

*In Loving Memory: Steve Gilman, Jay Hipkins, Rossana Milton, & Larry Freed*

## New technology developed which can predict GIST patient's response to drugs with amazing accuracy

By Jerry Call  
Data Analyst

Researchers have developed a test that can accurately identify over 20% of GIST patients that are unlikely to respond to currently approved treatments. In addition, it can identify which patients need a higher dose of some drugs, which patients should avoid adjuvant treatment and can even direct some patients into specific, tailored clinical trials as well as which patients should avoid specific clinical trials.

Using this test, some new GIST patients with advanced disease could completely skip treatments that have been identified as poor choices and immediately be directed into trials for their specific type of GIST, saving years of treatment with expensive drugs that often have significant side effects.

These patients can access effective treatment at a point when they are much healthier and more likely to benefit.

The test uses readily available tissue blocks from a patient's previous surgery or biopsy. Specialized, but widespread, laboratories are able to analyze the tissue to determine the likely genetic driver of almost any GIST patient's cancer. Preliminary evidence from a large cohort of GIST patients suggests that patients having this test live longer than patients that don't have the test; even after adjusting for multiple confounding factors.

**This test will be available to all GIST patients starting in . . .**

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## The Werners - Finding the New Normal Living with Wildtype GIST

By Carol Tordella  
Web and Design Associate

Bryce Werner was a regular middle-schooler living an average 12-year-old life in Pennsylvania when suddenly everything was thrown wildly left of normal by a GIST diagnosis.

"It started with a cough," Bryce said. Bryce's pediatrician tested for him for whooping cough since it was prevalent in the area at the time. That test was negative and thinking Bryce might have an infection because of a low-grade fever, antibiotics were prescribed.

With no improvement and increasing fatigue and loss of appetite, his mother, Tiffany, took him to the doctor again. This time, the doctor on-call detected the presence of the tumor.



*The Werner Family – (left to right)  
Arianna, Tiffany, Cameron, Bryce, Chris*

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# Believe in Hope - A GIST Story

By Virginia Terrebonne  
GISTer

My name is Virginia VanMeter Terrebonne. I am a 56-year-old female originally from Michigan. I was living in rural Louisiana with my three dogs when I was diagnosed with GIST. Thanks to my sister, Veronica, I am now living in Florida with my dog, Hope. I moved to Florida to be closer to my sister.

In January 2013, a small mass was found on my adrenal gland after having a CT scan for another issue. I was sent to a urologist who said it was nothing to worry about and suggested a follow-up CT scan in six months. When I went back to the urologist for that six month scan, he said let's wait six more months, I agreed. That was a big mistake.

One year later, January 2014, a CT scan found a large 13.6 x 11.2 x 10.6 mass in my left abdomen. I was sent to a general surgeon who did an EGD, which is an endoscopic procedure, and a colonoscopy. The biopsy of the spot in my stomach came back negative. However, the surgeon knew I had stomach cancer but not what type. I was then sent to an oncologist. A search online found that stomach cancer was almost always fatal. I thought I was going to die. It was so unreal. I remember thinking, "This cannot be happening to me."

Next, the oncologist set up a needle biopsy at the local hospital. My sister Veronica drove from Florida to Louisiana to be there for the biopsy. The day before the biopsy the hospital called and said the procedure had been canceled. I found out later that it could have caused the GIST to spread and that my surgeon had intervened to cancel the biopsy. My surgeon then scheduled me for another EGD. The plan was to take samples and while I was on the table, send it off to the lab for testing and to keep doing this until a test came back positive.

The next month, February 2014, I was officially diagnosed with GIST. My surgeon said I was very lucky as I had the good kind of cancer. Then he proceeded to tell me about the life-changing surgery that was upcoming. I was not feeling very lucky but at least he gave me hope. When I went to the oncologist for the treatment plan it consisted of neoadjuvant Imatinib (Gleevec) for six months to a year to shrink the tumor, then surgery. I don't remember if I was offered any other option. All I remember is my oncologist saying, "If you were my mother I'd recommend this treatment plan." After that I don't think I heard another word she said. All I could

think about was "Am I old enough to be your Mother?". I think this thought consumed me for a few weeks. Once I realized that yes, I am old enough to be her mother, I then accepted the fact that I have cancer.

Because of the young age of my first surgeon, I felt I needed one with more experience and a second option. I went to another surgeon and ended up staying with him. He was an oncologist surgeon and had extensive experience with stomach surgery and was very familiar with GIST. He actually had trained my first surgeon. This surgeon agreed with everything my previous surgeon and oncologist had said about treatment. He was very aggressive in my treatment plan. When there was a delay in getting approval for the Gleevec he got on the phone and got the ball rolling. I also had a CT scan every 30 days after starting Gleevec.

After the first 30 days my tumor had shrunk to 8.2 x 7 x 5cm, a total of 15.2cm gone!. I was so happy to get this news. The second month there was no change. I was crushed; it's hard to explain what was going through my mind at this time. I'd break out crying for no reason at all. This caused problems for me at work. They wanted me to go on what I call "happy pills", and see a counselor. When I spoke to my oncologist she said what I was going through was normal and that if I wanted something she would give it to me, but it was not necessary. I opted to let nature take its course with my emotions.

When my 90-day CT scan came up, I was real nervous about it and was again expecting bad news when I went to see my surgeon. But he came into the room with good news. My tumor had shrunk to 4.2 x 6.4 x 5.5cm and it was time for surgery. This was another 4.1cm gone from last time. I was totally not expecting this as my oncologist said six months to a year before surgery and it had been only three months.

Both of my sisters were coming to Louisiana to be with me for my surgery, so it was a few weeks before we could schedule it. I was very nervous about this surgery as I was told it was life-altering and they really did not know what would be removed until they actually opened me up and looked at everything. The tumor on my stomach was at the top close to the esophagus and was also touching my kidney and spleen as well as the adrenal gland tumor, so they were unsure if these organs would be impacted as well. While



*LRG Member*  
*Virginia Terrebonne*

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# LRG Discusses Importance of Real World Evidence in GIST Research at the FDA

By Denisse Montoya  
Patient Registry Director

On April 6th, 2018, Executive Director, Norman Scherzer; Data Analyst, Jerry Call; Real World Evidence Scientist, Yu Wang, and Patient Registry Director, Denisse Montoya, of The Life Raft Group, were invited to present at the Oncology Center of Excellence Research Rounds at the Food and Drug Administration (FDA). The goal of this presentation was to illustrate, based on data from the LRG Patient Registry, how overall survival in advanced GIST patients has improved over time and how this correlates with the ability to access new drugs.

During this presentation, our team compared data from the LRG database to data from different studies, including clinical trials. Results showed that patients in our database had a better overall survival rate than patients in such studies. The improvement in overall survival is strongly linked to the access of subsequent lines of treatment after first line treatment fails. Real world evidence helps to provide a faster understanding of the efficacy of oncology drugs by enhancing the generalizability of clinical trial results to patient

populations not studied in registration trials.

Another possible correlation to higher overall survival in our database might be due to patient engagement. Being a proactive and involved patient has a positive effect on patient outcomes. Engaged patients tend to take preventive measures, which could include mutational testing, constant evaluations and check-ups.

This presentation allowed the Life Raft Group to demonstrate the importance of real world data in current GIST research. This type of data can provide patients, healthcare professionals, and researchers with first-hand information about people with certain conditions, both individually and as a group, to increase the understanding of the GIST patient's journey.

We would like to emphasize that none of this data could have been obtained without the valuable help of our courageous patients (particularly those who gave all), caregivers, and collaborators. The LRG truly believes that collaboration will drive us closer to a cure. We look forward to more potential collaborations that will grow and develop GIST research.

## Scottsdale Arizona hosts the first GDOL of 2018

By Laura Occhiuzzi  
Senior Director of Outreach and Engagement

The Life Raft Group held its first GIST Day of Learning 2018 in sunny Scottsdale, Arizona on March 10th. GDOLs are free, one-day programs that provide both education and support to the GIST community. Top GIST specialists present the latest on research and treatment options as well as provide a comprehensive review of the science behind GIST. GDOLs provide an opportunity not only to meet and interact with local expert practitioners in an intimate setting, but also for patients to connect with one another in a supportive environment.

Over 60 patients, caregivers and researchers attended the weekend event. Mahesh Seetharam, MD and Donald Northfelt, MD both from Mayo Clinic Hospital in Phoenix, opened the day with an Introduction to GIST 101. Many of the attendees were newly diagnosed, so this session was very informative.

patients. Nabil Wasif from Mayo Clinic Phoenix provided insight about "Surgery: What to Expect and Management After Surgery". Scott Kriegshauser, MD from Mayo Phoenix discussed the "Role of Interventional Radiology in Treatment of localized Metastatic Disease", followed by Michael Gordon, MD from HonorHealth Scottsdale who discussed "Treatments, Promising Clinical Trials and Immunotherapy". Eric Yancey, Pharm.D closed out the day with a discussion about "Management of Drug Side Effects".



*Laura Occhiuzzi with  
GDOL Scottsdale participants*

GIST Days of Learning provide an opportunity to interact with the physicians and presenters as well as other patients and caregivers. The session was extremely interactive. A huge thank you to all the physicians who spent the day taking questions from the attendees. I would like to personally thank both Nikki Morales and Colleen Carney for sharing their stories with us.

Thank you to Novartis, Bayer, Pfizer and Deciphera for sponsoring our 2018 GDOLs.

Surgical Management of GIST is a concern for many GIST

# Salud con Datos – Partnering to Share Real World Data in Latin America

By Sara Rothschild  
Senior Director of Program Operations

Over the past few years, The Life Raft Group has been strengthening its efforts in Latin America as it focuses on harnessing data to improve GIST patient outcomes. We have built strong relationships with GIST patient advocacy groups, who, in turn, have formed key connections with a network of physicians that treat many of the GIST patients in their respective countries.

With a shared goal in mind, both patients and doctors see the need to improve the lives of GIST patients in the region. Many countries do not have access to the GIST therapies that are conversely approved and reimbursed in the US and Europe. It is important to understand the patient diagnostic and treatment journey to relay to health authorities the need for better access to life saving treatment.

Taking this into account, The Life Raft Group convened a two-day meeting in Miami, Florida this May, called Salud con Datos (Health with Data) to discuss data projects from Argentina, Chile, and Mexico, and set goals for 2018. Our objectives were focused on:

- Improving Health with Data
- Generating Knowledge through Publications
- Highlighting the Patient Perspective
- Building a Stronger Network

The outcome of this meeting was very exciting! We discussed the expansion of ongoing trials in Latin America as well as creating a regional database connected to the Life Raft Group. It is anticipated that our efforts will yield positive results by generating real world data as we look to improve patients' lives and work toward a cure. We look forward to sharing more about these projects in the future.



*Salud con Datos Meeting participants in Miami, Florida*

## Clinical Trials Transformation Initiative Member Meeting

By Laura Occhiuzzi  
Senior Director of Outreach and Engagement

As part of the Life Raft Group's continuing mission to be actively involved in improving the quality of healthcare for cancer patients, I attended the Clinical Trials Transformation Initiatives (CTTI) member meeting in Rockville, Maryland from April 23-24th. CTTI is a partnership between the FDA and Duke University which seeks to develop and drive practices that will increase the quality and efficiency of clinical trials.

The theme for the two-day networking event was: Opportunities in an Evolving Health Care Environment. Meeting objectives included:

- Learning about forward looking efforts to shape medical product research for the future
- Considering opportunities for CTTI to help stakeholders prepare for clinical trials as they are likely to evolve over the next ten years
- Laying the foundation for new CTTI projects

Presentations included a panel addressing "Global Perspectives on Regulatory Priorities to Improve Public Health", which covered ICH, European, and developing countries perspectives; discussions on "Novel Approaches with Promise" and "Using Case Studies to Highlight and Influence Change". There was also a group discussion focusing on "Implications for CTTI's Mission and Strategy" considering both future projects and potential changes in focus for the CTTI.

This was a good opportunity to share the Life Raft Group's story with members of other advocacy groups, government and the private sector as two of the CTTI's recommendations are to involve patient groups as equal partners and to utilize patient registries to conduct more efficient clinical trials.

The meeting confirmed the importance of real world data and real world evidence, a primary focus of the LRG. The LRG is a member of the CTTI Steering Committee, which provides input into decisions about CTTI priorities, projects and recommendations.

# Global Spotlight



Dmitry Bukhtenkov is the newest LRG Global Representative for Russia. Born in Moscow, Dmitry holds a degree in law and economics. He is the co-founder of Biopolis, LLC, and a task leader in the Strategy/Planning/Business Development Unit at United Heavy Machinery Plants.

Inspired to learn all he could about GIST when his mother was diagnosed with GIST in 2017, Dmitry decided to gather info from the LRG website and to partner with the LRG after conversing with Piga Fernandez, Global Relations Consultant, and Sara Rothschild, Programs Operations Senior Director, at the LRG.

He's interested in creating a online GIST forum, connecting with GIST specialists in Russia to share knowledge and experience, and collaborating with other advocacy and cancer groups in Russia with the same intention.

Elo Mapelu is the new Global Representative for Kenya. Elo is the current Chairman of Henzo Kenya, a community of CML and GIST patients. Henzo Kenya seeks to create awareness about these cancers, provide emotional and social support and education, as well as advocating on cancer related issues that affect their members and the general public.

Elo shared, "Coming together in the Henzo community has encouraged these patients to go on and keep the fight against cancer on. We meet together on clinic days to share experiences and pray together. This intrinsic system of support gives strength to the patients as they see that their journey and hope is shared by many."

Henzo is among the most active cancer patients' groups in Kenya and has played a key part in the emergence of unified voices in advocacy. The organization seeks to destigmatize cancer, which affects therapy outcomes, and make strategic alliances with similar organizations, like the LRG, to find solutions to obstacles relating to cancer care.



## *In Loving Memory of Lawrence B. Freed*



After a long journey with GIST, Lawrence B. Freed passed away Friday, February 23, 2018 surrounded by his loving family. He was the beloved husband of Linda (Menak).

Larry was born June 1, 1949 in Manhattan and raised on Long Island by his late parents Charles and Doris Freed. He and Linda married on May 4, 1991 and moved to Connecticut in 1996 where

Larry worked for IBM Southbury until he retired due to his illness.

Larry is survived by his wife, Linda, mother-in-law, Rita Menak, brother-in-law and sister-in-law, Bob and Camille Menak; nephews Robert and Evan, and great-nephew, Rocco.

The family would like to thank Dr. Fitzhugh Pannill, Dr. Victor Chang, Waterbury Hospital and River Glen Health Care Center of Southbury for providing Larry with exceptional care and support throughout his lengthy illness. The family would also like to thank Larry's dear friend Dr. David Dressler for many years of compassion and understanding.

## Werners from Page 1

"She could actually feel the tumor pressing against his abdomen at that point," said his mom, "and Bryce didn't have any pain; he didn't feel anything at all."

One day before his 13th birthday, Bryce had his first surgery.

Fast forward two years.

Bryce is now a 15-year-old high schooler, living with Wildtype GIST, learning auto mechanics with a half-day at the local vo-tech and working on the rank of Eagle Scout. Bryce wants to be a mechanic.

The path to the new normal was not easy.

Bryce underwent two surgeries – with the first, the Werners were told to prepare for the worst because there were multiple tumors with a large one pressing on Bryce's organs. When the surgeons went in, they saw a tumor wrapped around a blood vessel. They performed a biopsy and closed.

The prognosis was benign, but at the follow-up visit with the oncologist, that prognosis had changed to malignant. Testing revealed GIST. The Werner's local oncologist referred them to the Dana Farber Cancer Institute in Boston, sharing frankly that he didn't have experience with GIST and wasn't comfortable treating Bryce.

Because of the GIST experts at Dana Farber, mutational testing was done and revealed the SDHA deficient gene mutation for which there is currently no effective drug therapy.

"When Bryce came back with the SDHA, , Dr. Janeway of Boston Children's Hospital said it's typically a genetic mutation. She had suggested at that point to have genetic testing done on all five of us to see if it was something that mutated in Bryce on conception or was something that was passed down," said Tiffany.

Arianna, Bryce's older sister, Cameron, his younger brother, Tiffany, his mother, and his father, Chris were tested. Arianna and Chris tested positive for the SDHA gene mutation. Familial GIST is very rare with about 50-100 known cases in the world, according to cancer.net.

"They now have the diagnosis of hereditary paraganglioma syndrome. They have a higher risk of forming paragangliomas that are associated with the SDHA gene mutation," she continued. "With them, they do the scans typically every two years and they do the blood and urine test once a year."

Bryce's second surgery was extensive, removing part of the tumor, stomach, kidney, gallbladder, omentum, and a part of his small intestine, which left him with considerable pain as well as dumping syndrome which is common for this type of surgery.

"My stomach hurts and my back is almost always in pain. There are days that I am extremely exhausted and even my limbs are heavy. I haven't had to change as much active stuff; it's more what I eat. Food goes through me really fast," said Bryce. He has to be careful with sugary foods but abstains from pain medications.

"Bryce doesn't like medicine. He never has," said Tiffany. "I feel like in life he does a lot of things he doesn't want to do. Life has been unfortunate in that way. There are things he can control such as choosing to take pain meds. I try to let him control as much as he can."

"Pain meds don't really help me, and they change how I feel," Bryce said.

Since Bryce's surgeries, Tiffany has changed what she serves her family nutritionally.

"We've changed our diet considerably. Prior to this we were eating frozen food all the time, fried stuff all the time, which is how they still like to eat but I don't put that stuff in the house. So, we've tried cutting out corn syrup, we've tried cutting out a lot of the processed foods, white sugars, things like that. I'm a realist...I'm not going to say you can't have the soda, you can't go out to your friend's house and eat Cheetos and whatever. I'm just not going to supply it in our house. We still go out to eat. He knows his limits."

Bryce has also learned the importance of advocacy along with his family. His local oncologist at the Children's Hospital of Philadelphia works in conjunction with the GIST experts at the Dana Farber Cancer Institute.

"As parents it's not easy to figure out the right path; then again, I'm very lucky because I do trust our doctors. If I have a question or I'm not comfortable with something they say, I'm ok saying that I feel differently or voicing my frustration or sending them an article or something like that. I'm fortunate that way, but I do know that there are a lot of people in the GIST community who don't feel like that – that they don't have doctors like that."

Tiffany and Chris have kept Bryce informed and present for his own care and treatment.

"I think of day one, with Bryce sitting in that hospital room

**"Just keep fighting; don't ever give up."**

**Werners continued on Page 7**

## Werners from Page 6

with doctors rushing in and out. Doctors pulled my husband and me into a different room with the oncologist and we were told, 'You need to prepare for the worst because of the way things look on scans,' and so Bryce, I think from the get-go, was uncomfortable with us leaving the room to talk about him. I think that was one of the only times we've ever done that. Going forward Bryce has been a big part of his care. We've always tried to encourage him to ask questions or if he's not comfortable with something he needed to tell us, but it's always been open conversation in front of him. It's never been sugar-coated. So, in that sense he's very much a part of his own medical plan," said Tiffany.

After two surgeries, Bryce still has three remaining tumors. Surgery is too risky right now due to the location in the liver.

Tiffany commented on this. "They were stable for a while and recently they've started growing. The one is growing a little faster than the other two, but because they're considered inoperable we're told that they can't do anything until they get too big and then they'll go in."

Monitoring with scans and blood tests is now a part of their lives indefinitely. Bryce has scans every three months to monitor the progression of his tumors. Big sister, Arianna, also has scans less frequently, unless she develops symptoms. It's another fact to deal with emotionally.

"I think that anyone you talk to who has cancer or has had cancer will tell you that scan anxiety is a real thing that you have before every scan. Last week was Bryce's scan and the week before that was Arianna's. It is emotionally exhausting, and Bryce's scans are so long that he gets his scans split up in two days," said Tiffany.

The Werner family has found their new normal.

"It's definitely hard to balance [dealing with GIST] and now that we're two years out, it's a little easier just because it's become our everyday and it's not something we have to think about every moment whereas for the first year, it pretty much consumed all of our thoughts and time," said Tiffany, "It's our normal now. And it's not who he [Bryce] is. It's a part of who he is."

Bryce's advice for other teens living with GIST as their normal, "Just keep fighting; don't ever give up."



**When:** July 15th, 2018

**Where:** Margaret Pace Park - Miami, FL & Virtually around the world

Learn More and Register at

[www.liferaftgroup.org/GISTDOIT](http://www.liferaftgroup.org/GISTDOIT)

## Technology from Page 1

... 2003.

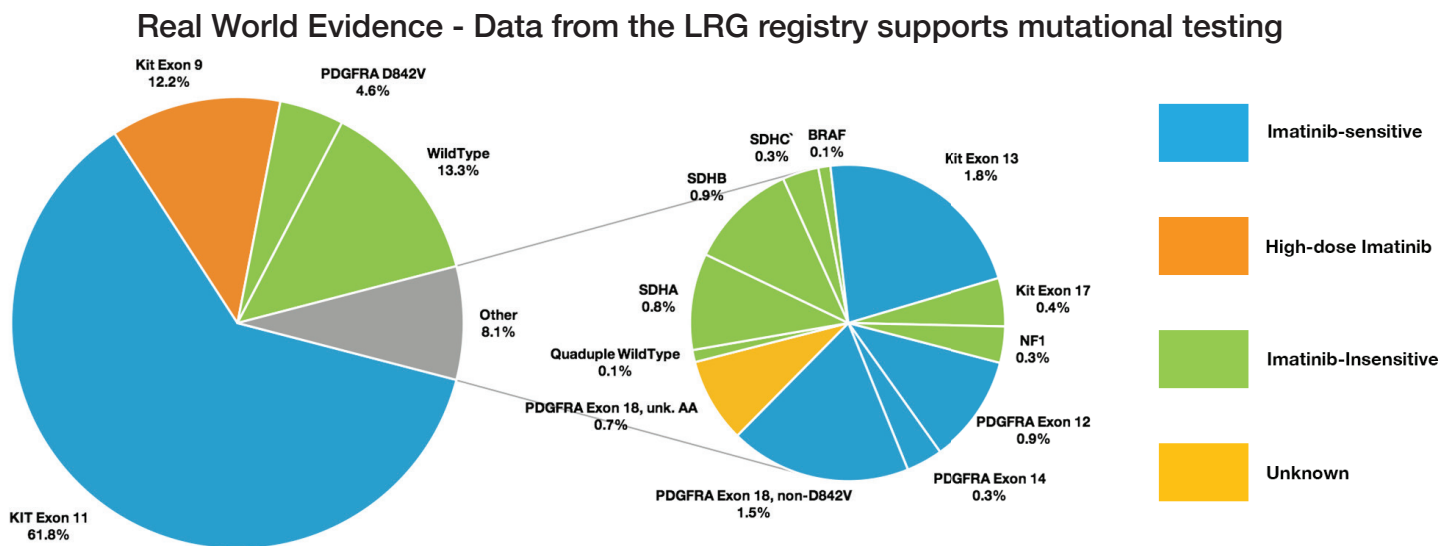
Okay, so the test isn't brand new, but the real question is; why aren't more people using a test that can do all of these amazing things that patients with other cancers can only dream about?

The test is called a mutational test and typically costs about a thousand dollars. This is almost always paid for by insurance. GIST experts all over the world recommend this test; and yet only about half of living patients in the LRG registry have the test. And using the LRG registry as a measure of testing is probably misleading because it represents some of the most engaged, proactive, educated patients in the world and the testing rate in the LRG registry is almost certainly higher than in the general population of GIST patients. In fact, the rate for mutational testing in the general oncology world may be as low as 1% in the USA (in 2010) to 17% in the Netherlands (in 2012) <sup>(1,2)</sup>. The testing rate for patients treated at GIST specialty centers is much higher; as high as 92% in the 2012 study from the Netherlands.<sup>(1)</sup> This is just of many reasons that GIST patients should consult with GIST expert doctors.

Researchers have made great progress in understanding GIST since 1998, and today many different sub-types of GIST are recognized. With the use of mutational testing, it's now possible to understand the driving force for almost all GISTs. Mutational testing has been available since 2003, but its use in GIST remains shockingly low.

A standard mutational test for GIST includes testing for mutations in KIT and PDGFRA and is sufficient to find the driver mutation in about 80% to 85% of GIST patients. Additional testing, including, but not limited to, staining for SDHB is needed, but available, for those patients without a KIT or PDGFRA mutation.

Figure 1 (Below)



**Note:** All data presented is from the LRG Patient Registry. Other series of patients and population-based studies may vary somewhat from these percentages.

The KIT mutations in exon 11 that were the first found in GIST, remain the most common type of mutation making up 62% of all GISTs (LRG registry). Since they are both sensitive to first-line treatment (Gleevec/imatinib) and are the most common type of GISTs, they tend to drive treatment patterns in GIST. However, this leaves 38% of GISTs that are something besides KIT exon 11. From this 38% of all GIST patients, only 12% are fully imatinib-sensitive; 55% are insensitive to imatinib; 32% have intermediate imatinib sensitivity. Kit exon 9 mutations require a higher dose of imatinib and 2% of patients with a listed mutation type have unknown imatinib sensitivity. 20% of PDGFRA exon 18 mutations with an unreported amino acid, 2/3 of these can be expected to be the insensitive D842V mutations.

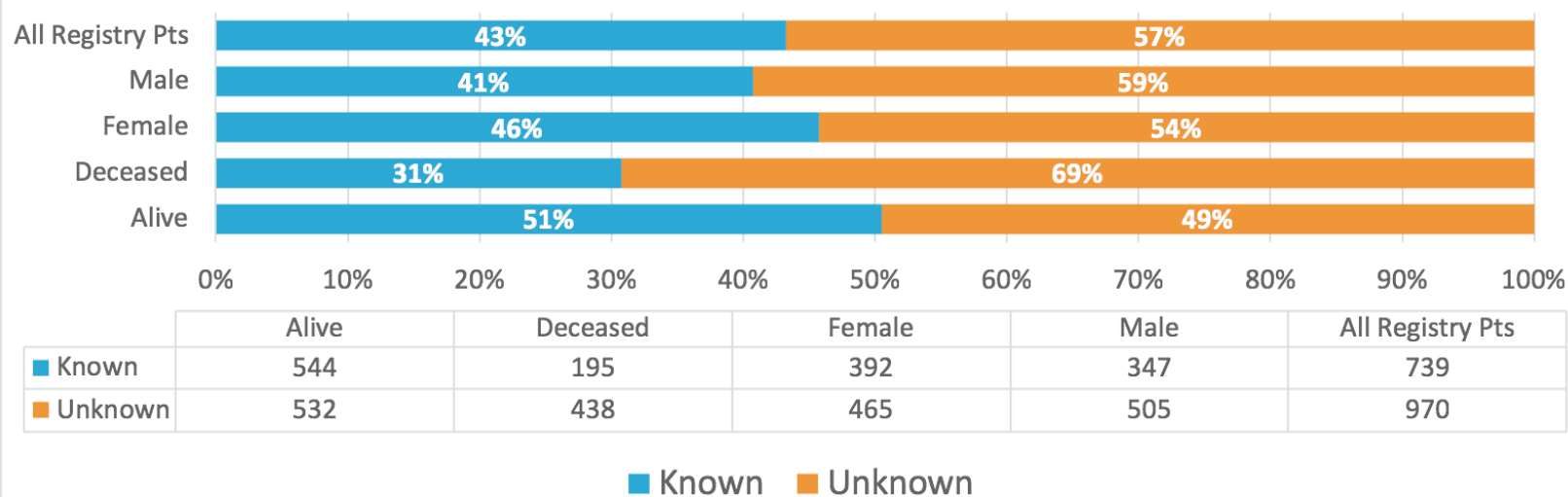
When we include all LRG patients with a known mutation type (n = 739) including the KIT exon 11 patients, two thirds (66%) are imatinib-sensitive, 12% have intermediate sensitivity, 21% are insensitive to imatinib and 1% have incomplete reporting and thus unknown sensitivity (figure 1).

### Data from the LRG Registry

In the LRG registry, 43% of patients (n = 739) reported a mutation to the registry (known) and 57% (n = 970) reported as unknown mutation (figure 2). The unknown most likely represents that the patient did not have any testing, but there may be some cases where testing was done and the patient either did not realize that testing had been done or did not know the result. The percentage of patients with known mutation has increased over time and 67% of LRG patients diagnosed in 2013 or later reported a known mutation.

The rate is also higher if we consider only living patients, with 50.6% of living patients having a known mutation. Unfortunately, this still leaves almost half (49.4%) of the living LRG patients without testing. A very high percentage when you consider that most living LRG patients are either currently metastatic (49%) or at high risk of a recurrence (71% of patients with known risk criteria that have not had a recurrence).

### Mutation Status in the LRG Patient Registry



**Figure 2 (Above)**

Using registry data, we calculated the overall survival times from patients with a known mutation and compared this to patients with an unknown mutation. We calculated this in a number of different stages of disease and overall survival was longer for patients with a known mutation in every stage of treatment through 3rd line. There are a number of confounding variables that make such a comparison difficult and we have identified at least some of these variables and included them in a multivariable analysis to estimate the effects of these variables on survival (using a Cox-proportional hazards model).

#### Variables that affect the data

The confounding variables that we have been able to identify include:

1. Date of diagnosis and date starting treatments (new treatments have improved survival over time and mutational testing rates have improved over time.).
2. Age – Younger patients have increased rates of testing and longer survival due to the predominance of SDH-deficient GIST in younger patients.
3. Gender – Females have longer survival times in GIST and have mutational testing at a slightly higher rate than males.
4. Patients with higher risk GIST or patients undergoing adjuvant treatment are more likely to get testing.

After including these variables in the model, mutational testing remains significant. Patients with a mutational test lived longer in our analysis and the difference can be as much as 80% higher risk of death for those without testing

(depending on stage).

In our opinion the most important confounding variable of all is very difficult to measure. We believe that being a proactive, engaged patient affects your survival, and proactive, engaged patients are much more likely to both ask for a mutational test and to seek out expert GIST doctors for consultations and additional treatments such as participation in clinical trials. The good news about this for patients is, that this is a variable that is almost entirely within a patients control. A patient can choose to become educated about their disease, to ask to see a GIST specialist, to ask for a mutation test, to become proactive and engaged in their care. Or if they need help, to ask a family member to be their advocate.

Mutational testing evolved over many years. With each new revelation, the evidence and value for testing became stronger and stronger. If mutational testing weren't available and we were suddenly presented with a new test that would do all of the things that mutational testing can do today, we would proclaim a tremendous victory and it would immediately become the standard of care.

**Note:** Mutational testing rates are lower for GIST patients with a low risk of recurrence. These patients may be seen more often in local oncology settings and under-represented in GIST specialty centers as well as the LRG registry. While not performing a mutational test for low risk patients not being considered for drug therapy may seem like a reasonable decision, there are other considerations, such as the risk of familial GIST for some SDH-deficient patients. Low risk patients not receiving drug therapy or mutational test should have enough testing to rule out SDH deficiency (such as staining for SDHB).

1. Pisters, P. W. T. et al. A USA registry of gastrointestinal stromal tumor patients: changes in practice over time and differences between community and academic practices. *Ann Oncol* (2011). doi:10.1093/annonc/mdq773
2. Verschoor, A. J. et al. The incidence, mutational status, risk classification and referral pattern of gastro-intestinal stromal tumours in the Netherlands: a nationwide pathology registry (PALGA) study. *Virchows Arch.* (2018). doi:10.1007/s00428-017-2285-x

## Hope from Page 2

waiting for my sisters to come, I went to the counselor my employer had suggested. The first thing this guy asked me was "Am I prepared to die?". I mean really, I'm going in for major surgery that could very well cost me my life and this guy is asking me if I was prepared to die. I wanted to tell him of course I'm not prepared to die. I'm too young to die! At this time, I really could have used some encouragement not negativity.

July 30, 2014 my surgery was finally performed. I was in intensive care for three days afterward, then transferred to the cancer ward. My lower esophagus sphincter and most of my stomach were removed along with the adrenal gland tumor. I was not allowed to eat or drink anything by mouth for about 30 days. The whole time I was in the hospital all I wanted was a drink of water. I really was not hungry but desperately wanted a glass of water. To this day I can only drink spring water; anything else tastes nasty.

While I was in the hospital they would send me for a swallowing test. I remember the first test the barium leaked out where the stomach and esophagus were attached. The technician asked me if I would be returning to surgery to have it fixed. Oh no, not more surgery. Eventually the bond between the stomach and esophagus healed without more surgery.

Three and a half weeks after surgery they started me on the feeding tube in preparation to go home. I was home less than a week when my incision burst, my feeding tube got clogged from the antibiotic and I had a fever. Back to the hospital I went for a week. Finally, the time came for me to be able to eat soft foods. Scrambled eggs, mashed potatoes and pudding. Eight weeks after surgery I was allowed to eat anything I wanted but am supposed to eat six small meals a day.

At the same time, I was released to go back to work. Both of my sisters had gone back home. I was in no way physically or mentally ready to resume working. I had no idea how to eat or even what to eat. To this day I still have issues with eating. I had a really hard time adjusting to working eight hours a day as my job was an hour away from home, so my days were 12 hours long. I suffered from dumping syndrome;

I was so tired I could not concentrate. I'd wake up in the middle of every night sick to my stomach.

For the next two years after my surgery, I thought I was going to die or lose my mind. Actually, at times I wished for death as life was so terrible for me at this stage. Then the local hospital sued me. I had literally been living on credit cards, spending a great deal every month on medical expenses. This was money that I just did not have.

My sister Veronica invited me to come live in her condo in Florida. This way I'd be close to both my sisters. I've been here for almost two years now and I can definitely say I feel a lot safer here. Mentally and physically I feel a lot better too. I now see a GIST specialist in Miami and I've joined a Living Strong exercise class at the YMCA where I met a lot of wonderful people. I'm finally living instead of existing. I've filed for bankruptcy so am getting my finances back in order.

My life has changed in so many ways. Because I am missing my esophagus sphincter I can no longer sleep lying flat on a bed and must sleep sitting up. I still suffer from reflux and I have more doctors than I do shoes. I have issues with eating and often feel ill after eating. I'm tired all the time; just going grocery shopping wears me out. My future is uncertain, but, I thank God I'm still alive and able to enjoy life.

I don't think I could have made it through this difficult journey without the help of my sisters. Both came and took care of me and my dogs while I was in the hospital. I'll always be grateful for their help and their continued support. My boss, Chris, also was a big help; she actually came and visited me in the hospital and at home when I was discharged. She also allowed me to keep my job by working from home here in Florida. I'll always be grateful for all she has done for me. I am also grateful for the GIST community - my very special friends who know how I feel and what I'm going through. And although I lost two of my dogs before moving to Florida, I still have my little girl Hope who is always there for a belly rub. She always knows when I need cheering up.

Living with cancer is not easy, physically, mentally and financially. We can only live to the best of our ability, attempting to live as normal a life as possible. I am very fortunate to have my sisters, my dog and my job. All three have given me the means and reason to keep on going.

My mottoes are "Life is Good", and "Hope: Believe in It." Cancer is not the end but the beginning of a new chapter.

## Events Calendar

**Life Fest - July 13<sup>th</sup>-15<sup>th</sup> - Miami, FL**

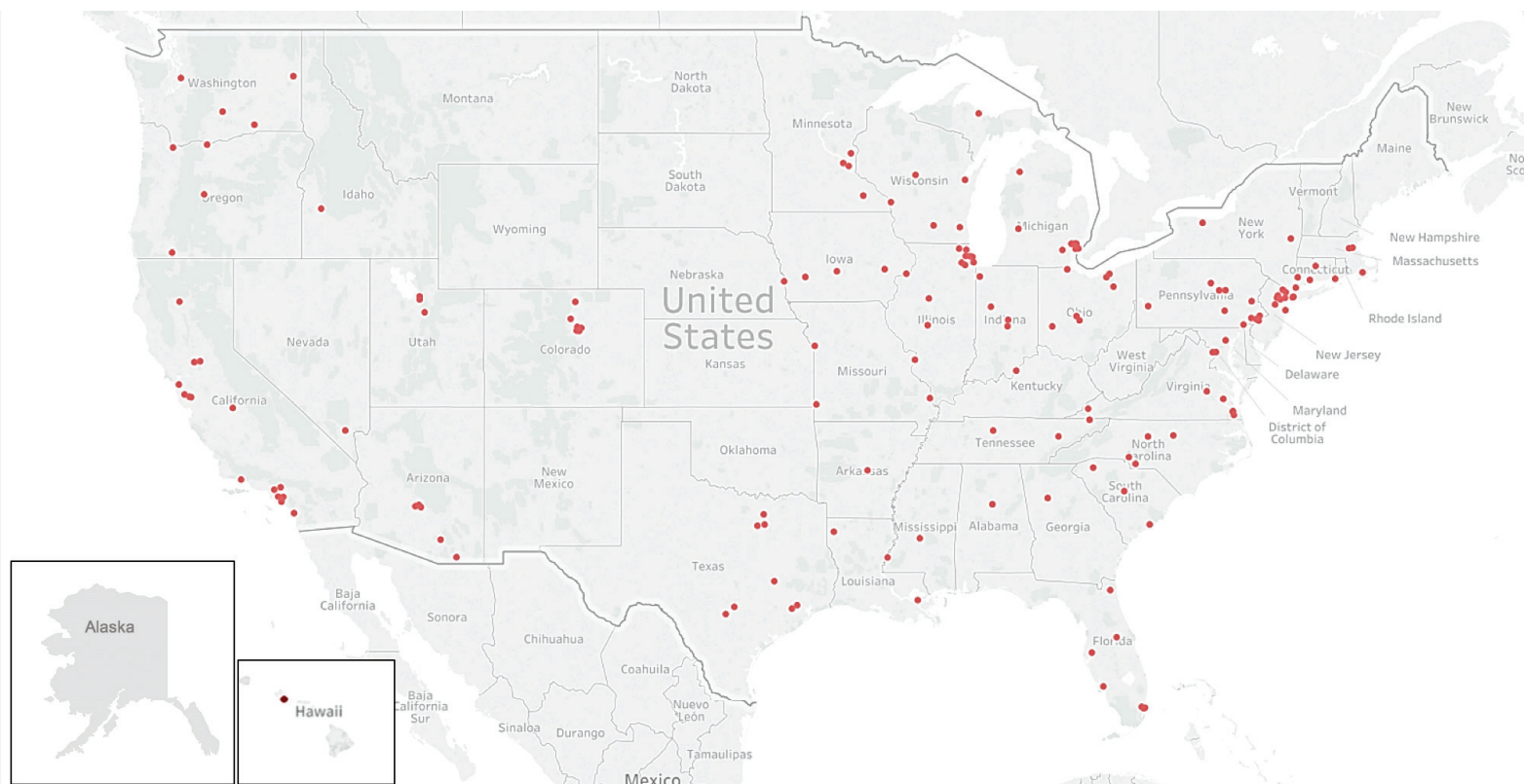
**GIST DO IT - July 15<sup>th</sup> - Miami, FL**

**Chicago Local Group Meeting - September 8<sup>th</sup> - Hinsdale IL**

**GDOL Michigan - October 27<sup>th</sup> - University of Michigan, Ann Arbor, MI**

**To get more info on our upcoming events head to [www.liferaftgroup.org/events](http://www.liferaftgroup.org/events)**

# Where LRG Members receive treatment in the US



Abington Memorial Hospital  
 Advocate Condell Medical Center  
 Akron City Hospital  
 Albany Medical Center  
 Allegheny General Hospital  
 Arlington Cancer Center  
 Arnett Clinic  
 Ashland Community Hospital  
 Audi Murphy Veterans Hospital  
 Banner Desert Medical Center  
 Baptist Hospital  
 Barnes-Jewish Hospital  
 Baylor University Medical Center  
 Bellin Memorial Hospital  
 Beth Israel Medical Center  
 Botsford Hospital  
 Boulder Community Hospital  
 California Pacific Medical Center  
 Cancer Care Northwest  
 Cass County Memorial Hospital  
 Cedars Sinai Hospital  
 Centegra Medical Center  
 Central Dupage Hospital  
 Chesapeake Regional Hospital  
 Children's Hospital of Philadelphia  
 Christus Santa Rosa Hospital  
 Christus Schumpert  
 City of Hope Cancer Center  
 Cleveland Clinic  
 Columbia Presbyterian  
 Comprehensive Cancer Center  
 Comprehensive Cancer Center of Nevada  
 Cook County Hospital  
 Dana Farber Cancer Institute  
 Danbury Hospital  
 Dean Health System  
 Desert Springs Hospital  
 Detroit Medical Center  
 Dixie Regional Medical Center  
 Duke University Hospital  
 Emory Hospital  
 Englewood Hospital  
 Evanston Hospital  
 Exeter Hospital  
 Fairview Wyoming Hospital  
 Fairway Medical Center  
 Falmouth Hospital

Fort Sanders Regional Medical Center  
 Fox Chase Cancer Center  
 Franciscan Skemp Medical Center  
 Freeman Health System  
 Geisinger Medical Center  
 George Washington University Hospital  
 Glenbrook Hospital  
 Good Samaritan Hospital  
 Greater Baltimore Medical Center  
 Greenville Hospital System  
 Hartford Hospital  
 Hematology-Oncology of Indiana  
 High Point Regional Hospital  
 Hoag Hospital  
 Holston Valley Medical Center  
 Huntsman Cancer Institute  
 Huron Valley Sinai Hospital  
 Illinois Cancer Center  
 Indiana University Medical Center  
 Inova Fairfax Hospital  
 Intermountain Medical Center  
 Iowa Methodist Medical Center  
 Jackson Memorial Hospital  
 James Cancer Center  
 Jennersville Regional Hospital  
 Jersey Shore Hospital  
 John C. Lincoln Hospital  
 Johns Hopkins  
 Kaiser Permanente  
 Karamanos Cancer Institute  
 Kellogg Cancer Center/Evanston Hospital  
 Kennewick General Hospital  
 Kirklind Clinic  
 Lankenaw Hospital  
 Las Vegas Cancer Center  
 LDS Hospital  
 Lee Memorial Hospital  
 Lehigh Valley Hospital  
 Lewisburg Cancer Care Center  
 Little Rock Hematology/Oncology  
 Littleton Adventist Hospital  
 Long Island Jewish medical Center  
 Los Alamitos Medical Center

M.D. Anderson  
 Madera Community Hospital  
 Marquette General Hospital  
 Massachusetts General Hospital  
 Mayo Clinic  
 Medical College of Virginia  
 Medical University of South Carolina  
 Memorial Medical Center  
 Memorial Sloan-Kettering Cancer Center  
 Memorial West Hospital  
 Mercy Hospital  
 Mercy Medical Center  
 Mercy Medical Center - California  
 Methodist Hospital  
 Miami Valley Hospital  
 Mid Columbia Medical Center  
 Mills Hospital  
 Mission Hospital  
 Moffitt Cancer Center  
 Monmouth Hematology Oncology  
 Mount Carmel East  
 Mount Sinai Medical Center  
 Munson Medical Center  
 Natchez Oncology Clinic  
 Naval Medical Center  
 Nebraska Medical Center  
 New York University Hospital  
 Newton-Wellesley Hospital  
 North Memorial Hospital  
 North Star Cancer Lodge  
 Northwest Community Health  
 Norton Suburban Hospital  
 O'Connor Hospital  
 Oakwood Hospital  
 Ochsner Hospital  
 Ohio State James Cancer Center  
 Oregon Health and Science University  
 Overlook Hospital  
 Palmetto General Hospital  
 Paoli Hospital Center  
 Peninsula Cancer Institute  
 Penn State Hershey Med Center  
 Pennsylvania Hospital  
 Piedmont Hospital  
 Pocono Medical Center

Poudre Valley Hospital  
 Presbyterian Hospital  
 Providence Hospital  
 Queen's Medical Center  
 Rankin Medical Center  
 Regional Cancer Center  
 Regions Hospital  
 Resurrection Hospital  
 Riverside Hospital  
 Robert Wood Johnson Hospital  
 Rocky Mountain Cancer Center  
 Sacred Heart Medical Center  
 Saint Vincent's Carmel Hospital  
 Santa Barbara Cottage Hospital  
 SC Oncology Associates  
 Scottsdale Healthcare North  
 Seattle Cancer Care Alliance  
 Sentara V.B. General Hospital  
 Sierra Vista Hospital  
 South West Florida Cancer Centers  
 Southeast Missouri Hospital  
 Southwest Hematology Oncology  
 Spectrum Health Butterworth Hospital  
 St Anthony Medical Center  
 St Francis Medical Center  
 St Vincent's Hospital  
 St. Agnes Hospital  
 St. Barnabas Hospital  
 St. Charles Medical Center  
 St. John Hospital and Medical Center  
 St. Joseph Hospital - California  
 St. Joseph Hospital - Wisconsin  
 St. Joseph Medical Center  
 St. Joseph's Hospital - Minnesota  
 St. Joseph's Regional Hospital  
 St. Josephs Hospital - Michigan  
 St. Josephs Mercy Hospital  
 St. Luke's Mountain States Tumor Institute  
 St. Peter's Hospital  
 St. Thomas Hospital  
 Stamford Hospital  
 Stanford Medical Center  
 Strong Memorial Hospital  
 Sutter Davis Hospital

Sylvester Cancer Center  
 Temple University Hospital  
 Texas Cancer Associates  
 Texas Childrens Hospital  
 Texas Oncology  
 The Cancer Institute  
 Thomas Jefferson University Hospital  
 Toledo Clinic  
 Tri City Hospital  
 Trinitas Hospital  
 Trinity Lutheran Hospital  
 Trinity Medical Center  
 Tuomey Healthcare System  
 U. T. Southwestern Medical Center  
 Union Regional Medical Center  
 University Hospital  
 University of Alabama  
 University of Arizona Cancer Center  
 University of California  
 University of Colorado Hospital  
 University of Iowa Hospitals and Clinics  
 University of Maryland Medical Center  
 University of Pittsburgh Medical Center  
 University of Texas Health Science Center  
 University of Wisconsin  
 Utah Valley Cancer Clinic  
 Valley Hospital  
 Vanderbilt Medical Center  
 Via Christi St. Francis Medical Center  
 Virginia Cancer Institute  
 Washington Cancer Institute  
 Waukesha Memorial Hospital  
 Wellmont Health System  
 Wesley Medical Center  
 Westerly Hospital  
 William Beaumont Hospital  
 Winthrop University Hospital  
 Wright Patterson Medical Center  
 Yale New Haven Hospital

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