recover again as he had so many times before. He barely thought about it for a moment: "I want to live out what time I have left feeling as good as I can. No more drugs." I realized he'd been thinking of this for a while, but he'd needed me to ask.

We went home on a Saturday night; at 9 pm a hospice nurse came to the house to meet with us. He was kind and gentle, and I liked him right away. He asked to see all the medications Larry had been taking; he logged them and explained that hospice would be providing all of Larry's medications from now on. I was surprised to find out they don't treat some medical conditions. They don't treat high blood pressure but they do treat low blood pressure. They don't treat diabetes either, so Larry would no longer be taking many of the medications he'd been taking. This worried us. However, in his case, we soon found that being off so many chemicals seemed to make him feel much better. His blood pressure was actually down and his blood sugar was almost normal. I want to add here that a couple of months later when his BP did become an issue hospice worked with us and allowed some medication to control it again.

On Monday, our home care nurse came by for the first time. She was assigned our area, lived close by, and explained again that we could call any time day or night for any reason. She asked questions, got to know us, and took the time to learn about the rare cancer called GIST. This woman, Jenny, became so close to us, she became a part of our family and a trusted friend. She explained services available like counseling, home care aides and equipment we might need. We did eventually get a hospital bed, a wheelchair, a bedside commode and a shower chair. All things designed to keep Larry comfortable and safe in our home. She also told us something that no other hospice person had mentioned: that if our hopes came true, that if Larry became strong enough, he could exit hospice and once again pursue treatment if he chose. Knowing we had this option, that it doesn't have to be a permanent situation, greatly relieved us both.

Many people do get better in hospice care. She theorized that some are so over medicat-

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# 10 things you need to know about hospice

1. **Comfort** is the goal of hospice – Many people think entering hospice is "giving up", but that's not true. Hospice is where you go to live comfortably with issues that are no longer in your control. The nurses and staff of hospice are there to assist you and your family in your own home, and are available 24 hours a day, seven days a week if needed.

2. **Daily living** – The comfort care nurses (Registered nurses and LPN's) are trained to provide advice and resources for the whole family. Each city and area has specific options available and the nurses know how to access these resources. Nurses aides for bathing is one example.

3. **Counseling** – Each hospice has trained professional counseling available; speaking to someone trained in assisting with the stresses that come with managing care can be a great asset. Chaplains are also available if requested as is children's counseling.

4. **Equipment** – A hospital bed, wheelchair, or walker is sometimes needed — these are just a few examples of things that are available through hospice.

5. **Medications** – In most cases, comfort medications are delivered directly to your door. Pain medications and others provided by hospice are available within hours of being requested.

6. **Home Visits** – A comfort care nurse will set up a schedule to stop by on a regular basis; you will have a number to call day or night to ask for a visit at any time, for any reason. This gives everyone involved peace of mind knowing help is just a phone call away. Other home visits can be counselors, home health aides, chaplain and the physician.

7. **Cost** – For those on Medicare, there is no cost. Medicare pays for the service. Check with your private insurance for other coverage. A doctor must sign a form of admission into hospice and release of care from his or her service.

8. **Not-for-profit hospice** – Just like it sounds, non-profit hospice organizations rely on private and corporate donations and government assistance. The benefit is they are not driven by profit and loss and do not have the limitations of a for-profit organization.

9. **Hospice Units** – If comfort care is no longer possible in the home, for any reason, a care nurse will assist in arranging for a care unit. Rooms in a facility much like a bedroom at home — not the sterile, noisy hospital setting but a comfortable living space with no visiting-hour restrictions. Family and friends may come and go, sleep and visit. Many give access to a kitchen. Pictures can be put up, or a favorite chair brought in. The idea is for the stay to be as comfortable and restful as possible. Many people go to a unit just for a few days. Pain management is one reason. When medications are restructured and comfort is restored, going home is a wonderful event. Transportation to and from these units is provided.

10. **End of life** – In facing this moment, and as it approaches, the nurses and staff are there for everyone. Whether at home or in a comfort unit room, every measure is taken to provide comfort and a peaceful transition with respect and dignity.

**By Janeen Ryan**
Patient Outreach Coordinator

# Clinical Trials and the search for greater efficiency

**By Phil Avila**
Newsletter Editor

Clinical trials are a key step in the development and approval of new drugs to treat cancer and often a lifeline to patients seeking options when other treatments have failed.

Reflecting its importance, the clinical trials process is getting a closer look from the medical research community for ways to improve efficiency and effectiveness. Two organizations, Enacct and CTTI, are working on projects that will help identify best practices in clinical trials.

Margo Michaels, executive director of Enacct, which stands for Education Network to Advance Cancer Clinical Trials, said her organization's National Cancer Clinical Trials Pilot Breakthrough Collaborative project is aimed at finding systemic changes in the process that will increase clinical trial accrual.

Enacct points out some of the shortcomings of clinical trials that led to the project on its website, www.enacct.org:

--While 20% of adult cancer patients are eligible to participate in cancer clinical trials, only 3% of those eligible actually participate, and the percentage is even lower for the minority and elderly populations.

--About 15-30% of NCI Coooperative group trials are closed early due to poor accrual.

--Accrual varies greatly: 15-20% of local sites involved in cooperative group studies never enroll a single patient, while 30% of sites enroll 70% of evaluable patients.

"Participation in cancer treatment clinical trials is a key measure for delivery of quality cancer care," Enacct asserts. Yet that is not happening.

For example, among some recent GIST clinical trials, the Phase III regorafenib trial was very successful in enrolling patients and led to the approval by the Food and Drug Administration of Bayer Pharmaceutical's drug Stivarga for third-line treatment of GIST earlier this year. However, the Phase III imatinib dose escalation study opened in January 2010 and closed in May 2011. It had planned to recruit 400 patients but only recruited five. It was not positioned in sites that saw newly diagnosed patients.
The Enacct project hopes to "get centers to implement changes to make accrual more possible," Michaels said.

One of the main issues the first phase of the project identified was the lack of systematic screening for participants at cancer centers, she said.

"Systematic screening is not happening in the majority of places," she said. Part of the project was working with cancer centers to change policies and procedures and put processes into place that will improve accrual.

"We have to make sure all eligible patients are approached," she said.

She also said a more strategic approach is needed in choosing trial sites geographically to reach a greater number of participants. "We have to make sure things like travel costs are built into the process," she said. "If there is a trial going on in New York and a person lives in Omaha, how are they going to get there?"

Michaels said clinical trial design is another critical issue. She would like to see more engagement of patient groups in the design process to make sure the right kinds of questions are being asked in studies.

Bray Patrick-Lane, Director of Stakeholder Engagement at CTTI, which stands for the Clinical Trials Transformative Initiative, said her organization "has just launched a formal recruitment and retention project." CTTI is a public-private partnership that works to create a better clinical trials process in terms of quality and safety.

"We are beginning to identify issues," she said. "The goal is systemic improvement, making the process better for all."

She added, "A lot of times trials never enroll, which is terrible for patients."

Jeff Allen, executive director of Friends of Cancer Research, said his group is also "very interested in how to improve efficiency" of clinical trials.

He sees the need for better physician education on what trials are available to patients. He also thinks patient groups can play a role in "shepherding treatments," particularly as targeted approaches become more common.

He acknowledged that an issue in clinical trials is the difficulty of doing combination studies with drugs from two different companies. "It's really hard to get two different companies to collaborate because of the financial implications," he said.
"But I would hope there would be more collaboration going forward."

He pointed to a successful lung cancer project with the Food and Drug Administration as an example of how collaboration can be helpful.

Dr. Patricia Keegan, who is Division Director of Oncology Products 2 of the FDA's Center for Drug Evaluation and Research, also thinks collaboration is becoming more important.

She said the FDA offers guidelines for clinical trials but "not so much specific best practices" because "we would not want to be prescriptive in order to provide flexibility."

She said with more targeted treatments being developed, clinical trials "in some ways have to change." Part of that will be greater collaboration among groups.

"To the extent that groups can partner together" that will help, she said, adding that rare diseases such as GIST "require many minds" to find a cure.

She said an advantage to collaboration is that findings can be more easily confirmed and built upon. She also pointed out that "the development of tests to identify subpopulations needs to get the same kind of attention" as drugs to treat the mutations they identify.

She sees an important role for advocacy groups such as the Life Raft Group (LRG) in "getting out the word and promoting participation" in clinical trials.

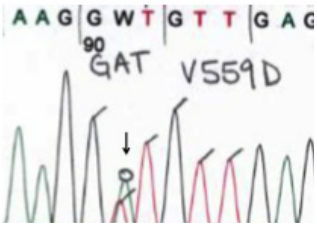
The LRG is working to develop a clinical trial model that would even go beyond that. The project aims to bring together pharmaceutical companies and cancer centers and leading researchers in a consortium that would have access to the LRG's Patient Registry and Tissue Bank, a valuable source of data for both trial design and recruitment.

The model would go a long way toward improving recruitment, particularly for targeted treatments that are aimed at limited populations.

# Research from Page 1

ical trials, it is well established that ability of imatinib to block kinase activity is dependent on the type of mutation present in the KIT or PDGFRA gene. For example, tumors with a KIT exon 11 mutation are highly sensitive to 400 mg of imatinib, while those with an exon 9 mutation are better controlled by a higher dose (800 mg). On the other hand, tumors with the PDGFRA mutation D842V are completely resistant to imatinib. For these reasons, it is important to genotype GISTs (determine their mutation status), and this has become standard practice in many laboratories around the world.

**Figure 1**




*Sanger sequence showing a green (A) peak overlying a red (T) peak in KIT exon 11, indicating a mutation that changes codon 559 from a valine (V) to aspartic acid (D). This is a common mutation that is sensitive to imatinib.*

Genes are somewhat like books, each one divided into a series of exons (chapters) that are made up of codons (words), which in turn are made up of bases (letters). In GISTs, mutations vary from a single base change (substitution of one letter by another) to deletions of up to a dozen or more codons (words) in a row. The KIT exon 9 mutation is caused by a duplication of two codons back-to-back, as though someone forgot to proofread the gene when it was copied during the growth of the cell.

Finding these mutations within the 3.2 billion letters (bases) that comprise human DNA requires the use of PCR (polymerase chain reaction). This approach revolutionized molecular biology in the early 1980s and is now the mainstay in all laboratory testing for tumor mutations. The details of PCR are beyond the scope of this article, but one can think of it as a means of Xeroxing selected chapters (exons) in any book (gene) in the library of the human genome. Xerox copying of the KIT and PDGFRA genes by PCR is the first step in looking for mutations in DNA purified from a GIST. Generating sufficient copies of these genes is necessary so that additional technologies can be used to read their bases (letters) and determine whether a mutation is present.

The standard method for reading DNA sequence is called "Sanger sequencing," named in honor of Dr. Frederick Sanger who first invented the method in 1975 and later received a Nobel prize for this breakthrough. Widespread adoption of Sanger sequencing led to the identification of mutations in many different kinds of cancer, including the 1998 discovery of KIT mutations in GIST. Sanger sequencing was also used in the initial sequencing of the entire human genome, which was a massive undertaking that was completed in the year 2000.

An example of Sanger sequencing is illustrated in Figure 1. Each of the four letters that make up DNA (A,C,G and T) is represented by a different color: green for A, blue for C, black for G, and red for T. When there is overlap of two different colors, this indicates the presence of a mutation (see arrows in the figure).

Sanger sequencing is used by laboratories worldwide for the routine genotyping of GISTs. It is reliable and can identify a mutation reasonably quickly (24 hours) once DNA from a GIST has been purified and amplified (Xeroxed) by PCR. However, Sanger sequencing does have one major drawback: one can only sequence one exon (chapter) of a gene at a time, and most sequencing machines can only handle between 16 and 64 samples at once. In order to screen a GIST for all common KIT and PDGFRA mutations, one must perform 7 different sequencing reactions, which is quite labor intensive.

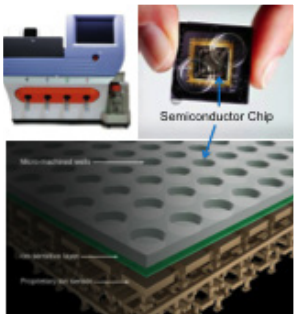
Fortunately, the next generation of DNA sequencers is radically changing the landscape. There are a couple of different chemical approaches used in these 'next-gen' systems, but what they share in common is a miniaturization of the sequencing reaction, such that instead of being limited to between 16 and 64 sequences these systems can sequence millions of fragments of DNA simultaneously. As a result, DNA is being sequenced faster and more completely than ever before, and the price of sequencing is dropping like a stone. The human genome project, performed using traditional Sanger sequencing, cost $2.7 billion to establish the first human sequence. Thirteen years later, this amount of sequencing can be done for $5,000.

Next-gen DNA sequencing is being widely applied in cancer research, including the studies being carried out by members of the Life Raft Group GIST research team. To date, more than three dozen samples of different types of GIST have been sequenced to identify alterations other than the familiar KIT and PDGFRA mutations that might play a role in the malignancy of these tumors. Interestingly, low-risk GISTs have relatively few mutations outside of KIT, while malignant GISTs have dozens of mutations across a wide diversity of genes. Unraveling this genetic complexity is one of the primary challenges facing us today, but it holds forth the eventual promise of uncovering new approaches to GIST treatment.

Until very recently, next-gen sequencing was used exclusively for research, but smaller, less expensive instruments are becoming available for use in clinical laboratories. At the Knight Diagnostic Laboratories, part of Oregon Health & Science University, we took delivery of a next-gen sequencer in March of 2011 and spent the next year developing and validating methods to sequence DNA from clinical tumor samples. The system that we chose is the PGM (personal genome machine) from a company called Ion Torrrent (www.iontorrent.com). What is remarkable about this platform is that the DNA sequencing is performed on the surface of semiconductor chips that resemble those inside a computer (Figure 2). This allows the chemical signals generated as DNA is copied to be turned directly into electrical signals that the computer can interpret. Thus, the output from the PGM is digital (actual letters), as opposed to the analog signal of Sanger sequencing (colored peaks that must be interpreted). The difference is rather like that between modern digital cameras that produce image files, as opposed to old-fashioned cameras that used film. We can generate a lot more information, and more quickly, using the digital approach.

Using next-gen sequencing, we can simultaneously sequence a whole panel of genes relevant to GISTs, as compared with looking at just seven exons of KIT and PDGFRA. The results are turned around in nearly the same time frame, and the difference in costs is nominal. Our new GIST panel is used primarily to assess 'wild-type' GISTs, which lack a KIT or PDGFRA mutation. The panel covers 21 other genes known to be important in GISTs, including the SDH genes that were recently found to be mutated in a subset of wild-type GISTs. It is our hope that by using this panel we will help to identify tumors with some of the more rare, but potentially targetable, mutations, including those occurring in genes like BRAF, HRAS, NRAS and NF1.

**Figure 2**




*A next-gen sequencer now being used by some clinical laboratories for tumor genotyping. Several million parallel sequencing reactions are conducted on the surface of the semiconductor chip.*

What's next? The revolution in DNA sequencing is not over. Indeed, within a year the cost for sequencing all of the genes in a GIST (not just a select panel) will drop to under $1,000, and there are 'nanopore' technologies on the horizon that will make sequencing even faster and cheaper still. Building computer centers and training personnel to handle all of this information is the next challenge, but the day is not far off when all tumors will be subjected to a complete genetic analysis before any treatment decisions are made.

# GDOL from Page 1

Al B. Benson III, MD FACP Professor of Medicine Associate Director for Clinical Investigations, Robert H. Lurie Comprehensive Cancer Center of Northwestern University, explained GIST in detail, describing the treatments available and how working with your whole treatment team is vital to successfully managing the disease.

Jim Hughes, LRG Clinical Trials Coordinator gave a talk on clinical trials, what's currently available and how to navigate them. This can be a particularly difficult avenue for anyone facing progression after having exhausted the currently available drugs. Jim is a wealth of knowledge and we encourage anyone in need of information on trials to contact him at **tjhughes43@comcast.net**.

At noon, we enjoyed the culinary delights provided by Sodexo of Northwestern University, The Chicken Marsala and Vegetarian Lasagna highlighted a terrific lunch which was a great time for all of us to talk and get to know each other better. A big thank you to Nicole Cattouse from everyone at the event. Well done!

The Pathology of GIST by Dr. William Laskin, MD Associate Professor of Pathology Northwestern University, was a highlight to the day. Dr. Laskin explained in easy to understand terms how the tumors can begin, how the cells of the GIST tumor work, and how mutational testing and information can be so important to treatment.

Lastly, everyone had an opportunity to ask the expert panel their questions. This is one of the most commented on areas of the day—so many people were glad they had a chance to share their questions and get detailed information from our esteemed panel.

On behalf of The Life Raft Group and all the attendees, many thanks to Northwestern University, and to Sharon Markman for all her assistance in making this such a successful event. And thank you to Dr. Benson, Dr. Laskin, Dr. Wayne, Dr. Agulnik and Jim Hughes for such wonderful presentations.

A special thank you goes out to Megan Cahill from Northwestern, whose assistance and company during the day was so greatly appreciated. To our volunteers, Jim and Margie Hughes, Tony Reynes for photographing our gathering, and to Shellie Neveles. It is only with the help of others that any of us succeed.

We are now planning the next GDOL event to be held in California, so stay tuned to our website, Facebook and Twitter for more details!






Check out more photos from the event at bit.ly/GDOLChicagoPics

# New blood test may be effective in detecting mutations

**By Phil Avila**
Newsletter Editor

A new blood-testing technology may lead to major changes in treatment of Gastrointestinal Stromal Tumors.

In a study presented in April by Dr. George Demetri of the Dana-Farber Cancer Institute at the American Association for Cancer Research annual meeting, the blood test was shown to be more effective than traditional biopsies in identifying secondary mutations in GIST.

The research was done with GIST patients who were participating in the Phase III clinical trial of regorafenib, now marketed as Stivarga by Bayer. Using a technology known as BEAMing Digital PCR, developed by Inostics, the researchers analyzed blood samples drawn from patients after the disease had become resistant to both imatinib and sunitinib, the first-line and second-line treatments for GIST.

A Dana-Farber press release explained that Demetri and his colleagues compared whether BEAMing technology or traditional tissue analysis was better at picking up "secondary" resistance mutations in the gene for KIT — abnormalities that emerged after the disease had become resistant to imatinib and sunitinib. The BEAMing technology proved far superior, finding such mutations in 48 percent of the blood samples, compared to only 12 percent found in tissue samples using traditional methods. Moreover, nearly half of the blood samples with secondary KIT mutations were found to have not just one such mutation, but several.
In the press release, Demetri said: "Older tools failed to show the breadth and depth of the cancer genomes in any single patient, and this can lead to failure in the process of choosing and evaluating new therapies for patients. A comprehensive approach to detecting and understanding the impact of different mutations in cancer within each individual patient has before now been impractical, but with this new blood test, we hope to make it easy to integrate it into research trials as well as, eventually, into routine clinical practice to make cancer care more precise and personalized to the needs of each patient."

Jerry Call, Science Director of the Life Raft Group, said the new technology may be several years away from practical application but could have two very important implications for GIST patients.

"First, it promises to allow doctors to be able to personalize medicine in a way they haven't been able to do before. They can give patients the right drug at the right time. As resistance develops to imatinib and sunitinib, they will be able to identify secondary mutations and treat them with a drug that works with those mutations." Combinations of drugs to treat several mutations may become more common and more effective, he said.

"Second, it may help provide better control for adjuvant treatment by knowing sooner when to respond with the right drugs."

He said it seems likely that the test could be optimized to detect either primary or secondary mutations, which would make it useful for adjuvant monitoring in GIST and possibly in other cancers as well

One of the issues that will need to be worked out, he said, is determining at what point detectable levels of mutations in the blood are clinically significant.

The LRG has already begun looking into the possibility of developing a plasma bank, similar to its tissue bank, that could aid in GIST research, he said. However, he said there will be a few logistical and regulatory hurdles that will have to be addressed.

"We want to do this as soon as possible," he said, emphasizing the value of this new technology. "In many ways, it will be easier for patients to obtain blood samples than tissue samples. It will be extremely valuable to have blood samples at different time points in treatment; something that is not easy to do with tissue.

He added, "We are very grateful to Dr. Demetri and Bayer for showing the effectiveness of this new technology."

To view Dr. Demetri's presentation, click here: **http://bit.ly/12WdYIX**

# Hospice from Page 3

ed that a period of time off the drugs lets the body get the rest it needs to build its strength back. She also mentioned she's had some patients in hospice for over two years. There's no particular time limit, which was also very comforting to us.

While we had once feared entering hospice, it quickly became the lifeline we didn't even know we needed. Over the next eight months any time there was an issue, a high fever in the middle of the night, unexplained nausea, confusion, and especially pain, we were able to get a nurse to the house within a couple of hours who was then able to assess what was happening and provide changes to medications to bring any issue under control. Four times this included checking into a hospice unit, a homey feeling room in a quiet facility with 24-hour nurses whose sole purpose is to make the patient and family comfortable.

Once there, they were better able to monitor what was happening, administer comfort measures, switch drugs, increase pain medications, whatever was needed to make him comfortable again. His stays lasted from two days to 10 days depending on the nature of the visit. Once stabilized, we got to go back home. It was a true blessing to have this dedicated team work so hard to keep my husband comfortable. Without them, he would not have been able to do as much as he did, for as long as he did, with family, friends, and me.
If you have any questions or would like more information on hospice care, please contact your local hospice or write me at **jryan@liferaftgroup.org**

# Carrie Broussard and her 'little brave warrior'

**By Phil Avila**
Newsletter Editor

Carrie Broussard gave birth to a healthy baby boy on May 1, after finding out she was pregnant in the midst of treatment with Gleevec. She named him Caelum, which in the Celtic origin means 'brave warrior' and in the Australian origin means 'a gift."

Little Caelum is both to Carrie, and after reading the first part of our series on family planning in the April newsletter, she wanted to share her story with other women with GIST.

Carrie was diagnosed with GIST in 2011 after giving birth to her first son, Dodson. Because her tumor was ruptured and she had liver abscesses, she wasn't able to start on adjuvant Gleevec right away.

"At the time, my doctors told me not to have children while on Gleevec," she said. She said she was heartbroken because she wanted a big family, but she began using an IUD to prevent pregnancy and planned to stay on Gleevec for several years.
She had been on Gleevec for 13 months when she learned that despite the IUD she was seven-weeks pregnant.

"I stopped Gleevec—figuring it's better to be safe," she said. "I didn't know what to do. I felt like I was really on my own."

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 women 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 http://bit.ly/18GALIP

Novartis Pharmaceuticals, maker of Gleevec, the FDA's approved first-line treatment for GIST, is currently conducting a clinical trial on pregnancy and exposure to those drugs but results won't be ready until at least 2014. See **http://1.usa.gov/11ikpkY**

Carrie feels blessed that Caelum's birth went smoothly. "I think I made the right choice," the 32-year-old mother said. She lives in Virginia with her husband, Les, and their two sons. Les is serving in the Navy and is stationed in Virginia Beach.

Her concern now is how the fatigue she expects to set in when she resumes Gleevec will impact her ability to parent a two-year-old and a newborn.

"I know how exhausted I got when I was on Gleevec," she said. "Hopefully, my energy levels will pick up." She also hopes to eventually resume work as a physical education teacher, a job she left after she was first diagnosed.

The LRG recently started a Facebook group for women that focuses on family planning issues that Carrie has been following. "I think it's a great idea," she said, indicating that any women who want to ask her about her experience can contact her there or email her directly at **cbroussard090608@gmail.com**.

## With your help, a cure is within our grasp!

You may have seen our spring appeal in your email or home mailbox…join us now as we work to find a cure for GIST. We know….a cure is within our grasp.

Simply go to www.liferaftgroup.org or mail a check to The Life Raft Group, 155 Route 46 West, Wayne, NJ 07470.

**Help us make a difference to the entire GIST community.**

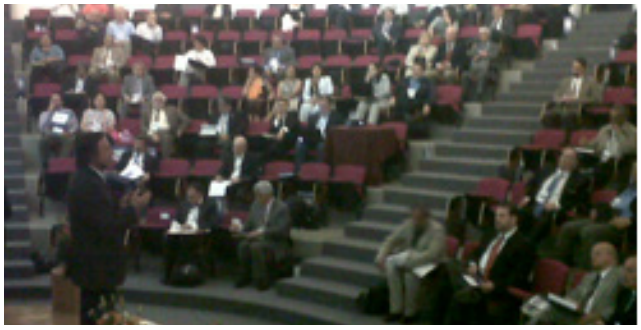
# Rodrigo Salas encourages universities to discuss GIST and other rare diseases

**By Piga Fernandez**
Global Relations Coordinator

Rodrigo Salas, the President of Fundación GIST México, participated in the XVL Ordinary Session of the Mexican Academy of Faculties of Medicine on April 19, where he and more than 80 university representatives discussed the problem of forgetting rare diseases like GIST in the curricula.

It is estimated that in México about six to seven million people suffer a rare disease, according to Eurordis. This number rises in Europe to more than 30 million. It is also estimated that about 2,000 people develop GIST in México each year, and most of them aren't diagnosed.

In order to develop new actions, Fundación GIST México has created new alliances with other organizations of rare diseases, like Proyecto Pide un Deseo México IAP, and has participated in diverse activities



*Rodrigo Salas at the Ordinary Session of the Mexican Academy of Faculties of Medicine*

with the universities. One example of this is the meeting with directors of faculties last April; the main objective was to create awareness and also ask the directors to include in their syllabi rare diseases like GIST. Mr. Salas also invited them to participate in the campaign "Que todo México conozca el GIST," or "All México knows about GIST," which includes workshops and even a contest for the students.
The first problem for rare diseases and GIST patients, in México and in Latin America, is to get an accurate diagnosis; by working with students and universities, Fundación GIST México hopes to end this serious problem.

# Joel Salazar again in the streets of Chile for GIST


Joel Salazar of Chile participated in a massive march in Concepción to create awareness about the high cost of cancer treatment.

# Marathon brings GIST awareness to Richmond, Va.


**By Gale Kenny**
Program Associate

The numbers of walkers, runners and spectators who gathered in support of Dana Pearson's GIST fundraiser in Virginia was both heartwarming and astonishing. Dana, a GISTer, a wife, and mother of two boys, had an idea to ask some friends to join her for the Monument Avenue 10K, a yearly event through the historic streets of Richmond.

"The Monument Avenue 10K is a huge race," commented Dana, "so I asked my friends via Facebook and email to join me, wear an LRG t-shirt, and/or donate to the fundraiser."

On Saturday, April 13, over 50 people joined together in support of Dana's philanthropic enterprise. The warm spring weather and the 40,000 people in and around the 10K brought high energy and an infectious excitement. Later, in the cul-de-sac outside Dana's home in Chesterfield, the fun continued. It was an honor to attend and to represent the LRG as a guest at this party, meeting all who had a role in making this fundraiser such a great success. Between the genuine southern hospitality and Dana's transplanted New Jersey neighbors I felt right at home! Friends continued to arrive all evening; the turnout in support of Dana was inspiring.

After the weekend, I asked her how she came upon this idea and she replied, "I was so inspired by Maura Cesarini and the work she had done trying to help The Life Raft Group find a cure. I thought to myself, 'I can do the same.'"

Maura had GIST and was a beloved longtime member of the LRG. She was awarded the 2012 Courage award by The Sarcoma Foundation of America for her accomplishments in patient support. Dana's total to date exceeds $2,300, and donations are still coming in. She has intentions of planning an event next year, with aspirations of bringing in more money for LRG research.

We are grateful for the support of the Pearson family and their friends as we continue on our mission to find a cure for GIST.

# Ralph Farmer: coach, optimist and 'bait loader'

Ralph Emmett Farmer of Greenwood, Indiana, passed away on April 20, 2013, following a courageous battle with GIST.

Ralph was born on Jan. 22, 1954, to Charles Eugene and Dorothy Jean (Peachey) Farmer, both deceased, at St. Francis Hospital in Beech Grove. He married Debbie (French) Farmer in August of 1981. The couple has three children: Brooks Michael Farmer, Hayley Jo (Ben) Molin and Marina Ruth Yee. They also have three grandchildren: Ava Elizabeth Yee, Nella Jo Molin & Graeme Emmett Molin.

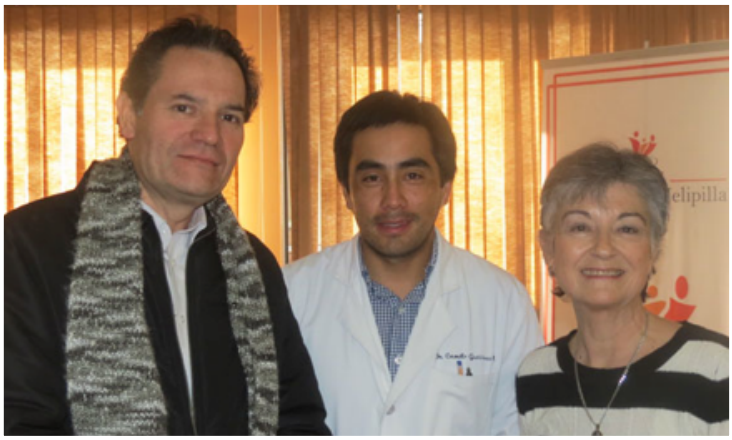
Ralph graduated from Decatur Central High School in 1972 and lived 41 years in the Decatur Township area in Indianapolis and Camby. He also lived in Martinsville for eight years and most recently resided in Greenwood, for the past 10 years.

Ralph was active in youth sports and through the Decatur Optimist Club helped start the little league football & girl's basketball programs in Decatur Township. Through many years of his life, he enjoyed coaching young people in various sports--always the encourager and greatest fan.

When Ralph was not coaching, he was playing semi-pro football with the Southwest Indy Hawks, flag football or as a player with the Capitol Oil Softball team. To this day Ralph still holds the record for most interceptions in a high school football game at Decatur Central. In his latter years, Ralph enjoyed skiing, golf, cycling and shuffleboard with friends. He was also the family navigator and "bait loader" on fishing trips.

In 1978, Ralph & brother Jeff purchased Hoosier Equipment Service Inc. and have maneuvered through the environmental construction business for 35 years. In just the past few years niece Heidi has become Ralph's business partner and trusted friend. Ralph made friends wherever business took him and he cherished those relationships. Ralph's integrity in business carried over to all parts of his life. If he told you he was going to do something, you did not doubt that it would be done--you could depend on what he said, all the time.

# GIST patient talks about her experience at the Hospital San Jose de Melipilla in Chile



Piga Fernández Kaempffer, pictured on right

LRG Global Relations Coordinator Piga Fernández Kaempffer, a GIST patient, gave a conference about her own disease, drawing the attention of professionals, who carefully listened as she shared with them from her perspective the evolution of this pathology.

Her case involved a difficult diagnosis that normally is detected after the patient has had a metastases and has difficult access to its treatment.

She took her time to explain to the doctors and medical interns that in the eventual presence of a Gastrointestinal tumor, and in front of doubts, specific tests should be made to confirm or rule out a Gastrointestinal Stromal Tumor, ensuring that the early diagnosis can stop its growth.

# Development arm loses Christine, but welcomes Lisa as new director

**By LRG Staff**

*Lisa Hart, Director of Development*

All of you who have been a part of The Life Raft Group for the past two years have had the pleasure of getting to know Christine Schaumburg, our Development Director. Christine came to us from her position as the mayor of Clinton, New Jersey. Christine recently left us for a new opportunity as the Executive Director of a shelter that provides women who are victims of domestic abuse support. We wish her the best of luck as she moves forward to do such important work.

We are also fortunate to have had Lisa Hart as our Assistant Director and Lisa has just accepted the position as our new Director of Development. Lisa comes to us with a strong background in fundraising and nonprofit management. Prior to coming to us, Lisa was a consultant for a variety of nonprofits, helping them identify ways to raise funds, event planning, grant writing, networking and strategic planning. She was the executive director for a children's science museum and the director of advancement at Valparaiso University, School of Law. Lisa and her husband, an executive with Bayer Pharmaceuticals, moved to the area last summer from Indiana. Lisa is a Chicago native.

# Alianza GIST gets two new reps as it prepares for June meeting in Miami

**By Piga Fernandez**
Global Relations Coordinator

As Latin American members meet this week, Alianza GIST has added two representatives, one from Brazil and one from Puerto Rico. Valaria Hartt joins us from Brazil, while Eileen Rolon will represent Puerto Rico.

With a Master of Science at Fundação Oswaldo Cruz (FIOCRUZ), the research branch of the Brazilian Ministry of Health, Rio de Janeiro, 2013, Valaria was a member of the postgraduate program of the Institute of Scientific and Technological Communication and Information in Health (ICICT). FIOCRUZ is the main institution for training and qualification of human resources for the Unified Health System (SUS) and for science and technology in Brazil.

As a Journalist specialized in health, who studied at the Faculdade de Comunicação Casper Líbero in São Paulo, Valeria is the executive editor of ONCO & magazine, a publication that presents itself as a vehicle committed to continuing education, to disseminate best practices in oncology and encourage early detection of cancer.

Her professional skills also involve research methods and medical anthropology acquired at Universidade de São Paulo (USP, 2006). Her experience with GIST started in 2010, when her brother-in-law was diagnosed with GIST.

*Eileen Rolon, from Puerto Rico*

*Valaria Hartt from Brazil*

On June 8 and 9, representatives of 14 Latin American countries met to review important GIST-related topics, including clinical updates, interpretation of reports, treatment adherence, effective communication strategies with medical professionals, patents, generics and similar issues, Tissue Bank and Patient Registry programs, and the Monterrey TEC GIST Course.

Drs. Jonathan Trent (Sylvester Cancer Center GIST Team), and Anette Duensing (University of Pittsburgh Cancer Institute) , Bob Chapman (ACS) and Cristina Parons Perez (CCGINTL) will lead the meetings.

Alianza GIST representatives also will share their experiences in a "Best Practices" Poster Session.

## LRG Calendar

**New Horizons - GIST**
Miami, FL
June 5th - June 7th

**Alianza GIST**
Miami, FL
June 7th - June 9th

**Night to Fight Cancer**
New York, NY
September 12th

**The Art of the Cure Gala**
Jersey City, NJ
November 7th

## New Local Group Leader

We are pleased to announce the newest local group leader for Connecticut, Pat Whitcomb.

## Are you experiencing side effects with Stivarga?

If you are currently taking Stivarga and are experiencing side effects, we want to know about them.

Send your side effects and any remedies you have to liferaft@liferaftgroup.org

Thanks,

Your friends at the LRG

# THE LIFE RAFT GROUP

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

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**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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| Belgium | Kris Heyman |
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155 US Highway 46, Suite 202
Wayne, NJ 07470
p: 973-837-9092
f: 973-837-9095
e: liferaft@liferaftgroup.org
w: www.liferaftgroup.org

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# Call for Artists

# WE WANT YOU!

**About the Event**

The Life Raft Group, (LRG) is seeking original art donations for a fundraising event to support cancer research and advocacy for the worldwide community of patients who have a unique cancer called gastrointestinal stromal tumor, GIST.

All artwork will be exhibited and sold at our upcoming gala, The Art of the Cure. We wish to feature visual artists from a variety of styles and media, including sculptors, ceramicists, fiber artists, jewelers, photographers and painters.

This distinctive event will serve a dual purpose of raising awareness for this little known cancer as well as to provide a spotlight on the talent and creativity of the artists who participate. All proceeds will benefit The Life Raft Group's continued commitment to patient survival.

**About the Cause**

The Life Raft Group has a simple focus: to cure a form of cancer -GIST (Gastrointestinal Stromal Tumors) and to help those living with it until then. Your support helps the Life Raft Group provide education, support and research towards finding a cure for GIST.

Fill out the Call For Artists Application Form on the next page.

For more information please contact Gale Kenny at
973-837-9092 ext 105 or at gkenny@liferaftgroup.org

# The Art of the Cure GALA

## Call For Artists

Guidelines:

Art can be any size. The pieces can be in any form.

Eligibility:

Open to any artist willing to donate what they created. Only original artwork will be accepted. We will accept paintings done in all media, sculpture, photography and drawings. You are donating the piece to help raise money for the Life Raft Group. The piece can be any size. We will be accepting art for The Art of the Cure Gala until October 31st 2013. Donated art will be available at the silent auction at the Gala on November 7th 2013. The pieces will be displayed throughout the event.

Sales:

All donated works become the property of The Life Raft Group. Any sales of donated art will go 100% to the Life Raft Group.

Artist Name: _____

Address: _____

City, State, Zip: _____

Email: _____

Telephone #: _____

Website: _____

Title of Work: _____

Estimated Value $_____

Medium: _____

Size: _____

155 US Highway 46, Suite 202
Attn: The Art of the Cure Gala
Wayne, NJ 07470

Email: gkenny@liferaftgroup.org
Phone: 973-837-9092 ext. 105
Fax: 973-837-9095