

Ensuring no one has to face GIST alone

In Loving Memory: Leslie Donigan, Mamadally Chamroo, Titus Mathew, Ron Agypt, Dirk Niebaum, Antonia Georgakopoulos, Patrick Mullen, T.M.A. Rajudeen, Kathy Bishop, Nikki Morales

Hope Prevails

A Young Mother's Struggle to Survive

By Carolyn Tordella, LRG Web & Design Associate

At 39-years-old, *Fatema Suterwala* (pictured right) was preparing to say goodbye to her husband and young son. Confused by this cruel twist of fate and wracked with pain, she was saved by a collaboration of medical specialists and GIST experts as well as the hope and support of her husband and friends.



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International Focus on the Power of Real World Data to Enhance Advocacy Efforts

New Horizons Meeting Gathers Advocates in NJ

By Sara Rothschild, LRG, VP Program Services

Not many of our readers know that The Life Raft Group has been involved with a global network of advocates since its inception. Every year country leaders gather to discuss scientific updates, regional issues, and unmet needs for the global GIST community. This international meeting was launched by Novartis Oncology in 2003 with the title, "New Horizons in Treating CML and GIST," with the goal of uniting patient organizations representing people living with CML and GIST. A few years ago, the conference divided into two separate meetings—one focused on GIST and the other on CML. Since then, the New Horizons GIST Conference has been organized by a GIST Steering Committee that

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Stepping into Personalized Side Effect Management with SideEQ

What Can SideEQ Do for You?

By Pete Knox, LRG Senior Director, Research

"Never judge a person until you've walked a mile in their shoes."

As a child, I remember hearing that quote quite often. Looking at it as an adult I can appreciate that this is really good advice. It teaches us to look at things from the perspective of others. But why shoes? What do shoes have to do with someone else's perspective? And what does this have to do with side effects? Let me explain a few things, and I believe the path will reveal itself.

Shoes and oncology

If you have ever shopped for shoes, you know there are a myriad of choices. Shoes are made in different materials, such as leather and canvas, and come in an endless variety of styles, like dress shoes, sneakers, or even shoes designed for specific pursuits; hiking, golf, or water shoes for the surf at the beach. Moreover, shoes come in different sizes and widths, and are usually sold in women's and men's versions - and for at least the last few hundred years, have a left and a right one that are shaped a little bit differently to accommodate the shape of each foot. Lastly, you know that no matter how much you examine these choices, you have to actually try the shoes on, because even though two pairs may be of the same size and width, they may also fit each person very differently.

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From Our Executive Director

We have had too many losses. There are no words. I will just share this poem with you for now.

- Norman J. Scherzer

God saw her getting tired
And a cure was not to be
So He put His arms around her
And whispered,
"Come to Me."

With tearful eyes
We watched her suffer, and
Saw her slowly fade away.
Although we loved her dearly,
We could not make her stay.

A golden heart stopped beating,
Hard working hands put to rest,
God broke our hearts
To prove to us,
He only takes the best.

- Anonymous



If you would like to light a candle in memory of a loved one, please visit <https://lrginmemoriam.org/>

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aims to unify the global GIST patient advocacy community with key opinion leaders and facilitate ways to increase survival worldwide. What you may not know is that these advocates have over the years become lifetime friends. We celebrate happy occasions together and commiserate when we lose dear friends. We have walked through GIST history together.

In May, The LRG happily reunited these advocates and hosted the large annual global conference called New Horizons GIST near our headquarters in Wayne, NJ. We had 45 participants from 18 countries. One of the meeting's most important goals was to share relevant medical and scientific information about GIST, but just as



Left to right: Nick Taylor, Sara Rothschild, Florence Thwagi



Left to right: Dr. Ciara Kelly, Kathy Gram, Tony DeFilippo, Dr. Ping Chi, Dr. Jason Sicklick

important is the exchange of ideas and experiences that each one has had in their countries around topics such as collecting real world information, mutational testing, and advocacy efforts with health authorities.

Sharing Research Updates

Dr. Ping Chi from Memorial Sloan Kettering Cancer Center (MSKCC) spoke of the challenges of imatinib-resistant GIST, citing that 14% of patients experience primary resistance and 50% develop imatinib resistance after two years. She also discussed how there is a need to improve front-line therapy for KIT/PDGFR wildtype GIST and explore better options for multiple refractory disease, as well as develop "liquid biopsies."

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Beyond the standard options of care, Dr. Ciara Kelly from MSKCC shared updates about two relevant clinical trials for the GIST community:

1. DCC-2618 (ripretinib) is designed to inhibit a broad spectrum of KIT mutations in exons 9, 11, 13, 14, 17 & 18 and PDGFRA in exon 18. Results show promising activity across all lines of therapy.

The INVICTUS Phase III trial of DCC-2618 vs. placebo in \geq 4th line GIST patients is complete.

The INTRIGUE Phase III trial of DCC-2618 vs. sunitinib in 2nd line GIST patients is currently recruiting.

2. BLU-285 (avapritinib) is designed to interact with KIT and PDGFRA. Based on data from the NAVIGATOR study, avapritinib was granted Breakthrough Therapy Designation by the U.S. Food and Drug Administration (FDA) for the treatment of unresectable or metastatic PDGFRA D842V-mutant GIST.

Blueprint also recently submitted their first NDA (new drug application) to the FDA for approval.

There is encouraging activity in the VOYAGER Phase III trial BLU-285 vs. regorafenib.

Mutational Testing is Key

As the group learned about these scientific breakthroughs, a key takeaway was the importance of mutational testing. Physicians stressed the importance of personalized precision medicine as a new paradigm shift in oncology. They demonstrated that technology such as next generation sequencing performed in diseases such as GIST can yield results that may potentially match with targeted therapies, emphasizing the importance of treating the right patient with the right drug at the right time. Still, the question remains: How do we make this applicable within a global context when this type of testing is not affordable or accessible in many countries?



Left to right: Matt Mattioli, Diana Nieves, Laura Occhuizzi, Pete Knox

Even if the testing is available, is the targeted therapy available in the country or can the patient afford it?

As global patient advocates, we need to understand the broad range of challenges that patients face with this new era of precision oncology.

Real World Evidence

The second half of the meeting shifted to the power of real world evidence in order to educate and inform global representatives of how to apply it in their advocacy efforts. For example, electronic health records can provide one piece of information about a patient treatment journey, but are there other forms of data that can complete this picture, such as from registries, social media, apps, wearable data, and patient reported outcomes? There are lots of pros and cons in assessing the benefits and drawbacks of real world data, but we need to pay attention to how it is already at work in regulatory and coverage decisions. We were pleased to hear two presentations of 'RWE in Action' from Rodrigo Salas of Fundación GIST México and Piga Fernández of Fundación GIST Chile in which they demonstrated how data from their registries has made a positive impact in the creation of national registries and the enactment of cancer laws, respectively.

In summary, the group left energized and unified. We are so excited to continue the dialogue on how to bring information to light in these changing times and how we can support one another with these efforts.

Global representatives gather for New Horizons conference



▶ HOPE PREVAILS continued from cover

Fatema's personal path led her from her family in India to university in the United States; working in NYC until she decided to return home in her mid-twenties. Diagnosed with GIST in India in 2006, her doctor performed surgery, but no follow-up treatment plan was advised. She truly thought her surgery at 25-years-old was the end of that episode of her life. The doctor had the knowledge to recognize the type of cancer Fatema had, but very little was known about GIST at the time and even less at that time in India so no adjuvant Gleevec was prescribed nor follow-up scans or testing.

Fatema met her husband, Shabbir, in 2007. They were married and made their home in California. In 2010, they were blessed with a beautiful baby boy. Just a few weeks before her child's second birthday in 2012, Fatema remembers complaining to Shabbir of stomach pains daily for a while. So began the next leg of Fatema's journey - one that is punctuated with both confusion and seemingly random moments of divine intervention.

A relative, who was a gastrointestinal specialist, recommended that Fatema have a CT. She did and was told by the doctor evaluating the scan that she had ovarian cancer. He seemed surprised that she was unaware of this.

"They told me I needed to be in surgery immediately. You cannot waste any time, they said. You need surgery as of yesterday, they pleaded," said Fatema.

Surgery was scheduled for the next day. Fortunately, as fate would have it, her medical team had her meet with a specialist in this cancer before the surgery. He looked at Fatema and said, "You're too young to have ovarian cancer." This specialist poured over her records and stated that she did not have ovarian cancer, but he believed she had GIST.

"He saved me from having unnecessary surgery. I was ready to do whatever these doctors said; ready to go under the knife, until this doctor came into my life. He said that since I already had surgery for GIST, that maybe I needed to take the medications a GIST specialist would recommend. I am so thankful for this - I cannot imagine what would have happened otherwise," Fatema said.

Fatema and Shabbir were then on a mission to find out

all they could about GIST. As they searched for a GIST specialist, her local oncologist (Dr. Dilprit Bagga) started Fatema on Gleevec. One of her tumors was about 25 cm at this point. They were able to get an appointment with GIST specialist, Dr. Bartosz Chmielowski, at UCLA. Within a few months, the treatment with Gleevec shrunk the largest tumor to about 4 cm and ultimately to 2 cm. She remained stable for a time. This treatment worked well for about three years and her team, local oncologist and GIST specialist, monitored her carefully.

"This was a blessing to have been on Gleevec and stable for all those years," she said. Fatema and Shabbir were figuring out how to best love and support their son, who they discovered had special needs which would require extra attention.

In 2016, however, that peaceful time was interrupted when the tumors showed growth and her medical team suggested second line treatment with Sutent (sunitinib). She stayed on Sutent from June 2016 to April 2017.

Fatema shared, "Things got really hard when I started Sutent. My legs were really hurting and I couldn't walk. All the typical side effects with Sutent were happening to me."



Shabbir & Fatema Suterwala and their son

Dr. Chmielowski was doing a trial with Opdivo (nivolumab) and Keytruda (pembrolizumab), but when Fatema applied, she was rejected. The couple did not back down. They applied again and again, and in May 2017, Fatema was accepted into the trial. Before the trial, Dr. Chmielowski biopsied the tumors - exon 11, 13, and 17. She was given the Opdivo, which she did well on for about a year. Despite a good beginning with tumor shrinkage and stability, one of her tumors showed a little growth and the trial protocol considered dropping her.

Her team suggested surgery. The couple agreed, but when the surgeon went in, he was faced with the dilemma of removing part of the stomach, which would change her life radically or keeping her intact physically. The surgeon opted for no removal. The Suterwalas were disappointed because this particular tumor wasn't responding to the immunotherapy. She was allowed to stay on the trial but after more growth was indicated at a later scan, Fatema was dropped from the trial in December 2017.

Fatema was devastated. She was already through three lines of treatment. What was the answer at this point? Fortunately, the Suterwalas were referred to Dr. Michael Heinrich at OSHU in Oregon, who was running a Phase 1 trial with DCC-2618 (ripretinib). After another round of

biopsies on the tumors, she began taking that drug in January 2018. This line of treatment was abruptly ended after two weeks due to adverse reactions including a full-body rash and severe hair loss. Dr. Heinrich continued guiding Fatema in her journey.

Once again, the Suterwalas were struggling to find a solution. Stivarga (regorafenib) was yet untried, but after ten days on this drug, Fatema again had a severe allergic reaction. Fatema was at a loss to understand.

“Why was all this happening? There are hardly any cures out there, and my body isn’t accepting any of the ones that there are.”

Searching for answers Dr. Chmielowski and Dr. Arun Singh suggested trying the immunotherapy drugs she had been on before, Opdivo and Keytruda, not as a trial, but on a compassionate use basis. It was approved and Fatema took the treatment from May 2018 until August when again the scans showed there was growth.

Many months before, the Suterwalas for BLU-285 (avapritinib) which was in trial. Fatema was not eligible to participate in that trial itself. Completing the process for compassionate use took eight months of letter writing, form-filling, and legalities, involving the legal team at UCLA, which had to certify that Dr. Chmielowski would be administering and overseeing her care.

After about six months with little medication, Fatema began taking BLU-285, three pills a day. A rash developed in roughly two weeks. Though they stopped the drug immediately, the doctor didn’t believe the drug was at fault, so they lowered the dose and slowly increased with time back to three pills. Some benefit was realized, but not all the tumors were stable. Adding Sutent back into the mix was tried next. Fatema was plagued with unrelenting nausea and bloating, and required four blood transfusions within a four-month time period.

The Suterwala's worldview changed radically around November 2018, when Dr. Chmielowski stated that Fatema should now consider palliative care. He suggested at this point that she needed to get her affairs in order.

“I heard him say those words, and all I could think was, that makes no sense. I’m not even forty-years-old. It’s not possible. I haven’t even seen my son celebrate his tenth birthday or all of the things in the future. This is it?” Fatema shared.

The next few weeks were full of physically and emotionally painful times. Well-meaning friends and acquaintances gave Fatema advice on how to prepare to die. Fatema bore it and began to record videos for her son, struggling to imagine how she would feel and what she would say to him for key events in his life such as graduation. It was a draining experience. Her husband,

Shabbir, reached out to The Life Raft Group for resources on how to talk to his young son about his mother dying as he worked to keep hope alive for a solution that would save her.

At the end of the month, Dr. Chmielowski contacted Fatema and Shabbir explaining that a doctor who had heard about her case during a virtual tumor board was moving from New York (Memorial Sloan Kettering) and was interested in meeting her and learning more. When the Suterwalas met with Dr. Brian Kadera, an oncology surgeon, and after viewing her scans he said that he was not sure he could get the tumors out, but he thought he might be able to help.

“It was a horrible situation. I couldn’t eat, or sleep, or do anything. I was getting bigger and bigger, and I was exhausted all the time. And this doctor is saying, ‘I want to do surgery, but I don’t know what the outcome will be. We might just open you up and then close you right back up again. Are you ok with that risk?’ Because there were no options, we decided to do the surgery. I had to take the chance,” Fatema said.

The Suterwala’s leap of faith was rewarded with success in December 2018, as Dr. Kadera was able to remove the largest tumor and scrape a smaller one off the bladder. The large tumor was the size of a soccer ball and contained about eight liters of fluid. Dr. Kadera was truly ‘Mr. Incredible.’

Fatema exclaimed, “It is a miracle! I didn’t have to get a bag. I didn’t lose a piece of my stomach. I can eat. Not completely clear margins but it’s much better than I was. We prayed so much, and we never lost hope. It all came together, and I feel like this time that I have now is a blessing and a gift. And I just want to share what I’ve been through with other people. Don’t lose hope because good things can happen.”

Fatema resumed taking BLU-285 once the stitches healed. The large tumor was biopsied and sent off to Dr. Heinrich at OSHU which revealed another startling reality. Fatema has a rare KRAS mutation, which is resistant to all KIT therapies. She is on her sixth line of treatment, scared, but hopeful as her team strategizes on how to manage her treatment.

The Suterwala’s story illustrates the needs The Life Raft Group strives to meet for all GIST patients - for more GIST awareness and knowledge for doctors, and a standard of treatment for GIST patients that includes seeing a GIST specialist, mutational testing, genetic testing if applicable, and a regular schedule of scans.

We also want GIST patients to have access to clinical trials, patient and caregiver support through peer support programs, more GDOLS, for oncologists to participate in virtual tumor boards, and to improve the quality of life and survival rates of GIST patients.

International Collaborations

Salud con Datos 2019 in NJ, USA

By Denisse Montoya, LRG Director, Patient Registry

International collaborations accelerate patient advocacy and affect policy changes and treatment protocols.



Left to right: Mary Paz Mastretta, Adriana Garzón, Jairo Becerra

On May 7th, representatives from Colombia, Chile, Mexico, and The Life Raft Group assembled for the annual Salud con Datos meeting in Wayne, NJ. During this

meeting, each country shared the accomplishments that have resulted from the goals set at the previous Salud con Datos conference, such as the establishing clinical trials in Latin America.

Also discussed was the founding of an international research collaboration with the creation of a regional patient registry database in which each country will integrate their de-identified clinical data into The Life Raft Group Patient Registry. The data will then be analyzed with a focus on studying the trends and characterization of GIST patients from each country.



Left to right: Matías Muñoz, Piga Fernández, Rodrigo Salas

This will help to create a patient profiling study, where many important factors can be identified and compared among countries.

The objective of this international collaboration is to study and analyze the epidemiological factors of GIST among patients across the world. We envision the outcome of this international collaboration will change health policies, assist with patient advocacy, and increase patient survival. We will do this by joining global data from the U.S. and Latin America, with the goal of spreading awareness by publishing our collaborative results.

Increasing patient survival is at the center of this collaboration. Many patients in Latin America lack access to the therapies and tests that are conversely approved and reimbursed currently in the U.S. and in Europe.

This collection of empirical data will illustrate the crucial importance of access to treatment, and subsequently help inform policy makers in Latin America and around the globe. This is a small snapshot of the many goals we are planning to accomplish.

Water of Life Fundraiser

By Jessica Nowak, LRG Director, Outreach & Engagement

Dr. Matthew Lurin's Fifth Annual Water of Life Whisky fundraiser was held on May 16th at the Manhattan Center Ballroom in New York City. There were over 150 people in attendance which included brand ambassadors and participants. Nearly \$20K was raised this year.



With the set up of a whisky-speed dating tasting, throughout the evening guests were able to sample a variety of different brands of whisky and enjoy the creative and delicious cuisine from Scoozie Events catering. Guests had the experience of talking with the brand ambassadors and learned how their brands'

whiskies were made, the history of the brand itself, while enjoying the tasting. It was a great night for everyone to meet whisky aficionados and new whisky lovers while helping to raise funds for #GISTresearch.

The Water of Life event is held in memory of Matt Lurin's stepfather, Joe Temperley, who was a GIST patient. Mr. Temperley introduced Matt to the world of whisky. "We hope to continue this tradition of introducing others to whisky's finer aspects with this event, while raising funds for GIST research and education for many years to come," stated Lurin.

Pictured on left: Sahibjeet Kaur, Denisse Montoya



On the Speaking Circuit with the LRG

By Mary Garland, LRG Director, Communications

Norman Scherzer was invited to speak at three prestigious events this spring; participating in a roundtable discussion, presenting a cancer survival plan, and speaking to a patient advocacy group.

As a direct result of The Life Raft Group's involvement in the Biden Cancer Initiative, Norman was invited to speak on March 26th at a Roundtable in Manhattan to discuss the growing disparity in cancer treatment that exists in urban areas. Former Vice President Biden spoke to the specially invited group, who then broke into smaller groups to brainstorm solutions to the challenges.



Joe Biden speaking to Roundtable participants

As the former Assistant Commissioner of Public Health for New York City, and a Disease Management Consultant for the Center of Disease Control (CDC), Norman's experience in issues that are challenging for cities should prove valuable for the Biden Initiative.



Kim Tankersley and Norman Scherzer

Invited to speak at the Metropolitan Business Network in Manhattan, an organization comprised of a select group of business owners and senior level decision makers

who represent a cross section of New York enterprises, Norman presented his Personal Cancer Survival Plan.

The plan was conceived in the early days of The Life Raft Group and is designed to provide a cancer agnostic outline of key tips to enhance survival from cancer. Many of the suggestions were a direct result of Scherzer's work to keep his wife and other patients with gastrointestinal stromal tumor (GIST) alive.

The presentation was well received by the networking group. With cancer as the second leading cause of death globally, it is likely that many will have to deal with cancer treatment. The Personal Cancer Survival Plan has been helping patients and caretakers for over eighteen years.

Norman's speech at the Biden Cancer Summit in September drew the attention of the National Breast Cancer Summit. On April 29, he joined a panel to discuss how patient advocates are leading science and pushing research agendas, most specifically, how advocates are leading and pushing for change and not sitting on the sidelines. The Life Raft Group's focus on real world data and real world evidence is at the heart of how we continue to be a catalyst for change. His presentation, "Building a Model for Patient-Driven Research: The Story of The Life Raft Group", provided an overview of how we impact patient survival. Potential collaborations were discussed, as the value in our model was well-received.

"I actually gave *four* talks recently. One so affected me that I had to walk away when I finished to compose myself. It wasn't the conversations I had at the Biden roundtable on treatment disparity, although the issue is one that concerns me. It wasn't the talk I gave at the Metropolitan Business Network, although that resulted in my helping a cancer patient the very next day. And it wasn't the talk I gave to the National Breast Cancer Coalition, although meeting with survivors moved me greatly. Instead, it was the talk I gave to a spouse of a GIST Cancer patient who was very close to the end of life. She wanted to know how he was going to die and whether or not he was going to be in pain. Sometimes it is not the audiences of hundreds or thousands where the most impact takes place. Sometimes it is an audience of one that moves us most. Every talk we give makes a difference."

- Norman J. Scherzer, LRG Executive Director

► SIDE EFFECTS continued from cover

The shoe salesman will help you find the shoes that fit your feet. In summary, shoes are different, because people's feet are different. Going back to our earlier quote above, this is why you would gain a new perspective from walking in someone else's shoes – because their feet, as their mindset, are different than yours. In effect, their shoes are “personalized” to their unique feet.

Precision oncology for a specific disease

If you have paid attention to the cancer medication landscape for the last few years, you will have begun to understand the parallel with shoes. A shoe salesman (or manufacturer) needs to take into account the individual nuances of a customer's feet as well as their style preferences and the specific purpose the customer has in mind. To borrow a phrase from oncology, think of this not just as fitting a foot, but as engaging in “precision footwear.” Oncologists (and drug manufacturers) do something similar. They take into account the patient's disease, tumor mutation result, and numerous other factors when prescribing or developing medications for cancer. This is referred to as “precision oncology.”

Imagine being told that these individual factors didn't matter, but instead that no matter what type of cancer you have, you will get the same drug as everyone else. Equally ridiculous would be walking into a shoe store and finding only one type of shoe, in one size and width. For many people, that would be a solution that just doesn't stand on its own two feet.

Precision oncology is definitely a welcome improvement, and the targeted therapies that have resulted will continue to prove beneficial to patients. GIST as a disease is a prominent example of this approach, but not the only one. Drugs have already been developed for numerous cancers that are mutation-specific, and in some cases, the benefit from these drugs has extended to multiple disease types that share the same mutation. A recent example is Keytruda (pembrolizumab), an immunotherapy drug that was developed for Non-Small Cell Lung Cancer and targets PD-1. This drug is now being used in other forms of cancer that harbor the PD-1 biomarker, such as Cholangiocarcinoma, Melanoma, and Hodgkin's Lymphoma, and is also being studied in combination with other drugs for GIST.

This approach works because oncologists have recognized the simple truth that patients may have different cancers, but in some cases, their disease is similar enough mutation-wise that they can benefit from the same drug. But, while in many ways these patients are similar, they are also quite different, both across diseases and within their own disease. This impacts

not only medication selection, but also side effect management. Let me give you a few examples of how this works.

Precision oncology & cancer medications

Imagine now that you are an oncologist and you are about to see two GIST patients back-to-back. Think about what you would prescribe for each patient. Here is the scenario for each one:

Patient #1: One primary tumor (stomach), high risk of recurrence

Patient #2: One primary tumor (stomach), high risk of recurrence

This oncology thing is pretty easy, right? Or is it?

Give each patient Gleevec and remember to collect their co-pay. Has some information been left out? Let me fill in some details.

Patient #1: One primary tumor (stomach), high risk of recurrence, **exon 11**

Patient #2: One primary tumor (stomach), high risk of recurrence, **wildtype**

Ah ha! You can now see that the first patient would most likely benefit from Gleevec, and for the second, Gleevec is probably not the best option. Case closed, right? Well...

Patient #1: One primary tumor (stomach), high risk of recurrence, **exon 11, 97 years of age, end stage renal disease**

Patient #2: One primary tumor (stomach), high risk of recurrence, **wildtype, 26 years of age, in otherwise perfect health**

As you are beginning to see, this oncology thing isn't nearly as easy as it appears at first glance. But, as you can also see, the key to understanding the problem lies in gathering as much meaningful data as possible. Having this data may reveal factors that make the individual case much more specific than the “textbook” one.

Moving towards precision side effect management

How does this scenario dealing with medication selection relate to side effects? It relates in at least two major ways. First, we must take a basic look at not only what a side effect is, but also what the impact of having a side effect could be on a patient and their treatment.

When side effects are severe enough, they can affect a patient's ability to continue taking their medication. In oncology research, this is known as compliance or adherence. The problem occurs when a patient either starts missing their medication enough to lower it to a

dose that stops working or stops taking the medication altogether. When either happens, the medication is no longer being taken at its expected dose to treat the disease and the patient can have a worse outcome. This is true of any patient with any cancer. In order to prevent this from happening, oncologists and the rest of the patient's medical team engage in what is known as "side effect management." These are methods to prevent or treat the side effects in order to keep the patient on medication whenever possible, or switch to a different one if necessary.

Second, we have to ask ourselves a fundamental question. Just as patients are different (and these differences need to be taken into account when selecting a medication) is the same true for side effects? Will patients of different types be more likely to experience a certain side effect, and also experience different ones from other patients? If this is true, do patients need to have their side effect management altered based on these differences? At The LRG, we believe the answer to these questions is YES, and we are aiming to collect the data to show it. This is where our SideEQ platform comes in (and also where you can help).

SideEQ and the quest for more (& better) side effect data

If you've ever seen a commercial for a medication for a disease of any type, you probably remember hearing them report the side effects you might experience. You may have also wondered where that information comes from. In most cases, the data comes from the clinical trial that resulted in the medication's approval by the Food and Drug Administration (FDA).

In a clinical trial, a side effect is usually termed an "adverse event" and patients are either assessed for them during their trial visits (for those events that require a diagnostic confirmation, like anemia) or are simply asked if they are experiencing them (for events like nausea, fatigue, or diarrhea). These events are then rated (usually on the National Cancer Institute (NCI) toxicity scale) and assigned a number based on their frequency or severity. This rating is geared more towards clinical outcomes as opposed to other factors, such as the impact on quality of life. The event and its associated rating is then recorded. When the medication is approved, the side effect is reported in the prescribing information. If a patient reports a new side effect to their physician after the drug has been approved, the doctor is obligated to report it to the FDA. How quickly it must be reported varies based on the severity of the side effect, with more severe ones having to be reported immediately while those of lower ratings are allowed to be combined and reported in longer time frames.

Another question you might ask when watching a medication commercial, particularly if it's one you are considering taking, is "will this side effect really happen to me?" The answer to that question is not that simple and goes to the heart of what we believe actually defines personalized side effect management. Trial data can tell you things like "24% of patients experienced fatigue" and also what the severity of the fatigue was. But were there any distinguishing traits among that 24% of patients or the 76% who didn't experience that side effect? The data rarely, if ever, reveals that information, and much like the medication example we used above, we feel that leaving out that data may mean we are missing essential information that can affect a patient's quality of life.

Let's take a similar approach as the one used in the medication example to illustrate the point further. You are back on the clock as an oncologist, and here are two of your patients, both of whom will be taking the same drug:

Patient #1: 46-year-old Asian male, with kidney disease, high blood pressure, and diabetes

Patient #2: 62-year-old Caucasian female, breast cancer survivor, with severe food allergies

Known side effects for this drug are nausea and fatigue. It may also cause allergic reactions or increased blood pressure in some individuals, though it is unclear what characteristics may cause that to happen based solely on the trial data. With this information, do you think it is possible that each patient could be at a different level of risk for each side effect? Would you rather know this information or not when trying to decide how to approach the management of side effects for these two individuals?

SideEQ's purpose is to gather data exactly like this and to ultimately put that data in the hands of physicians so they can select appropriate treatments and better manage patient side effects. This is the type of data that is not always collected in clinical trials and has been recently termed by the industry press as either empirical data or Real World Evidence (RWE). Whatever you choose to call it, The LRG has been collecting it faithfully in our Patient Registry since 2000. An example of early RWE was a study on dosage of 169 LRG patients on the original Gleevec trial which we presented at CTOS in 2004. This type of data is not designed to replace clinical trial data, but to enhance it. To best understand the soul of the platform (or to continue with the shoe metaphor, perhaps the "sole"), it would serve us to look at the platform more closely.

Let's take a look at The LRG's approach to collecting RWE data...

▶ SIDE EFFECTS continued on page 10

SideEQ is available for free at <https://www.mysideeq.org> for use on your computer. It is designed for use not only by GIST patients, but also those with other cancers. We did this deliberately for two reasons. One, we thought, in addition to benefiting GIST patients, the platform could help all cancer patients in general, and two, we felt that collecting data from different diseases would allow us to compare across disease states and see if side effects varied even for the same medication.

The goal is to obtain a clearer picture of how to personalize side effect management. When registering, there are a number of different data elements we ask the user to provide in addition to an email, username, and password. We also ask information about gender, age, and country of birth, in an effort to paint a more specific demographic picture. We plan on adding more of these fields in the future to help further understand what factors cause side effects to vary in patients. We also ask information about the patient’s disease and medications.

A number of diseases and medications are at the top of the list. We have a special interest in looking at these diseases because they usually share a medication in common with GIST, or in the case of some medications, because they are some of the most frequent ones patients report taking. We have the ability to change this listing very easily, which gives us the flexibility to list not only drugs that are currently approved, but also those that are still in trial such as Blueprint’s BLU-285 or Deciphera’s DCC-2618. We are also able to add drugs when requested by patients.

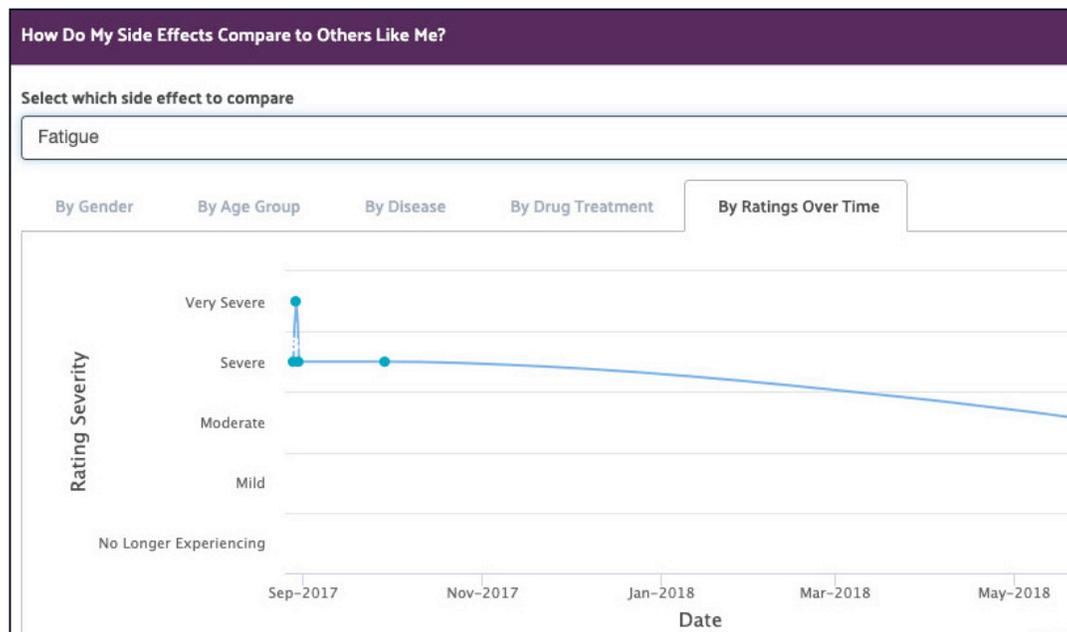
In addition to the common drugs and medications, choosing “select other” allows the patient (or caregiver, as they are also allowed to create an account to report on the patient’s behalf) to select from a larger list of diseases and medications.

Once that is completed, the patient moves on to their newly created profile, where they can select the side effects they are currently experiencing.

This example is test data, so there may be more side effects selected than might normally be the case. Our preliminary data from SideEQ suggests that in many cases patients do report multiple side effects.

Once you have selected your side effects, you can begin rating them; this should be done periodically. We use this information to determine how side effects change over time, and you can also use it as a type of diary to see if side effect changes are associated with other life changes, such as diet or lifestyle.

The format for this rating method was selected based on our conversations with the Food and Drug Administration (FDA) when we first developed SideEQ, and its inclusion in a pilot project observational trial that the FDA suggested. One very important suggestion the FDA made was to add a question about which side effect causes a patient the most concern. This provides another level of personalization, as the side effect that most impacts a patient's quality of life will vary from person to person.



This emphasis is something not often found in standard side effect data collection and speaks to the patient's viewpoint, which we believe is especially important when personalizing treatment.

In the example to the left, we see the specific side effect of fatigue charted over time. As mentioned, in addition to helping The LRG understand how side effects may change over time, it also serves as a type of diary for the patient. Imagine this was your data, and you also realized that when your fatigue abated, you had also changed your diet,

or perhaps started getting more sleep. Wouldn't this be valuable information to help you manage your side effects?

Hand-Foot Syndrome
Side EQ / Side Effects / Hand-Foot Syndrome

Expert Tip

Although targeted cancer therapies are generally considered to have less side effects than traditional chemotherapy, the need to take these drugs for extended time periods (in many cases indefinitely), presents new challenges. Some chemotherapies cause skin toxicity. One of the more troublesome is a side effect known as hand-foot syndrome (HFS), also known as hand-foot skin reaction (HFSR). It is estimated that up to 30% of patients taking Nexavar (sorafenib) or Sutent (sunitinib) will experience HFS when all degrees of severity are taken into account. With Stivarga (regorafenib), rates of HFS were up to 67% in clinical trials when taking into account all degrees of severity.

Hand and Foot Syndrome Coping Strategies:

- Full-body skin exam; emphasis on palms, soles, prior to the start of a TKI associated with HFS.
- Consider procedure to remove pre-existing hyperkeratotic (thickened skin) areas or calluses that may predispose them to HFS.

[Read More](#)

Related Tips

Foot creams Hand-Foot Syndrome

1 [Comments \(3\)](#) [12 July 2016](#) [lrgstaff_1](#)

Finally, in addition to collecting data to help The LRG (and ultimately, physicians) understand over time how side effects may vary based on different factors, we want to give patients information they can use **right now** to manage their side effects.

This is where the other "side" of SideEQ comes in. For each side effect, management tips for them have been provided, and there is a forum to discuss them as well as a way to post tips for management. On the left, is an example from the page on Hand-Foot Syndrome.

What does SideEQ mean for you, the patient?

We do not collect data simply for the sake of collecting. Our objective is to help patients live longer and improve their quality of life. We feel that by making side effect management more personalized, we can get closer to this goal.

What can you do to help us get closer to this goal?

If you haven't joined SideEQ, please join us and over 400 patients who have already done so. Your data will not only help GIST (and other cancer) patients, but also can help you individually, as it may allow you to see patterns that will help you better manage your side effects and improve your quality of life. This is an outcome we can all stand behind. If you already are a part of SideEQ, please continue to update your side effects and quality of life data, as we need to understand how it changes over time.

Also keep posting tips and responding to other's posts. What we need now is more data and better data.

That can't happen without you.

The First GIST DO IT Walk NJ Held in Loving Memory of Ted Wolf

An Amazing Day in Verona Park



By Jessica Nowak, LRG Director of Outreach & Engagement & Carolyn Tordella, LRG Web & Graphic Design Associate

On May 4, 2019, The Life Raft Group held its first GIST DO IT Walk in New Jersey, at Verona Park. Despite the drizzle, over 50 people were in attendance and over \$18K was raised for #GISTresearch.

LRG Senior Vice President Laura Occhiuzzi thanked our sponsors and donors and expressed gratitude for everyone who joined us for the event. Our Event Sponsor was Idea Village Products Corp. of Wayne. Kessler Rehabilitation Center was our Bronze Sponsor. We are also grateful to Walgreens in Verona, who sponsored a table at the walk.

Tammy Wolf, wife of GISTer Ted Wolf, presented the Wolf Strong Award to Chelsea Ozeri, the most successful fundraiser of the GIST DO IT Walk NJ 2019. Chelsea, a new LRG member and recipient of the 2nd annual Wolf Strong Award, raised over \$10K for #GISTresearch. This award will be presented each year to a Patient Philanthropist. (Read Chelsea's story: thelrg.org/2019/05/patient-of-the-month-chelsea-ozeri/).

Left to right:
Diana Nieves,
Laura Occhiuzzi,
Chelsea Ozeri,
Tammy Wolf



“This is a tribute in so many ways. I know how much he [Ted] loved the Life Raft Group. We both learned so much in our eight years of this fight we had together. Thank you for all the hard work you and your team does every day.”

Tammy Wolf
LRG Member, Caregiver

Ted, who passed away in July of 2018, received the first Wolf Strong Award at our debut GIST DO IT Walk at Life Fest Miami in 2018.

Tammy flew in from Florida to attend the walk and was joined by close friends and coworkers from Charlotte, NC. Remembering Ted, they saw the bench in the park with a quote that said, "I love walking down memory lane because I get to run into you." Tammy said that it hit home. "It meant something to all of us. I felt like Ted was there in spirit and to have this tribute to him, him being a legend for his courage and strength, meant a lot."

Prior to presenting the award and the beginning of the walk itself, Tammy shared from her heart about her husband's courageous eight-year journey with GIST to the crowd of staffers, friends, family, and Life Raft Group members. (View Tammy's speech: <https://www.youtube.com/watch?v=nVhA8QKkqgc>).

Tammy and Ted were able to have eight years together after his initial GIST diagnosis. Stressing the importance of patient and caregiver education, she shared, "When Ted was diagnosed, two of the clinical trials that he participated in weren't even in existence yet. I got three more years because of those trials. I think about the impact they had. His quality of life was really manageable for the eight years, until the last three months of his life. I think about what strides have been made in just the eight years. More people are living with it and managing it. The more education that people have about GIST, the better the chances of managing it well, because it's so rare, scary and unknown. The Life Raft Group was a sanctuary where he educated himself."

"The GIST walk was such an empowering event. Being out in nature with others living with GIST, as well as my husband, friends and family, was so energizing. I really felt the love and support of those around me—it just lifts you right up and out of the fog."

**- Chelsea Ozeri, LRG Member,
Recipient of Wolf Strong Award 2019**

The LRG is grateful for the Wolfs for all their efforts to bring awareness about GIST, and to Chelsea for the amazing work she did fundraising for this walk.



Chelsea Ozeri with family & friends

Opportunities to Volunteer with the LRG

In addition to fundraising (as seen in the GIST DO IT Walk article), and working with The LRG GIST Peer Program (page 16), you can help The LRG with in these roles, if you have time and the necessary skills.

We are looking for talented, skilled writers and WordPress experts to further our communication goals and website objectives. Apply at: bit.ly/VolunteerLRG or contact Jessica Nowak at jnowak@liferaftgroup.org

Volunteer Science Writer

The volunteer should be proficient in both writing and in analyzing scientific information and translating it into content that can be easily understood by readers, both scientific professionals and the general public. Superior understanding of terminology and formatting of scientific publications is desired. A genuine sense of curiosity and love of research is a plus.

A bachelor's degree in English, journalism or communications is required. Coursework in science or experience working in a scientific or medical field is preferred.

Volunteer WordPress Web Expert

The volunteer should be proficient in creating posts, pages, and events in WordPress and have a working knowledge of website publishing requirements, including working with images in Photoshop.

A graphic design and/or web development background is preferred.

Networking & Collaboration in Action

ASCO 2019

By Laura Occhuizzi, LRG Senior Vice President

LRG Directors attended the Annual American Society of Clinical Oncology (ASCO) Conference to network and research collaboration possibilities among over 40,000 doctors, researchers, pharmaceutical companies, and other patient advocacy groups.

Sara Rothschild, LRG VP, Program Services, Matt Mattioli, Director of Operations, and I attended the ASCO Conference in Chicago from May 31 to June 4. ASCO is one of the largest cancer conferences of the year. The theme of this year's meeting was "Caring for Every Patient, Learning from Every Patient." *This is what we do at The LRG.*

Meeting with advocacy groups whose mission is similar to ours, spending time with our volunteers and watching collaboration in action through our meetings with the Pediatric & SDH-Deficient GIST consortium and the Sarcoma Coalition were the highlights of the event. Our Pediatric & SDH-Deficient GIST Consortium met and shared research updates. This international group of researchers, GIST medical experts, and patient advocacy groups is an excellent example of collaboration in action. In addition, the poster session discussions provided valuable information reflecting the latest data from researchers on lab-based studies and clinical trials.

We were supported by Board Member, Jim Hughes, and volunteers Rob Taylor, Eric Biegansky, and Anthony Cashin. The Life Raft Group manned a booth in the Patient Advocacy section, distributing materials and networking with attendees and other patient advocacy organizations.

For me, getting to know our volunteers Rob, Eric was invaluable. Their passion and dedication to helping The Life Raft Group was inspiring. The opportunity to discuss the needs of patients helps direct our future projects. To highlight the difference patients can make in research efforts, Dr. Joshua D. Schiffman from Huntsman Cancer

Institute and member of our Pediatric & SDH-Deficient GIST Consortium, dropped by the booth to present Eric with an award for his donation of tissue for research. Patients can truly play an important role in research in many ways.

Being able to put faces to names enlivens the work we do. It was a great opportunity to touch base with so many GIST experts. Meetings with GIST specialists allowed us to discuss future collaborative efforts. We are planning our 2020 GIST Days of Learning. Meeting with both Dr. Breelyn Wilky (University of Colorado) and Dr.

Michael Wagner (University of Washington, Fred Hutchinson Cancer Research Center) at ASCO helped us to solidify our plans.

On the global front, we met with Dr. Matías Chacón of Argentina and Luciana Holtz from Oncoguía, our Brazilian representative, to discuss our collaborative effort to expand our patient registry with Latin American data. We are looking forward to continued conversations as we strive to

increase survival in Latin America.

The overwhelming theme running throughout presentations and meetings was the importance of testing, especially Next Generation Sequencing. As cancers become more complex as we discover new subsets, this becomes an important advocacy issue. We will continue to share this message with our community as testing is a top priority for The Life Raft Group.

We also attended meetings with pharmaceutical companies, Novartis, Blueprint Medicines and Deciphera, both to learn more about their research efforts, and to discuss how we can work together to support our patients. In addition, we are expanding our relationship with the Biden Cancer Initiative relating to their clinical trial initiative and how our sophisticated GIST Clinical Trials database can be utilized.



Left to right: Laura Occhuizzi, Dr. Breelyn Wilky



Left to right: Rob Taylor, Anthony Cashin, Laura Occhuizzi, Sara Rothschild, Matt Mattioli



You are surrounded by a wealth of knowledge at ASCO. We took advantage of every opportunity presented to see what we could learn from others. In the evenings, we attended events such as the President's Reception, both Novartis Global and U.S. meetings and Sylvester Comprehensive Cancer Center's Miami Nights.

The Life Raft Group continues to work to build relationships that support our mission to help our patients survive and thrive. ASCO continues to be an important part of that mission.

Abstracts and posters from the ASCO 2019 Meeting that present findings on GIST can be found here: https://abstracts.asco.org/239S/search.php?zoom_query=GIST&op.x=59&op.y=8



Left to right: Dr. Michael Wagner, Laura Occhuizzi

ISPOR 2019

The Future of RWE & Improving the Quality of Patient Survival

By Pete Knox, Senior Director, Research

Two members of The LRG staff recently attended the annual ISPOR meeting in New Orleans. ISPOR (International Society for Pharmaceutical Economics and Outcomes Research) is the leading society for global health economics and outcomes research (HEOR). The conference theme was, "Rapid. Disruptive. Innovative. A New Era in HEOR," A wide variety of compelling topics in HEOR were addressed.

The LRG presented our Real World Evidence (RWE) initiatives, interacted with researchers, and also served on the newly formed RWE special interest group. Nearly 4,000 healthcare stakeholders attended.

Yu Wang, LRG Data Scientist, presented the LRG Data and Research Model, including the Patient Registry and SideEQ, and discussed how this data helps us gain insight on ways to improve survival and quality of life for GIST patients.



Pete Knox, LRG Senior Director of Research, attended an invitation-only meeting that kicked-off ISPOR's RWE special interest group.

The LRG is both honored and excited to be a part of this group. Active participation will be key as it will allow the LRG to be part of the process to help define RWE going forward and assess the challenges of implementation. By identifying these challenges, they can be more successfully addressed. This will allow us to further improve our ability to affect patients' survival and quality of life. Also, it will open up a dialogue with insurers and health systems to better understand how best to facilitate payment for medications and testing, a goal towards which we continually strive.



To learn more about The LRG's long history of involvement with RWE and how RWE fits into our research model, please check out the first issue of LRG Science available at: <https://liferaftgroup.org/wp-content/uploads/2019/05/lrg-science-feb-2019-1.pdf> and to read more about ISPOR see www.ispor.org.

The LRG GIST Peer Support Program

Sharing Your Experience by Being There for Other GIST Patients and Caregivers

By Diana Nieves, Senior Director, Outreach & Engagement



Last month, we posted information on our new program to support our members. The GIST Peer Program is an additional support system to help patients and their caregivers through a very difficult time in their lives. Why? They may just be finding out they or a loved one has GIST, or they are experiencing a recurrence and they want to be able to talk with someone.

Many times, whether it's at a Life Fest, GDOL, or other LRG events, we have heard that patients feel alone. Caregivers, too. GIST is such a rare disease, and they feel like there's no one else out there that's experiencing what they are. Who can they turn to for that extra support?

Our GIST Peers complement what a State Leader might be able to offer. The State Leader is there to organize support meetings and bring groups together to unite the GIST community so patients and caregivers know that they are not alone. The GIST Peer is there for that phone call, "Hey, I'm having a rough day. I just heard from my doctor. I just had this test. I'm feeling afraid and alone. I just want someone to hear me and talk to me." The GIST Peer will be there for that person and in those situations. Our GIST Peers have walked this journey; they know it.

A rare disease like GIST is more isolating for people because there are just not many people diagnosed. GIST is unlike breast cancer, which unfortunately encompasses a much larger group and therefore garners more support, education, and research. Anywhere you go, you can always find at least one person who has been affected by breast cancer. GIST isn't like that, and it's especially difficult in more rural communities where patients and caregivers are struggling to find people who are going through the same things.

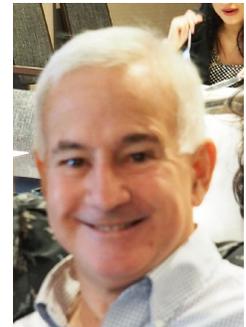
Santy DiSabatino, our Volunteer National GIST Peer Director, is a volunteer with his own GISTory. You can read Santy's story on our website (bit.ly/SantyDiSabatino).

Santy is retired and when he applied for a volunteer position with The LRG we knew that his background in education and a passionate voice for patient advocacy would serve this position well.

How Can You be Matched with a GIST Peer?

When someone fills out a membership application, they can request to have a GIST Peer or at any time someone could just go online to our GIST Peer Program page and request a Peer (bit.ly/GISTPeerProgram). At this point in time, your GIST Peer might be someone out-of-state, but as our volunteer roster grows, we expect to be able to match up peers with patients and caregivers in their own state. Patients will be matched to patients, caregivers to caregivers, as well as those with similar circumstances, considering age, mutation type (ie. Pediatric), or even those who lost loved ones that need support.

"I am very excited to join this Life Raft Group initiative as the National GIST Peer Director. As GIST patients, we understand how stressful and confusing living with GIST can be. I know how support from others can make a difference in their lives. I look forward to working with the mentors who will volunteer their time to support others in our GIST community.



I saw this quote today on the internet and thought it fit perfectly with supporting this important initiative. The quote reads, 'Never underestimate the difference YOU can make in the lives of others. Step forward, reach out and help. This week reach out to someone that might need a lift' ."

**- Santy DiSabatino, LRG Member
& Volunteer National GIST Peer Director**

Volunteer Your Time

Go to liferaftgroup.org/volunteer
Or contact: DNieves@liferaftgroup.org



Do You Have Personal Experience with GIST as a Patient or Caregiver?

You can become an LRG GIST Peer and provide support, empathy, and understanding to people with GIST or their caregivers, family members or a close friend. The LRG exists to reassure GIST patients and their caregivers that they are not alone on their GIST journey. Our goal of supporting the community does not stop if patients lose their battle with this disease. The LRG is also seeking volunteers who have lost a loved one to GIST and are willing to offer support to others.

We look forward to serving our members in this capacity and encourage those with the desire to help other GIST patients and caregivers to apply via application at: bit.ly/VolunteerLRG.

One Voice Against Cancer (OVAC) Advocates for Cancer Patients

By Teena Petersohn, LRG Contributor & Board Member

OVAC is a coalition of over 50 nonprofit cancer organizations who advocate on behalf of cancer patients to deliver a unified message to Congress and to the White House on the need for increased cancer-related appropriations. The LRG is a member of OVAC.

I was honored to once again attend the One Voice Against Cancer (OVAC) meeting during the Annual Lobby Day in Washington, D. C. on May 13th & 14th. This was my 4th year attending, and each time it has been a very rewarding experience.

There were over 100 people in attendance representing 32 states. We were a mixture of patients, caregivers, survivors, health care professionals and researchers, all who, one way or another have been touched by cancer and feel the need to speak out.

We spent Monday afternoon being prepared to meet with our Congressional representatives. Although it can seem overwhelming, it is really a very simple procedure. You first introduce yourself and tell where you are from so that the Senators know, and the Representative knows you are from their district.

You then relay your personal reason as to why you are there, and then make your "ask." We were told that our personal stories make a bigger impression on them than the actual amount we are asking for.

Although I am not there to specifically lobby for #GISTresearch, the story of my GIST journey is a very powerful one that shows them not only how research can be a life saver for patients, but also how not all patients respond to current treatments, confirming the need for funding for further investigation. On Tuesday, we made our way to Capitol Hill. Appointments had been prearranged with our own state Senators and the Representatives from each district represented. Sometimes you get to speak directly with the Congressperson, and other times you get to speak with one of their staffers. Either way, it is a great opportunity to convey the message.

The ask this year was for continued funding of NIH, NCI and the CDC for continued research, prevention and better treatment for all cancers.



Teena Petersohn

At this event, I had the opportunity to network with many new people. Some are there year-after-year and you get to renew former friendships.

It continues to be a very humbling experience to represent cancer patients in this important mission.

I flew to DC on May 12th, which was Mother's Day. As my own mother passed away from stomach cancer, I felt this was a great way to honor her, and my daughters understood this.

For more on OVAC: www.ovaconline.org



By Diana Nieves, LRG Senior Director of Outreach & Engagement

The Life Raft Group held a GIST Day of Learning (GDOL) in Tampa, at Moffitt Cancer Center, on May 16th, 2019. This was the first GDOL presented in Tampa. 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.



Left to right: Diana Nieves, LRG Board Members Jim Hughes, Teena Petersohn, Laura Occhuizzi, LRG Board President Jerry Cudzil

“This was the first GDOL I have attended and I was VERY impressed. Great presenters, great presentations, great audience involvement and great host accommodations. Thank you, LRG for making this all possible. You are the BEST!”

Teena Petersohn
GIST Thriver & LRG Board member

Who Attended GDOL Tampa?

Over 80 patients, caregivers, Moffitt Cancer Center practitioners, and friends attended the weekend event. Several new members joined our GIST community during the course of the day as well. Dr. Andrew Brohl (Moffitt) welcomed everyone and opened the day with a GIST 101 presentation. Dr. Ricardo Gonzalez (Moffitt) followed with a presentation on Surgical Management of GIST. Dr. Jonathan Trent of Sylvester Comprehensive Cancer Center presented on Rare Subtypes of GIST, followed by a presentation from Dr. Ghassan El-Haddad (Moffitt) on Liver Directed Therapy.

All of the doctors also participated in a panel discussion where patients and caregivers asked questions about GIST, treatments, side effects management, etc.

One participant commented, “Love this type of communication and the audience Q&A. Learned more from this discussion than others.” While another participant stated, “This program was great. It was good to see the great minds together and all the work they do behind the scenes.” Patients also shared their

GIST journey experiences. Finally, LRG member Jeff Davis inspired us all to keep moving forward to enjoy life to the fullest despite the health challenges we may be facing.

Thank you to Bayer, Deciphra, Genentech, Novartis, and Pfizer for sponsoring our 2019 GDOLs.

Left to right: Diana Nieves, Marian Ritter, Laura Occhuizzi, Dale Ritter



Left to right: Teena Petersohn, Laura Occhuizzi, Diana Nieves, Tammy Wolf

Interested in having a GDOL in your city? Contact Diana - DNieves@liferaftgroup.org

Ron Agypt - In Memoriam

Ronald George Agypt, 62, born in Johnstown, PA on June 3, 1956 to George Abraham Agypt and Mary Jane (Abraham) Agypt (both deceased), passed away on April 10th, 2019, at his home in Alpharetta, GA after a valiantly fought battle against cancer. He is survived by his wife, Kim, and their three sons, Christian and his wife Rachel, grandchildren Simon and Adalia, Brett and his wife Sara Jane, grandchildren Miles, Amelia, and Evelyn, and Tyler and his girlfriend Melanie; his nieces, Dominique and Marissa; his siblings, Greg Agypt and Janice Agypt, both of Johnstown; and his faithful dogs, Cooper, Rooney, and Riley.

Married to Kim for 38 years, his love for her was unequaled to any of his passions and achievements. He considered himself the luckiest man on earth.

A member of St. Mary Antiochian Orthodox Christian Church and a graduate of Westmont High School in 1974, Ron attended the University of Pittsburgh before embarking on a 38-year career in the insurance industry. Ron spent 33 years with Combined Insurance Company of America and AON Worksite Solutions, starting as a door-to-door salesman and working to become the youngest vice president in the company's history at age 30. He went on to serve as the Senior VP of Aflac for Broker Development and the Chief Sales Officer of HUB International. He also served on the Board of Directors for Sterling Life Insurance Company, Legal Club of America, Better Business Bureau of Northern



Kim and Ron Agypt with their beloved grandchildren

Illinois, and The Life Raft Group. Yet if you asked him his greatest accomplishments, he would first bring up the countless Little League titles he won coaching his sons, or his undefeated record in the "Ring of Honor."

Ron developed a legacy of love. He lived as we all should, striving to forge an easier path for those who walk behind us. He graciously left us with the understanding that our lives are measured not by what we achieve, but by the number of people we welcome into our hearts. He will be missed, but his lessons continue to grow and multiply in an ever-widening circle of joy, love, and light.

A memorial service was held on Saturday, April 27th, 2019 in Alpharetta, GA.

In lieu of flowers, the family asks for donations to be made in Ron's honor to the Harlem Heights Charter School in Fort Myers, FL, or The Life Raft Group.



Ron Agypt, LRG State Leader and Board Member

Sometimes you get to know and understand somebody in a relatively short span of time when that would normally take a lifetime. That short span of time would create some defining moments that enable you to talk about somebody as if you knew them for a lifetime. It is like that with Ron Agypt. We met originally when he was still partially responding to therapy and focusing on how he could help others by joining our Board and reaching out to other people by working to develop other treatments.

As time went on and he began to move from treatment to treatment, it became clearer that they weren't working. I observed a combination

of courage and serenity as someone comes to accept that their life was going to end and that it was okay. He accepted, after a while, that it was time to stop these treatments and he left us with a photograph. This photograph is of him and Kim. They are holding each other on the couch and I see the caption of this photo being "Serenity."

And it says more than thousands of words could ever say about the courage, and the love between two people, and their mutual acceptance, if you will, about the reality that things were about to change. Ron would no longer be with us. I've had many moments with the Life Raft Group, unfortunately with many who've lost their lives, where you come to understand what it's like to say, it's okay now, it's okay to let go. That was Ron; that was serenity.

- Norman J. Scherzer, LRG Executive Director

State Leader Spotlight

John Abrams, Colorado, USA

John Abrams, our new LRG State Leader for Colorado, has a vision of helping others cope with GIST.

John's story spans a journey with three types of cancer. First, misdiagnosed in 1997 with leiomyosarcoma, he had a mass removed, followed by four months of traditional chemotherapy. In 2001, he was diagnosed with prostate cancer. Two years later, a gallbladder attack led to the discovery of metastatic GIST, which was treated with Gleevec. In 2004, John was diagnosed with a rare form of non-Hodgkin's lymphoma for which he received radiation treatments. John is no stranger to cancer and the trials that come with the journey.

Due to severe hand cramping side effects from Gleevec, John retired from his profession of dentistry. Presently, he does management and clinical consulting for younger dentists and flips houses with his son, Andrew. He enjoys time with his wife, three children, and five grandchildren. Afternoons he can be found on the golf course. As a couple, the Abrams enjoy traveling the world, but every summer they look forward to vacationing in Breckenridge, Colorado with their entire family making precious memories.

John refers to himself as the "luckiest, unlucky guy I know." He hopes that his ability to persevere during trying times will motivate and inspire others living with GIST. Plans for his first local support group meeting in September are in the works.



John Abrams and his family

➔ Interested in becoming a State Leader? Contact Diana - DNieves@liferaftgroup.org

Global Representative Spotlight

Adriana María Garzón Pinzón, Colombia



Adriana's journey with cancer began 15 years ago. After conquering Stage 3 breast cancer, she changed her professional path and poured her skills, talents, and experience into serving other cancer patients. In 2004, Adriana, Senator Sandra Ceballos (deceased), Dr. José Caicedo, and Dr. José Robledo founded ONES, the first NGO (non-governmental organization) to promote breast cancer awareness. ONES advocated for a law to establish actions for the standards of care for cancer.

Adriana was also a part of the founding council of Asociación Amese, an organization that supports women with breast diseases. In 2010, she created Fundación SIMMON, a non-profit organization dedicated to contributing to a better quality of life for people with cancer,

their families and caregivers. At Fundación SIMMON, you can find support groups, legal counseling, wellness workshops, patient meetings, loan natural hair wigs, training and support for caregivers, volunteer opportunities and a house full of hope. SIMMON is one of the most recognized cancer patients' organizations in Colombia among patients, decision makers, similar organizations and other health system stakeholders.

As an LRG Global Representative, Adriana hopes to collaborate in any actions, events, or advocacy efforts that contribute to the timely diagnosis and to provide patients that are going through this journey with the support and hope they need.



Update on a New Clinical Trial Offered to Eligible GIST Patients



Deciphera Pharmaceuticals is testing an investigational drug called ripretinib (DCC-2618) as a potential new treatment option for patients living with GIST.

About Ripretinib

Ripretinib is an oral investigational drug designed to treat GIST that are growing because of changes in specific genes. By targeting the inhibition of signals from the genes that cause cancer to grow and spread ripretinib may provide benefit to patients living with GIST.

Study Overview

The INTRIGUE study is a Phase 3 clinical trial testing the investigational drug ripretinib (DCC-2618) for patients living with GIST that are no longer on imatinib due to progression or intolerance. The study is being conducted to learn more about the safety of DCC-2618 and how well it works against cancer, as compared to sunitinib (Sutent), in patients who have previously received imatinib (Gleevec).

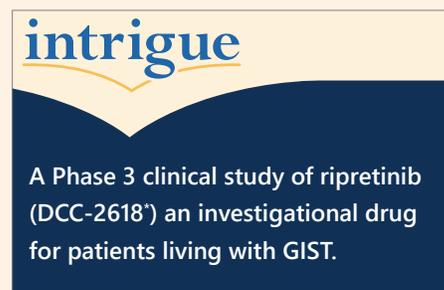
Approximately 358 GIST patients will participate in the trial worldwide. In addition to meeting other eligibility criteria, patients may be eligible to join the study if they:

- Are at least 18 years old
- Have been diagnosed with GIST and received prior treatment with imatinib only
- Are willing and able to comply with study procedures

For more information contact: clinicaltrials@deciphera.com or visit clinicaltrials.gov

Disclaimer: Please note that DCC-2618 has not been approved by the United States Food and Drug Administration (FDA) or any other regulatory agencies for sale or use by the public.

The information contained wherein is provided solely to inform patients about the existence of this trial, and does not in any way constitute endorsement by the LRG nor is it intended to serve as medical advice. Any questions about how this trial may fit into your overall treatment plan should be discussed with your healthcare team. Sutent and Gleevec are approved for the treatment of GIST by the FDA and other regulatory bodies around the world.



How are **YOU** celebrating



GIST Awareness Day (GAD) is July 13th

What are you doing to mark the day? Need ideas?

Go to our GAD page (bit.ly/GAD-July13th) for ideas. Post photos on social media: hashtag #GAD and #GISTAwarenessDay. Remember to tag #liferaftgroup, too!

We'd love to post some of your photos on our 2019 GAD Gallery as well, so send them to Mary Garland, Director of Communications at mgarland@liferaftgroup.org

Nicole Morales - In Memoriam

Dear Nikki,

You have left us too soon, but your presence will be felt far and wide for a very long time. From the moment I first spoke with you on the phone, I knew that you were a fighter. We met in person in San Diego three years ago; your mother, Jana, and bestie Andrea beside you. I met your husband John later and I knew you were surrounded by an amazing support network. Little did I know then that your network of friends and family were far reaching. This is such a testament to you, Nikki, and your zest for life.



Looking through social media this past week, I have come to know you even better. From your college days with your sorority sisters, your friends in Arizona, and the beautiful pictures of your wedding day. All of these illustrate the love and happiness that filled your life. These memories will live on in everyone that cherished your friendship.

You were a true warrior, respected and amazed by all who watched you fight this fight for so long. We all glimpsed the 'inner Nikki' by observing your various hair color changes, the furry pink kitchen chairs in your new house, the honest emotion of your blog, and your love of kittens to name just a few.

Though you faced overwhelming challenges, you faced them with grace, humor, and dignity. When we met in Scottsdale, you walked into the restaurant with long gray hair. We laughed together when you said it made you look like Lady Gaga, but internally I thought to myself what a statement she's making - "Never let life's challenges get you down. Plow through it and embrace life as it's handed to you."



You continued to face your diagnosis by immersing yourself in ways to make a difference. Your 30th birthday was a fundraiser to support GIST research. Your fundraising efforts were continuous though the years and you engaged Andrea to do the same. You joined us last year at Life Fest where you were awarded the Allen Tobe Volunteer of the Year award by The Life Raft Group. There wasn't a dry eye in the house as you shared your plea for change and your heartfelt story.

You were always there when I needed you as well. As the Arizona state leader, a speaker and volunteer at both GIST Days of Learning and Life Fest, you never ceased to amaze me by being present and giving of yourself. You flew across the country this past March to attend GIST Laugh in Washington, DC, a comedy fundraiser hosted by Andrea for The Life Raft Group. You had just been discharged from the hospital, but your

courage, strength and determination would not allow you to miss the event. You were surrounded by friends from across the globe who loved you, united to support research.

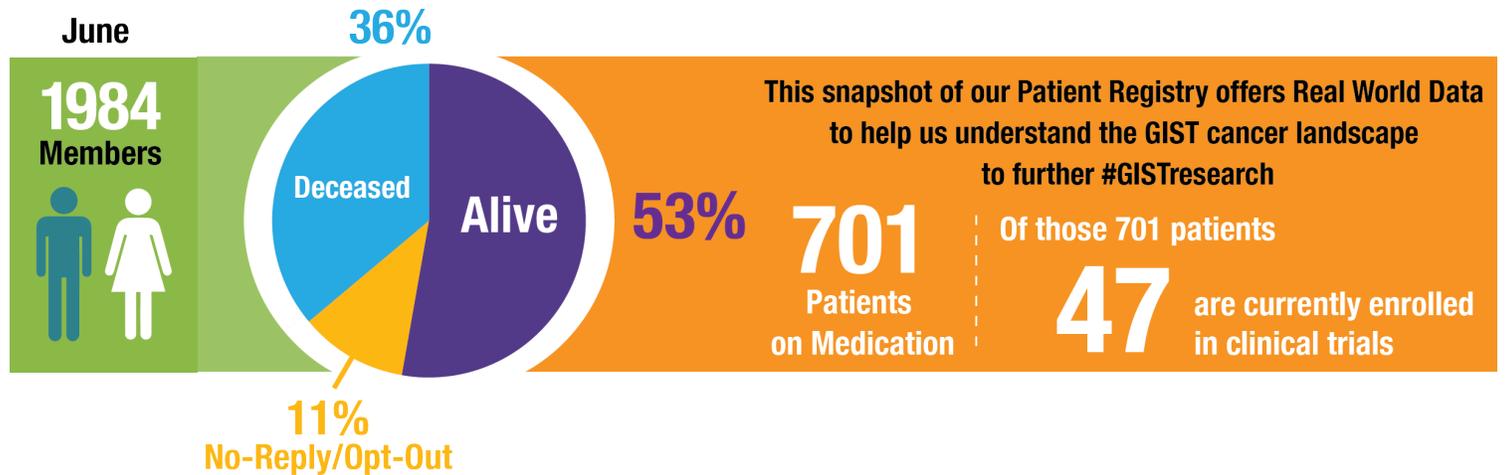
At The Life Raft Group, we are grateful for your incredible support of our GIST community, fundraising toward a cure, and your part in the formation of the Pediatric & SDH-Deficient GIST Consortium. You will be missed by so many including all of us here. When I think of courage, Nikki, I will think of you. When I think of strength, I will think of you. You have forever changed my life and the lives of so many others and for that I will always be grateful.

Rest in Peace, dear Nikki -

Laura

(Laura Occhuizzi, LRG Senior Vice President)

Patient Registry Data



Thank you to our Major Donors for February, March, April & May

William Balassone

Carlos Baldor

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Bayer HealthCare LLC

Blueprint Medicines Corp.

BST Consultants

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Anand Khubani

Novartis Pharmaceuticals Corp.

Pfizer Global Pharmaceuticals

Rodrigo Salas

Kay Stolzer

Schwab Charitable Fund

Dina Wiley

The LRG Calendar



For more information:

lifteraftgroup.org/event/lifestest2020/



Saturday Sept. 28th, 2019 9am to 4pm

For more information:

<https://lifteraftgroup.ca/>

email: malcolm.sutherland@lifteraftgroup.ca

The Life Raft Group Global Community

LRG Staff

Executive Director	Norman Scherzer
Senior Vice President	Laura Occhiuzzi
Vice President, Program Services	Sara Rothschild
Senior Director, Research	Pete Knox
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Global Relations Coordinator	Piga Fernández
Grants Consultant	Kathleen Gronet
IT Consultant	James Lee

LRG Volunteers

Pediatric GIST Official Greeter	Erin MacBean Gail Mansfield
Clinical Trials Coordinator	Jim Hughes
Staff Photographer	Michelle Mattioli
General Counsel	Steven Pontell
State Liaisons	Charles Burke Rick Isaias
National GIST Peer Director	Santy DiSabatino
Science Team	Erin MacBean Paula Vettel David Josephy Michael Josephy Joan Krakowsky Jim Hughes

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John Poss
Rodrigo Salas
Mia Byrne (Ex Officio)
Ray Montague (Ex Officio)

Interested in Volunteering?

Contact: Diana Nieves, LRG Senior Director,
Outreach & Engagement - dnieves@liferaftgroup.org

Interested in serving on the LRG Board of Directors?

Contact: Laura Occhiuzzi, LRG Senior Vice President
locchiuzzi@liferaftgroup.org

42 Life Raft Regional Chapters

Find info for a local & global reps at liferaftgroup.org/find-a-support-group/

Alabama	Kyle Brown Gina Smith	Maine	Jodi Merry	Pennsylvania	Jeffrey Bernstein Tiffany Werner
California, Northern	Martha Zielinski	Maryland	Wendi Lax	South Carolina	Paula Stover
California, Southern	Dina Wiley	Massachusetts	Ed Kreutz	Tennessee	Alice Sulkowski
Colorado	John Abrams Donald Hurd	Michigan	Ellen Rosenthal	Texas	Dee Hawkins
Delaware	Cindy Bones	Michigan - West	Cliff Kopp	Utah	Mike Ginsberg Carrie Callister
Florida	Marian Ritter	Minnesota	Yu Dupont	Vermont	Elizabeth Ching
Hawaii	Erin Rakes	Missouri	Katie Bloss	Virginia	Sally Jackson
Idaho	Janet Conley	Nevada	Joan Smith	Washington	Alicia McRae Jack Tinnea
Illinois	Jim Hughes Marlene Nei	New Hampshire	Jenna Colby	West Virginia	Susan Caperton
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Kansas	Christine Engel	North Carolina	Jennifer Higgins Carolyn Dewalt	Wyoming	Alan Quille
		Oklahoma	Jane Rowan		

60 Life Raft Global Liaisons See global news & resources in our International section on our website.

Argentina	Mariel Garibaldi	Hungary	Zoltan Kalo	Poland	Piotr Fonrobert
Australia	Roy Neil	India	Nikhil Guhagaka	Puerto Rico	Eileen Rolon
Austria	Amy Bruno-Lindner	Iran	Negar Amirfarhad	Romania	Simona Ene
Belgium	Gerard van Oortmerssen	Ireland	Carol Jones	Russia	Dmitry Bukhtenkov
Bolivia	Vicky Ossio	Israel	Avi Zigdod	Samoa	Leasi John Galuvao
Brazil	Luciana Holtz	Italy	Barbara Tamagni Colombo	Saudi Arabi	Mohamed-Elbagir Ahmed
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Czech Republic	Jana Pelouchová	Nepal	Atul Upadhyay	Thailand	Kittikhun Pornpakakul
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Germany	Markus Wartenberg	Pakistan	Sobia Wali Muhammad	U.K.	Jayne Bressington
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Guatemala	Silvia Castillo de Armas	Phillipines	Roy Mijares		
Hong Kong	Thomas Chow				

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